‘They make me feel worthy’

‘RDNS was there for me when no family was’

‘I can talk about things

I cannot talk with family or friends’

‘When I finish tablets, they come. If I am sick, they come’

‘ "invaluable" emotional support, especially for those who live alone, living longer’.

‘They helped me when I was homeless’

Project Team: Liz Crock, Nalla Burk, Judy Frecker, Oscar Morata, John Hall

The Royal District Nursing Service HIV Program in a changing epidemic: an action evaluation

Final report

Elizabeth Crock 17th September 2013

Disclaimer

The work in this project was undertaken in partial fulfilment of the requirements of The University of Melbourne for the degree of Master of Public Health. The views expressed are those of the author and may not reflect the views of The University of Melbourne, School of Population Health or of the Royal District Nursing Service Limited.

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Acronyms & abbreviations

Acquired Immune Deficiency Syndrome	AIDS
Antiretroviral therapy	ART
Clinical Nurse Consultant	CNC
Gay, Lesbian, Bisexual, Transgender, Intersex, Queer	GLBTIQ or LGBTI
Human Immunodeficiency Virus	HIV
Men who have Sex with Men	MSM
RDNS Homeless Person's Program	HPP
Royal District Nursing Service	RDNS
Royal District Nursing Service HIV Team/Program	HIV Team/HIV Program
Victorian AIDS Council/Gay Men's Health Centre	VAC

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EXECUTIVE SUMMARY

Background

The HIV Program at Royal District Nursing Service (RDNS) provides home– and community–based nursing care, support, education, counselling and health promotion to People Living with HIV (PLHIV) in Melbourne, Victoria[1]. Whilst most PLHIV in Australia are living well, many RDNS HIV clients face poor health outcomes, complex social problems, stigma and discrimination, and experience barriers to access to services, despite the availability of effective treatments. Furthermore, emerging issues including co–morbidities, 'premature' ageing and changing demographics in PLHIV pose challenges for community–based nurses in maintaining skills and knowledge, especially in a 'low prevalence' HIV epidemic. Evaluation of the RDNS HIV Program was critical to inform its development.

Aim

The aim of this project was to evaluate the RDNS HIV Program in relation to HIV clients' current and projected needs, to develop and improve the program and plan for future service provision. Specifically, it aimed to identify and describe HIV clients' needs, considering: the current model of care, the Australian HIV epidemic dynamics and service use. Second, it examined workforce development needs through evaluating district nurses' educational preparation regarding HIV (including issues around ageing, co–morbidities, cultural and diversity competence, ethics and law). Third, it examined HIV Program data in view of the Program's human resources, sustainability and responsiveness to changing needs.

Methodology

This was a formative evaluation based on action research principles. A mixed methods approach was taken, utilising quantitative data from 10 years of RDNS HIV Program reports, 86 HIV client and 372 RDNS staff questionnaires, and qualitative data from 15 key informant interviews and the surveys. Surveys were conducted over a 6 –week period in March–April 2013. Data was entered into Survey Monkey® and analysed with its built–in tools and through Excel©. Qualitative data was thematically analysed.

KEY FINDINGS

Client profile and needs – HIV Program Data

Client demographics

HIV clients receiving care from RDNS are a very diverse group, and have a range of co–morbidities that render their care in the community complex. Findings of this evaluation suggest that clients of the RDNS HIV Program are, on average, 10 years older than PLHIV generally in Australia. There are increasing numbers of women and people from refugee backgrounds, along with a significant proportion of long–term survivors. Many experience mental health problems and cognitive impairment and have substantial needs for HIV nursing expertise and community support.

Human resource use

HIV–related human resource use (nursing hours) has increased markedly over the past 10 years, peaking in 2009. Additional HIV nursing roles were implemented in 2003 at two high case load sites which have increased the Program's capacity. Several sites have high case–loads with inequitable HIV specialist resource allocation.

Evidence of increasing demand on human resources, and subsequent greater educational needs of staff, is supported by the literature, HIV Program data, client and staff surveys, qualitative data from interviews with key informants and staff comments.

Client survey

Service description

A diverse and representative sample of 86 clients was achieved, including nearly 40% from culturally and linguistically diverse backgrounds and over 8% indigenous clients.

The HIV Program provides a holistic service targeted to individual needs. The program broadly encompasses care coordination, medication management, psychosocial support, health promotion, health education and mental health support. Clients' comments added richness to the Program description:

Practical support

> *'Personal care attendant visits me weekly to help me arrange my clothing, paperwork. I am totally blind' (*65 year old gay man, long term survivor).

> *'It is good because helped me get better and kept explaining things when I didn't remember, and help me remember my appointments, when I didn't understand letters (*32 year old Sudanese woman).

Moral support

> *'Make me feel worthy. All you nurses, doesn't matter who, have made me feel worthy, it's true' (*48 year old gay man, long term survivor).
>
> *'I can talk about things I cannot talk with family or friends'.*

Information, health education

> *'Help me understand my health problems. Talk through things'.*
>
> *'She made information about my illness easier to understand'.*

Client satisfaction

Client satisfaction was evaluated in the domains of communication and accessibility, and quality of care (knowledge and skills, continuity of care, support, ethical practice, frequency and duration of visits, responsiveness and reliability, and cultural competence). Clients were also asked what they valued most about the service.

Clients expressed a high degree of satisfaction with the service. The model of care provided by the HIV Program is highly valued by clients and other HIV sector service providers:

> *'Of all the support services, RDNS is the most useful and dedicated and does the most useful work'* (HIV+ heterosexual man).
>
> *'Empathy, compassion and personalization – this is not a "one–size–fits–all" approach and I really appreciate that'.*

Accessibility and communication

Client were mostly satisfied with accessibility to RDNS, agreeing that finding information about RDNS and making an appointment was easy, although fewer agreed that after hours support was easy to access.

100% said they could understand nurses' responses when they asked questions, one noting:

> *'Better than I can understand my doctors at times'.*

Visit duration and frequency

Most were satisfied that nurses visited for an appropriate length of time or as often as was required (98%). One commented *'not long enough'.*

Quality of care

Knowledge and skills

86% said RDNS nurses skills in HIV were of a high standard 'all the time'.

'My RDN (sic) is someone knowledgeable who I can talk to about multiple chronic illnesses (Nurse has more time than my HIV specialist). It's comforting to have a regular visit... Get advice re illness and treatment. Never felt judged by RDN'.

'Some nurses do not seem to know as much about HIV but they are still good'.

Continuity of care

Clients agreed that they 'mostly' received care from staff who were known to them (continuity of care).

'They explain everything I need to do. They know me well and I know them well. I have confidence'.

Ethics

Ethical principles, values and practices such as trust, commitment to confidentiality, respect, and advocacy within health services are very important to HIV clients. Nearly all said nurses were sensitive to their situation and respected their confidentiality.

'[They] don't judge me, everyone else judges me' (49 year old gay man, long term survivor).

'Treat me and my husband with respect' (53 year old woman, newly diagnosed).

'Felt confident that confidentiality would be maintained'.

Cultural competence/sensitivity

Cultural competence or cultural safety in the HIV sector is essential for the care of people from culturally and linguistically diverse backgrounds as well as GLBTI.

Clients reported getting services in the language they wanted (98%) and 100% of those for whom this was relevant said they felt nurses 'respected their culture'. Two commented that they did not want an interpreter. Two said:

'I would like services in Italian'.

'Respect my culture – they help me a lot'.

98% said nurses were accepting of their life and health care choices.

Need and expectations for support

82% of respondents said the 'care provided meets their needs' all the time, and 84% said 'care meets their expectations' all the time, indicating high congruence between what clients think they need and what they expect of the service. Many commented on the supportive nature of nursing visits:

> *'I know I need input. I recognise I am not self–sufficient. I have problems procrastinating and RDNS helps me with my mental blocks'* (Gay man, long term survivor).
>
> *'My wife and I are on our own with near no support. Each visit with our nurse was like a friend or family coming into our home. This was a huge support for my wife'* (57 year old heterosexual man, newly diagnosed).

Responsiveness and reliability, complaints

A majority were satisfied with RDNS' responsiveness:

> *'They come to see me when I need it, even when I have been in crisis accommodation'* (young male, homeless, newly diagnosed).
>
> *'Because of this, in September 2011, the nurse saved my life'* (52 year old gay man, long term survivor).
>
> *'Value is exceptional. Have not experienced such a great level of support. Always on hand. Trust'.*
>
> *'When I finish tablets, they come. If I am sick, they come'* (41 year old Ethiopian woman, refugee, newly diagnosed).

Few felt if they made a complaint to RDNS, it would be ignored.

What clients value most

Clients spoke of many elements of care that they valued highly. They valued the relationship they developed with nurses, confidence that their privacy and confidentiality would be maintained, regularity of visits, and being able to talk about issues that they could not discuss with others. The importance of RDNS helping them stay in their own home was also mentioned:

> *'African people, they talk [about people in their community with HIV], me not like talking to them [about HIV]. Me happy [with RDNS nurses]. I not like African people [knowing about her HIV]' (*41 year old African woman).
>
> *'I most value the sensitive nature in which they thoughtfully manage my needs'.*
>
> *'The relationship developed over short period of time – very comfortable with nurse'.*
>
> *'The nurses make me feel at ease and more acepting (sic) of the condition, easy to talk and understand'.*
>
> *'They are there for you. They help you mentally and emotionally'.*
> *'RDNS allows me to stay at home, which makes me very happy'.*

Future needs

Clients' views on their needs in the next 5 to 10 years

Clients expressed most concern about HIV specialist nursing service provision being available to them, 'friends dying'; 'dying of AIDS', 'being forced to leave my home'; 'HIV– and non HIV–related illnesses', 'pain', 'having to go to a nursing home' and 'finances'. Many were concerned about 'being able to get the health care I need'. Anxiety and sadness were concerns for many:

> *'Sadness has always been there' (*49 year old gay man, long term survivor).
>
> *'My youth is gone. I worry about companionship and being with services and people who are non–judgmental as I age'* (76 year old gay man).

Over a third hoped to return to work/study or independence.

> *'I would like to be a contributing member of my society/community. I would need help and assistance in all areas. I am lonely and desperate, how can I get more help?'* (53 year old Asian man, newly diagnosed).

Clients' future priorities for care from RDNS included assistance to stay in their own homes, staying out of hospital, understanding their health conditions, and advice on care they might need. Preparing an Advance Care Plan was rated important by many. Few saw becoming independent of RDNS as important, seeing the care as a component of helping them maximise their independence:

> *'Helping me achieve independence for as long as possible'.*

This comment suggests that ongoing involvement of RDNS (and other services) does not necessarily represent a loss of independence for some, but a way to achieve longer–lasting independence

Key informants' views

Interviews with HIV sector workers and HIV specialists (nursing and medical) identified ageing, co–morbidities, increasing diversity more (women and children, refugees), public health issues related to drug use and unsafe behaviours, increasing numbers of newly diagnosed people, the risk of a potential epidemic amongst injecting drug users, and social isolation as key issues for the future that would impact upon RDNS' service.

> *'We know that with premature ageing, either caused by the disease or by the drugs or by a combination thereof, we're going to see more*

people requiring increased community and then residential or high level care' (HIV Specialist Nurse, external agency).

*'[…] clients who have got schizophrenia, who have got HIV who are out in the community they are a public health risk because they are unable to negotiate or their delusional system won't allow them to negotiate safety…I think that we will do a lot more close liaison [with RDNS] and working with co–clients in that I am seeing a lot more disabilities, intellectual disabilities…' (*Senior Public Health Nurse).

Strengths

Key informants identified the HIV Team's role in advocacy, community development initiatives (such as a nutrition program), education role and high quality service response as key strengths of the HIV program.

Service gaps

The key informant interviews identified lack of continuity of care, inadequate HIV specialist nursing support, need for better care coordination across services, and the need for mental health expertise as 'occasional' gaps in the service.

*'there's been a handful of people I've seen recently where I have thought, that they DO need ONE nurse at home, because of the types of problems they have, so I think there's a group that need the consistency […]I suspect that maybe you're not always resourced to do that' (*HIV Specialist Physician).

Mainstreaming

'Mainstreaming' was raised by key informants as a potential future concern. HIV sector workers, especially those who are HIV positive themselves, are wary about calls for mainstreaming:

*'I actually choose services that are HIV savvy, I won't go outside of that' (*Peer support worker, HIV agency, HIV+ woman).

'It would bother me if it was mainstreamed [into RDNS] because you've got a whole bunch of people who aren't educated and you don't know what their response is going to be. If they're educated, we don't have that issue, we can go to one of you guys and it's all OK, we have that confidence in you and we don't have to speak up. If there's any discrimination that goes on (laughs) you guys DEAL with it. You bear the brunt of it FOR us' (Peer support worker, HIV agency, HIV+ve woman).

Staff survey – Workforce development needs

Knowledge and skills

RDNS staff report significant knowledge deficits in all areas of HIV care, but especially those most pertinent to this client group – needs of specific populations/vulnerable groups

(such as gay men, refugees), HIV prevention (post exposure prophylaxis), medical management (antiretrovirals, medication toxicities, co–morbidities), legal and ethical issues ('right to know' a diagnosis, privacy, disclosure, discrimination), mental health and psychosocial needs. Disturbingly, many report ambivalence about Standard Precautions, the foundation stone of safe clinical nursing practice in terms of infection prevention.

Attitudes

Staff are generally willing to provide care to PLHIV, though fewer are comfortable in doing so, most citing inadequate knowledge.

Limited exposure to HIV clients in their area, complexity of HIV clients' issues, lack of knowledge, concern over clients' mental health drug use or behaviours and inability to provide continuity of care were seen as potential concerns in caring for PLHIV.

A number of staff, principally managers, expressed lack of understanding of and support for the HIV Program, suggesting that having specialist staff 'de–skills' other staff, and that clients should be (or already are) treated 'the same' as all others, effectively 'mainstreamed' into RDNS.

> *'Having an HIV Resource nurse takes opportunities away from primary nurses – they then become deskilled'.*
>
> *'HIV clients should be seen and treated as every other client not discriminated or made to appear "special"'.*

There is incongruence between the views of field staff, most of whom report low levels of skills and knowledge yet are interested to learn more and partake in care of PLHIV, some managers suggesting that they have been 'deskilled' and that care should be 'mainstreamed', and key informants who describe PLHIV's concerns about disclosure and poor treatment in health services. Field staff acknowledge the supportive role of the HIV Team and the need for expertise.

Key informants in the sector note that stigma and discrimination are still prevalent and it is this, in particular, that affects PLHIV's access to and experiences within services:

> *'…stigma, less so discrimination, but stigma, profoundly affects the lives of every single person living with HIV. There is no one I know with HIV who has not experienced some form of stigma that makes them feel bad, unworthy, ashamed and then of course all that stuff that that raises for them.[…] (*Senior Manager, HIV agency, HIV+ gay man).

Practice

A significant proportion of staff is concerned about contracting HIV in the workplace, even in 'no risk' situations. For example, 68 respondents (21.6%) were concerned about contracting HIV from 'drinking from a cup in a client's home'. Unease about whether pregnant staff should visit HIV clients was expressed. A significant number of staff, including managers, support the use of computer 'alerts' regarding HIV clients, justifying the practice in terms of infection prevention. Nearly 20% said they would 'use special measures with HIV clients that they would not use with other clients', and over 18% said they 'would use gloves during every aspect of client care (including history–taking)'.

> *'I would make alert HIV positive. This may not be required but I would err on the side of precaution with pregnancy'.*

A majority of staff (72%) said they felt they had a duty to disclose an HIV client's status to another nurse; 14% were unsure. 7% said they would disclose a client's HIV status to a council worker; 12% were unsure.

Many others commented simply that they use standard precautions at all times:

> *'It's not the clients we already know about, it's the unknown clients, universal precautions are there to protect all' (*DN Specialist).

Other comments indicate careful and nuanced thinking around this issue.

Stigma and discrimination

Some practices mentioned above amount to active discrimination (the use of 'alerts' regarding HIV status; excessive infection control precautions); others (such as generic intake policies and inflexible work practices) can result in indirect or passive discrimination if they pose a systematic barrier to access to some groups. Specific HIV Program practices, ('assertive outreach' approach, use of an unmarked car/no uniform to protect privacy, holistic model of care led by specialists) aiming to reduce barriers to access to care and promote quality care were not supported consistently. The Program itself is seen by some as unnecessary:

> *'The stigma associated with this disease is kept alive by assuming that a "special" team of nurses are required to look after these people. I do not believe we need a team for these people'* (Clinical Nurse Consultant).

> *'Cars & uniforms, I don't see where what people drive or wear as important, it needs to be promoted as "normal" to the client, if the clients have an issue can they access a clinic, LMO or pharmacist?* (Management role).

> *'[…] management feel they require too many resources to accommodate need'* (District Nurse Grade 2).

Such views, increasingly widespread across the organization, undermine the integrity of the HIV Program. Policies or practices that recognize and support HIV Program clients due to specific sensitivities related to the diagnosis and its psychosocial implications, are at risk of being dismantled or ignored because they are not understood and do not align with broader organizational practices.

Program development, service improvement

Many clients expressed the view that no change was needed to the service. Some made practical suggestions such as reminder calls before visits, and 'more resources'.

Key informants suggested that an HIV Program requires a supportive structure and flexibility to deal with HIV clients' specific needs including concerns about disclosure of their status, mental health and cognitive problems. Peer support and professional supervision for HIV Team staff was recommended. Mental health expertise was seen as essential for the HIV Team by one respondent.

Two HIV sector managers expressed views about the 'vulnerability' of the HIV Program, suggesting it be removed from RDNS and auspiced by a community–based organisation such as VAC who has its own medical and nursing services:

> *'My concern is that it's a vulnerable animal, an endangered species if you like. […] we've got this good working relationship with RDNS, it's a world first unique model of integrated care and I think it's not valued enough perhaps within RDNS itself. I think it needs to be front and centre' (*Senior Manager, HIV organisation).

> *'I think there would be merit if the RDNS HIV Consultancy Team was integrated into an HIV specific service such as VAC as its work is at risk of being diminished within RDNS bureaucracies or ultimately disappearing'* (Senior Manager, HIV organisation).

Nevertheless, these respondents also saw the future as requiring greater collaboration and partnerships between organisations.

Expansion of the service through Telehealth, especially for rural PLHIV, was suggested.

Sustainability

Gaps in the RDNS HIV Program service perceived by HIV sector workers related to lack of continuity of care and inadequate number of HIV–educated nurses. Sustainability

problems are identified by HIV Program staff relating to reduction in resources dedicated to nursing education, workloads and cumbersome management structures.

To build capacity within the HIV Program and to allow for succession planning, HIV Team staff propose replacement of staff leave with appropriately trained staff 'reliever(s)'. This would also help prevent loss to follow up of vulnerable clients who are difficult to engage with services and require specific expertise, for example, those with complex social or mental health problems and are newly diagnosed. It is this group who are most at risk of poor health outcomes that can also lead to public health risks.

Leadership and management

An efficient and effective management structure and dynamic leadership is essential to Program sustainability and development. In March, 2012, the HIV Team developed a discussion paper on the management of the HIV Team which outlined difficulties with its management structures – inconsistent lines of reporting, lack of support for a cohesive team approach affecting productivity and quality of care and a lack of resources tied to Program planning, growth and development [2].

Effective leadership structures in HIV care have been recognised as essential to strengthening social justice and human rights in all aspects of HIV response[3]. Good leadership structures help ensure the voices and needs of all affected (especially those most disenfranchised) are recognised and reflected – this helps protect the interests of vulnerable groups and promotes equitable distribution of services[3]. The development of a Senior Clinical Nurse Advisor (HIV) or Team Leader/Coordinator for the HIV Program is proposed to enable ongoing Program development, evaluation, seek funding opportunities and so on. Program development requires a long–term commitment from RDNS to its HIV Program.

Conclusions and Recommendations

This study provides evidence for the specific needs of RDNS HIV Program clients, and a detailed description of the role of the HIV Team in the care in the community. It provides a contribution to the literature regarding a cohort not previously described. Knowledge gaps and sustainability concerns have been identified within the agency that must be addressed to enable quality care and to plan for the future.

The role of HIV specialist nurses in the community is central to bridging the gaps between clinics, other specialist services and generic community services, especially in low HIV prevalence settings such as Australia[4]. They help facilitate transition from hospital to home and establish communication and networking between hospital and community teams. They work with family, carers and other community health workers for the benefit of PLHIV and their assessments in the home can identify issues affecting adherence, welfare and well–being that may not have been identified before[4]. They educate the community as well as other services about HIV and provide holistic care[4]. This project demonstrates that the RDNS cohort requires special attention, expertise and resources for the Program to have a sustainable workforce, develop and meet the needs of PLHIV into the future.

The HIV Program must grow to respond to emerging issues. Utilisation of this evaluation is enhanced through the articulation of practical and realistic recommendations.

Immediate and longer–term recommendations are made for HIV Program Support and staff education based on the findings. Organisation–wide professional development is recommended. Feasibility of expansion of the service into rural areas should be investigated.

The following recommendations are made for RDNS for the development of the HIV Program. These align with the priorities of the 6th National HIV Strategy[5] including emerging issues (ageing, co–morbidities) focusing on priority populations, models of care and workforce development, and the Victorian HIV Strategy[6].

HIV Program Evaluation Recommendations

Organisational	Next 12 months	1–3 years
Capacity building	1. Implement role of Senior Clinical Nurse Advisor (.5 EFT) to enable Program development and better resource utilisation (see Draft Position description in Appendix 9). 2. Adjust HIV Resource Nurse hours as detailed in footnote[1]. *Consider HIV Resource Nurses to cross site boundaries.* 3. Implement backfilling of HIV Team staff for any more than one week with 'permanent reliever' position • For succession–planning, skill development and to build capacity in engaging marginalised clients, reducing barriers to access. 4. Recognise and streamline relationship between HARP RDNS/HIV and RDNS HIV Program to facilitate seamless referral and integration of services, efficient resource use, documentation and accurate data collection for improved Program reporting and planning.	5. Review management of HIV Team with a view to reducing number of line managers to one. 6. Model HIV Program on Homeless Person's Program and consider partnership with HPP to foster Program development, research, staff support, education, shared resources, capacity building. (e.g. outreach to high and low HIV case load GPs, co – locations at other services). 7. Reconsider funding of mental health nursing role within the HIV Team; support for mental health training for HIV Team staff. 8. Implement Professional supervision for HIV Team staff. *Consider expansion of RDNS HIV service into rural areas (with a view to Telehealth consultations with CNCs, local Resource nurses and clients).*
Workforce development	9. Reinstate RDNS HIV Program into staff orientation program. • HIV prevention information made explicit in the context of Standard Precautions and information provided on staff safety and pregnant staff visiting HIV clients to demystify misconceptions and fear.	10. RDNS participate in 'Rainbow Tick' campaign and 'How2'[7, 8] through Gay and Lesbian Health Victoria to enhance cultural competency. *Consider reinstating dedicated HIV educator position or incorporate into Senior Clinical Nurse Advisor role.*

1 Heidelberg – increase from 16 hours to 32 hours per week; Moreland – increase to 40 hours per week; Essendon – new position, 24 hours per week. Re–assess hours at Caulfield and Altona.

Policy and procedures	11. Policy review – recommit to relevant, specific HIV policies in consultation with HIV Team advice (intake, assessment and care plan, referral). • Promote across RDNS to foster recognition and understanding of the impact of stigma, fear and prejudice for those infected/affected by HIV to this day that results in barriers to access to services. 12. Review and provide education on RDNS policy on computer 'alerts' to prevent discrimination and further stigmatisation.	
Marketing and branding	13. Provide banner to be used at community events (including Rainbow Tick approval once achieved), to promote RDNS as HIV and GLBTIQ–friendly.	14. Improve marketing and profile of the RDNS HIV Program internally and externally, through dedicated webpage. • Review brochures at regular intervals with HIV Team
Partnership Strengthening	15. Review and recommit to Partnership Agreement with Victorian AIDS Council/Gay Men's Health Centre HIV Services with HIV Team and identify and formalise other HIV sector Partnerships. 16. Invite representative of PLHIV organisation(s) to participate in RDNS consumer reference group.	

HIV Team	Next 12 months	1–3 years
Workforce development	1. Utilise evaluation data in reviewing internal and external education – in particular, for sessions on HIV and ageing, psychosocial issues, prevention, specific populations, legal and ethical issues, stigma and fear, health literacy, engagement and retention in HIV care. *Collaborate with Diversity Team, Quality Manager, Education department, Safety, Health and Environment.*	2. Implement regular educational 'road shows' to sites 3. Revise and update RDNS HIV Manual for RDNS staff – 'Caring in the Community' and carers' booklet, 'Positive Caring' to promote the HIV Program model of care and education role.
Policy and procedure	4. Policy review – recommit to relevant, specific HIV policies (intake, assessment and care plan, referral) (see also 11 above).	5. Develop HIV assessment tool and nursing care plan. 6. Revise HIV staff position descriptions utilising national competency standards to promote understanding and recognition of roles[9].
Model of care	7. Further develop HIV holistic model of care, document. 8. Presentations and promotion of model of care.	
Partnership Strengthening	9. Review and recommit to Partnership Agreement with Victorian AIDS Council/Gay Men's Health Centre HIV Services and identify and formalise other HIV sector Partnerships (see 15 above).	
Research and evaluation		10. Develop research and evaluation plan, conference presentations, publications (pending support of and implementation of Senior Clinical Nurse Advisor or similar role).

Chapter 1: Introduction

Background

The HIV epidemic was first recognised in Australia in 1982 and over 31,000 people have since been diagnosed, with 6,837 deaths recorded to January 2012[10]. In Victoria, over 7,000 people are currently living with HIV [11]. Whilst most PLHIV in Australia are living well due to effective combination antiretroviral therapy (ART), a minority experience poor health outcomes, late HIV diagnoses, and multiple co–morbidities[12]. The RDNS HIV Program has a key role in engaging and caring for this group, amongst the most vulnerable, marginalised and disadvantaged PLHIV in Victoria.

Community context

The RDNS HIV Program was established in 1985, at which time the organisation was proactive in educating staff and their families about HIV[13]. RDNS' HIV Team now consists of 3 Clinical Nurse Consultants (CNCs) working across Melbourne and the Mornington Peninsula. There is an RDNS HIV Liaison Nurse at one public hospital. In 2003, 2 additional roles were established ('HIV Resource Nurses'), providing hands–on clinical care at high case load RDNS centres[1]. An HIV educator was part of the Team but the role was discontinued in 2006[2]. A new HIV CNC position funded through the Hospital Admission Risk Program (HARP) based at the Royal Melbourne Hospital, employed by RDNS commenced in 2010 works closely with the HIV Program but is not currently considered part of the Program.

The HIV Program is integrated with HIV Services at the Victorian AIDS Council/Gay Men's Health Centre ('VAC') through a Partnership Agreement now in its 23rd year, ensuring provision of 24–hour care and support to PLHIV. RDNS provides clinical services and volunteers provide social and practical support. Education is facilitated between the two organisations through a reciprocal arrangement. The HIV Team has informal partnerships with agencies in the sector, including Positive Women, Straight Arrows, Living Positive (Victoria) and a wide network of hospitals, community health centres and organisations.

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[2] The RDNS HIV Program is funded by the *Sexual Health and Viral Hepatitis Section, Health Development Unit, Prevention and Population Health Branch,* Victorian Department of Health.

The HIV Team can undertake outreach at the Positive Living Centre, Positive Women, Straight Arrows, Catholic HIV/AIDS Ministry and other locations as needed and often receives referrals and first engages with clients at these venues.

RDNS HIV model of care

The current model of care of the HIV Team encompasses: nursing consultancy, education and support to field staff[3], clinical care, health promotion, strong individual and structural advocacy, care coordination and assertive outreach to HIV clients[4]. A social model of health and strong primary health care focus underpin the HIV Program model.

HIV Resource Nurses perform most hands–on care at the high case load sites, with support of the CNC, working with site–based primary nurses where appropriate. The HIV Resource Nurses meet regularly with the CNC for supervision, education and support. They have undertaken further study in HIV care, and are skilled in: supporting clients, carers and staff, managing complex medication regimes, treatment of opportunistic infections and cancers, mental health, drug and alcohol, homelessness advocacy and support, and recognizing HIV–related cognitive impairment and behaviour issues. They are confident and highly competent in providing care to HIV clients. At sites without Resource Nurses, the CNCs seek to educate and support primary nurses to deliver care. In many cases, the CNCs coordinate care for clients with complex needs with limited yet essential involvement from the sites.

Challenges within the model of care

There can be difficulties attracting, utilising, educating and retaining RDNS field staff in HIV client care for a range of reasons:

- Clients who are newly diagnosed with HIV require advanced specialist assessment and interventions including education and referral to specialist services;
- Engagement with this client group requires responsiveness, assertive outreach, a proactive, holistic approach, and a commitment to continuity of care – some RDNS

[3] Field staff include district nurses, allied health and community care aides.

[4] Such as those who are homeless, transient or in unstable housing, and those who cannot meet at their own home due to fear or inability to disclose their HIV status or sexuality to family members or housemates.

sites are limited in their ability to provide this continuity due to resource constraints and competing priorities;

- Clients often have mental health or alcohol/drug issues and need for crisis intervention which is beyond the competence/scope of practice of local nurses. The HIV CNCs and mental health nurse can coordinate referrals and specialist mental health care through established networks more effectively and efficiently;
- Some HIV clients will not accept visits from staff in uniform or with marked cars. To ensure equity of access to services, the HIV Team CNCs do not wear uniform or have marked cars for this reason and are flexible to meet in places other than a client's home if needed; this is especially important with clients from some ethnic groups.
- Clients may disclose they are engaging in risky sexual or drug using behaviours that require intervention by skilled clinicians and referrals to the Department of Health Contact Tracers; sound ethical judgment, decision–making and expertise is required.
- Continuity of care is compromised by the use of casual or 'relieving staff' for extended periods, or primary nurses routinely changing areas. To maintain client engagement with the service, the CNCs must substitute.
- Since February 2010, HIV is no longer a core component of the RDNS staff orientation program, and unlike any other specialties (continence, aged care, diabetes), HIV is not covered adequately, if at all, within most university nursing curricula.

The current model of care has developed in response to client needs and in conjunction with the development of community services within the VAC/GMHC and the HIV sector more generally. There is no other service able to provide this level and type of care in Melbourne. Sustainability concerns were identified by the HIV Team staff prior to this evaluation related to these issues.

Policy context

A key priority of the 6th National HIV/AIDS Strategy (2010), is 'Emerging issues': the increased needs of people living long–term with HIV and ageing, models of care, and workforce development for services caring for PLHIV [5], p. 31.

Rationale

The HIV Team has responded to an increasing number of referrals, and has increased access to services for people with HIV in the past 8 years, tripling the Program's numbers, from 42 in 2003 to over 140 in 2013 and 30 more through the new HARP HIV Program at Royal Melbourne Hospital. This trend is likely to continue.

The HIV Program cares for people from new HIV diagnoses to palliative care, within a health promotion framework and is a recognised lead nursing organisation with HIV expertise. As PLHIV survive longer, their health and social problems have become increasingly complicated and challenging. Many have mental health, drug/alcohol issues, cognitive impairment, frailty and experience homelessness [14]. A high proportion are gay men who have had life–threatening illnesses and suffered multiple losses, often with no social recognition[15]. Those from culturally diverse backgrounds commonly face other problems related, for example, to refugee status, many presenting late with HIV disease [16]. These are the PLHIV who require the services of RDNS' HIV Program[17]. Each requires a high level of specialist nursing assessment and skills to optimise their health and well–being, with benefits for public health in terms of HIV prevention education and antiretroviral adherence support. Recognition of these challenges by HIV Program staff and their concerns about program sustainability provided the initial impetus for this evaluation.

There is an urgent need for research into the current and projected needs of RDNS HIV clients and consequent service demand trends. Emerging issues include accelerated ageing, multiple co–morbidities, cognitive decline and mental health problems, on a background of financial hardship and marginalisation.

This evaluation aims to improve client outcomes through contributing to evidence on the current and future needs of PLHIV, and the nursing profession's preparedness to meet these needs into the future in the community setting. It will contribute to the body of knowledge on special issues for PLHIV, especially those who are ageing. Evaluation of the Program is critical for accountability and quality improvement. Additional benefits include capacity–building in evaluation within RDNS[18].

Chapter 2: Aim and Objectives

The key RDNS HIV Program objectives pertinent to this evaluation include:

- 'To recommend ongoing development of the Program within the agency in response to changing needs of community and clients in light of new HIV–related knowledge'; and
- 'To provide appropriate education programs and support to RDNS staff involved in caring for people living with HIV'[19], p. 6.

The aim of this evaluation is to provide an analysis of the HIV Program clients' current and projected needs, and staff educational preparation in providing care for HIV clients. Specifically, the evaluation objectives are:

- To identify and describe the needs of HIV Program clients in view of the current client profile/demographics and epidemic dynamics, to develop and recommend options for HIV Program development. This includes consideration of:
    - Longevity, ageing, and co–morbidities of the client group;
    - RDNS staff's educational preparation in HIV and their competence in relation to providing clinical care, cultural diversity, and understanding and addressing ethical issues arising in HIV care.

Key evaluation questions and the associated research tools selected are outlined in Table 1.

Table 1: Key evaluation questions and research tools

Evaluation questions	Evaluation/research tools
1. What are the needs of RDNS HIV clients in view of: – the current client profile/demographics; – HIV epidemic dynamics and projections; – Potential barriers to nursing, care and support?	• RDNS HIV Client survey • RDNS HIV Program reporting data • Literature review • RDNS Staff survey • Key informant interviews
2. What are the workforce development needs of RDNS in relation to HIV client care and for future Program development?	• RDNS Staff survey • Literature review

Scope of the evaluation

The primary data sources for this evaluation were client and staff surveys. The client survey helps describe RDNS' current role in providing client care, answering questions about current and future needs, satisfaction with the service and what clients value most. Qualitative data from comments made within the survey and through key informant interviews provide further contextual information. Document review through examination of HIV Program data and literature reviews assists to answer evaluation questions about client needs, workforce development and human resource requirements. The staff survey answers evaluation questions about knowledge, attitudes and practices in relation to the care of HIV clients.

Ethics approval

The RDNS Human Research Ethics Committee granted approval for this project on 15 October 2012, with minor amendments completed by 25 February 2013. The HREC Approval letter is included in Appendix 2.

Chapter 3: Literature review

Literature on emerging needs of PLHIV

Ageing, premature ageing

By 2015, it is estimated that over half of PLHIV in the USA will be over 50 years of age[20], with similar trends occurring in developing countries with better availability of antiretroviral treatments [21]. The average age of Australians living with HIV is over 45 years and the number over 60 has been increasing at 12% per year since 1995. In Victoria, the proportion of PLHIV over age 55 has increased from 2.7% in 1985 to 11.2% in 2000 and 25.7% in 2010, with a predicted further increase to 44.3% by 2020 [22]. In comparison, the average age of current RDNS HIV Program clients is estimated to be 55.6 years (excluding 2 children below 7 years) indicating that this cohort is ten years older than the average for PLHIV in Victoria.

Research indicates that older people with HIV have multiple co–occurring diseases ('co–morbidities'), experience anxiety about ageing, high rates of depression, reduced self–esteem (sometimes related to altered body shape and image), and feel the need to carefully manage disclosure of their HIV status (and/or sexuality) in the face of stigma and perceived stigma [23]. The nursing literature on ageing PLHIV also emphasizes co–morbidities, long–term medication toxicities and drug interactions, erectile dysfunction, diabetes, peripheral neuropathy, hepatitis C, and renal disease [24, 25] as concerns requiring attention. Significant strengths have also been reported amongst PLHIV in developing resilience and a positive outlook[23, 26].

One large international case control study showed that, compared with HIV–negative controls, HIV–positive people have a higher rate of co–morbidities (or non–infectious co–morbidities) at all ages; however, the most significant rate was amongst those over 60, where the rate of co–morbidities in PLHIV was 63% compared with 12% for HIV–negative controls [27]. In addition, co–morbidities appear about 10 years earlier than they do amongst HIV negative people. Non–AIDS related conditions or co–morbidities that disproportionately affect PLHIV include cardiovascular disease, diabetes, osteoporosis, liver and kidney disease, mental health issues, cognitive problems, drug and alcohol problems to name a few. Cardiovascular disease can be related to untreated HIV infection and certain antiretroviral therapies[28].

Whilst AIDS–defining cancers remain the most common cancers in PLHIV, both HIV–related and non–AIDS–defining cancers are increasing and are much more prevalent amongst PLHIV than within the general population[29]. Hospitalization rates for PLHIV have been reported as 50–300% higher in a cohort of HIV patients in Australia than in comparable groups (by age and sex) in the general population, with age being significantly associated with hospitalisation[30]. Mortality rates amongst PLHIV are still around 10–fold higher than in the general population[30].

Thus, as PLHIV live longer, the prevalence of co–morbidities increases significantly, and negatively affects health related quality of life – PLHIV require enhanced community support [31].

Mental health and cognitive impairment

A comprehensive study into the needs of older people with HIV in the USA reported that ageing people with HIV experienced depression at a rate about 13 times greater than the general population[32]. Studies have identified issues around higher rates of suicidal ideation, rumination and perseverating thoughts in older PLHIV, especially related to cognitive decline[33].

Mental health issues and drug and alcohol problems continue to compound vulnerability for PLHIV. It is also recognised that appropriate management of people with HIV–related cognitive illnesses is a particular challenge, with this group requiring intensive levels of care in the community [5, 32].

Mental health issues, cognitive impairment and/or drug and alcohol problems can have negative effects on treatment adherence – this is particularly relevant for the RDNS client cohort [34].

Long term survivors

Specific needs of long–term survivors with HIV include those raised above, as well as psychological and emotional concerns relating to grief and loss, particularly for gay men. International studies have shown that older gay men often struggle with issues such as the interruption of their life trajectory many years ago, maintaining their health and dealing with HIV treatments[35]. Many gay men overseas and in Australia had their social networks decimated, and their lives were shaped by the epidemic in the 1980s[36]. Although the HIV population in Australia is becoming more diverse, it still affects gay men

disproportionately, especially those who have been infected long term. There is global and Australian literature documenting that gay, lesbian, transgender and intersex people (GLBTI) experience systematic discrimination within health care systems and now that many are requiring aged care services, they are having to confront discrimination again, often at their most vulnerable [37].

Newly diagnosed – women, heterosexuals, culturally and linguistically diverse people

There is evidence that HIV infection rates in Australian have risen to the levels of the mid–nineties, with a rise of 8% in 2012 after rates had been stable for the previous 4 years [38]. There has been an increase in the proportion of people diagnosed late, from 30.1% in 2002 to 33.5% in 2007–2011[38], p. 29, most from culturally and linguistically diverse backgrounds (CALD) .

The epidemic demographics are shifting with more people from refugee backgrounds being diagnosed and an increase in women, principally from high prevalence countries or who have contracted HIV from a person from a high prevalence country [38]. There have been increases amongst Aboriginal and Torres Strait Islander (ATSI) people, and while 37% are associated with heterosexual contact between men, 34% are reported amongst heterosexuals and 18% amongst injecting drug users[38]. 8% of HIV infections in Australia have been amongst people who inject drugs, however half of these also report homosexual contact [39]. These groups are more likely to be economically disadvantaged, living in areas with reduced access to HIV services [40].

Stigma and discrimination

Stigmatisation of PLHIV, and self– or internalised stigma are reported by most, if not all PLHIV [41]. This continues to affect their lives and their experiences within health care. In the most recent 'HIV Futures'[5] report, 26.4% of respondents said they had experienced discrimination in health care settings (mostly relating to infection control, avoidance and confidentiality breaches) [42].

Stigma and discrimination can be heightened for newly arrived migrants/refugees within their own communities. They can experience multiple barriers to access to services

[5] The HIV Futures report is a three yearly survey of PLHIV in Australia conducted by the Australian Research Centre in Sex Health and Society.

including language, lack of familiarity with the health system, ability to deal with medical terminology and dependence on family members to access services, and fear that disclosure of HIV status will lead to ostracisation or risks such as violence[16].

Geographical distribution

Victorian data indicates that the largest number of new HIV infections derive from the North West Region of Melbourne, now surpassing the Southern Metropolitan Region [43]. A recent report into HIV and Ageing recommends 'decentralised support services and programs to outer suburbs and regional areas' [23], p. 98. RDNS is one of the few services with HIV expertise that is not centralised and covers all metropolitan areas, however, does not service regional areas. A recently opened rapid HIV testing Clinic in Fitzroy is likely to lead to further increase in diagnoses in this region[44] and likely referrals to RDNS. The new HARP CNC role (described on page 16) has also led to increases in referrals to RDNS in the Northern and Western Regions, especially PLHIV who are reluctant to engage with services outside the hospital setting.

People with high support needs

The Victorian HIV/AIDS Strategy states:

> *Sub–groups of people with HIV/AIDS continue to experience difficulties in accessing treatment care and support services. Agencies are encouraged to identify vulnerable groups of people with HIV/AIDS and to design a range of strategies and services to better meet their needs6,* p. 25.

In reference to homeless PLHIV and others with high support needs the National HIV Strategy points out:

> *People who have high support needs are at greatest risk of disease progression and also, possibly, of onward transmission. Some are also at risk of being lost to follow up. Specialised and better co–coordinated services are needed to respond to their needs*[6] p. 37.

Internationally as well as in Australia, there are high rates of homelessness amongst PLHIV and high rates of HIV amongst the homeless [6]. Many, if not most, RDNS HIV clients live without the support of family and friends generally expected within society with ill–health. This can be because of stigmatization and rejection within their own ethnic community, or fear of rejection if they disclose their HIV status or sexuality, or for other reasons such as a history of injecting drug use, and consequent ostracisation or marginalization. Many HIV clients belong to sexual minorities, or have engaged in stigmatized behaviours resulting in

their being marginalized from mainstream community and services; all have complex needs.

A 2009 report notes that:

> *[N]one of the existing studies or data sets provides sufficient evidence concerning those people living with HIV who have complex needs. […] PLWHA[6] who are in short term or sheltered housing, those who have significant mental health issues and those who have drug and alcohol dependencies will continue to require high levels of support and are clearly under–represented in the current evidence base'* [40] p. 24.

This research report provides evidence for the community–based needs of such a group.

Knowledge gaps

One recent, extensive North American study synthesised the state of current knowledge into HIV and ageing and areas where there is a dearth of research data and identified the following as key issues where there are significant knowledge gaps:

- Co–morbidities, polypharmacy, and the need to emphasize maintenance of function;
- The complexity of assessing HIV versus treatment effects versus aging versus concurrent disease;
- The inter–related mechanisms of immune system ageing and inflammation; and
- A required focus on issues of community support, caregivers, and systems infrastructure [20].

These gaps are evident in the Australian setting as well. This research project contributes to knowledge in the fourth area in particular.

Implications for RDNS

PLHIV are an increasingly diverse population, comprising gay and other men who have sex with men (MSM) (still the majority), heterosexual women and men, often from refugee or asylum seeker backgrounds, often living in outer suburbs where services are scarce. Increasing diagnoses are likely result from the new HIV rapid testing clinic in the north of Melbourne.

[6] People Living with HIV/AIDS (PLWHA), now referred to as PLHIV.

There is an increase in serious non–AIDS–related conditions in ageing PLHIV, and increased treatment complexity[22]. Homelessness and poor housing amongst PLHIV is also a significant concern, posing additional barriers to engagement with health services.

The implications of the changes translate into increasing complexity, high human resource requirements, and specific issues for education and training for RDNS. There is a need for a proactive, progressive response to improve access to, and quality of care for these groups.

The majority of people prefer to remain in their own homes as they age. As the sole community nursing agency providing specialist care to PLHIV, almost all of whom have high support needs, RDNS can anticipate a significant increase in service demand based on this information alone. The literature review aids the evaluation by providing evidence substantiating the HIV Team's observations and experiences in recent years, informing survey tool development and later, data analysis.

Literature on evaluation approach and design

Evaluation approach

Literature was purposefully reviewed on formative evaluation and action research approaches. This was a 'formative' or 'developmental' evaluation [45] in the spirit of 'action evaluation' [45]. In developmental or formative evaluation, the evaluator is part of a collaborative team, engaged in a 'long–term ongoing process of continuous improvement, adaptation and intentional change'[46], p. 225. The evaluator's main role is in elucidating team discussion with 'evaluative questions, data and logic, and to facilitate evidence–based decision–making' [46], p. 225. In formative evaluation, as Patton conceives it, 'understanding dynamic program processes and their holistic effects on participants' is of central interest to evaluators so as to provide information for program improvement [47], p. 18.

Although the HIV Program is longstanding, developmental evaluation is important to inform Program improvement as clients' needs change and HIV education is reviewed. The evaluation aims to ensure the Program meets current client needs through examining emerging evidence and research findings [46].

The approach draws upon action research, emphasising collaboration with stakeholders in order to promote action and change[46]. A participatory approach was deemed suitable as HIV community–based nursing emphasises participation by clients, promotion of

independence, health promotion and empowerment [9, 48]. Peak advocacy bodies (Positive Women, Straight Arrows, and Living Positive Victoria) representing HIV positive people were central to the participatory approach, sharing their expertise through interviews. A representative of Victorian AIDS Council/Gay Men's Health Centre (VAC – peak advocacy body and service provider) was a member of the Project Team. VAC, whose own volunteer–based service depends on RDNS HIV Team support (and vice–versa) has a deep interest and stake in the development and strengthening of the RDNS HIV Program[49].

Evaluation design

This was an internal evaluation[50]. As such, it can be considered part of a continuous quality improvement cycle relying on the availability of internal expertise[46]. The HIV Team CNCs were key evaluators, having knowledge of the agency, and theoretical, practical, education and ethical expertise in HIV. Limitations of internal evaluation are recognized by the Project Team (potential or perceived bias, lack of specialist evaluation skills and independence, possible reluctance of participants to provide negative feedback); however, these disadvantages were outweighed by its benefits. These include reduced costs, harnessing the Team's expertise, knowledge and insights[50], and their commitment to quality improvement, responsiveness and utilisation for Program development. Additional benefits including capacity building in evaluation, helping foster an organisational culture that values evaluation and utilisation[18], p. 41.

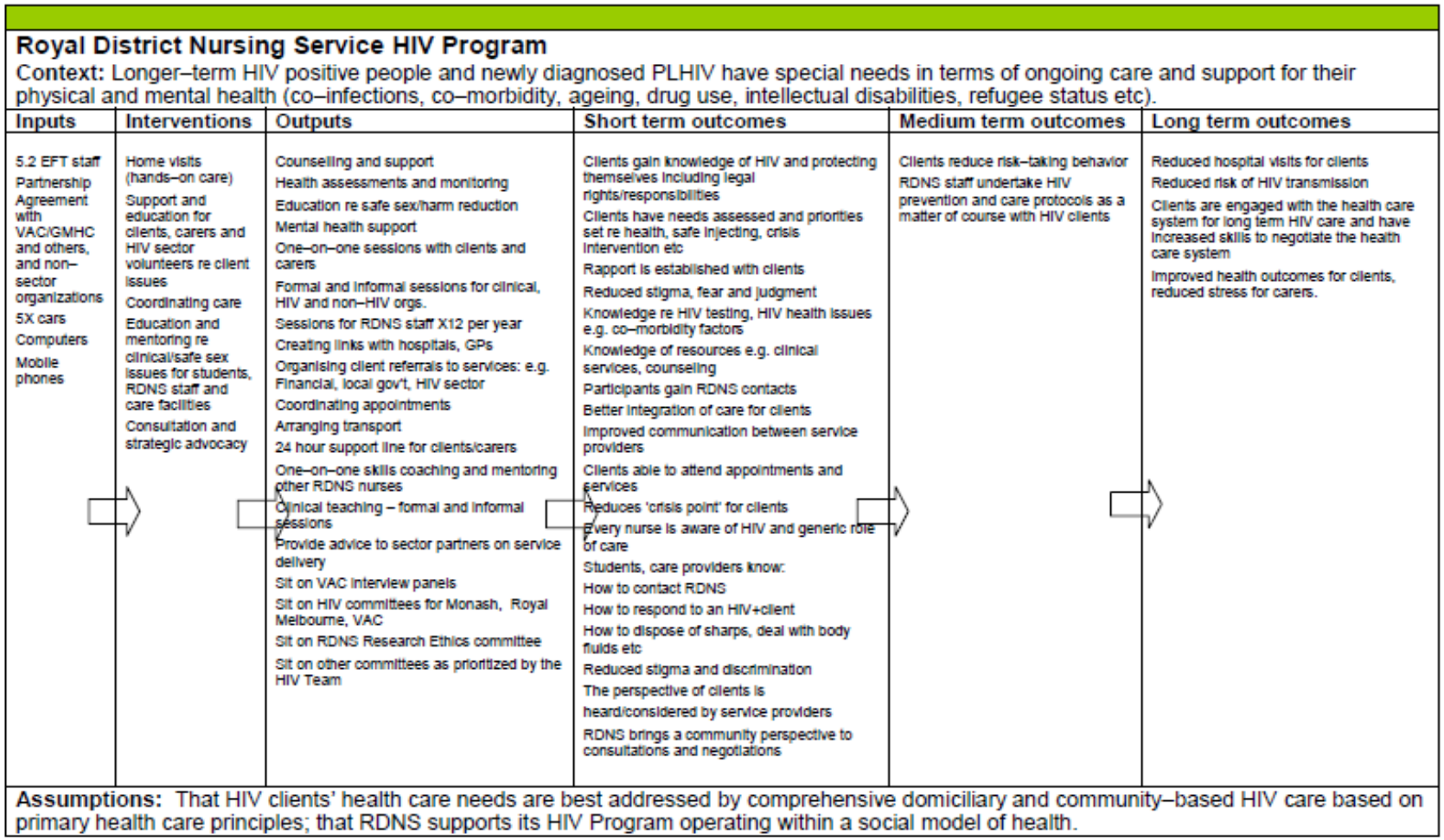
In keeping with the design, utilisation of findings was considered throughout. Attention was given to relevance, credibility and quality of the findings, and communication and timeliness of reporting will be incorporated into the recommendations[46].

Chapter 4: Methods

A budget was approved by RDNS management to allow one CNC to be replaced for 14 weeks part–time as Research Project Worker from 25 February to 3 June 2013 (Appendix 3).

A Program Logic model was developed in 2010 for program clarification [46](3) which synthesizes its main elements – clinical care, education, care coordination, support, consultancy and advocacy [51](4). This was used to help focus the evaluation and develop the survey tools [45] (see Figure 1).

Figure 1: HIV Program Logic model (adapted from Successworks, 2010).



Royal District Nursing Service HIV Program

Context: Longer–term HIV positive people and newly diagnosed PLHIV have special needs in terms of ongoing care and support for their physical and mental health (co–infections, co–morbidity, ageing, drug use, intellectual disabilities, refugee status etc).

Inputs	Interventions	Outputs	Short term outcomes	Medium term outcomes	Long term outcomes
5.2 EFT staff Partnership Agreement with VAC/GMHC and others, and non–sector organizations 5X cars Computers Mobile phones	Home visits (hands–on care) Support and education for clients, carers and HIV sector volunteers re client issues Coordinating care Education and mentoring re clinical/safe sex issues for students, RDNS staff and care facilities Consultation and strategic advocacy	Counselling and support Health assessments and monitoring Education re safe sex/harm reduction Mental health support One–on–one sessions with clients and carers Formal and informal sessions for clinical, HIV and non–HIV orgs. Sessions for RDNS staff X12 per year Creating links with hospitals, GPs Organising client referrals to services: e.g. Financial, local gov't, HIV sector Coordinating appointments Arranging transport 24 hour support line for clients/carers One–on–one skills coaching and mentoring other RDNS nurses Clinical teaching – formal and informal sessions Provide advice to sector partners on service delivery Sit on VAC interview panels Sit on HIV committees for Monash, Royal Melbourne, VAC Sit on RDNS Research Ethics committee Sit on other committees as prioritized by the HIV Team	Clients gain knowledge of HIV and protecting themselves including legal rights/responsibilities Clients have needs assessed and priorities set re health, safe injecting, crisis intervention etc Rapport is established with clients Reduced stigma, fear and judgment Knowledge re HIV testing, HIV health issues e.g. co–morbidity factors Knowledge of resources e.g. clinical services, counseling Participants gain RDNS contacts Better integration of care for clients Improved communication between service providers Clients able to attend appointments and services Reduces 'crisis point' for clients Every nurse is aware of HIV and generic role of care Students, care providers know: How to contact RDNS How to respond to an HIV+client How to dispose of sharps, deal with body fluids etc Reduced stigma and discrimination The perspective of clients is heard/considered by service providers RDNS brings a community perspective to consultations and negotiations	Clients reduce risk–taking behavior RDNS staff undertake HIV prevention and care protocols as a matter of course with HIV clients	Reduced hospital visits for clients Reduced risk of HIV transmission Clients are engaged with the health care system for long term HIV care and have increased skills to negotiate the health care system Improved health outcomes for clients, reduced stress for carers.

Assumptions: That HIV clients' health care needs are best addressed by comprehensive domiciliary and community–based HIV care based on primary health care principles; that RDNS supports its HIV Program operating within a social model of health.

Data Collection and Analysis

A mixed methods approach to data collection was taken[52]. Triangulation, through the use of several data sources (combination of quantitative and qualitative data) and analytical methods strengthened the evaluation design and enhanced the interpretation of findings[53].

Data collection

Planning and development of the evaluation was informed through consultations with RDNS' HIV Program Manager and HIV CNCs, who identified trends and challenges in the care of PLHIV. Community workers within VAC were consulted to provide support for the project's rationale. The CNCs and VAC reported increases in women and refugees, mental health and cognitive issues, early ageing, and new, late diagnoses of clients with AIDS–defining illnesses, all requiring skilled specialist input and increasing pressure on services.

Literature review

Literature was reviewed in 3 key areas:

- Changing needs of PLHIV in the Australian setting and internationally; this provided data on normative needs [54]contributing to the evidence–base and the project's rationale.
- Evaluation approaches and research methods applicable to the aims and objectives[45]; and
- Research tools for evaluating needs of PLHIV in the community setting, and for assessing nurses' knowledge, attitudes and practices with respect to HIV community care.

The literature review was reported in Chapter 3.

A review of international tools for evaluating clients' needs and staff knowledge, attitudes and practices with respect to HIV was undertaken in developing the survey tools. The questionnaires used were adapted for the RDNS setting from four international tools selected by the Project Team[55-58]. Questionnaires are useful when resources are limited and can be disseminated inexpensively, whilst protecting privacy [46].

RDNS HIV Program data

Client demographics (age, sex, ethnic background, key diagnoses, and living arrangements), human resource hours and major activities undertaken were extracted from

RDNS databases in de–identified form. This provided quantitative data for comparison over time. This is aggregate data collected routinely for Department of Health reporting at minimal cost, making efficient, effective use of existing sources [46].

RDNS HIV Program data analysis

HIV Program data was used to describe the current client profile, trends in care provision, and hours of HIV Team education and training delivery from 2001–2011 inclusive, with the assistance of Ms. Jane Howard (University of Melbourne).

This data helps answer evaluation questions about the accessibility/reach of the HIV Program and changing service demands (expressed needs) [59].

Surveys – Client questionnaire

A questionnaire for RDNS HIV clients was developed to help answer evaluation questions about effectiveness of the HIV Program including quality of care, current services and anticipated needs (Appendix 4a).

The questionnaire comprised 23 questions and was administered in hard copy. Clients registered on the RDNS HIV Program, a total of approximately 140 clients, were eligible to participate.

Inclusion Criteria:

- Diagnosis of HIV infection.
- Registered on the RDNS HIV Program.

Exclusion Criteria:

- Have a condition (e.g. cognitive impairment, intellectual disability, mental illness) the severity of which would compromise the capacity of the individual to complete the survey.

Nurses utilised a Cognitive Capacity Checklist to guide their decision about inviting clients to participate (Appendix 4b). The HIV Team considered all eligible clients on an individual basis before participation was invited.

HIV Team nurses assisted clients to complete the questionnaire if needed during a scheduled visit, helping to maximise response rates and inclusion of people from all backgrounds. A phone interpreter was utilised where required and agreed upon. Clients could elect to post their survey back to the research project worker in a stamped, self–addressed envelope. The questionnaire was piloted within VAC. It took about ten minutes to complete. Information obtained in the survey, where appropriate, was responded to by

RDNS staff in reviewing clients' current care plan, so there was a potential immediate benefit for individuals if new or unaddressed issues were raised that required action.

Questionnaires were delivered to clients over a 6–week period (25th February – 16th April 2013). Clients were given a copy of the Plain Language Statement (Appendix 4c). Consent was implied by clients' responding to the survey.

Following collection, the researcher entered client survey data into Survey Monkey ®, a web–based survey development and analysis tool.

Surveys – Staff questionnaire

All RDNS clinical and nursing managers, field staff, and specialist staff including HIV Hospital Liaison and Allied Health were eligible to complete the questionnaire. This was an HIV Knowledge, Attitudes and Practice questionnaire comprising 20 questions (Appendix 5a). It addressed evaluation questions about quality care, staff education needs and agency preparedness for care for HIV clients. Responses were entered directly by respondents into Survey Monkey ®. The questionnaire was piloted by 5 RDNS staff and took approximately fifteen minutes to complete.

An email advising of a pending survey was sent to all nurse managers on March 4th 2013 requesting they encourage staff to participate in the survey (Appendix 5c). On March 6th 2013, an 'Invitation to Participate in RDNS staff HIV Survey' was sent to 968 RDNS clinical and nursing management staff, including a Plain Language Statement and web–link (Appendix 5b). The invitation explained that the questionnaire was to identify learning needs, skills, attitudes and practice in relation to HIV, that participation was voluntary and responses anonymous. A link was provided in the email to the online survey (Appendix 5a). Two reminders were sent to staff via email through their site managers – one two weeks after the first email, and one a week before the survey closed. A response of 250 surveys was anticipated.

Quantitative data analysis – surveys

Client and staff surveys were analysed by the researcher using Survey Monkey's ® built–in tools. Cross–tabulation was performed according to staff position for questions where it was helpful to identify a group of staff who responded in a certain way to questions. Further analysis was conducted with the assistance of Mr. Alex Nikolovski (VAC) and Ms. Charne Miller (RDNS) using the software Excel ©.

Qualitative data analysis – surveys

Qualitative data deriving from client and staff surveys consisted of comments and responses to open–ended questions. Four Project Consultant meetings were held in April/May 2013 where data were analysed to identify themes and select verbatim quotations as illustration [45].

Key stakeholder informant interviews

Key informant interviews were conducted to provide expert, experience–based opinion on current and future needs of PLHIV, and ideas for Program development (Appendix 6a). 5 interviews were planned, however 15 were conducted due to the high level of support for and interest in this project within the HIV sector. Representatives of RDNS HIV Team and the HIV Program Manager, Positive Women (Victoria), Straight Arrows (Victoria), Living Positive (Victoria), the State–wide HIV Consultancy, Victorian Infectious Diseases Service, Victorian AIDS Council/Gay Men's Health Centre and a Public Health Nurse were invited to participate in a semi–structured interview. The HIV Program Manager declined to be interviewed as the questions concerned future client needs outside his expertise. Each was contacted directly by the researcher or a Project Consultant, and provided with a copy of the Plain Language Statement and Consent Form (see Appendix 6b and Appendix 6c).

Key stakeholder informant interviews–analysis

Qualitative data deriving from key informant interviews were transcribed, coded according to emergent themes by the researcher and further analysed by the Project Consultants. Verbatim quotations were selected to illustrate themes. Explanatory models and concepts were generated by the Project Team to assist in developing recommendations [45] p. 162.

Analysis was undertaken collaboratively with the HIV Team and VAC representative. Feedback was obtained through a participatory communication strategy throughout each phase of the evaluation with a focus on action [45].

Conclusions and recommendations will provide guidance and advice on courses of action for the Program Manager and the HIV Team in light of evidence [46].

Ethical considerations

Relationships between research and staff, staff and clients

One researcher has relationships with RDNS staff who were invited to complete the on–line questionnaire. Participation was entirely voluntary and anonymous, minimising risks of coercion.

The project worker and nurses who offered the questionnaire to clients to complete and could assist in its completion had established professional relationships with clients. To avoid clients feeling pressured or coerced to participate, it was explained to them that participation was voluntary and their care would not be affected in any way if they declined to participate, with the option of returning the questionnaire in a pre–paid envelope at a later stage. They were given a copy of the Plain Language Statement (Appendix 4c).

Given the goals of the project and the nature of the questionnaire, clients were mostly eager to provide their input and the benefits of participating likely outweighed any perceived feeling of coercion.

However, clients may also have felt that they could not respond negatively to questions or provide critical feedback given their relationship with RDNS staff, and staff assistance in completing the questionnaire have might compromised its integrity or truthfulness. It was emphasized that the purpose of the project was to identify and describe clients' changing needs, to plan for the future and to improve the service where required, thereby maximising the chances of clients providing frank feedback whilst obtaining necessary assistance to complete the questionnaire if needed. Clients were advised that they could also ask another person to assist them; however, given the stigma surrounding HIV and reluctance of many HIV clients to disclose their diagnosis, this option was not acceptable to some. In the interest of maximising participation of clients from all diverse backgrounds, the HIV Team believed the best option was for HIV Team staff themselves to assist clients who needed help and that HIV clients would prefer this option if they required assistance, in order to preserve their privacy. Indeed this was the case.

Social, cultural, linguistic, religious or other sensitivities

Many sensitivities needed consideration during this project, relating to HIV, clients' sexuality, disclosure of HIV status, mental health problems, issues regarding children, and cultural sensitivities around discussing HIV status and its implications. For these reasons, questionnaires were hand–delivered to clients, not mailed to them, and assistance to

complete the questionnaire was offered. Only HIV Team staff assisted with questionnaire completion because all are skilled in dealing with and responding to the sensitive issues that can arise in their daily work with PLHIV. If new or unexpected sensitive issues arise, HIV Team staff is competent in making appropriate referrals for support.

If clients were from a non–English speaking background, and they required and provided consent to the use of an interpreter, in was anticipated linguistic issues could arise in the interpretation of the questionnaire. The questionnaire was formulated with this in mind, with lay and non–technical language being used that would be comprehensible to people with limited English and/or low literacy. Client names were not to be divulged to the interpreter service since this can be a barrier to clients participating if HIV–related issues are to be discussed.

Attention to social sensitivities included nurses withholding delivery of the questionnaire and Plain Language Statement unless privacy was assured; if other people were present at a given visit, it could have been inappropriate for the nurse to discuss this project. HIV Team staff are very careful to preserve clients' confidentiality in this regard at all times.

Vulnerable population

Clients on the RDNS HIV Program, by the nature of their conditions, have distinct vulnerabilities, sometimes including mental health problems and cognitive impairment. As is recognised in the NHMRC National Statement on Ethical Conduct of Research[60], this group is entitled to participate in research, taking into consideration their distinctive vulnerabilities as research participants. HIV Program nursing staff, when recruiting clients, excluded any who had a condition (e.g. cognitive impairment, intellectual disability, mental illness) the severity of which would compromise the capacity of the individual to participate. RDNS staff did not recruit clients who would be unable to provide informed consent. If any undue distress or discomfort were to arise during the completion of the survey, the nurse was to use professional and clinical judgment to respond appropriately and provide support and the client could discontinue participation. Since this was principally a client needs assessment, it was the opinion of the researcher that there was a very low risk of distress or discomfort being caused by participation in the project. Any burden involved in the research project could be justified by its potential benefits which include current and future individual care planning and RDNS HIV Program development.

Other ethical issues such as withdrawal of consent (see Appendix 6d), data management, data use were addressed in the Ethics application. The study was conducted in accordance with National Health and Medical Research Council (NHMRC) ethical requirements [60].

Chapter 5: Results

The results of this project include data analysed from client and staff surveys, HIV Program reports, key informant interviews and document reviews.

Key issues for PLHIV identified in the literature review include:

- Ageing, premature ageing [20, 21 22 24, 25 23 28].
- Comorbidities including HIV related cancers, medication toxicities, co–infections [29 31].
- Stigma and discrimination [41 42].
- Mental health and cognitive impairment (17) [5, 32].
- Long term survivors – gay men and grief and loss [35 36].
- Newly diagnosed – women, heterosexuals, culturally and linguistically diverse, late diagnoses [38 40].
- People with high support needs [6].
- Research knowledge gaps [20].
- Geographical distribution [23]

The implications of emerging issues identified in the literature for the HIV Program include increasing complexity, impact on human resources, and specific topics for education within RDNS. There is a need for a proactive, progressive service response to ensure access to, and quality of care for all PLHIV who require it.

RDNS HIV Program data and demographics from client survey

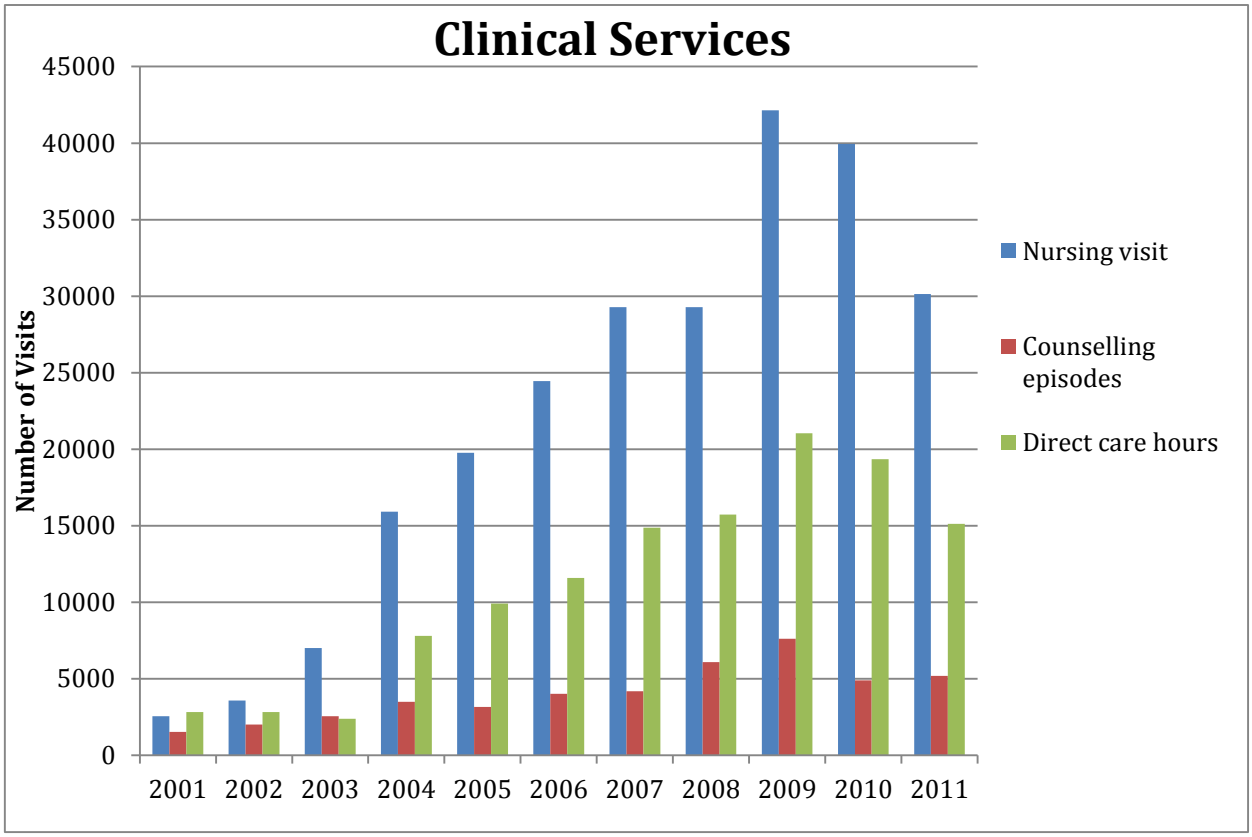
HIV Program data

HIV Program reporting data from 2001 to 2011 inclusive[7] was analysed for trends in three areas – Clinical services[8]; Stakeholder planning and evaluation; and Education (internal and external). Graphs are presented in Figure 2, Figure 3 and Figure 4.

[7] Financial year reporting periods.

[8] Note: data for 2002 in the three graphs to follow are estimates due to missing data for that year,

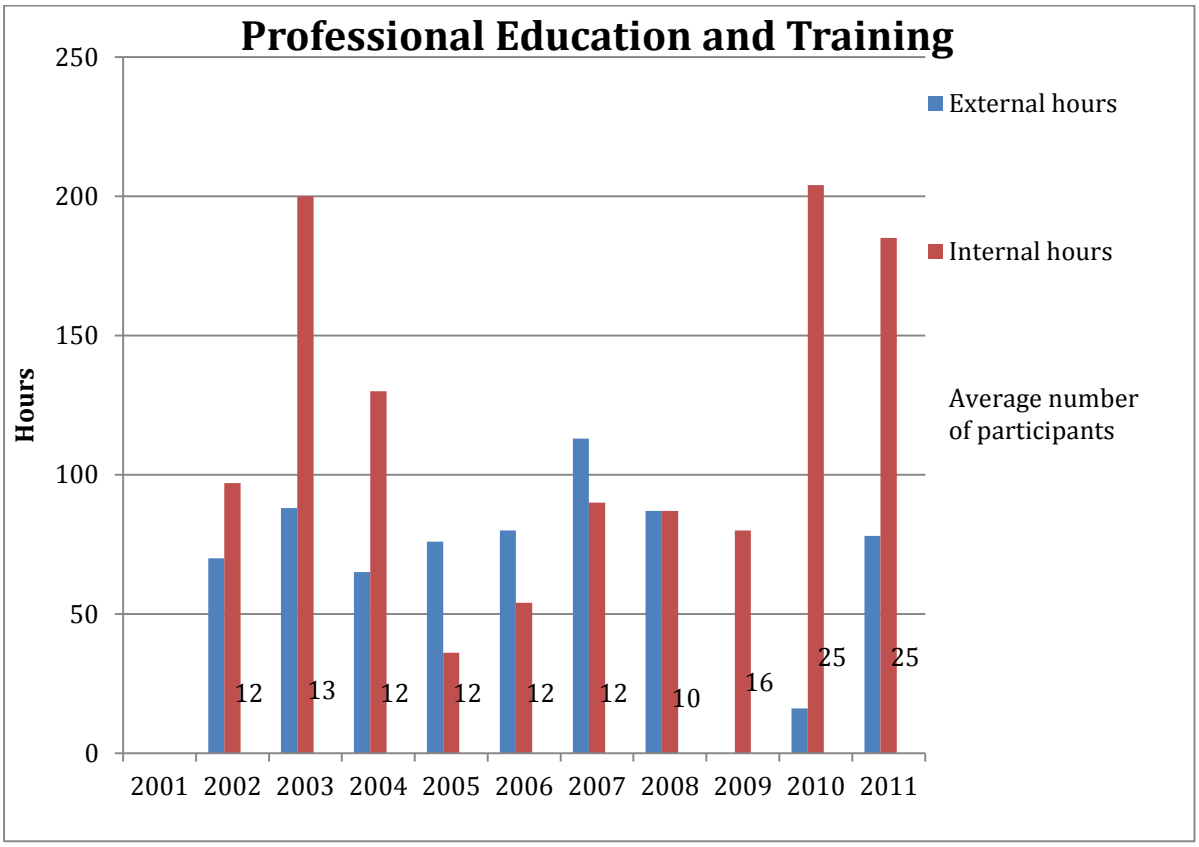
Figure 2: HIV Program data – Clinical services 2001–2011.



Clinical services data indicates an increase in visits and service hours from 2001 to a peak of 21,036 in 2009, with a decrease in 2010 and 2011. This decrease is likely to reflect the lack of one CNC for 9 months in 2010–2011 with reduced program capacity. Other issues affecting reporting data for 2009–2011 include a new computer system, and a reduction in codes used within the organization, rendering it difficult for HIV Program staff to capture their work accurately. Counselling episodes have also increased incrementally to a peak in 2009, as for direct care hours.

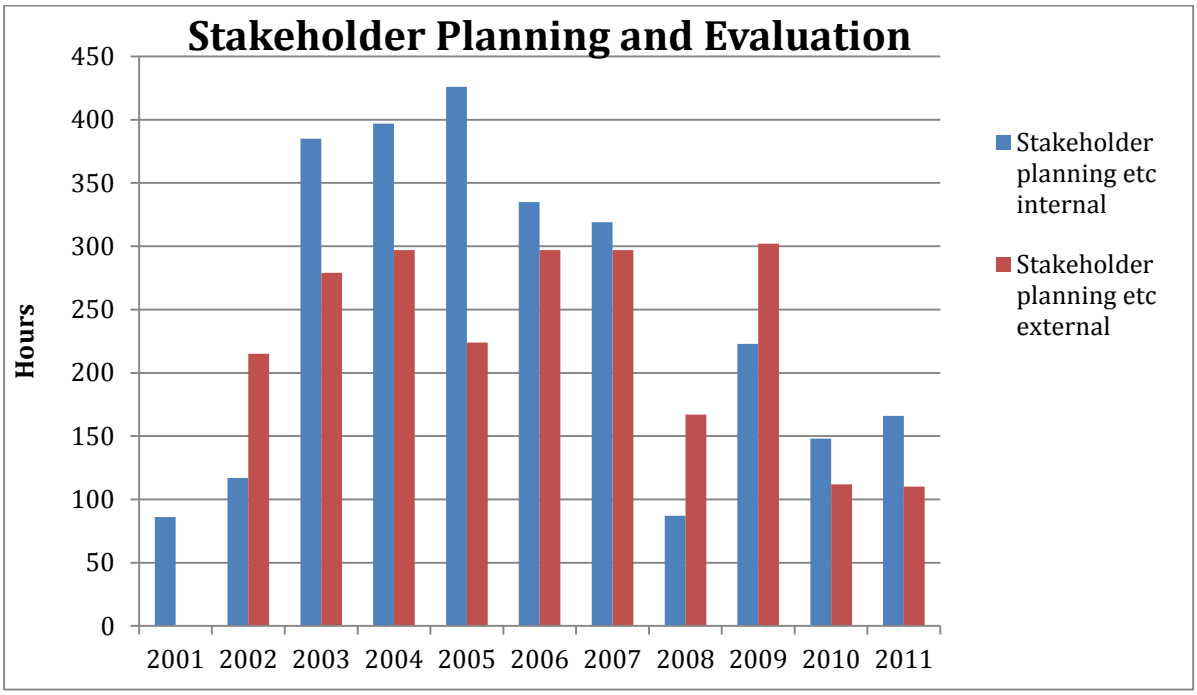
Clinical services for HIV Program clients generate additional funding for RDNS through the Home and Community Care (HACC) Program.

Figure 3: Professional Education and Training 2001–2011.



Education and Training hours peaked in 2003, with varied reporting until 2010. The HIV Team has had no dedicated educator position since end 2006. There has been a significant increase in internal and external education delivered by the CNCs in the last 3 years despite (or due to) the lack of an educator role.

Figure 4: Stakeholder Planning and Evaluation 2001 –2011.



Stakeholder planning and evaluation hours were highest in 2003–2004, with other peaks in 2006 and 2009, but in the last two years has reduced. This is likely to reflect under–staffing and reduced participation of the HIV Team in sectoral consultations and activities. It also may simply reflect fewer sectoral consultations during a given period following a change of state government.

Data was then reviewed by RDNS regions and then by RDNS site over the most recent 3 year period to examine human resource use in more detail. Hours by region are depicted in Figure 5. Number and hours of visits are depicted in Figure 6 and Figure 7.

Figure 5: Hours of care by RDNS region 2010–2012

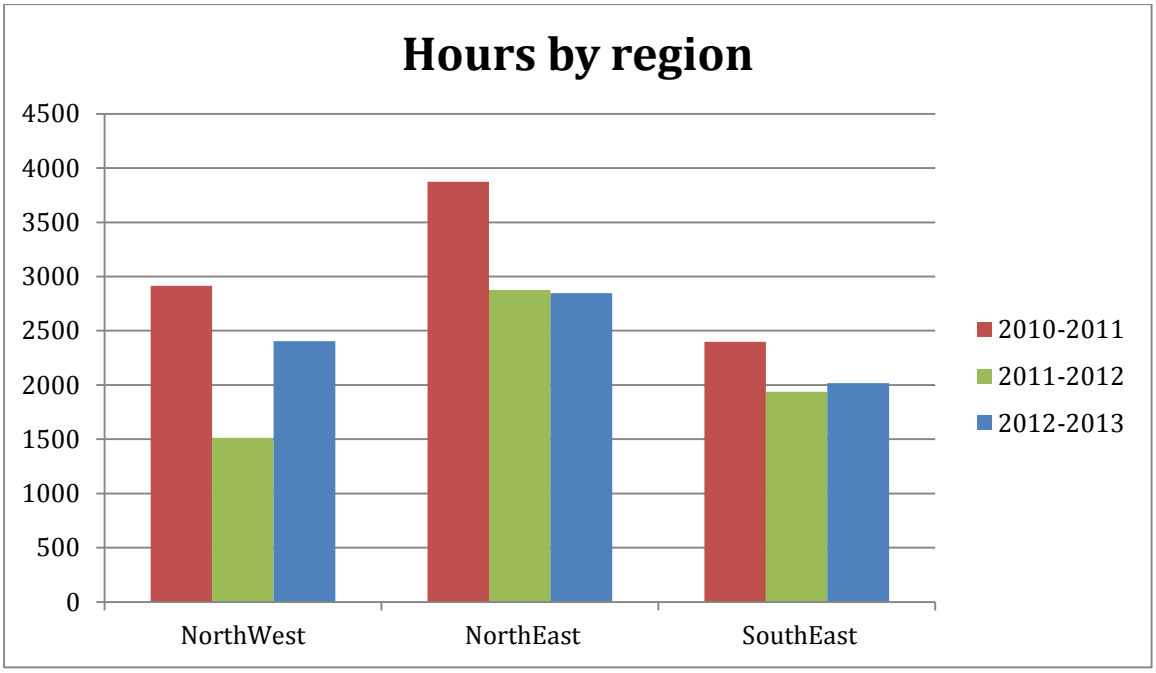


Figure 6: Number of visits by RDNS site

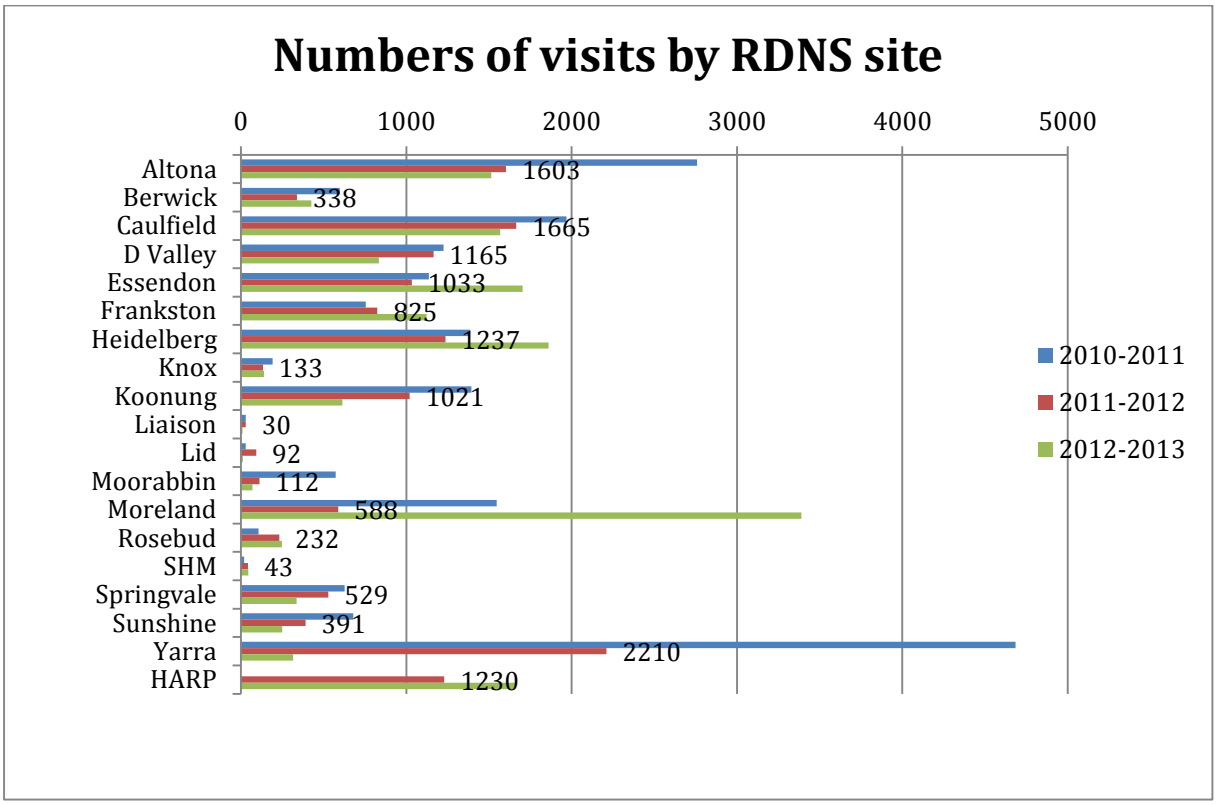
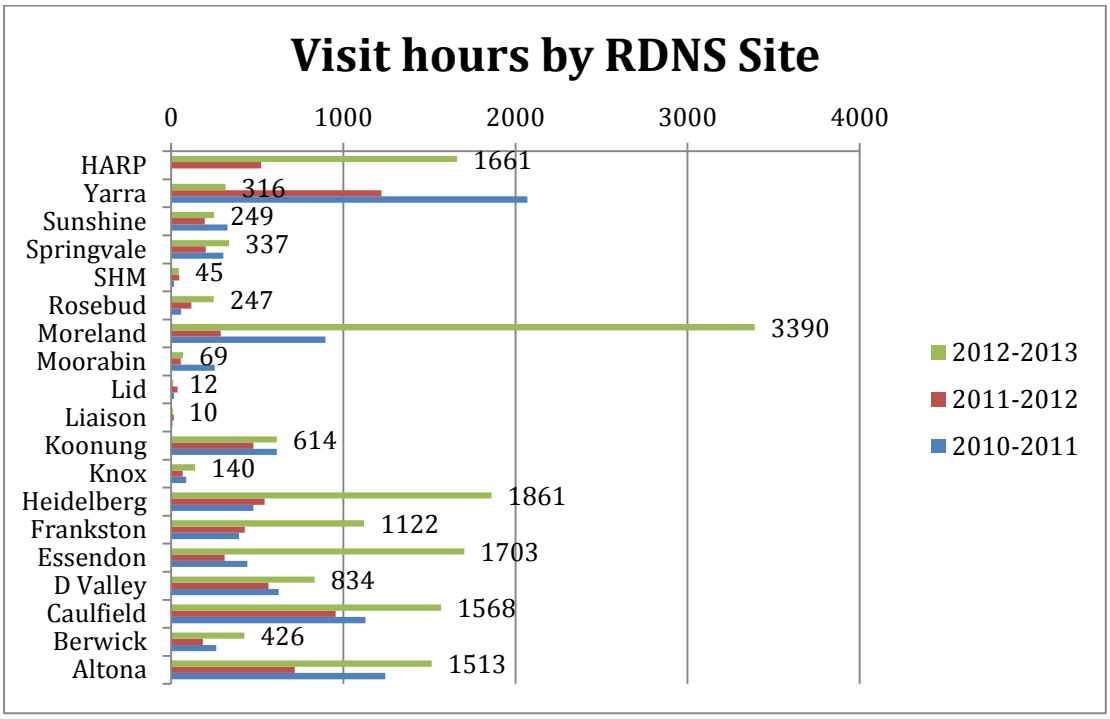


Figure 7: Hours of visits by RDNS site



It can be seen that Heidelberg, Essendon, Caulfield, Altona, and Moreland register the greatest number of visits and utilise the highest number of hours of care. Following the closure of Yarra site in 2012, Moreland in particular has grown significantly, taking over the former Yarra catchment area. Frankston, Diamond Valley, Koonung, and Sunshine are sites to monitor. The HARP Program through Royal Melbourne Hospital and RDNS is also growing and likely to have a flow–on effect to the HIV Program over time, especially in the North Western Region, as was its purpose.

Client demographics from HIV Program data

Client profile – Age

Demographic data suggest that on average, clients were aged in their late 40s and early 50s. A majority of HIV clients are aged between 40 and 60 years, with other large groups in their 30s and 70s. Figure 8 displays the age distribution of HIV Program clients overall for the 2012 calendar year.

Figure 8 HIV Program age distribution of clients living with HIV, 2012 (N=174)

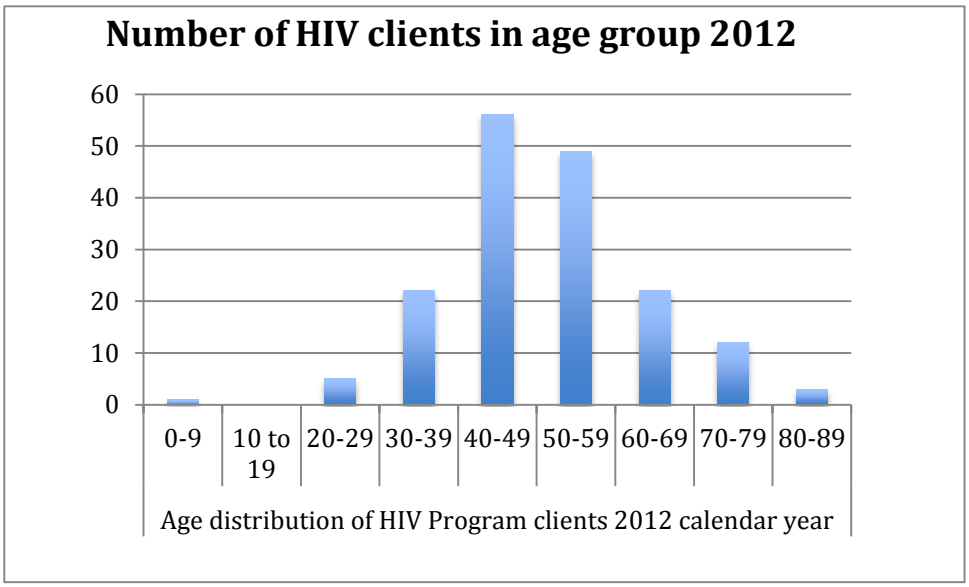
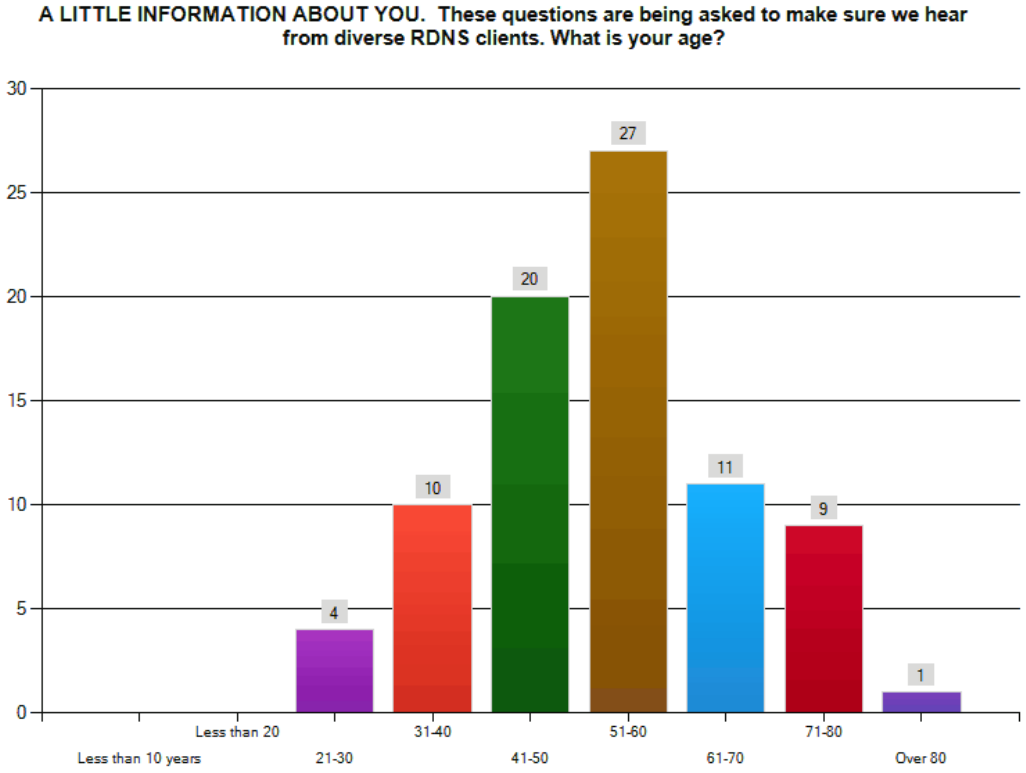


Figure 9: Sample group age distribution of clients living with HIV, 2013 (N=86)



Of those who participated in the survey, there is a slight over–representation of clients in the age group 51–60, the largest group (Figure 9). In the HIV Program overall, more clients are in the 40–49 year age group (Figure 8).

Client profile – country of origin and language

Clients come from a wide range of countries and a disproportionate number from refugee–producing countries (currently over 16% of clients registered on the HIV Program) (

Table 2). In the survey sample, diversity was achieved through proactive and culturally–sensitive recruitment by the HIV Team staff, such that fewer clients were born in Australia in the sample than in the Program overall. Thus, CALD clients are over–represented.

Table 2: Country of origin of HIV Program clients, 2012 (N–174) and project sample (N=83)

Country of origin	2012 N = 174	%	Project Participants N = 83	%
Australia	114	65	46	55.4
Indigenous	11	6	7	8.4
England	6	3.4	7	8.4
Italy	5	2.9	6	7.2
New Zealand	6	3.4	6	7.2
Africa (Sudan)	6	3.4	2	2.4
Africa (Ethiopia)	3	1.7	1	1.2
Africa (Other – Ghana, Zimbabwe)	–	–	2	2.4
Vietnam	4	2.3	–	–
Cambodia	3	1.7	–	–
Other*	27	15.5	24	28.9

* includes N=1 or N=2 for all other countries [N=83 clients because not all responded to this question].

Clients on the HIV Program speak over 23 languages at home[9]. Survey participants spoke 22 languages at home and in this respect can be considered representative of HIV Program clients.

Client profile – gender identity and sexuality

83% of clients on the HIV Program were male and 17% female. Women are over–represented in the sample, comprising 24.4% of respondents (Table 3). Data on sexuality was not available from the Program data.

[9] These were: Arabic, Chinese, French, Greek, Hindi, Italian, Japanese, Maltese (X2), Thai, Telegus, Malay, Mandarin, Croatian (x2), Dutch, Turkish, Nuer, Amharic, Macedonian, Tiwi, Shona.

Table 3: Gender identity and sexuality of sample (N= 82, 81)

Gender Identity (N=82 responses)		Sexuality (N=81 responses)			
		Gay/Lesbian	**Bisexual**	**Heterosexual**	**Other**
Female	20 (24.4%)	–	2 (10%)	18 (90%)	
Male	62 (75.6%)	41 (67.2%)	7 (11.5%)	11 (18%)	7(11.5%
Intersex/Transgender/Other	0	–	–	–	–

Client profile – co–morbidities

Records from the 2012 calendar year for HIV Program clients indicate that co–morbidities are prevalent amongst the client group including opportunistic infections and cancers, co–infections (Hepatitis C and B), mental health issues and cognitive impairment (Table 4). This data underestimates co–morbidities, because it relies primarily upon referral information (often incomplete or scarce) being entered into a database (often missed). Clients were not asked about co–morbidities in the questionnaire.

Table 4: HIV Program data – client co–morbidities 2012 (N=174).

Co–morbidity	Number and percent (%)
Opportunistic infections	16 (9%)
Other lung disease	10 (6%)
Hepatitis C	23 (13%)
Hepatitis B	16 (9%)
Hepatic Encephalopathy	3 (2%)
Cancers	19 (11%)
Cognitive impairment/dementia	21 (12%)
Mental health problems	71 (41%)
Drug and/or alcohol	22 (13%)
Osteoporosis/osteonecrosis/arthritis/fractures/joint replacement	17 (10%)
Cardiac	12 (7%)
Pain	11 (6%)

Client profile – other significant characteristics

Around 4% of current RDNS client admissions overall are homeless clients [61],[62]. Amongst HIV clients, this figure is approximately 15%, with many experiencing recurring homelessness[10]. This represents nearly 4–fold increased risk of homelessness for HIV clients compared with general RDNS clients. Aboriginal and Torres Strait Islander clients represent 0.7% of general RDNS clients[63], but about 8% of HIV Program clients, indicating eleven times greater proportion of ATSI clients. Around 10% of HIV clients are on the social work 'at risk' register at any one time, a highly disproportionate percentage of all RDNS clients on the register[14].

Surveys – Client questionnaire

The client questionnaire was administered between March 1st and April 12th 2013. The number of clients on the HIV Program at time of recruitment was 140. The goal was to survey all eligible clients. Approximately twenty were ineligible at the time. 86 responses were received (72% response rate) with a completion rate of 97.7% (84 responses). To maximise inclusion, HIV Team nurses or carers assisted with questionnaire completion. 60% received assistance from a nurse or carer to complete the survey[11]. This can be considered a high response rate [45]p. 155, acknowledging under–representation of those most unwell who were ineligible to participate.

Clients who did not complete the survey or were not offered it include those who were acutely unwell at recruitment stage, language difficulties and inability to access (or declined assistance from) an interpreter, severe cognitive impairment, or urgent social problems such as housing crisis. Another factor limiting inclusion was the time–frame. It was resource–intensive for staff to ensure all clients were offered the opportunity to participate and survey administration time was limited to one month due to the project

[10] Data on homelessness is collated by the HIV Team and is estimated to be currently 15%, including primary (e.g. on the streets) secondary (temporary shelter, refuges, emergency accommodation) and tertiary (boarding houses etc.) homelessness. Others are marginally housed (living in housing situations close to the minimum standard) or in unaffordable private rental; some are in overcrowded new migrant situations (see Chamberlain et al., 2006).

[11] Reasons for requiring assistance included visual impairment, language difficulties and difficulty accessing an interpreter, poor concentration, and low literacy.

requirements and wait for Ethics approval. The unintentional exclusion of clients can result in sampling bias [64]; it is likely that bias underestimates clients' health problems.

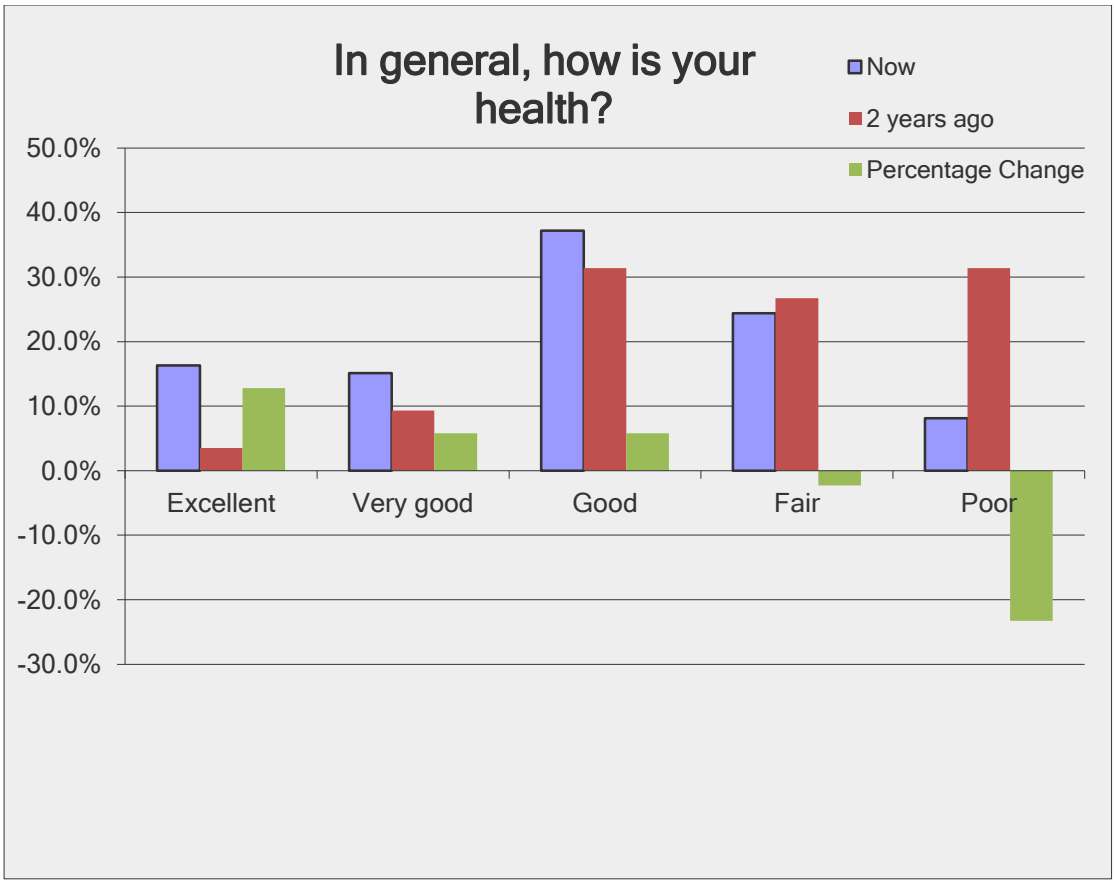
Clients' responses

Q1and **Q2** Health status

Clients were asked about their health now, and 2 years ago.

Clients provided more positive rating of their current health status (68.6% 'excellent/ very good/ good') compared to perceptions of their health two years prior (44.2% fair/poor), a difference that was statistically significant [χ^2 (1) =10.75, p<0.01], as depicted in Figure 10. This could suggest that clients who are engaged with the district nursing service believe their health has improved.

Figure 10: Self–reported health now and two years prior



Q3 Confidence in health maintenance

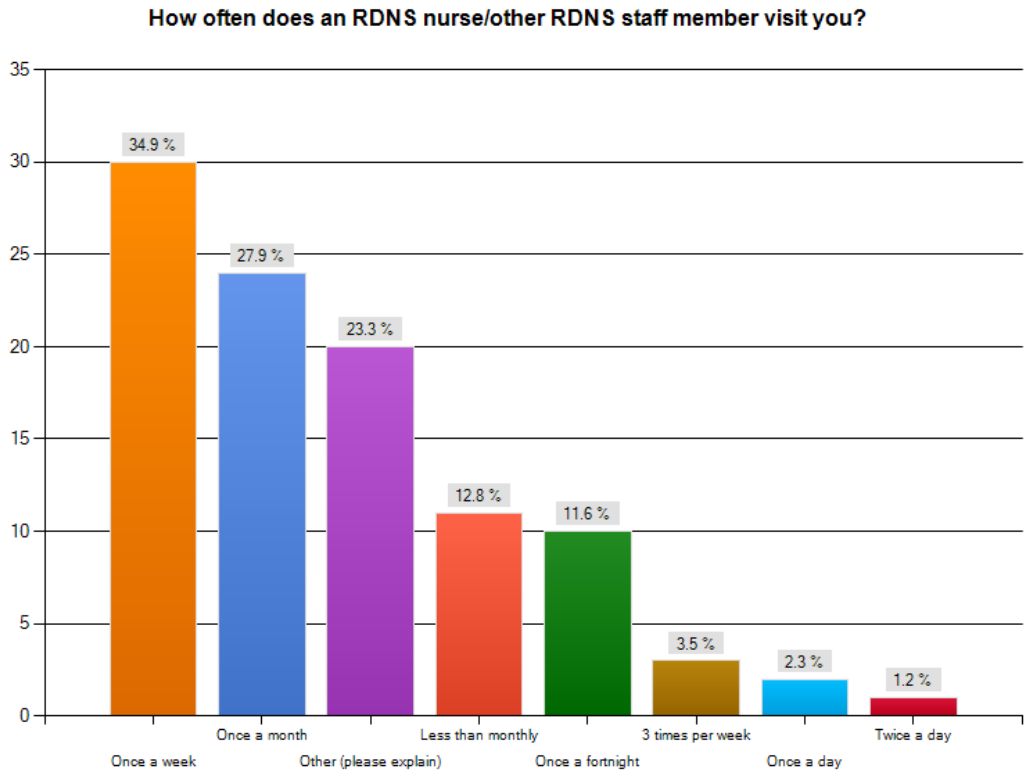
Clients were asked how confident they were that they could maintain their health in the coming 5 years. 59% were very confident or confident; 14% were not confident or very unconfident; 25.9% were unsure.

Q4 Visit frequency

Clients were asked how often they received a visit from RDNS. The most common frequency was once a week (34.9%), once a month (27.9%), followed by less than monthly (12.8%) once a fortnight (11.9%), 3 times per week (3.5%), once a day (2.3%) and twice a day (1.2%). See Figure 11.

Those who responded 'other' wrote 'every 3 weeks' ; 'I see different staff – Mental Health nurse and CNC'; 'sometimes a lot more, at one stage a few months ago more than [once] weekly'; 'more often if needed, that's the truth', and 'at first visits were weekly but I am managing health better now'. These comments indicate the service is responsive to changing needs, flexible enough to accommodate extra visits when needed and to reduce visits when clients' health improved.

Figure 11: Frequency of visits



Q5 Duration of association with RDNS

Clients had been with RDNS for < 3 months to > 20 years. The highest proportion (16.5%) had been clients for 6–12 months, with other peaks at 11–13 years (9.4%), 2–3 years (10.6%), 3–5 years, 9–10 years, (11.8%) and 6–8 years (14.1%). A small proportion,

(8.4%) had been clients for 14 to over 20 years (Figure 12). Comments included ‘on and off over the years’, and ‘10 months since diagnosed’. Some clients require support for a period, then may be discharged and later require services again. Engaging with health services (and subsequent retention in HIV care and treatment) is of critical importance here. Clients are aware that the service is available and that they can access it easily. Some who have been clients for many years reported moving in and out of the Program, and some have only been able to maintain their health at home with support.

Figure 12: Length of time an RDNS client

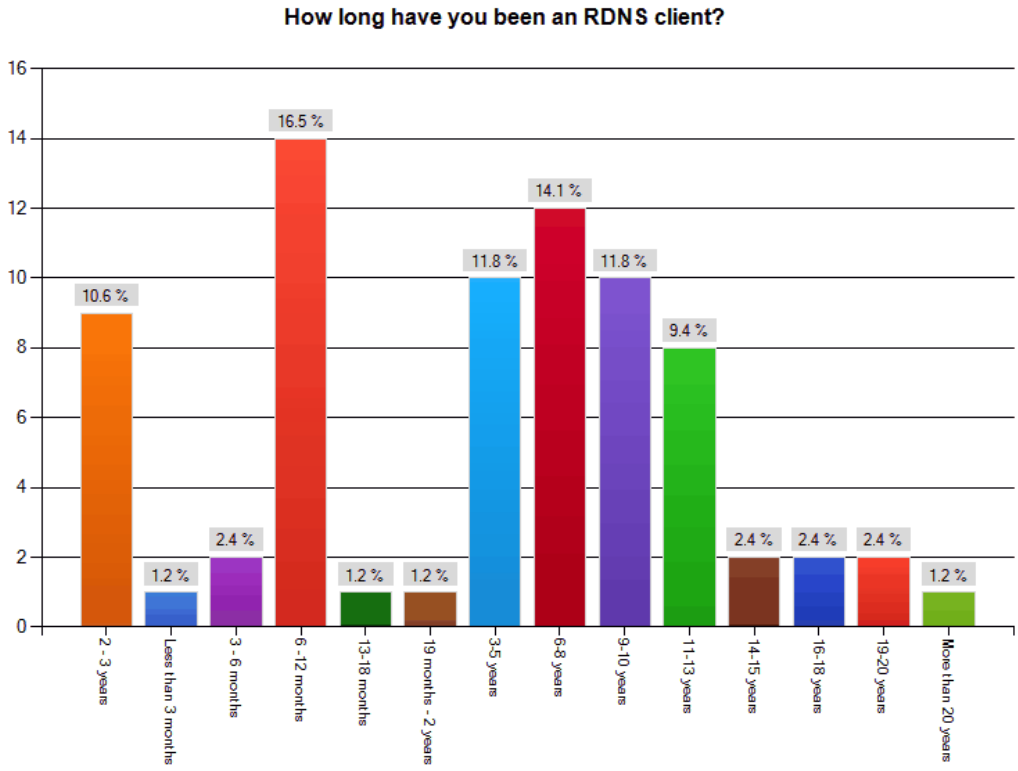
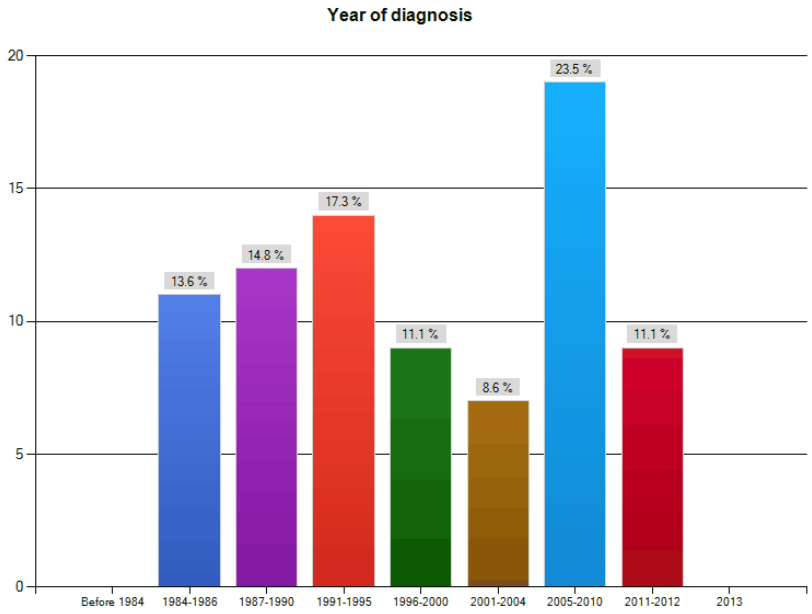


Figure 13: Year of HIV diagnosis



45.7% of respondents are long–term survivors, diagnosed from 1984–1995, before potent ART was available. The second highest proportion of respondents was diagnosed from 2005–2010. Over 11% were diagnosed in 2011–2012 (Figure 13). This data demonstrates that the HIV Program is accessed by clients at all stages of infection.

The Project Team considered that the relatively high proportion of new diagnoses might be due to the impact of the new HIV HARP role at Royal Melbourne Hospital: 5 of those who were diagnosed from 2011 –2013 were on the HIV Program, and 4 on the HARP HIV RMH Program. The important point to note is that many more newly diagnosed clients are accessing the HIV Program and they tend to be those who present late with HIV disease. On the other hand, long–term survivors, a significant number of HIV Program clients, are disproportionately at risk of early ageing, medication toxicities, treatment failure and a high incidence of mental health problems and social isolation, indicating significant support needs. This is the largest client group.

Service description

Q7 In order to gain a picture of care provided (an element of expressed need[59]) clients were asked to indicate which of a range of 35 activities RDNS staff did for them, or with them. The activities were grouped into six domains for analysis (Figure 14):

A. Health monitoring and support

B. Health Promotion and Prevention

C. Medication management and adherence support

D. Mental health support

E. Housing/financial and

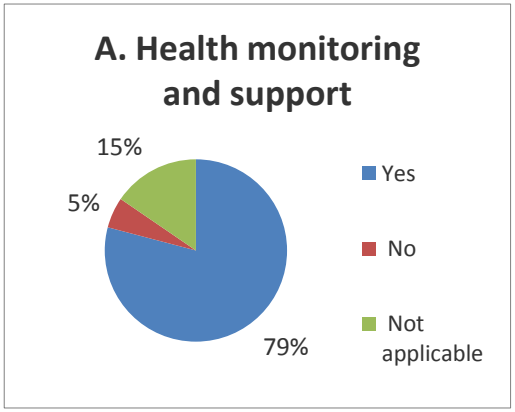
F. Care coordination.

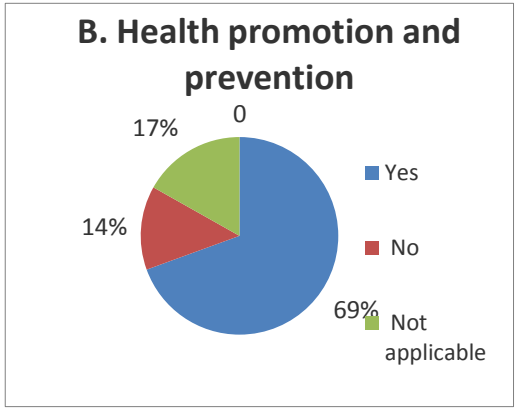
Details of activities are presented in full in the Client Questionnaire, Appendix 4a, and the codings in Appendix 7.

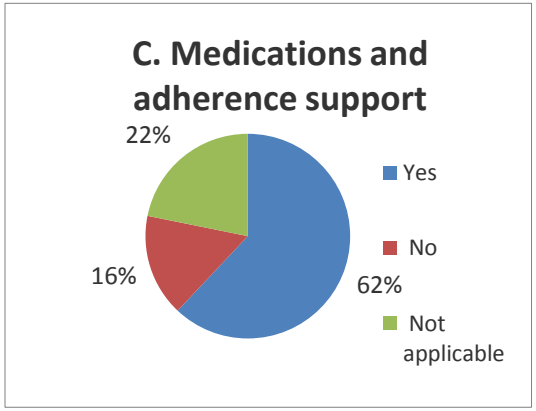
RDNS assists a majority of clients in all these domains (see Figure 14). The majority of clients (87%) identified that RDNS assisted them with activities fitting within the mental health support domain. This included 'mental health support, help me with emotional issues, when my mood is low or I feel stressed; cope with my situation; listen when I talk (support/counselling)'.

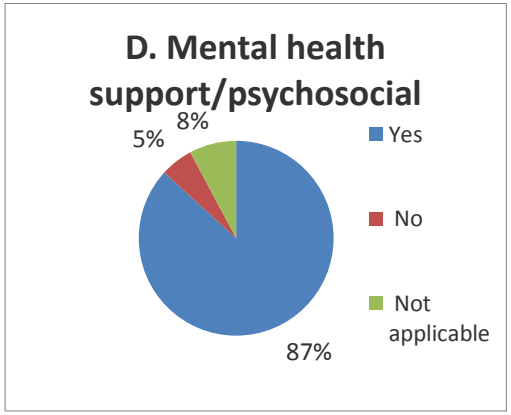
To compare across domains, the domains in which clients responded 'yes' are portrayed in Figure 15. Whilst psychosocial/housing financial support is the lowest reported (31%) it in notable that over one third of clients have difficulties in these areas.

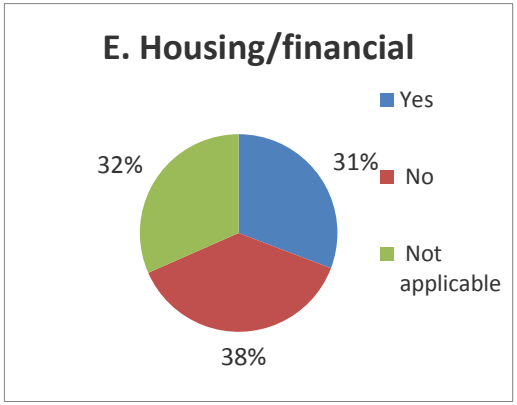
Figure 14: Domains of care provided











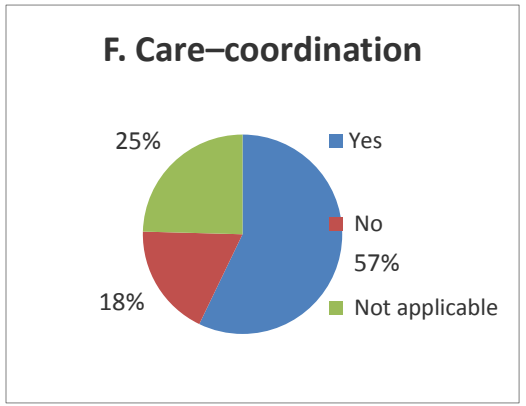
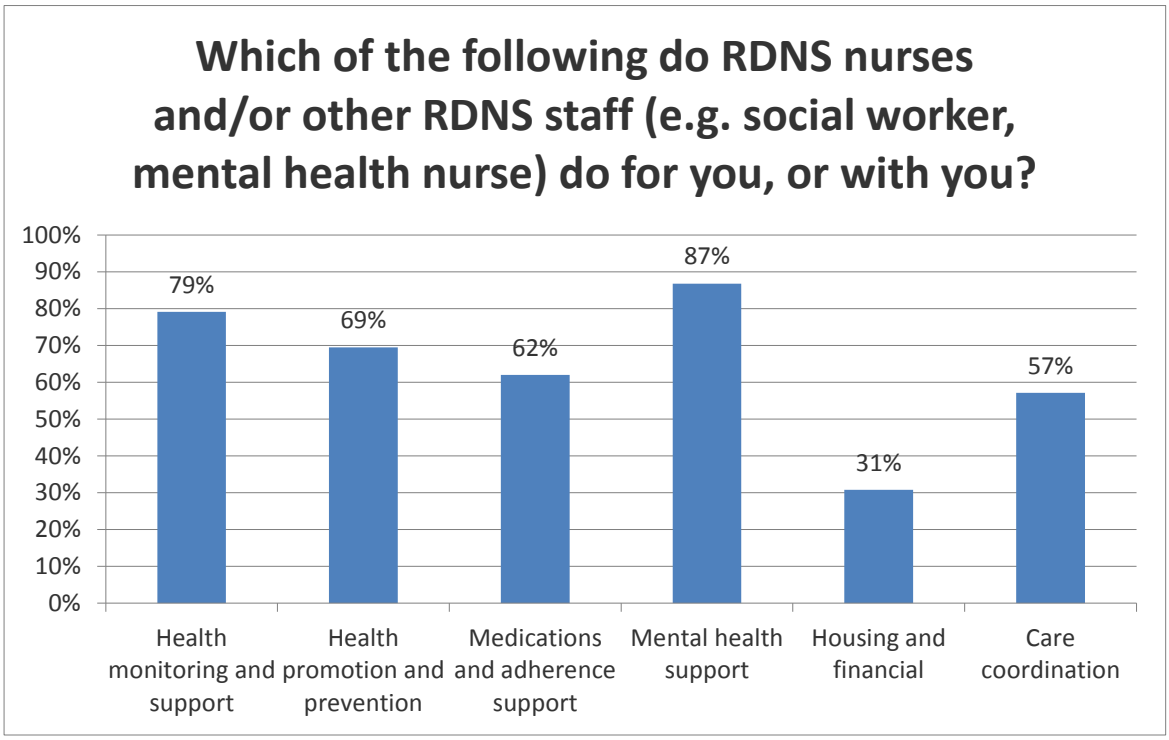


Figure 15: Summary of key areas that RDNS assist clients with



Q8 Clients were asked what else RDNS staff did for them or with them. 34 responses were received. These were classified according to themes identified by the Project Team (Table 5).

Table 5: Clients' descriptions of what else RDNS did for/with them

Practical support and care coordination	'Facilitated transport to the PLC for transport to medical appointments'. 'Diabetes nurse came for education'. 'They helped me when I was homeless'. 'Injections for Vit. B'. 'Social worker – support, bills, housing, school'. 'Fill dosette box weekly'. 'Personal care attendant visits me weekly to help me arrange my clothing, paperwork. I am totally blind'.

Mental health support/empathy	‘Make me feel worthy. All you nurses, doesn't matter who, have made me feel worthy, it's true’.
	‘RDNS nurse was there for me when no family was’.
	‘Counselling, help me’.
	‘I can talk about things I cannot talk with family or friends’.
	‘Moral support/encouragement/peace of mind’.
	‘"Invaluable" emotional support, especially for those who live alone, living longer. HIV Program is a unique support service’.
Information/education	‘They answer questions that I ask them. They keep me informed on different things’.
	‘She made information about my illness easier to understand’.
Social support	‘Enjoy casualness and ease of visits and relationship, like little reminders that I am world's greatest backburner’.
	‘Go out when I need to de–stress’.
	‘As I have no family here my RDNS nurse gave hope and great support’.
Health support	‘Very good, medicine good, talking, coming when I want, coming, if I not home, coming next week' (verbatim).
	‘Provide ongoing phone support. They are there to assist with medications, any worries I have […]’

Further elements of care coordination, mental health support, and crisis intervention for people who are isolated because of their HIV and social problems are described by clients. Other pertinent points raised are that family support may not be readily available for PLHIV. Unlike for other illnesses where family and friends gather to provide support, HIV–stigma can lead to ostracisation from traditional supports and therefore reliance on ‘HIV–friendly’ community–based services.

Two clients made negative comments:

> *‘Don’t recognize the meds I take. Not arriving on time. Trouble in getting meds from chemist. Arriving when I’m healthy’; and*
>
> *‘My life is private. It’s my business’.*

Q9 addressed satisfaction with services in the past twelve months.

Client satisfaction was evaluated in the domains of communication and accessibility, and quality of care, including knowledge and skills, continuity of care, support, ethical practice, frequency and duration of visits, responsiveness and reliability, and cultural competence (Figure 16). Clients were also asked what they valued most about the service.

Care provided by the HIV Program is highly valued by clients and other service providers. Clients expressed a high degree of satisfaction with the service.

> *'Of all the support services, RDNS is the most dedicated and does the most useful work'.*
>
> *'The unique person–centred care for HIV Positive People can be life–changing, especially helping clients gain independence and maintenance of health'.*
>
> *'Empathy, compassion and personalization – this is not a ''one–size–fits–all'' approach and I really appreciate that'.*

Accessibility and communication

Client were mostly satisfied with accessibility to RDNS, agreeing that finding information about RDNS and making an appointment was easy (98%). Fewer (49%) agreed that after hours support was easy to get, although 40% said this was not relevant for them.

57% rarely or never feel uncomfortable talking about personal or intimate matters with the nurses.

96% said they were involved in decisions about their care at home.

100% said they could understand nurses' responses when they asked questions, one noting:

> *'better than I can understand my doctors at times'.*

Visit duration and frequency

Most were satisfied that nurses visited for an appropriate length of time or as often as was required (98%). One commented 'not long enough'.

Quality of care

Knowledge and skills

86% said RDNS nurses skills in HIV were of a high standard all the time.

> *'My RDN (sic) is someone knowledgeable who I can talk to about multiple chronic illnesses (Nurse has more time than my HIV specialist). It's comforting to have a regular visit... Get advice re illness and treatment. Never felt judged by RDN'.*
>
> *'Some nurses do not seem to know as much about HIV but they are still good'. 'Depends on who visits'.*

Continuity of care

98% agreed that 'the nurses who visit know me well' most times.

82% said care met their expectation all the time.

> *'They explain everything I need to do. They know me well and I know them well. I have confidence. Respect my culture – They help me a lot'.*

Ethics

Ethical values, principles and practices such as trust, commitment to confidentiality, respect, and advocacy within health services are very important to clients. 99% of clients said nurses were sensitive to their situation and respected their confidentiality. Ethical principles such as confidentiality, trust, respect were frequently raised by clients.

> *[They] don't judge me, everyone else judges me* (49 year old gay man, long term survivor).
>
> *'Treat me and my husband with respect'* (53 year old woman, newly diagnosed).
>
> *'Felt confident that confidentiality would be maintained'.*

Cultural competence/sensitivity

Clients overwhelmingly reported getting services in the language they wanted (98%) and 100% of those for whom this was relevant said they felt nurses 'respected their culture'. Two commented that they did not want an interpreter.

One said 'I would like services in Italian'.

98% said nurses were accepting of their life and health care choices.

Need and expectations for support

82% of respondents said the care provided 'meets their needs' all the time, and 84% said care 'meets their expectations' all the time. Many commented on the supportive nature of nursing visits:

> *I know I need input. I recognise I am not self–sufficient. I have problems procrastinating and RDNS helps me with my mental blocks* (gay man, long term survivor).
>
> *My wife and I are on our own with near no support. Each visit with our nurse was like a friend or family coming into our home. This was a huge support for my wife* (57 year old heterosexual man, newly diagnosed).

Responsiveness and reliability, complaints

A majority (79%) were satisfied with RDNS' responsiveness:

'They come to see me when I need it, even when I have been in crisis accommodation' (young male, homeless, newly diagnosed).

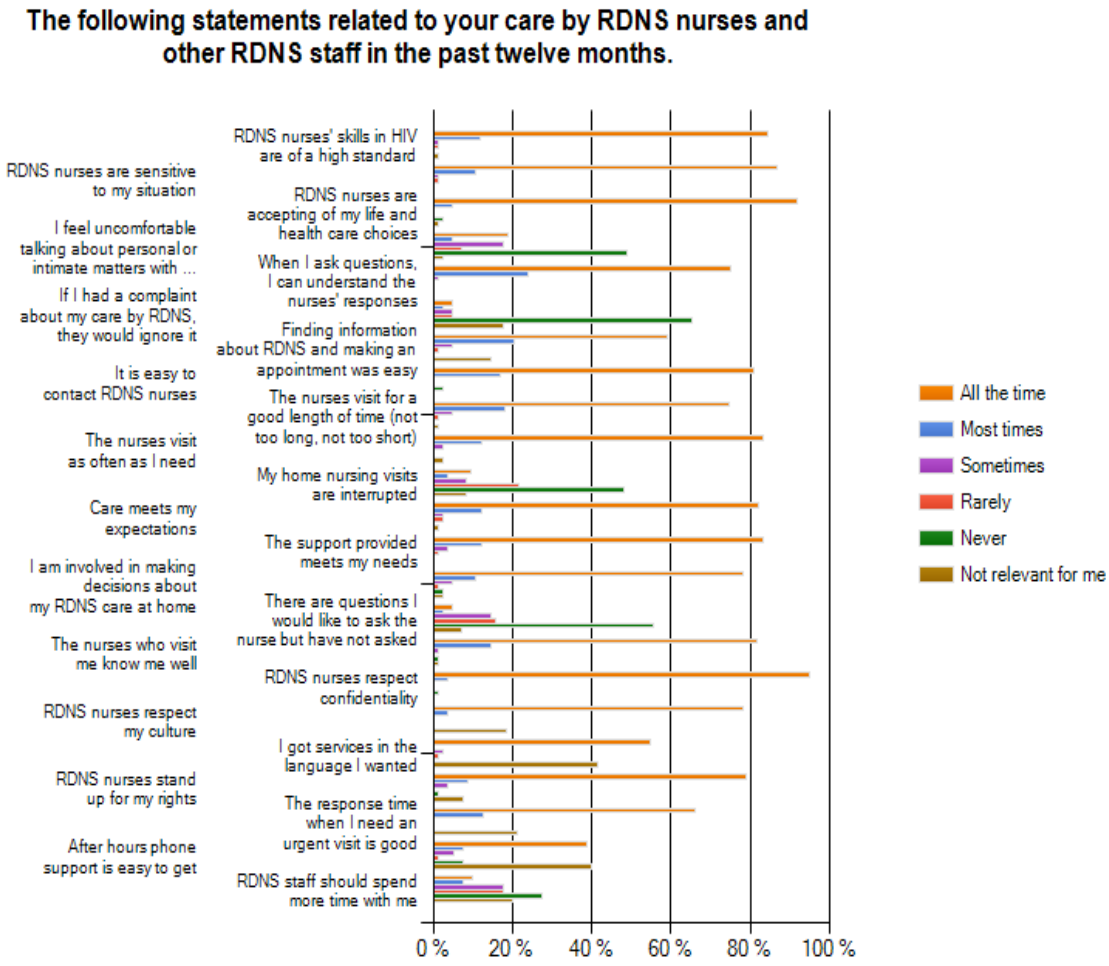
'[They are] there when I need them, and answer my calls quickly'.

'Value is exceptional. Have not experienced such a great level of support. Always on hand. Trust'.

'When I finish tablets, they come. If I am sick, they come' (41 year old Ethiopian woman, refugee, newly diagnosed).

Only 12% felt if they made a complaint to RDNS, it would be ignored. One mentioned that her complaint was ignored when she contacted the organisation by email to the Complaints department.

Figure 16: Client satisfaction in past 12 months



Q10 Clients were asked to rate how important they thought a series of 16 items were in relation to improving care or access to care. Four choices were given 'Not important at all, somewhat important, Important and very important'. Full responses are given in Figure 17; responses are then summarized in Figure 18 according to two choices only, 'Important' (comprising 'Very important' and 'important') and 'Not important' ('somewhat important' and 'not important at all') to simplify the analysis.

Figure 17: Clients' opinions of importance of ways to improve care and access to care

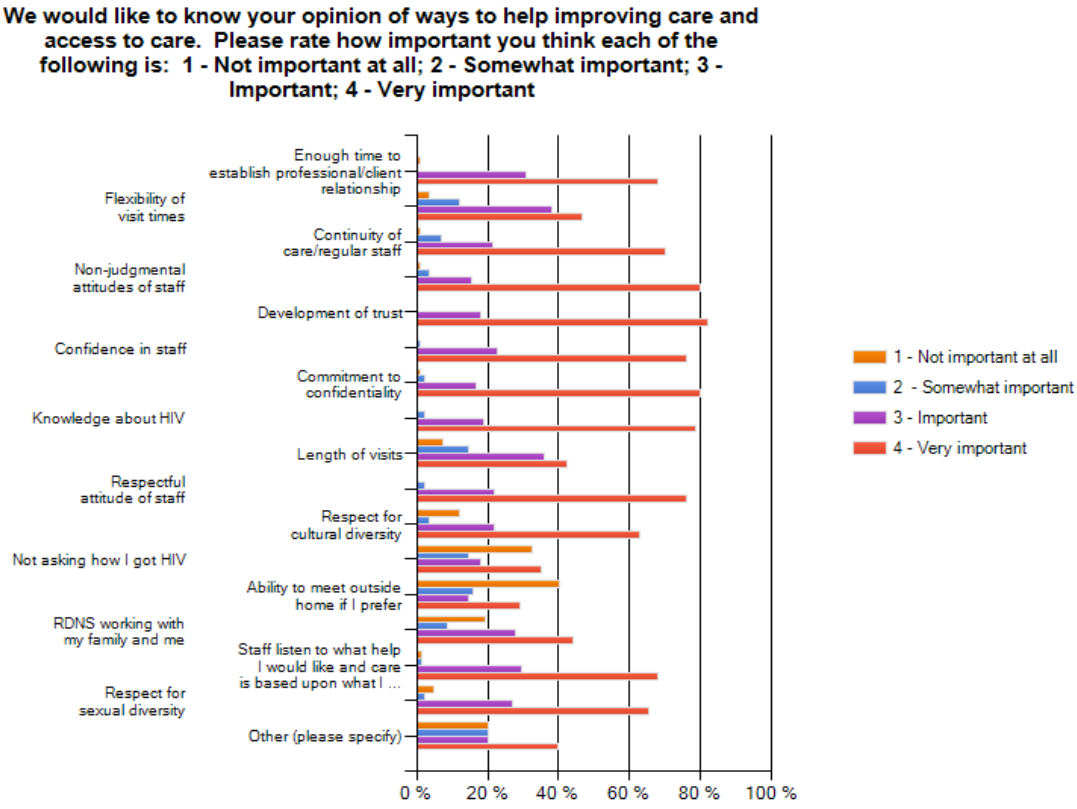
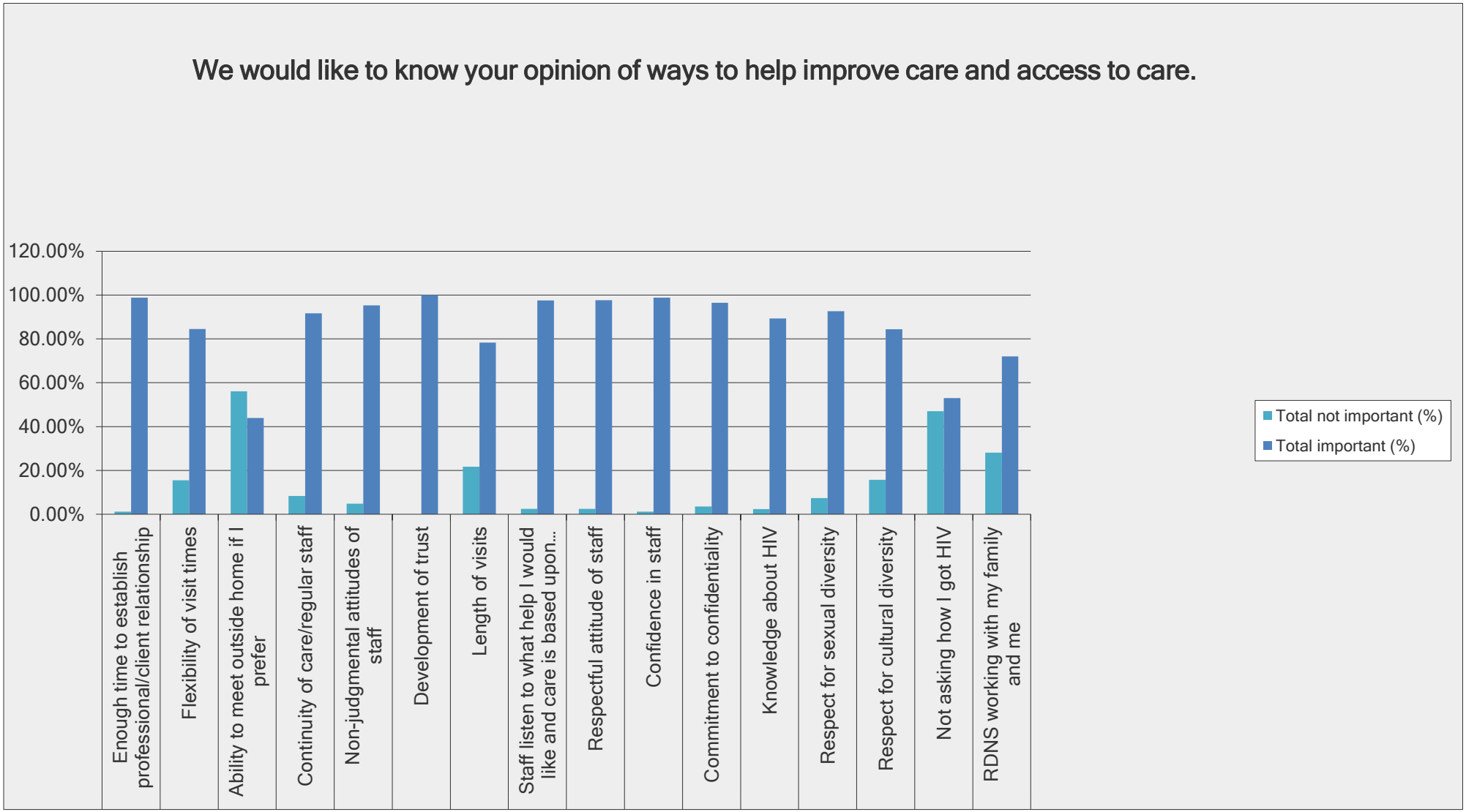


Figure 18 Clients' opinions on relative importance of ways to help improve care and access to care



Most items were rated important by the majority of clients. All considered trust important (100%), followed closely by 'enough time to establish professional/client relationship' (99%); 'respectful attitudes' and 'confidence in staff' (98%); 'client centred care' (97%); 'commitment to confidentiality' (over 96%); 'non–judgmental attitudes (95%), 'continuity of care/regular staff' (92%), 'knowledge about HIV' (90%) and 'respect for sexual diversity' (93%). 72% said it was important for RDNS to work with them and their family.

Fewer said it was important to have 'flexibility to meet outside the home if I prefer' (44%) though this nevertheless indicates that some clients may be uncomfortable with home visits (e.g. due to non–disclosure of their HIV status to family or housemates).

53% saw it as important for staff not to ask how they contracted HIV. Many thought the item about cultural diversity was not relevant for them and so answered 'not important', however the total who believed this was important was 84%.

Some clients commented regarding specific topics; for example:

- Regarding meeting outside the home, wrote 'I don't go out'.
- Regarding confidentiality, said 'vital';
- Regarding 'receiving services in the language I wanted', said 'I did not want an interpreter'.

This last comment highlights the difficulties for some clients living with HIV who are concerned about members of their ethnic group interpreting for them for privacy reasons or confidentiality concerns.

Regarding staff 'not asking how I got HIV', said 'I have never had that asked', and another commented 'I am happy to tell, I tell the nurse everything'. The importance of trust, confidentiality, confidence, and the professional relationship to this client group is highlighted in these comments. Poignantly, referring to the question of family, one client crossed out the word 'family'.

Q 11 Clients were asked if there was anything they valued most about the RDNS HIV service and 68 open–ended responses were received. These were analysed and categorised into themes by the Project Team; illustrative quotes are found in Table 6.

Table 6: What clients value most about the service

Ethics/values • ***Empathy*** • ***Respect*** • ***Confidentiality*** • ***Trust*** • ***Kindness***	'Respecting my culture', 'Treat me and my husband with respect' 'Empathy, compassion, personalisation' 'Never felt judged', 'they don't judge me, everyone else judges me', 'They make me feel at ease and more accepting of my condition' 'Felt confident that confidentiality would be maintained'. 'African people, they talk [about people in their community with HIV], me not like talking to them [about HIV], I not like African people knowing [about her HIV]. Me happy [with RDNS]'. 'Value is exceptional – trust'. 'I value everything about the service…my nurse is kind'. 'Countless kindnesses and humour'.
Knowledge	'Someone knowledgeable who I can talk to about multiple chronic illnesses, nurse has more time than my HIV specialist, get advice regarding illness and treatment'.
Communication	'Talking with me, what kind of problem [do you have]?' 'Explaining things when I didn't remember'.
Education	'Open to knowledge and experiences of the client to learn from'. 'Specialised support'. 'Has been able to explain medical terms better than my doctor'. 'Help me to remember appointments when I didn't understand letters'.
Care/concern/ **Reliability/commitment**	'Regular opportunity to share my HIV journey'. 'Commitment of the nurse to check on my situation'. 'The regularity', 'make me feel needed'. 'They come and see me when I need it, even when I was in crisis accommodation' 'Regular visits', 'reliability', 'support'.

	'They encourage me to carry on'; 'I know I need input. I recognise I am not self–sufficient'.
	'When I finish tablets, they come; if I am sick, they come'.
Responsiveness	'Always on hand'.
	'[…] because of this in September 2011 the nurse saved my life'.
	'Of all the support services, RDNS is the most dedicated and does the most useful work'.
Social support	'My wife and I are on our own with near no support. Each visit with our nurse was like a friend or family coming into our home. This was a huge support for my wife'.
Mental health support	'Being a good listener', 'understanding, empathy', 'support', 'They help you mentally and emotionally'.

The qualitative information provides further detail of the comprehensive nature of the work done with HIV clients. Several themes help distil its ethical dimensions, articulating elements of care that clients value. The stigma felt by some is apparent in their emphasis on confidentiality, trust, empathy about their condition and in becoming more accepting themselves of their HIV status. Experiences of isolation, sometimes from family or community are evident.

The role of district nurses with expertise in HIV in helping to counteract deep–seated stigmatization and isolation has not been explored in the literature. This data provides valuable insights into PLHIV's need for ethically–informed and ethically–competent care.

Future needs

Q12 Clients were asked about concerns they may have for the coming 5–10 years. 30 topics were proposed – results are detailed in Figure 19. In Figure 20, clients' responses are broken down into 'percent not concerned' and 'percent concerned' ('a little concerned', 'somewhat concerned' plus 'very concerned').

Figure 19: Clients' concerns for the next 5–10 years

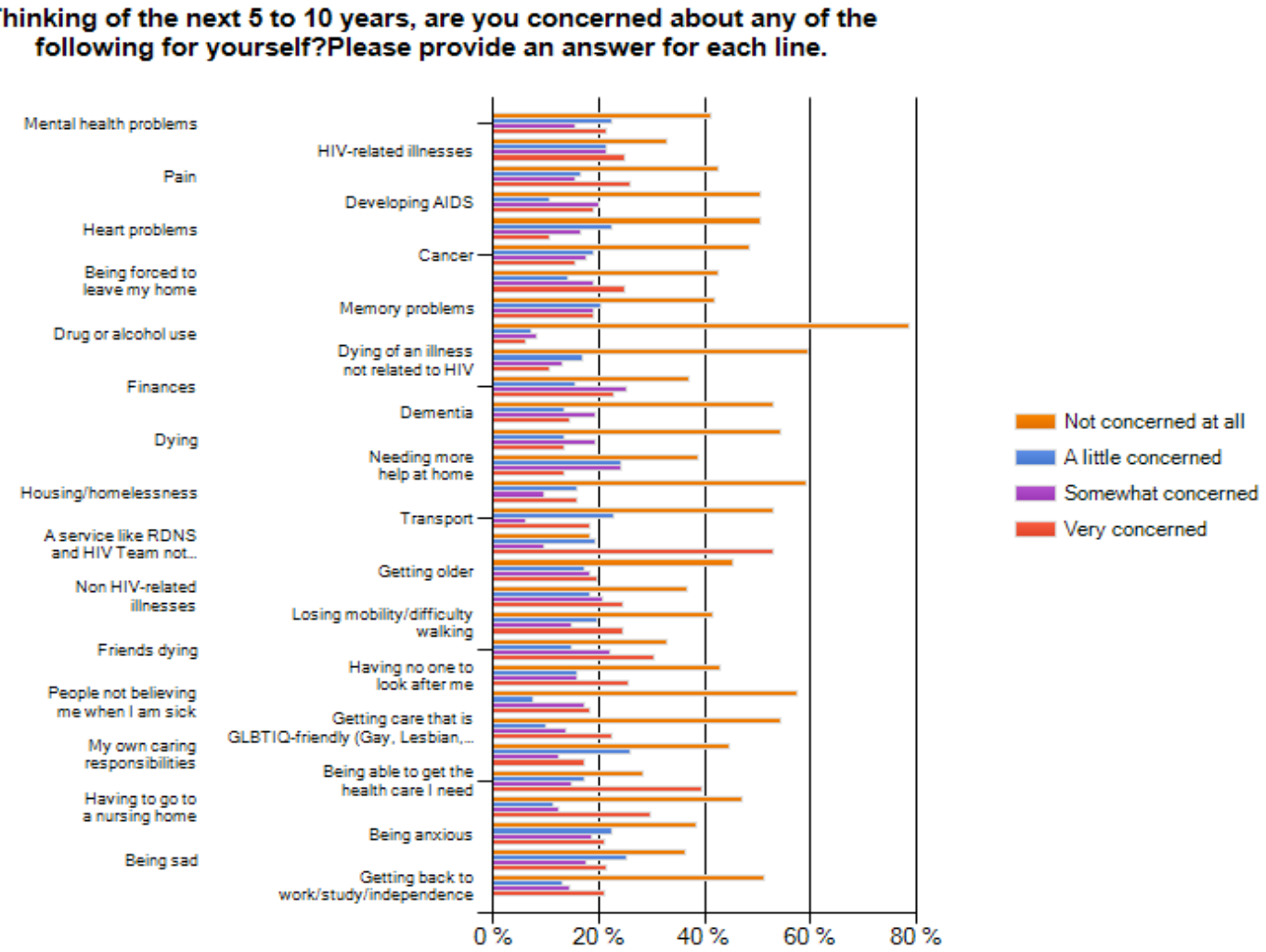
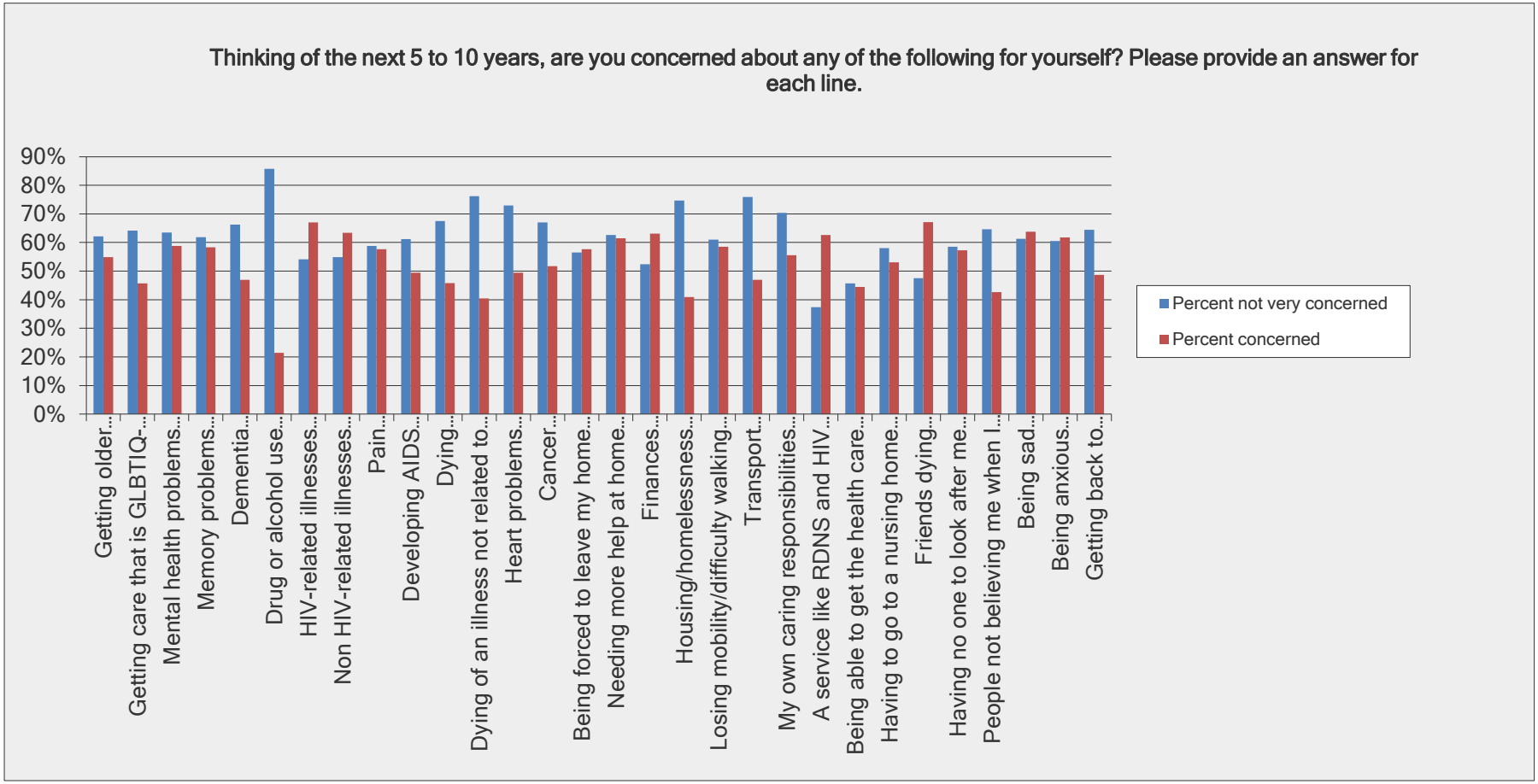


Figure 20: Clients' concerns for the next 5–10 years



As can be seen in Figure 20, the greatest number of responses expressing concern were: 'friends dying' (67%); 'HIV–related illnesses' (67%), non HIV–related illnesses' (63%) 'A service like RDNS and HIV Team not being available to me' (63%). Anxiety and sadness were concerns for 62% and 64% of respondents. 'Finances' were of concern to 63%; 61% were concerned about needing more help at home. 'Mental health problems (59%), memory problems (58%) and 'dementia' (47%) were also significant concerns. Other concerns included: 'Being forced to leave my home' (58%); 'Pain' (58%); 'getting older' (55%); cancer (52%); 'developing AIDS' (49%); 'having to go to a nursing home' (53%) and 'having no one to look after me (52%). 49% hoped to return to work/study or independence. 56% were concerned about their own caring responsibilities into the future. Fewer clients expressed concern about 'being able to get the health care I need' (44%). 41% were concerned about housing or homelessness. 21% were concerned about drug and alcohol use.

The concern about friends dying was unexpectedly high, so cross–tabulation was performed with long–term survivors (those diagnosed 1984–1995), considering that this group may have been over–represented amongst those concerned about this issue. Indeed, 15/25 (60%) of those who responded that they were very concerned about friends dying were long–term survivors, who comprised 43% of all respondents.

Clients' concerns are supported by the literature on PLHIV's changing needs and by expert opinion (HIV Team CNCs, HIV agencies, HIV Specialist Physicians).

Key informant interviews – future needs

Qualitative data from key informant interviews (Appendix 6a) provides additional information as a form of triangulation about projected needs. This data was transcribed verbatim and themes identified by the Project Team. The first question asked what the interviewee saw as the future needs of PLHIV in the forthcoming 5–10 years[12].

[12]The remainder of the key informant interview data is addressed separately later.

Table 7: Key informant interview themes on future needs of PLHIV

Ageing	'Ageing with HIV, and the ambiguities currently around understanding what is normal ageing and what is HIV–related ageing morbidity (Executive, HIV agency, HIV+); 'We know that with premature ageing, either caused by the disease or by the drugs or by a combination thereof, we're going to see more people requiring increased community and then residential or high level care' (HIV Specialist Nurse, external agency).
Co–morbidities	'Neurological or cognitive issues […] some people go on to get HIV dementias' (Senior Public Health Nurse). 'diabetes, heart disease' (HIV Specialist Physician) 'Functional psychiatric issues like HIV mania, HIV psychosis, depressive illnesses' (Senior Public Health Nurse). 'osteoporosis, cardiovascular' (Peer support worker, HIV agency) 'drug and alcohol, mental health' (Senior Manager, HIV agency)
Women and children	'Requests for reproductive services, specific medical issues around that (HIV Specialist Physician). 'The other growth area […] women and children… they need ongoing community support. […] The mothers need help to stay engaged in care. They do have layers of complexity that the general population that are not positive who are having babies seem to self–manage' (HIV Specialist Nurse). 'Children that are coming from overseas who are already HIV positive […] often again with complex needs, either resettlement issues, because they're positive and perhaps they've had suboptimal treatment overseas or no treatment (HIV Specialist Nurse).
Public health issues	[…] clients who have got schizophrenia, who have got HIV who are out in the community they are a public health risk because they are unable to negotiate or their delusional system won't allow them to negotiate safety…I think that we will do a lot more close liaison [with RDNS] and working with co–clients in that I am seeing a lot more disabilities, intellectual disabilities…' (Senior Public health Nurse).
New diagnoses	'we're seeing more and more referrals coming with people being diagnosed, young people […] they are going to need to be supported both medically and emotionally particularly in the first few years' (Community worker, HIV agency)

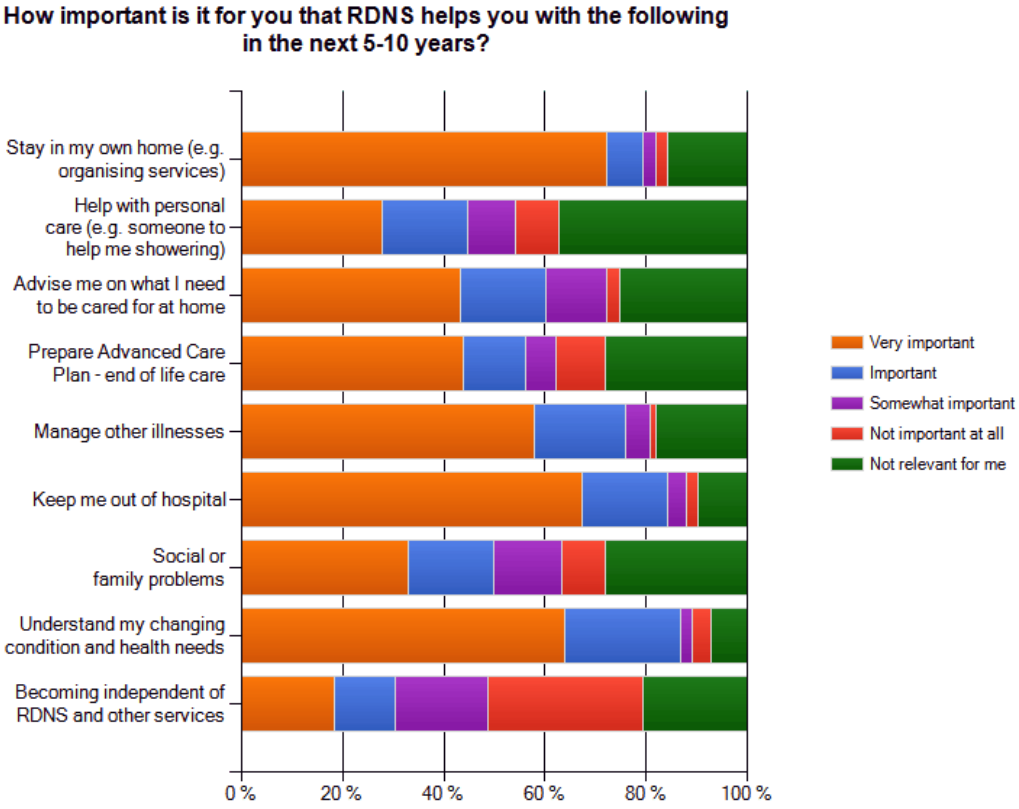
	'With the new diagnoses, there's going to be a need for a lot of education' (HIV Clinic Nurse and Researcher, public hospital).
Diversity, refugee populations, injecting drug users (IDU)	'We aren't going to be seeing less HIV amongst that group [refugees and asylum seekers]' (HIV Physician).
	Injecting drug users – 'we need to at least consider the possibility of infections amongst injecting drug users – we need to be mindful of the experience in Canada, they were patting themselves on the back, both Vancouver and Montreal have experienced substantial epidemics' (HIV Physician).
	'What we are seeing a lot more of is drug and alcohol problems […] and of course the whole issue of methamphetamine and ice, again a really complicated and difficult area…' (Public Health Nurse).
Social isolation	'Certainly women's experiences of isolation and stigma and discrimination are still very prevalent' (Senior staff, HIV agency).
	'We have a lot of clients out there who are HIV positive over a long period of time, psych trouble or cognitive and they are alone […] lonely, depressed, unmotivated…' (Senior Public Health Nurse).

All 15 HIV sector workers identified ageing, 'early ageing' or 'premature ageing' as a pressing concern. All HIV sector workers emphasize the multiple co–morbidities experienced by PLHIV and those served by RDNS in particular. Two commented on the future need for 'high level care' in the home setting.

The key informant interviews provide supplementary evidence supporting the issues seen as concerns by clients, especially mental health and cognitive issues, and raised several new ones not raised in the client survey, including women with children requiring additional support, the rises in new diagnoses, and the potential for a larger epidemic amongst IDUs. The importance of RDNS in providing consistent, comprehensive services for people with mental health problems or intellectual disabilities for protection of public health is also of interest and is arguably an under–recognised element of the role of the HIV Program.

Q13 asked clients how important it was for them that RDNS help them with a series of 9 items in the future (Figure 21).

Figure 21: Clients' rating of importance of assistance from RDNS in future



More clients rated 'stay in my own home' as more important than any other issue (78%) followed by 'keep me out of hospital' (65%); 'understand my changing health condition and needs' (62.5%); 'advise me on what I need to be cared for at home' (42.5%) and 'help me prepare an Advanced Care Plan' (42.5%). 35% thought RDNS could help them with social or family problems, 30% 'help with personal care (e.g. help me showering), and only 19% wanted RDNS to 'help them become independent of RDNS or other services'. The largest proportion (around 30%) said this was 'not important at all', indicating that for many, the long term involvement of RDNS is an important element of their being able to remain at home. Some thought these were not relevant to them (15.7% – stay in my own home [lived in supported accommodation]; 37.3% 'help with personal care'; 28% 'prepare Advance Care Plan'; 28% 'social or family problems'; 20.7% 'becoming independent of RDNS'.

Clients also made comments:

'Helping me achieve independence for as long as possible'.

This comment suggests that ongoing involvement of RDNS (and other services) does not necessarily represent a loss of independence for some, but a way to achieve longer–lasting independence. Others commented:

> *'I'd prefer not to be independent'.*
>
> *'For now, I do most myself. In the future, I might need more help. I'd accept someone coming to my home'.*
>
> *'I did not know what an advance care plan was, but have documented in my will. I will ask RDNS to help me with an advance care plan'.*

The last comment illustrates the benefits of a participatory action research approach where the project itself was able to raise awareness, enabling clients to address issues previously not considered.

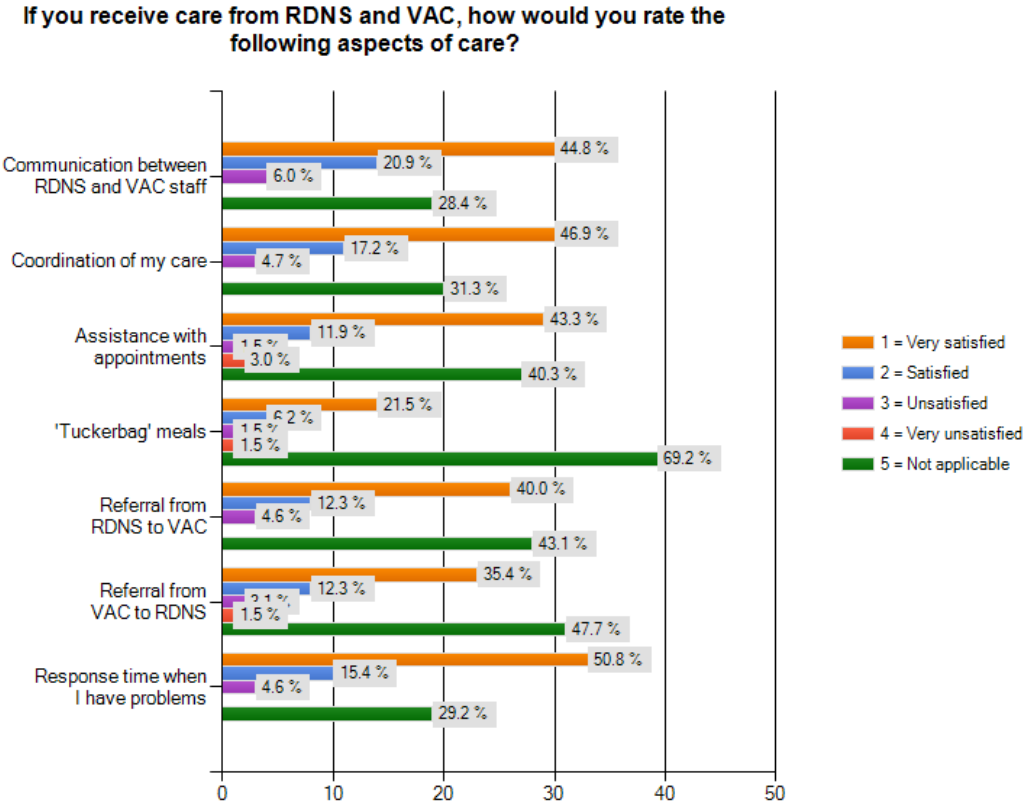
Field notes taken by the researcher during the survey indicate that several clients seemed to have difficulty thinking of the future and responded to this question considering only their current health status and needs. This was sometimes related to mild cognitive impairment.

The following two questions pertained to RDNS' Partnership with the Victorian AIDS Council/Gay Men's Health Centre HIV Services Program.

Q15 Clients were asked whether they were aware of RDNS working closely with VAC. 80.5% responded 'Yes', and 19.5% 'No', indicating an overall good awareness of the collaboration.

Q16 Clients were asked how they rated 7 components of the care provided by the two services together (see Figure 22).

Figure 22: Satisfaction with RDNS/VAC partnership activities and care



Of those for whom a component of the joint care was relevant, most reported they were very satisfied or satisfied.

- Communication between RDNS and VAC – 44/48 (92%)
- Coordination of my care – 41/44 (93%)
- Assistance with appointments – 37/40 (93%)
- 'Tuckerbag Meals' [13]– 18/20 (90%)
- Referral from RDNS to VAC – 34/37 (92%)
- Referral from VAC to RDNS – 31/34 (91%)
- Response time when I have problems – 43/46(93%).

[13] The Tuckerbag Project was a joint health promotion project between RDNS HIV Program and VAC/GMHC Community Support. It comprised fortnightly deliveries of nutritious food and recipes to isolated clients living with HIV at risk of malnutrition, with the aim of developing their skills in cooking and shopping for nutritious food and improving their social inclusion.

Some commented:

> *'I don't get enough support from VAC'.*
>
> *'It has been a struggle just to get basic transport assistance to my basic medical appointments, especially since I cannot drive or use public transport at present. I'm at the bottom of the rung. If I say something that offends someone, I'll be the first to be cut off, I'm very dispensable'.*

This last comment exposes feelings of vulnerability and dependence on volunteer–based services with limited resources.

Others said:

> *'Tuckerbag was a bit wasted on me as I couldn't get up and stand long enough to use them. My balance is no good. Connected with what's going on with the brain'.*
>
> *'Allowed me to stay in the property I'm renting with confidence that the short to medium term will see little change, good for my state of mind concerning security and ongoing, relative independence'.*
>
> *'All the time and respect for all the medical/nurses, people that have helped me over the years. There has been the odd nurse who shouldn't have come'.*

Q17 The final question asked clients to suggest how to make RDNS HIV service better for themselves and other HIV clients. 59 responses were received.

Themes identified are found in Table 8.

Table 8: Clients' suggestions for improvement

No changes	'Nothing changes'; 'it's good the way it is now'. 'In my case RDNS has proved itself an essential service many times'. 'Sustain the role of HIV specialist nurse'. 'Is good. If worse, I ask nurse'. 'If it isn't broken, don't fix it'.
More resources	'more staff, more availability'; 'more HIV nurses and deliver tablets'; 'having more time, 15–20 minutes, half an hour more'.
Practical suggestions	'a reminder call about the appointment 24 hours in advance'; 'nurse taking me to hospital' ;

	'Daily arrival [time] so I could sleep in, go into town, go into university, DASSI worker. Flexibility. Feel like I'm kept in the house'.
	'Stop people talking about my being moved into a nursing home. It's vital for me'.
Education	'If you're going to deal with positive people, you HAVE to do the course, you have to, it's stupid'.
	'Train more staff to understand HIV and clients' needs. We are the forgotten people'.
	'More need for help in the ageing process, non HIV–related problems i.e. cancer etc. I've wasted 30 years worrying about HIV and now they're laughing it off as a chronic illness. Now I'm in more trouble than ever with cancer and other things. 'Cos what are they going to push you onto? Normal district nurse type thing? *They* won't be interested'.

Key informant interviews – strengths, gaps in service, 'mainstreaming', suggested improvements

Some data from key informant interviews was reported above; where it aligned with **Q12** of the client questionnaire, regarding future needs. The following section reports on the remainder of the key informant interviews, exploring the themes of 'Gaps in services', 'Strengths of RDNS HIV services', 'Mainstreaming', and 'Suggested improvements'. Sub–themes were identified through content analysis by the Project Team, and illustrative quotations used. These are summarised in Table 9.

Strengths of the RDNS HIV program were described as their role in advocacy, community development, education (for internal staff but also externally, and for clients themselves) and 'an outstanding service response'.

Gaps in services that experts in the HIV sector identified included inadequate specialist support and lack of continuity of care at times. HIV Team respondents noted the difficulties providing adequate cover for leave with no backfilling of HIV Team roles. This especially affected clients who are vulnerable or hard to engage, where assertive outreach approaches

may be required and considerable sensitivities and skills in developing trust and engagement are required.

The RDNS HIV Program itself is seen as vulnerable by two external agencies and there is a perception that care coordination can be fragmented. In a broader sense, rural PLHIV are seen to have reduced access to services.

HIV sector specialists also discussed the issues of mainstreaming, expressing significant concern that mainstream services remain unprepared to care for PLHIV. These concerns centred on ongoing stigma and discrimination, including internalised stigma, and lack of knowledge of health workers. HIV sector workers do not share the view that 'HIV is just another chronic illness', and explained that there are still specific issue for PLHIV around disclosure of their HIV status, fear amongst the public, and actual experiences of stigma and discrimination that make it 'different'.

Table 9: Themes and sub–themes from key informant interviews (N=15)

Theme	Sub–theme and Quotations
Strengths of RDNS HIV Program	**Advocacy** 'You are like British Bulldogs. It's a protection for us; it alleviates a lot of stress and concern: it's also about quality of care. Confidence in accessing services where we know there is not going to be any issue about how we're dealt with and to me that's huge…The strengths are that you advocate for us, you're well informed […] you're not only educating other people about HIV but you're also educating us about some of the issues' (HIV agency worker, HIV+). **Community development** 'Offering much more than just medical supports; psychosocial stuff. The Tuckerbag Program, which I think is fantastic. Those kinds of community development programs that [RDNS] are offering. […] building capacity and nutrition and assisting people to actually have better food' (Senior Executive, HIV agency). **Education role** 'I see you guys as a vital part of that education, so you're educating IN YOUR WORKPLACE and advocating for us IN YOUR WORKPLACE which has ripple effects' (HIV agency worker, HIV+ woman). 'The nurses themselves are invaluable in training our volunteers and staff in regards to issues around HIV […] and clients as to how to look

after themselves better; that's a real strength and a real plus' (Manager, HIV agency).

Service response

'The outstanding service response which has been in place. The working relationship between RDNS and VAC is unique, it's exemplary, you're always available for staff, for clients, for carers, for family members [...] we've always had a 24 hour nurse–on–call service' (Manager, HIV agency).

Gap in services

Lack of continuity, inadequate specialist support

'My fear is that as those numbers of people grow, will the service be funded appropriately to deliver those services? It's getting to the stage where people in their early 50s are behaving physically like 60 year old people' (Peer support worker, Heterosexual HIV+ man).

'there's been a handful of people I've seen recently where I have thought, that they DO need ONE nurse at home, because of the types of problems they have, so I think there's a group that need the consistency […] I suspect that maybe you're not always resourced to do that' (HIV Specialist Physician).

'I think sometimes there's not enough of the specialist HIV [nurses] or that's the perception that I have. […] maybe if there was a bigger pool of people who either had an interest or were trained or had more of a feel for HIV or an understanding' (HIV Specialist Nurse, external agency).

'There are problems with sustainability of the Program as HIV Team staff are not replaced when taking leave – this affects the care of clients who are hard to engage, chaotic, have mental health problems and challenging behaviours and places enormous strain on the Team attempting to cover for each other' (HIV Specialist Nurse).

Vulnerability of the HIV Program

'My concern is that it's a vulnerable animal, an endangered species if you like. I often tell people when I speak publically that we've got this good working relationship with RDNS, it's a unique partnership that's now in its 22nd year, worldwide unique, world first unique model of integrated care and I think it's not valued enough perhaps within RDNS itself. I think it needs to be front and centre' (Manager, HIV agency).

Fragmented care–coordination

'The reality is that these patients, we may not use the term, but they ARE being case managed, the 'pointy end' people, by a range of

players […] it's counter intuitive that a number of organisations have their own sort of care plan and in system and structure, and I think there should be more integration' (HIV Specialist Physician).

Rural PLHIV

'We still have this sense that you don't do as good a job for them, there aren't the services in those places […], there are issues of stigmatisation in their community and not acknowledging their positivity' (HIV Specialist Physician).

Mainstreaming

Stigma and discrimination (fears)

'My concern would be that we are mainstreamed, that's a real concern for me because there IS no guarantee that we'll be treated equally …' (Peer worker, HIV agency, HIV+ woman).

'I actually choose services that are HIV savvy, I won't go outside of that' (Peer worker, HIV agency, HIV+ woman).

'It would bother me if it was mainstreamed [into RDNS] because you've got a whole bunch of people who aren't educated and you don't know what their response is going to be. If they're educated, we don't have that issue, we can go to one of you guys and it's all OK, we have that confidence in you and we don't have to speak up. If there's any discrimination that goes on (laughs) you guys DEAL with it. You bear the brunt of it FOR us' (Peer support worker, HIV agency).

'I continue to believe that stigma, less so discrimination, but stigma, profoundly affects the lives of every single person living with HIV. There is no one I know with HIV who has not experienced some form of stigma that makes them feel bad, unworthy, ashamed and then of course all that stuff that that raises for them.[…] lots of people living with HIV experience self–stigma within health services' (Senior Manager, HIV agency, HIV+ gay man).

Lack of knowledge

'The general nurses aren't educated enough about confidentiality. It's quite a sensitive issue' (HIV Clinic Nurse/Researcher, public hospital).

'It's not going to be their priority to be educated, that goes without saying (within RDNS) – I think education needs should sometimes be opportunistic around HIV because they are not going to waste their study days doing it, but it doesn't meant they are not interested just in their day to day work they need to do what's more relevant to what they are actually doing now' (HIV Specialist Nurse).

Not 'just a chronic illness'

'Diabetes doesn't have a stigma attached to it. HIV does. And if someone jumps away from you in horror, how do you think that affects that person? Or if someone discloses your status, how do you think that affects that person? It has huge ramifications throughout their life' (Peer support worker, HIV agency, HIV+ woman).

'There's this, you know "HIV is analogous to diabetes, and heart disease, and we hear that a lot, but I still think even in 2013, there are still some unique parts of HIV that make it different to diabetes or heart disease. […] You're never going to hear somebody in a café or out in public say "I was at the doctor and you know my T cells are falling and my viral load is up", it's just not going to happen. So to me there are still some unique issues and that's around disclosure, stigma, discrimination and the perceived, you know it's still treated as a dread disease by the general population' (HIV Specialist Nurse, external agency).

Suggested improvements or changes

Flexible workforce, supportive structure

'If I were running district nursing, I would think that we have got to have an HIV service that is incredibly flexible, incredibly able to move and accommodate specific needs that you don't necessarily see with other types of general clients and you've got to be in a system that's able to manage, negotiate and deal with these issues'.

'Staff managing people with psych problems or cognitive problems or maybe managing people are have maybe undetectable viral load so they are not HIV/AIDS patients but they are co–morbid with a whole range of other – it's bloody hard work and I think staff out there in RDNS need to be in a supportive comfortable environment where they can get peer support, where they can discuss cases with like–minded people' (Senior Public Health Nurse).

'I think this client group is complex enough that we actually need a team coordinator to do some of that non–clinical…to do proper advocacy and work on a bigger picture' (HIV Specialist Nurse).

'The development of a Team Leader/Coordinator for the HIV Program should be prioritised to enable ongoing Program development, evaluation, funding growth and so on' (HIV Specialist Nurse).

'Idealistically, every nurse should have the capacity to provide best practice, quality care for HIV clients. However, given that this client group is often scattered, and given that in the structure of RDNS primary nurses rotate, I have concerns about the implications of both, from a resource point of view, around CNCs providing education, but

in particular about providing continuity and best practice care' (HIV Specialist Nurse).

Telehealth

'Nurses providing support [for rural clients] through telehealth […]; the experience we've had with one or two patients with telehealth. Technology has got some really exciting opportunities with them' (HIV specialist Physician).

Removal of the HIV Program from RDNS

'I would like to see it removed from RDNS and the services relocated alongside community–based care so there's a full continuum without this disconnect between agencies. […] we could provide more services, a wider range of services to more clients if we co–joined the existing community–based services with what are the existing RDNS services' (Senior Manager, HIV agency, HIV+).

'I think there would be merit if the RDNS HIV Consultancy Team was integrated into an HIV specific service like […] as its work is at risk of being diminished within RDNS bureaucracies or ultimately disappearing (Manager, HIV agency).

Mental health expertise

'[…] RDNS should have staff in this area who have a good mental health background who can do good mental status examinations who can consult on the management of people with psych problems or people with cognitive problems…' (Senior Public Health Nurse/Mental Health Nurse)'.

Partnerships

'The future will be greater partnerships, greater collaboration, greater joint work in supporting complex clients' (Senior Manager, HIV agency).

Recommendations from HIV sector

Two external agency representatives suggested that the HIV Program be removed from RDNS and placed within a community organisation. Nevertheless, they also saw the future as requiring greater collaboration and partnerships between organisations.

Key informants suggested that an HIV Program requires a supportive structure and flexibility to deal with HIV clients' specific needs including mental health and cognitive problems, along with peer support and professional supervision. Mental health expertise was seen as essential for the HIV Team by one respondent.

Expansion of the service through Telehealth, especially for rural PLHIV, was suggested.

Leadership and management

In March, 2012, the HIV Team developed a discussion paper on the management of the HIV Team which outlined difficulties with its management structures – inconsistent lines of reporting, lack of support for a cohesive team approach affecting productivity and quality of care and a lack of resources tied to Program planning, growth and development[17]. Whilst a Clinical Support Manager has recently been appointed, the HIV Team currently has 6 additional line managers to report to.

Effective leadership structures in HIV care have been recognised as essential to strengthening social justice and human rights in all aspects of the HIV response[3]. Good leadership structures help ensure the voices and needs of all affected (especially those most disenfranchised) are recognised and reflected – this ensures the protection of vulnerable groups and equitable distribution of services[3]. The Team CNCs recommended the development of a Team Coordinator/Senior Clinical Nurse Advisor role to facilitate Program development, evaluation, funding growth, policy and publication review, to coordinate education. This would require longer term commitment from RDNS to its HIV Program.

Staff survey

The Staff questionnaire, produced on Survey Monkey® was sent to all clinical staff and nurse managers (968 staff) between March 6th and April 6th 2013. One week prior to this, an explanatory email was sent to managers requesting that they encourage staff to complete the questionnaire. Two reminders were sent, one after two weeks, and one a week before closure (April 6th).

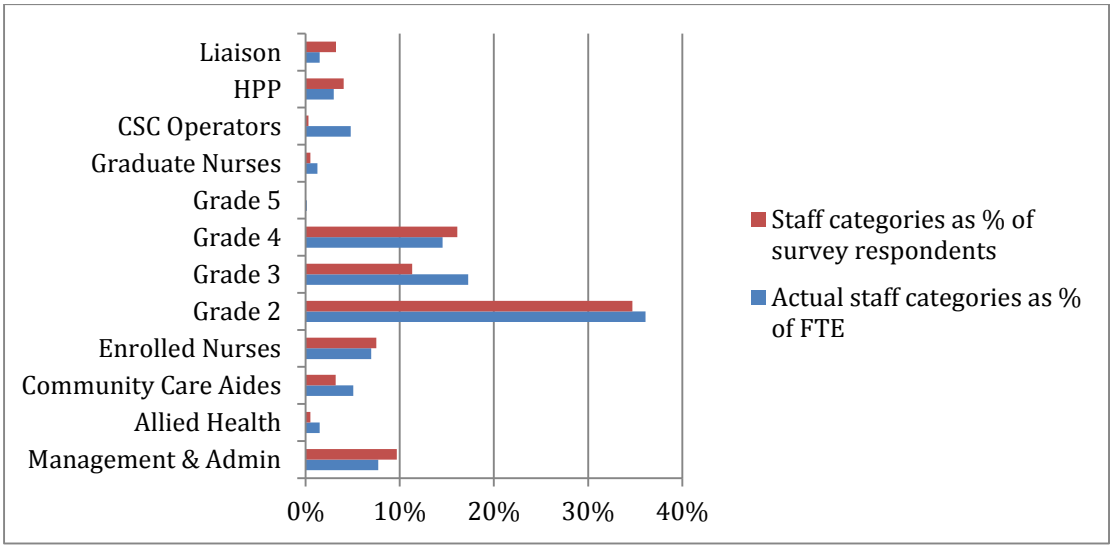
Of the 968 questionnaires distributed, 372 were returned representing a 38.7% response rate. Given this population and sample, a confidence interval of 3.98 was achieved (95% confidence level at 50%). 299 staff completed all questions (completion rate 80.4%).

Staff demographics

Respondents can be considered broadly representative of the RDNS staff profile at the time of the survey. The distribution of respondents to the survey was compared to the study population for their staffing classification (see Figure 23). Chi–square tests were used to determine if the representation of each staff type in the survey was equivalent to that of the

population. Due to small sample sizes, statistical tests could not be performed for allied health, Grade 5 nurses, graduate nurses, and Customer Service Centre (CSC) operators. Examination of descriptive results suggests equivalent representation for all groups with the exception of CSC operators who appear to be under represented in the survey sample. There was no significant difference between the proportions of staff types in the sample and population for all remaining staff types with the exception of Grade 3 nurses. Grade 3 nurses accounted for 17% of the RDNS staff population, and were under represented in the survey sample (11.3%), a difference that was statistically significant [$\chi 2$ (1) =7.25, P<0.01]. There was a larger percentage of Hospital Liaison Nurses responding to the survey (3.2%) than are represented in the RDNS population (1.5%); however this difference was not statistically significant.

Figure 23: Staff profile respondents (N=372) and overall RDNS staff profile (N=962) at time of survey



Q3 Contact with HIV clients

Over 50% of staff reported never having seen an HIV client in the last twelve months and another 36.1% had seen 1–5 HIV clients during that time. Only 3.9% of staff had seen more than ten clients in the past 12 months.

Q5 HIV education

52% of staff said they had undertaken HIV education through RDNS (140 responses) with a majority (74.6%) saying they had undertaken 'informal education on the job' and 'self–education' (71.9%).

Q6 Use of HIV knowledge

61.3% said they had used information/knowledge from HIV training in their daily work. Several commented that they had not seen HIV clients or were not working in a clinical field.

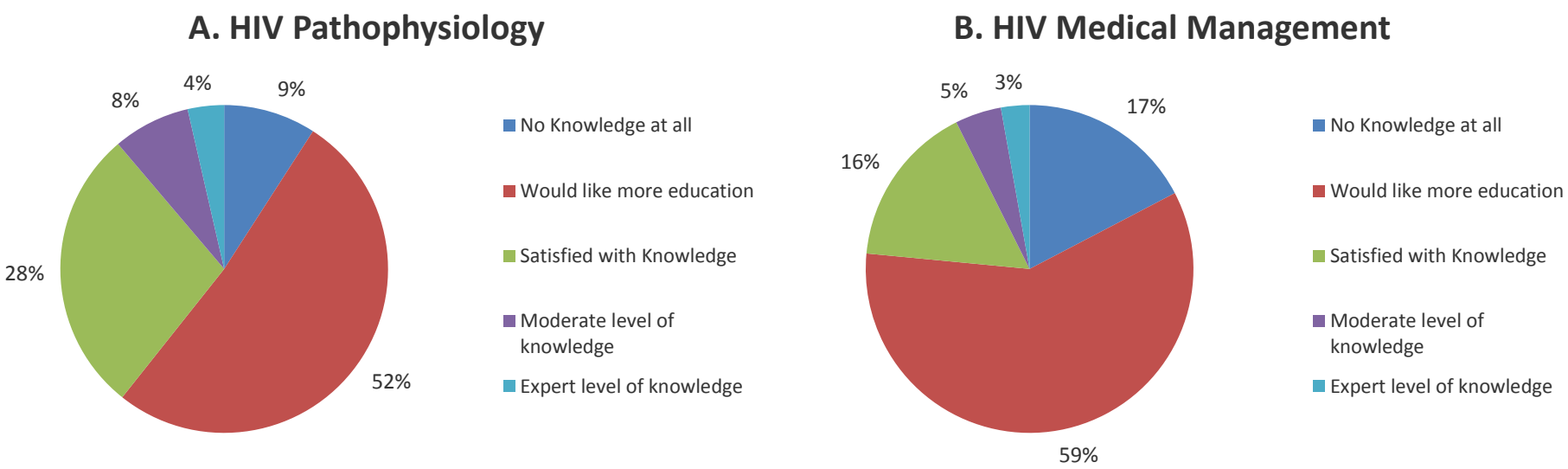
Several key questions are reported on in more detail for this report – those that relate most strongly to the client data; namely, RDNS staff's Knowledge (2 questions), Attitudes (3 questions) and Practice (2 questions) with respect to HIV. Additional questions asked for ideas and suggestions on program improvement from staff. Focussing on these areas helps answer evaluation questions about staff's educational needs and the Program's sustainability.

Knowledge and skills in HIV

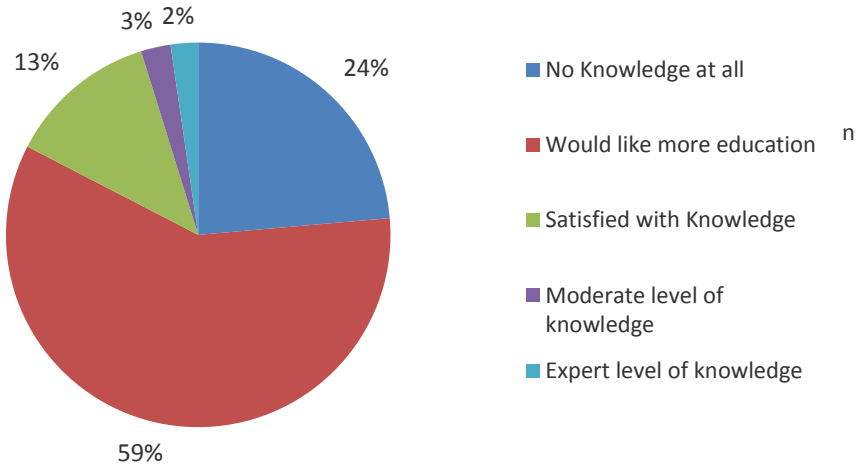
Staff were asked to rate their level of knowledge in HIV on a scale from 1–5, where 1 = No knowledge, 2 = would like more education on this topic, 3 = satisfied with my level of knowledge; 4 = moderate level of knowledge, and 5 = have expert knowledge on this topic. 340 staff responded to this question. Results are depicted in Figure 18 for each topic (for full details of each topic, see HIV Staff questionnaire (Appendix).

To encapsulate the results for this report, topics were grouped into 7 broad domains: HIV Pathophysiology, HIV Medical management, HIV Prevention, HIV Psychosocial, HIV Epidemiology, Specific populations/vulnerable groups, and HIV Legal and Ethical. The categories are itemized in Appendix 8a. Results are shown in Figure 24 (A–G).

Figure 24: Staff self–reported knowledge and skills according to domains



E. HIV Specific Populations / Vulnerable Groups



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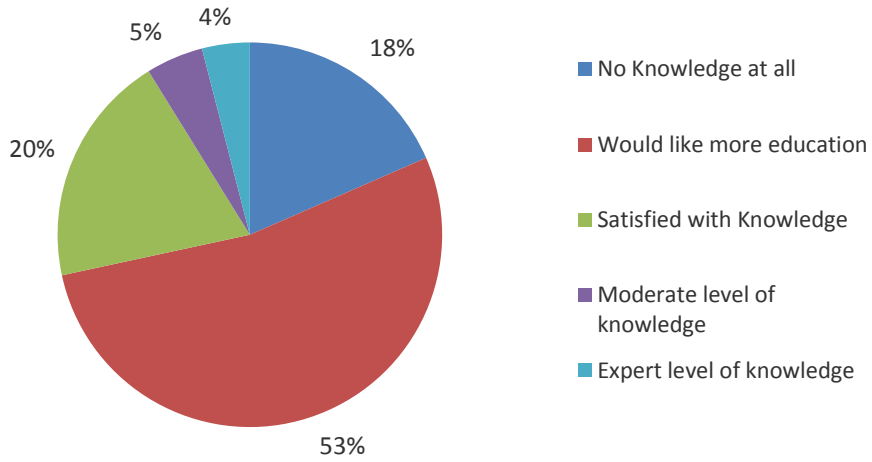
F. HIV Legal and Ethical



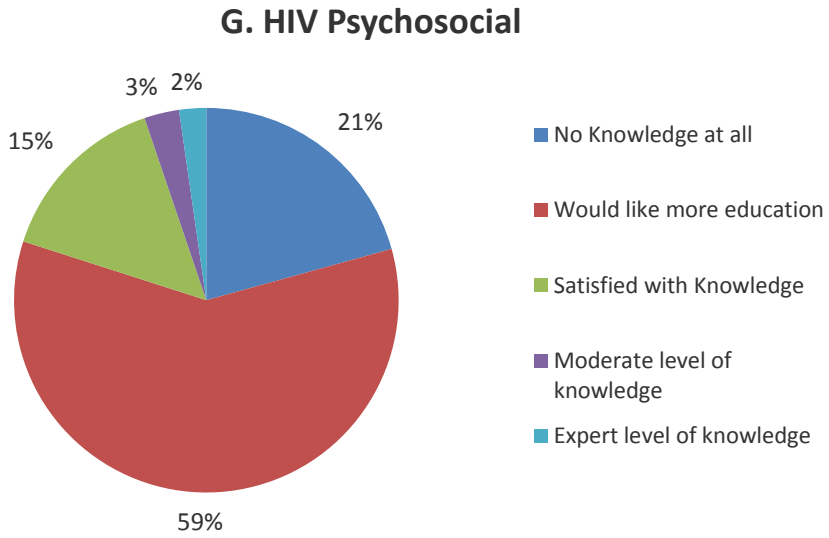
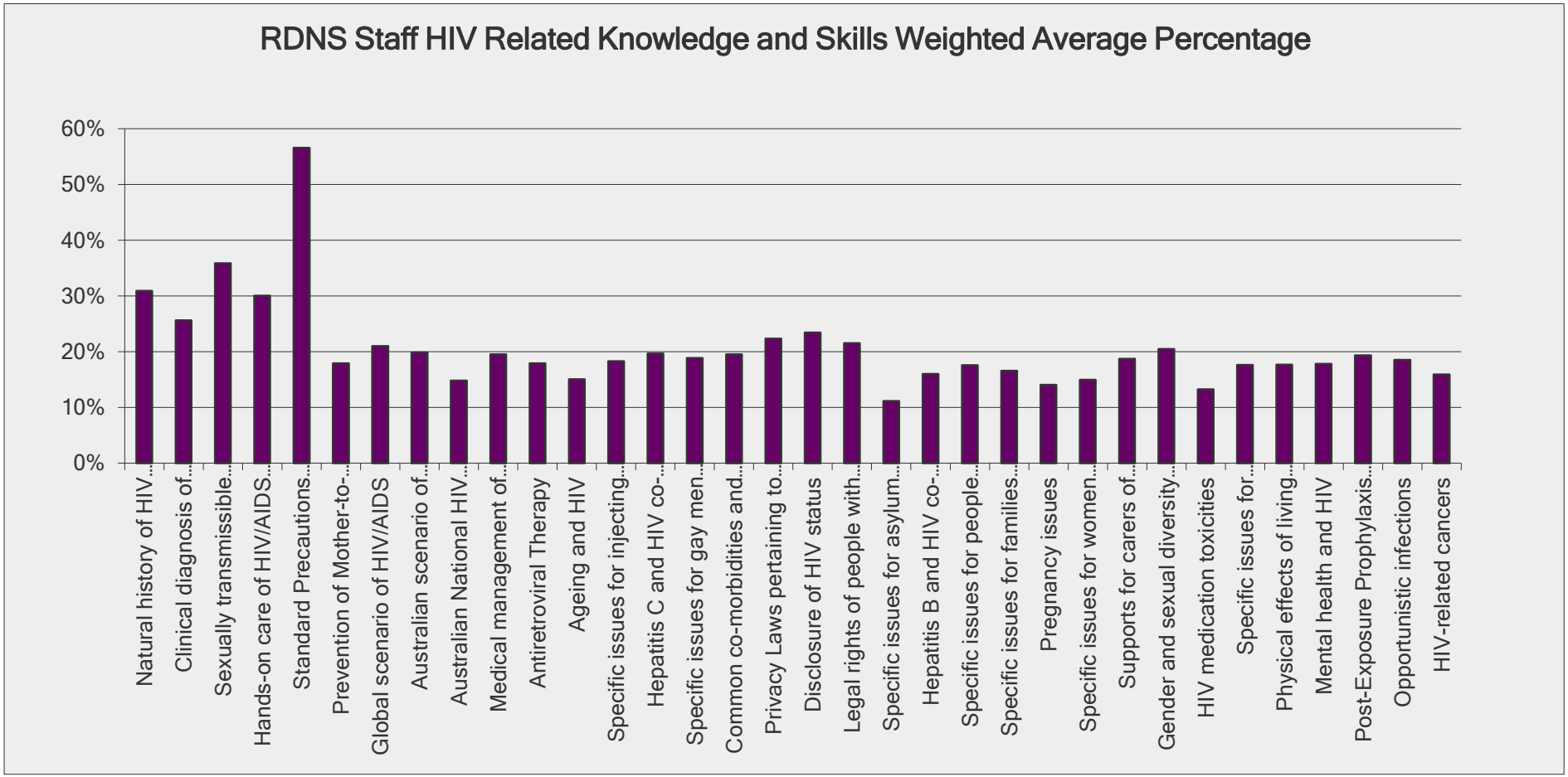

G. HIV Psychosocial
3%
2%
21%
15%
59%
No Knowledge at all
Would like more education
Satisfied with Knowledge
Moderate level of knowledge
Expert level of knowledge

Figure 24 (A–G) indicates that in all domains of HIV–related knowledge, the majority of RDNS staff who responded to the survey have no knowledge or would like more knowledge. Figure 25 helps to emphasize specific areas where staff report knowledge gaps, in relative terms.

Standard Precautions is the only area where more staff reported higher levels of knowledge. This is to be expected as Standard Precautions is basic to nurses' education, as it is for other health care workers. There was a small proportion of staff (2.1%) who said they had 'no knowledge of Standard Precautions' and 17.8% who said they would like further education on this topic. 17.2% said they were expert in Standard Precautions. It could be argued that every nurse (and health worker) should be expert in this area, and that it is universally important, not just in the HIV context.

Charts A–G Figure 24 indicate the greatest proportion of staff reported knowledge gaps about specific populations/vulnerable groups (83%), followed by psychosocial (80%), medical management (76%), epidemiology (75%), legal and ethical (71%) and HIV prevention (66%).

Figure 25: Staff knowledge and skills, weighted average percentages



Topics where over 70% of respondents reported no knowledge or more education needed include:

- 'Specific issues for asylum seekers living with HIV' (90.6%)
- 'HIV medication toxicities (88.6%)
- 'Post exposure prophylaxis' (78.8%)
- 'HIV antiretroviral therapies' (80.6%)
- 'Prevention of mother–to–child transmission' (80.1%)
- 'Privacy laws, disclosure of HIV status, legal rights' (over 70%)

It should be noted that some topics do not relate just to HIV, especially legal issues around disclosure, privacy and legal rights – they are applicable to clients across the organization and within health care. It can be argued that breaches usually have greater implications in the context of HIV and other blood borne viruses. It is a concern that a majority of staff report low levels of knowledge in these areas.

18 comments were received, 15 noting that the staff member was not working in a clinical role. The other 3 expressed interest in learning more about the topics:

> *'Would like to know more because it is such an interesting area and also because we need to be familiar with all of this to support staff in direct care'.*

Q 8 asked staff to rate their skill level in caring for HIV clients (Figure 26). Only 4.5% said they were very skilled; 24.9% reported moderate skills; 24.9% few skills; 10.9% they have never worked with HIV clients but have some skills', and 22.9% said they 'would like to know more and become more skilled'.

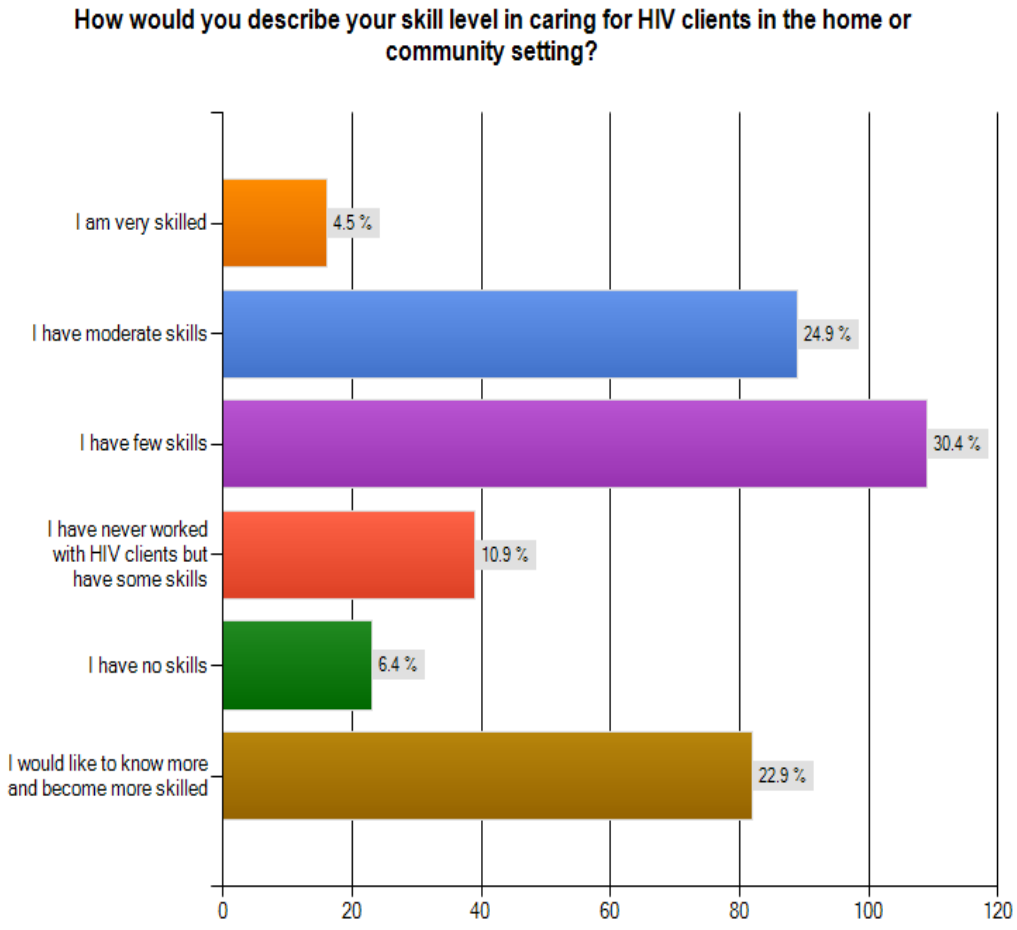
19 comments were made:

> *'I believe that HIV is like any other chronic disease that we manage in the community. You cannot be skilled in every disease process but I do not believe that this is not [sic] any different for HIV'.*

Several comments referred to out–dated knowledge but most were eager to learn more:

> *'very rusty/out of practice';*
>
> *'I would need to do a refresher';*
>
> *'I would like more skills but applications for training have been declined'.*
>
> *'I think ongoing education is essential'.*

Figure 26: Staff self–reported skill level in caring for PLHIV

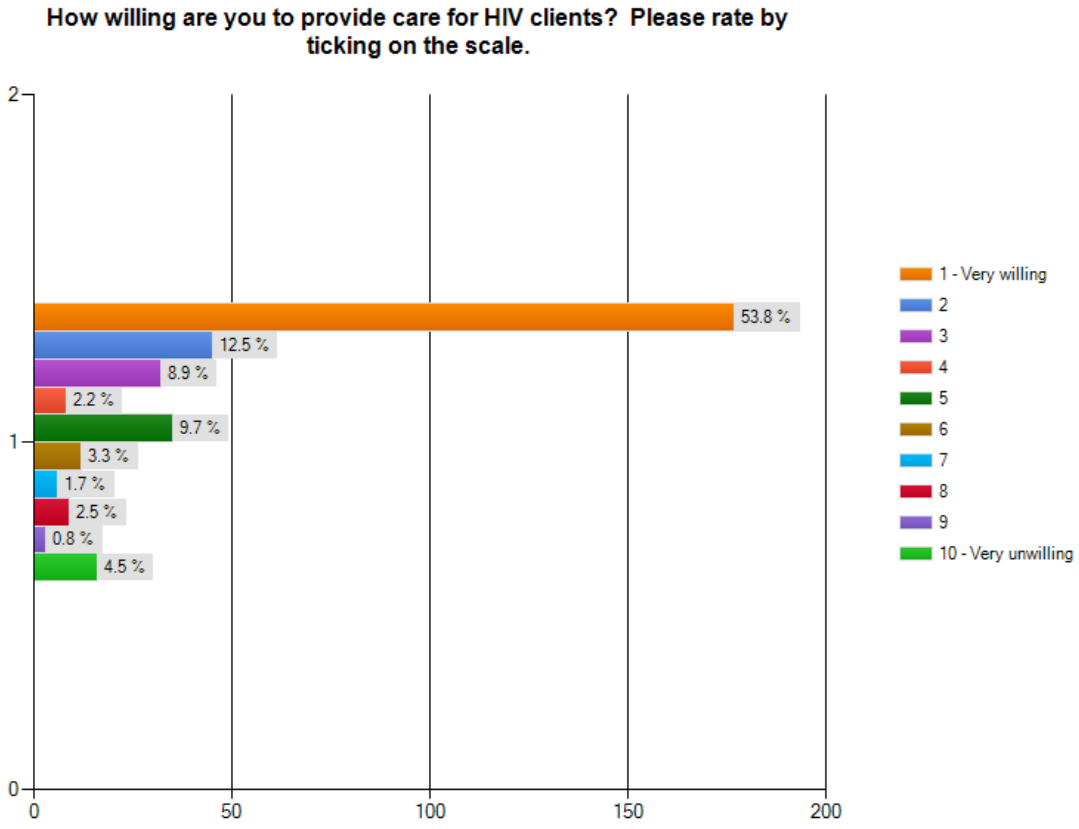


Attitudes

5 questions addressed nurses' attitudes to caring for PLHIV, to HIV itself, and to the RDNS HIV Program. Staff were asked about willingness to care for HIV clients, comfort level in caring for clients, and an open–ended question asking directly about perceptions of HIV clients and the Program itself. It is important to explore nurses' (and other RDNS staff) attitudes to help answer evaluation questions about quality of care and educational needs.

Q7 Staff were asked how willing they were to care for clients with HIV and asked to tick on a scale from 1–10 (1 – very willing and 10 – very unwilling). Results are shown in Figure 27.

Figure 27: Willingness to care for PLHIV (N=359).



On the whole, Staff were willing to provide care, with only 9.5 % tending to be unwilling.

Comments (N=11) shed further light on factors affecting willingness, most relating to the need for further education:

'if given the necessary education';

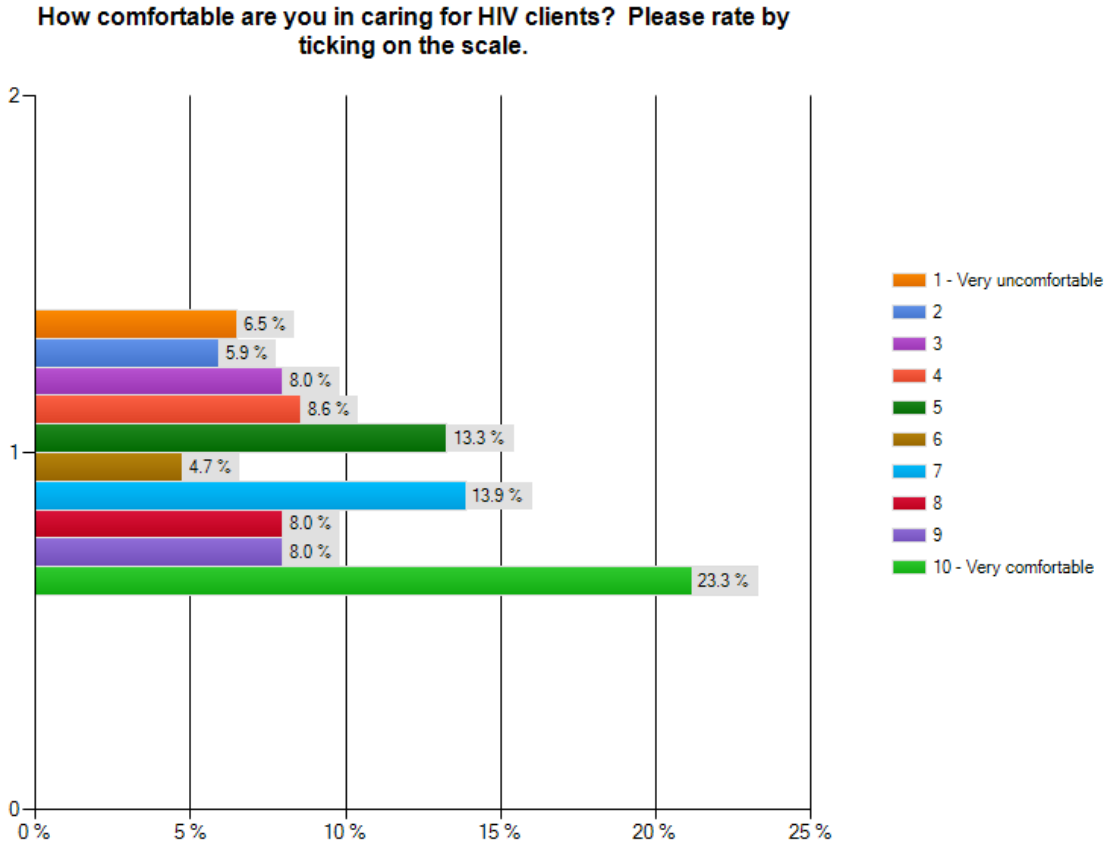
'willing, but would need more education and practical skills';

'Would ask for advice/support if I need it'.

Q10 Staff were asked how comfortable they are in caring for HIV clients, by ticking on a scale from 1–10 (1–'very uncomfortable' and 10 –'very comfortable'). Results are shown in Figure 28.

Figure 28: Comfort in caring for PLHIV (N=339).

More staff were uncomfortable in providing care for PLHIV than were unwilling, with 6.5% very uncomfortable and 29% tending towards uncomfortable (ratings 1–4). 23.3%



were very comfortable.

27 comments were made, again shedding further light on reasons for discomfort. 21 of these referred to the need for more education, with the remainder stating 'N/A' or 'not in a clinical role'.

Q 11 Perceptions of the HIV Program and clients

Staff were asked: 'How are HIV clients and the RDNS HIV Program perceived within your workplace? Positive and negative examples would be welcomed, in the interests of quality improvement.'

248 responses were received, with many staff taking the time and effort to explain their perceptions and those that they have observed within the organization.

Thematic analysis was conducted by examination of responses by the Project Team. These are depicted in Table 10 with illustrative comments.

Table 10: Staff perceptions of the HIV Program and HIV clients

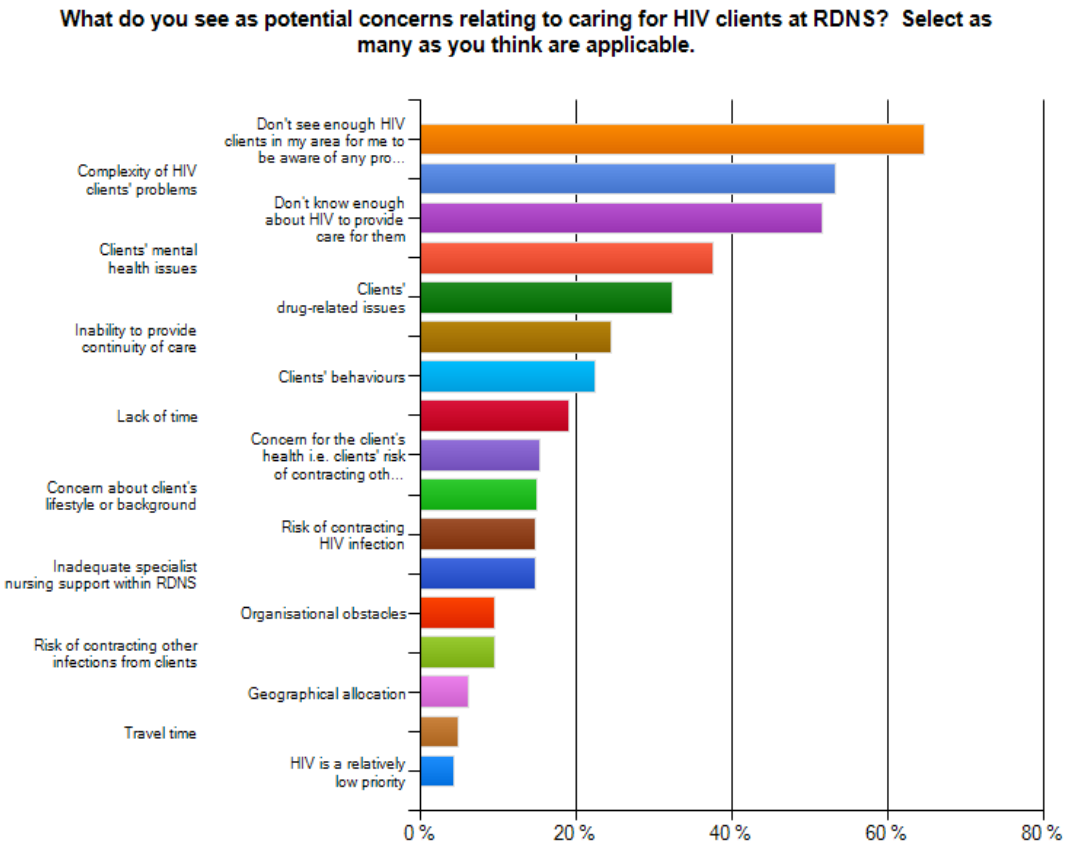
Positive (66)	'very well within my close colleagues'
	'invaluable to RDNS staff – a wealth of knowledge to staff who may have minimal education in supporting HIV +ve clients
	'very positive, hospital staff are often surprised we have HIV Consultants and the doctors in the hospital find it a great back up for clients' well–being'.
	'Greatly respected'.
	'HIV staff very approachable would feel comfortable seeking information/support'.
	'RDNS is seen as an organisation that offers clinical and emotional support to HIV clients and their families'.
'Same'	'I believe we treat all clients the same'.
	'HIV clients are just another client which we need to respond and care for. We need to be accurately assessing each and every client in line with individual needs […] We need to consider how having HIV affects their ability to access health care just like we need to consider the factors influencing a client who has dementia or is Indigenous etc.'.
Fear/apprehension/avoidance (9)	'… [some] staff that have had no experience with HIV seem frightened and apply stereotypes'
	'some nurses are highly anxious to care for HIV clients […] due to the lower number of clients we see only for HIV related illness'
	'Often feelings of uneasiness when visiting especially when dealing with sharps or wound care as worried about contracting disease'.
Knowledge deficits (24)	'Still have staff that won't visit HIV clients […] some of our staff were unaware of the RDNS Program'.
	'I think that people's reluctance is due to lack of knowledge, once that is dealt with care would continue as with all other clients. We have a duty of care to ensure our knowledge is up to date with all procedures'.

	‘When I receive a new client with HIV in my area I find it a bit stressful simply because I am not well educated in caring for them’.
Limited involvement (51)	‘We don't hear anything about the HIV clients. It seems there are only certain nurses that attend their care. I don't know how many clients with HIV we have but doesn't seem like many’.
	‘We only have 1 client with HIV at our centre that I am aware of and only a limited number of people are involved in his care due to some behavioural/ mental health issues’.
Specialist field/ complex clients (35)	‘Management feel they require too many resources to accommodate needs’.
	‘Managers tend to underrate the specific client group needs and specific clinical skills required to visit positive clients. They tend to think that anyone one can attend the client visit, experienced or not, known to the client or not. Field staff are much more aware of the complexities and sensitivities and seek support from the HIV Team members when planning to visit positive clients’.
Stigma, discrimination (11)	**Clients not ‘special’**
	‘In general, they see HIV clients as "special" in a derogatory way. Some people believe that they are "over–serviced" and that they should be treated "like everyone else". Little staff have an interest in HIV.’
	‘I do not believe that HIV status clients should get any more special treatment than our other chronic disease clients. The stigma associated with this disease is kept alive by assuming that a "special" team of nurses are required to look after these people. I do not believe we need a team for these people, perhaps a resource nurse at each site as we do with diabetes, wound care etc.’
	‘Mostly accepted but with prejudice, during informal discussion, e.g. they are too spoiled, we do too much, they could do more. Some staff discriminate on religious bases, still perceived as a gay issue’.
	Need for ‘alerts’, extra caution
	‘I felt it should be specified in the diagnosis and precautions added to care plan and notes’.
	‘I guess with some degree of caution’.
	‘Some staff are reluctant to provide care once aware client has HIV, can be hysterical about their and their families’ safety’.

‘Clients with Hep C & HIV are flagged as "risk factors" and "alerts" are created during CSC intake & screening process. I understand that this can help identify that the client has special needs but I also think this is a lot discriminatory and wish it did not happen. We don’t put up alerts for our left–handed clients.’

In **Q 12**, Staff were asked what they saw as potential concerns relating to caring for PLHIV at RDNS (see Figure 29). 14 options were given, plus opportunity to comment. The most common response reported was ‘don’t see enough HIV clients in my area for me to be aware of any problems’ (64.6%) followed by ‘complexity of clients’ problems’ (53.2%) and ‘don’t know enough about HIV to provide care to them’ (51.7%). Mental health and drug–related issues were also seen as potential concerns (37.5 and 32.3%). 24.6% reported that ‘inability to provide continuity of care’ as a possible concern. Only a few saw (4.3%) saw ‘HIV is a relatively low priority’ as a potential concern.

Figure 29: Potential concerns relating to caring for HIV clients



28 comments were made, several stating ‘not in a clinical role’. Others ticked a response only because they could not progress to the next question otherwise (responses made simply to progress to next question included ‘travel time’, ‘geographical allocation’). Comments reflected safety concerns, avoidance and not knowing what to say.

Open–ended responses to questions 11 and 12 were cross tabulated according to staff level, as a theme arose around a perception that the HIV Program ‘deskills’ staff and treats clients as ‘special’ when they are ‘the same’, rather than up–skilling through its educative and consultancy role. The following comments on the HIV Program derive from staff at Management level.

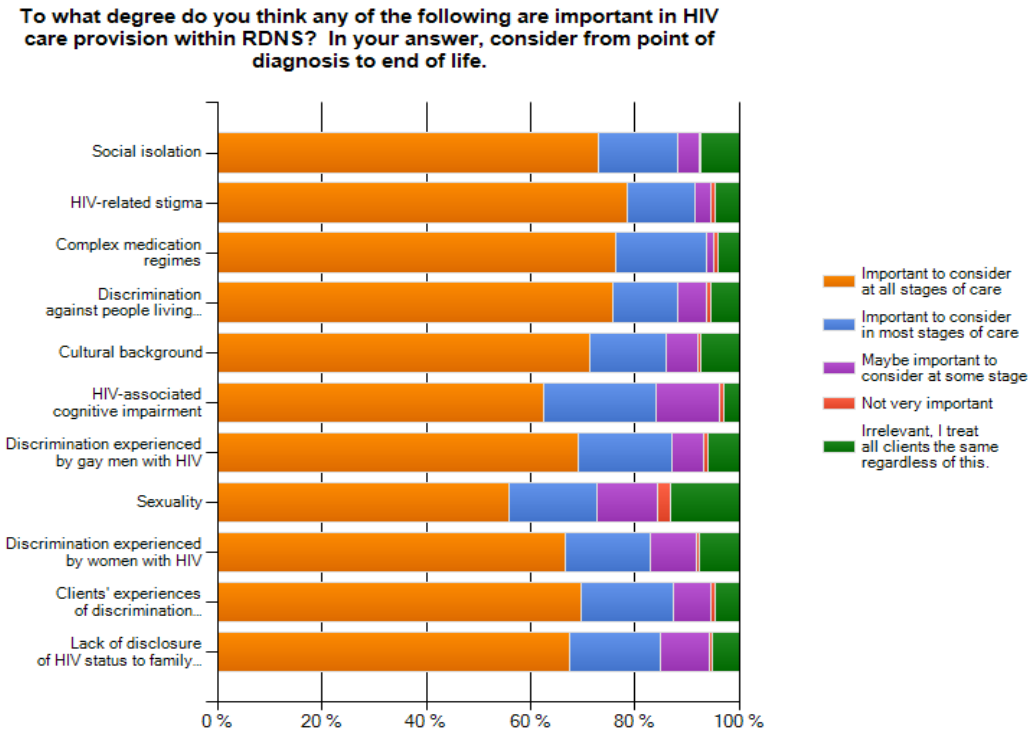
HIV Team de–skilling staff, clients not ‘special’

> *‘Why are HIV clients treated differently? Staff are involved with, and P/N (primary nurse), other specialities e.g. Palliative Care clients so why not have the HIV clients also?’*
>
> *‘Having an HIV Resource nurse takes opportunities away from primary nurses – they then become deskilled’.*
>
> *‘HIV clients should be seen and treated as every other client not discriminated or made to appear “special”’.*
>
> *‘The clients should be referred and given same care & treatment as all other referrals with P/N having access and back–up support of the HIV CNC’.*
>
> *‘RDNS needs to remove the view that these clients are “different”, as HIV is now considered with less fears and taboos [...] public education is better’.*

Such views raise contentious issues for RDNS and for the HIV Program that must be addressed as they can be influential in developing policy and procedure and setting the ‘tone’ for how clients are cared for at given sites, and can lead to misunderstanding about HIV clients’ specific needs and issues they face. This will be further discussed in the following chapter.

Q 13 Staff were asked to what degree they found a range of issues, drawn from the literature, important in HIV care provision.

Figure 30: Staff opinions on importance of particular issues in HIV care



As can be seen in Figure 30, the majority of staff recognized the importance of social isolation in the lives of PLHIV (over 88%) and that it needed to be considered at all or most stages of care. Similarly, over 90% recognized that HIV–related stigma and discrimination were important to consider at all or most stages of care. Lack of disclosure of HIV status to family and friends, HIV–associated cognitive impairment, cultural background and clients' experiences of discrimination within health care seem to be recognized by most staff as important. Interestingly, sexuality was the issue most likely to be considered less important, with 13.3% responding that it is 'irrelevant, I treat all clients the same regardless of this'.

20 comments were made, including the following:

> *'All clients need to be treated universally with dignity and compassion'* (Management role).
>
> *'What has sexual orientation go to do with it?' (Division 2 Nurse).*
>
> *'Requires a lot of time'* (District Nurse Grade 2).
>
> *'It is a very sad day when health professionals discriminate or judge someone' (District Nurse Grade 3).*
>
> *'All clients should be treated with respect […] however the stigma of HIV can add complexities to their care that you need to be aware of'.* (Clinical Nurse Consultant).

> *'Positive clients that require RDNS assistance are for the most part highly complex and require individualized care plan, disease specific and have far more potential complications than that of a non–positive person with chronic disease'* (District Nurse Specialist).
>
> *'I believe you need to approach the client holistically'* (District Nurse Grade 3, Assessment Nurse).

Responses indicate a strong awareness of the range of issues that can affect HIV client care in particular and therefore need to be taken into consideration during most, if not all, aspects of care.

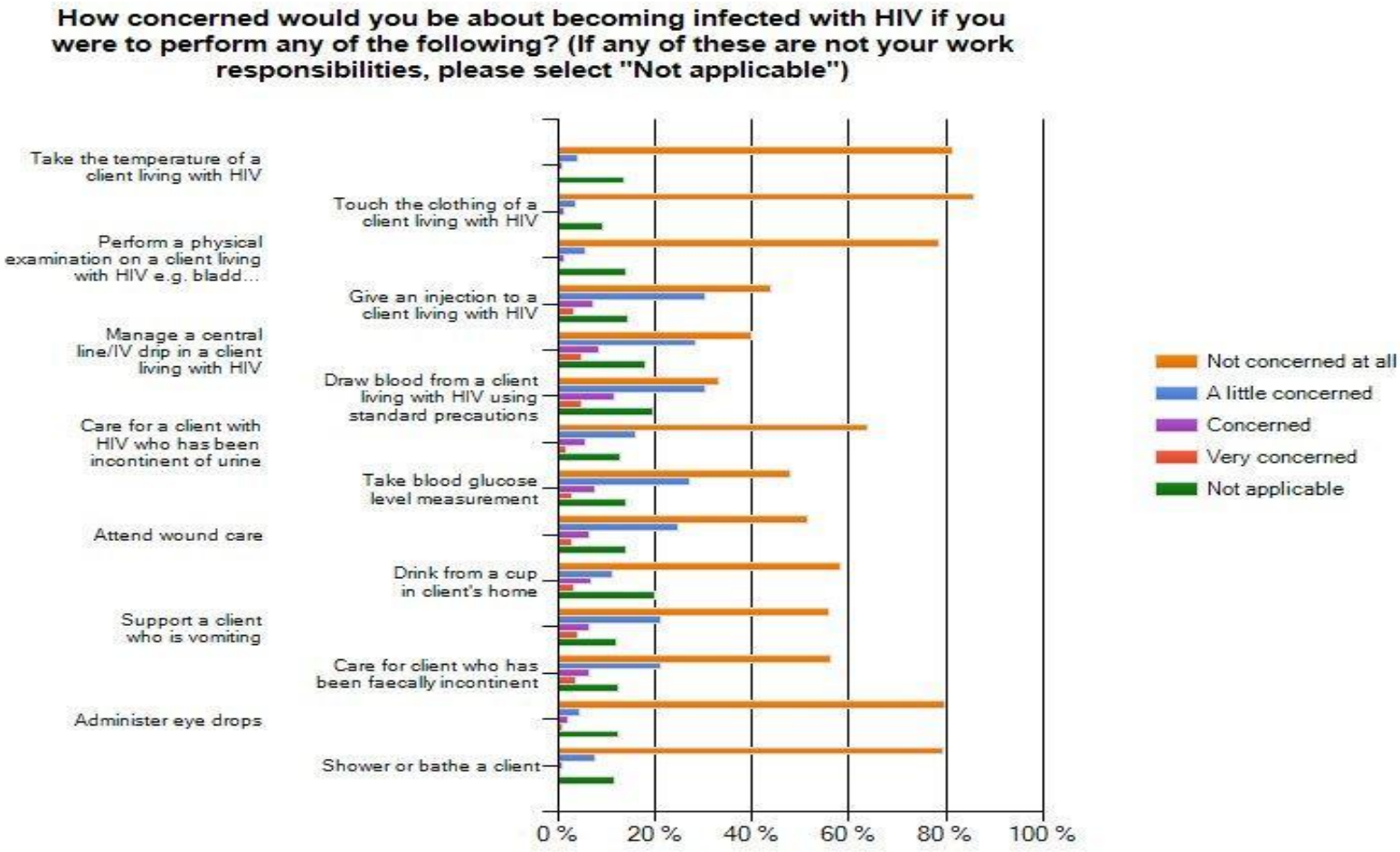
Some commented that this question was ambiguous and difficult to answer.

Practice

Infection prevention and control

Q14 Staff were asked how concerned they would be about contracting HIV if they were to undertake a range of 14 nursing procedures (Figure 31).

Figure 31: Staff concerns about HIV transmission in undertaking specific procedures or care



For the purposes of this report, the activities were categorised into three risk levels:

1. ‘No potential body fluid exposure therefore no HIV transmissions risk’;

2. ‘Potential body fluid exposure with negligible HIV transmission risk and

3. ’Potential body fluid exposure with potential HIV transmission risk’.

Levels of concern were collapsed into ‘total concerned’ and ‘total not concerned at all’.

The findings are depicted in the three graphs to follow: Figure 32,

Figure 33 and

Figure 34.

Figure 32: Total numbers of staff concerned/not concerned about contracting HIV

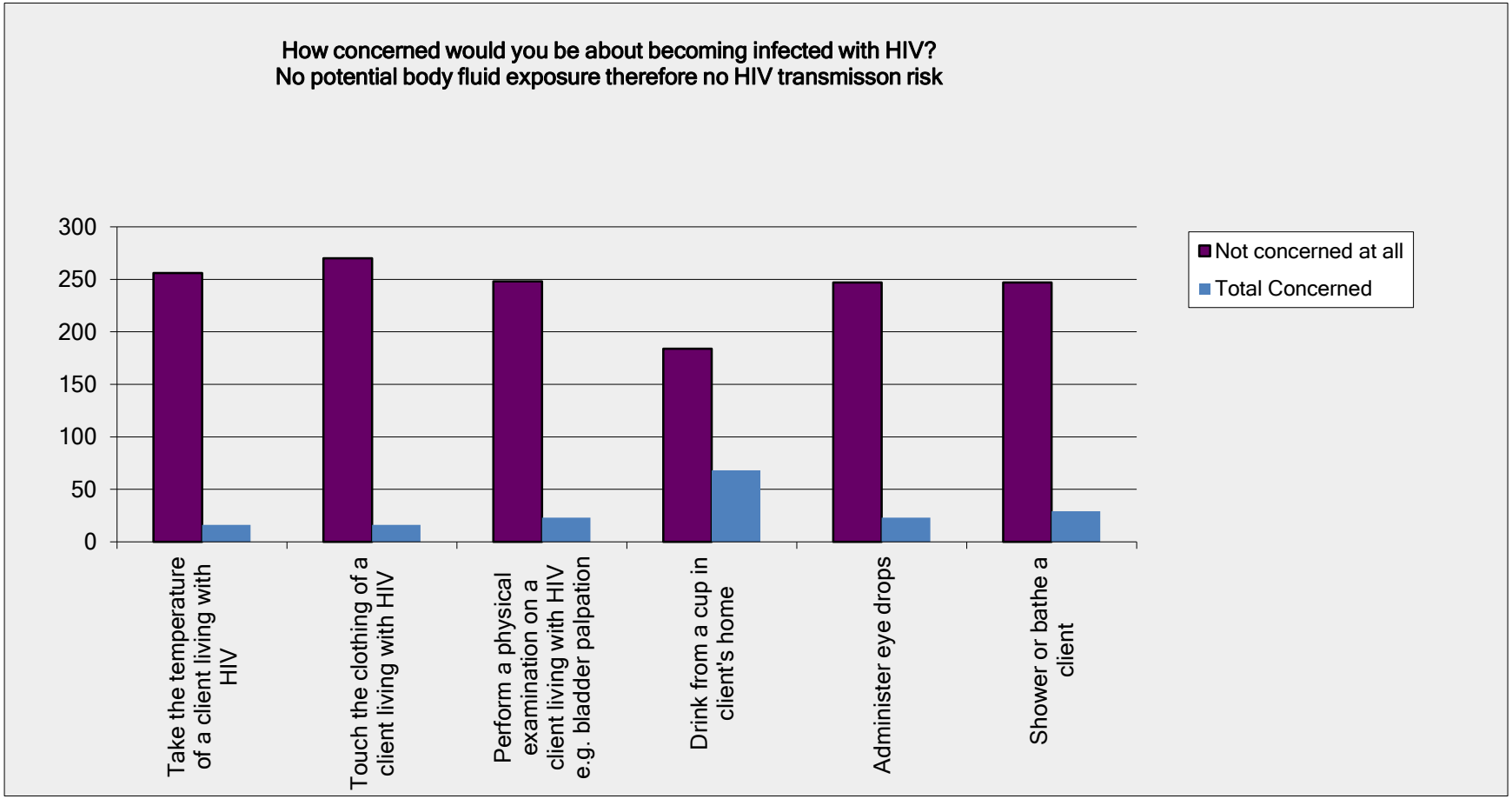


Figure 33: Total numbers of staff concerned/not concerned about contracting HIV

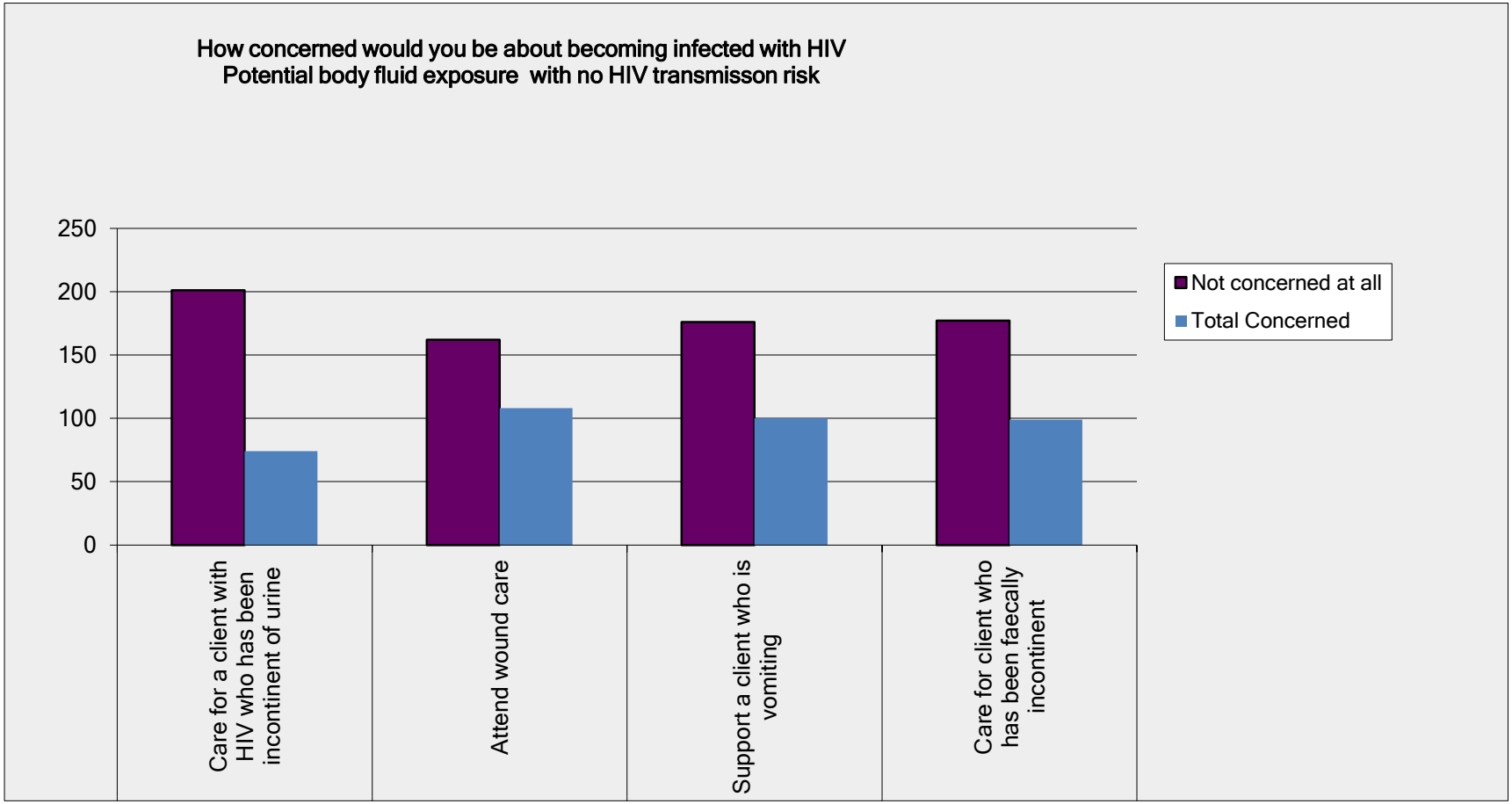
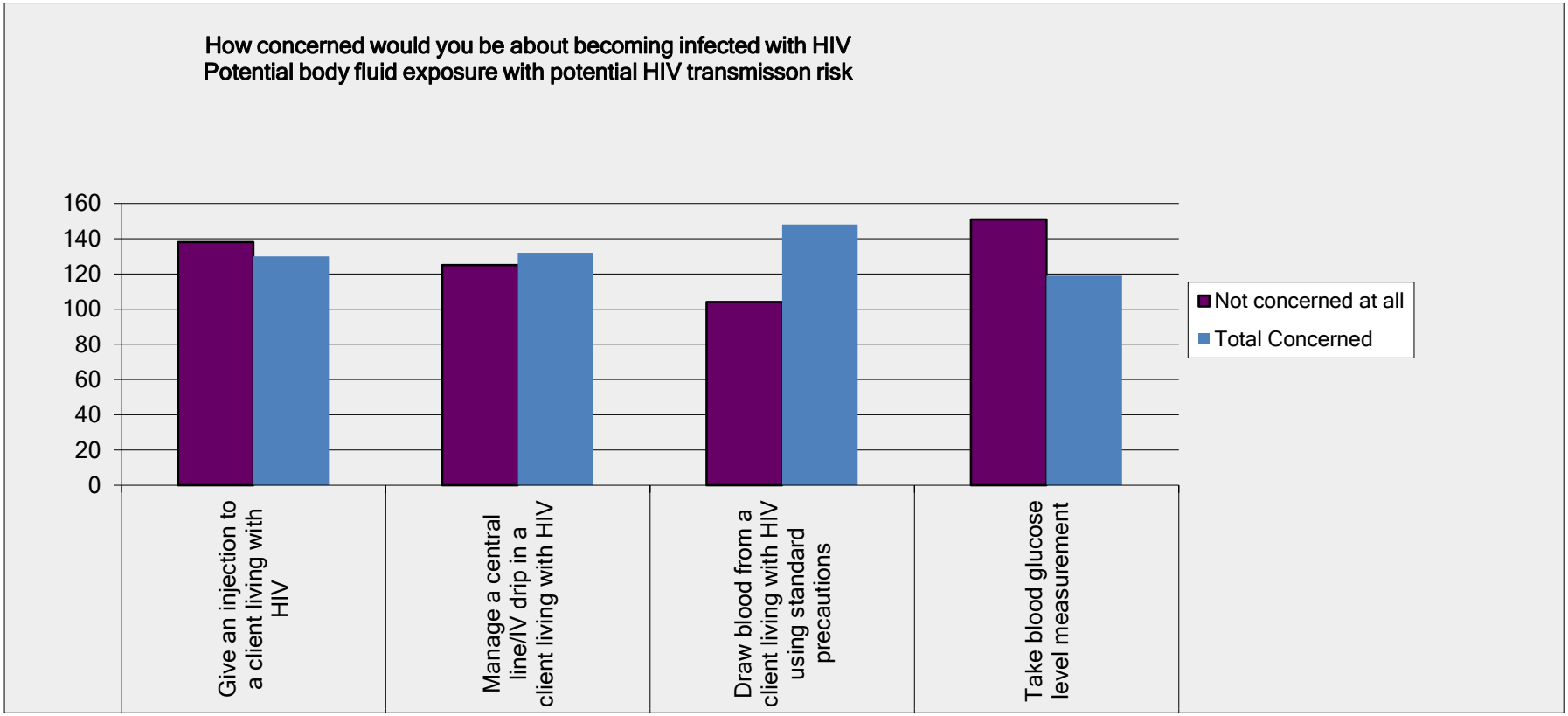


Figure 34: Total numbers of staff concerned/not concerned about contracting HIV



As expected, respondents were not concerned at all about undertaking most procedures where there was no risk of HIV transmission. However, a total of 68 (21.6%) were concerned about 'drinking from a cup in a client's home'.

In the second scenario, Figure 33, more respondents were concerned about the risk of HIV infection, and in Figure 34, (actual risk of transmission), far more were concerned than in the previous two scenarios.

The biggest anomaly was in the numbers concerned about contracting HIV from drinking from a cup (Figure 32). This was explored further by cross–tabulating by staff type to ascertain whether those who were not registered nurses might be over–represented.

Those who were 'very concerned' included Division 2 (Enrolled nurses), Grade 2 RNs, Grade 3 and a CNC. Those 'concerned' included Division 2, Grade 2's, Grade 3s, CNCs, Clinical Coordinator. Only one respondent who was concerned was a Community Care Aide (CCA), the level of staff who receives least training and have no nursing qualification.

Of those who were 'a little concerned', most levels of staff were represented, including Division 2, Grade 2s, Grade 3s, Clinical Nurse Specialists, CNC, Clinical Coordinators and 2 CCAs.

The three graphs indicate that there is concern amongst almost all levels of staff with respect to HIV transmission prevention. Attention must be drawn to addressing transmission risk perceptions in education across the organization.

45 comments were made in reference to this question which provides perspective on staff's concerns.

Table 11: Comments by staff on perceptions of infection risk

'I'd be concerned about catching the flu from a client with it, or gastro, but more concerned about catching a more serious disease. Accidents happen despite precautions' (Division 2 RN).
'I would be more concerned that I would be putting the client at risk as they have a compromised immune system' (Grade 3).
'Only concern re urinary incontinence would be if the client had haematuria or was menstruating. Wound care: if bleeding wound. Vomiting: blood stained vomitus' (Grade 2 RN).
'My "little concern" of these tasks would be with any client, not just HIV clients; I am always ultra–protective with any fluid substance' (Grade 2 RN).
'I have chosen very concerned, only because I feel I have not had enough education on this subject in my nursing career, I would honestly like to have a day of training that involves HIV only' (Division 2 RN).
'These +ve clients need as much if not more professional support … than average clients due to feeling like "the untouchables"; to normalize their treatment/surroundings is very important. By drinking out of one of their cups in the home will support them in this area and give reassurance that you are respectful and treat them without bias' (District Nurse Specialist).
'I do not take drinks or food at any clients' homes. Pertaining to the above, I could be in a position where I may need to assist a client with continence concerns, vomiting, exterior and non–invasive care, for this I would like further education' (Social Worker).

Many others commented simply that they use standard precautions at all times:

> *'It's not the clients we already know about, it's the unknown clients, universal precautions are there to protect all' (DN Specialist).*

Overall, comments indicate careful and nuanced thinking around this issue, not uninformed or irrational fear.

Q15 Staff were asked how concerned they thought their partner or family would be about their caring for PLHIV at work (see Figure 35). A total of 52.6% thought their partner or family would be concerned. 25 comments were made, responses mainly referring to lack of education amongst the wider public:

> *'Most likely because they are not health trained'.*
>
> *'Lots of infectious situations require care: they would trust in systems being established and followed'.*
>
> *'Lack of insight and understanding about the efficacy of universal precautions'.*

'I don't believe my family are educated about the illness and think it's easy to "catch"'.

Some were more personal:

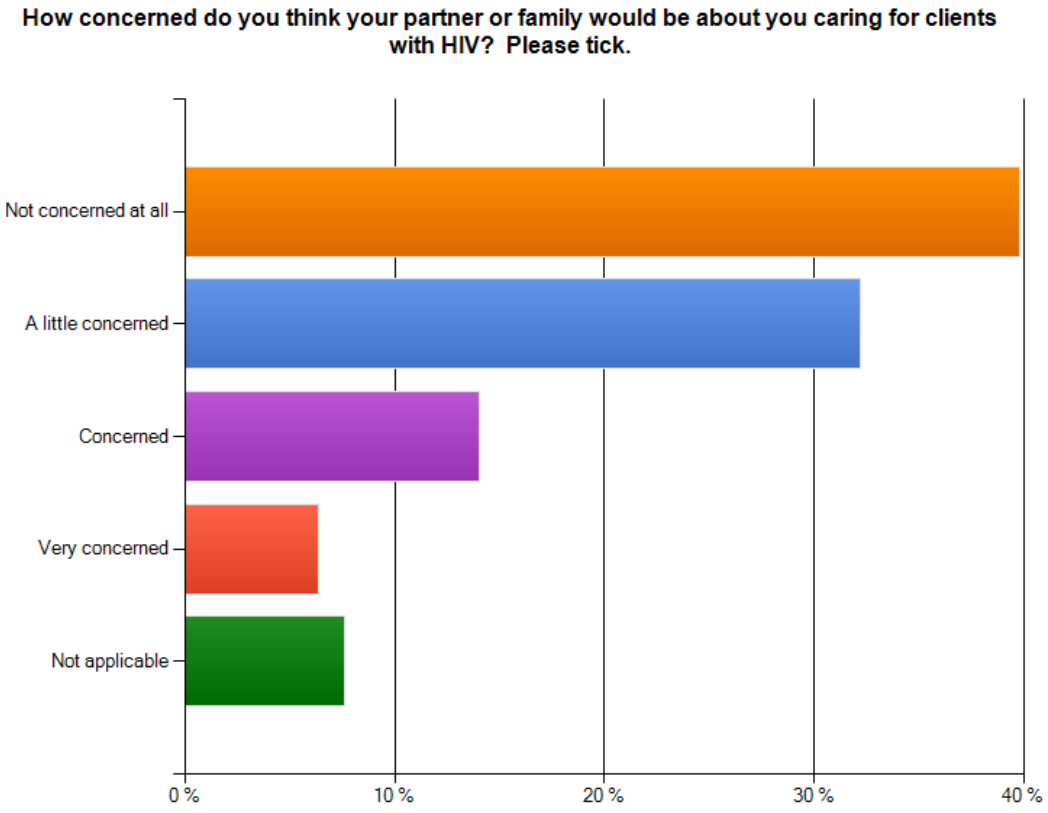
'Protective of me since chemotherapy as my immune system is not up to scratch'.

Several mentioned that they do not discuss clients with family, a strong commitment to confidentiality:

'As I do not discuss my clients with my family they would have no reason for concern'.

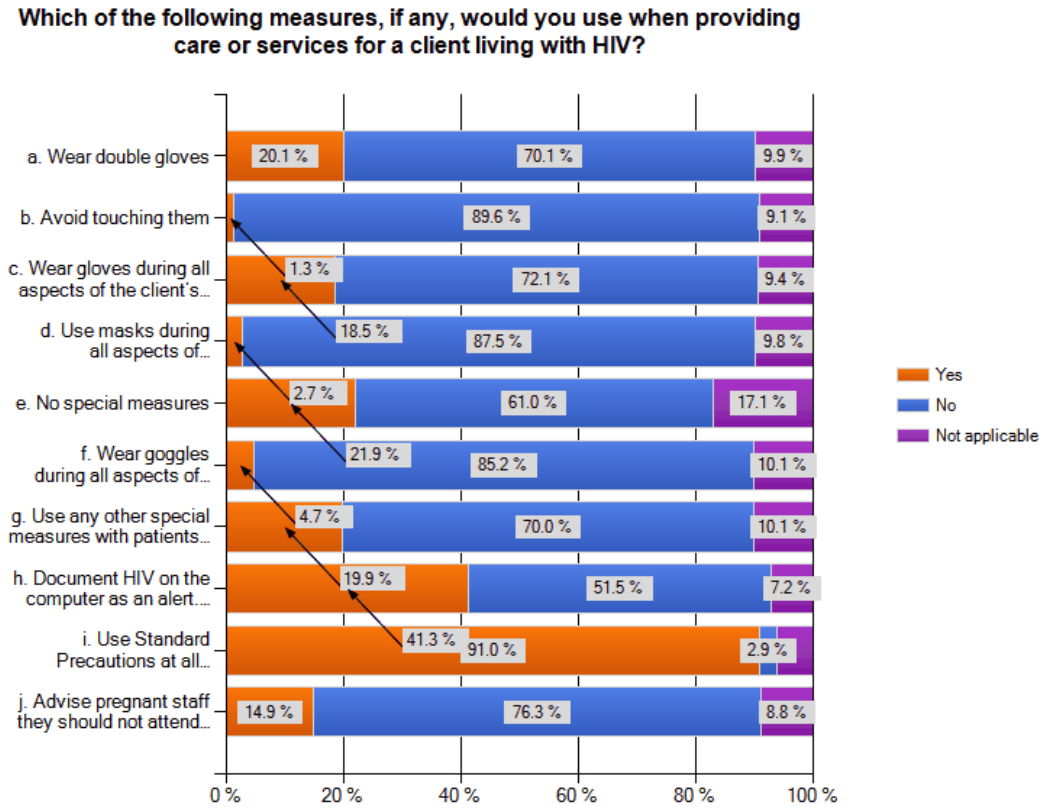
'In the interest of client confidentiality I would not disclose any client with any diagnosis to my partner'.

Figure 35: Staff opinions on family or partner concern



Q16 pertained to practices. Staff were asked 'Which of the following measures would you use when caring for a client with HIV?' and 8 actions itemized.

Figure 36: Measures staff report they would use providing care to a client with HIV



91% said they would use Standard Precautions in all aspects of their work.

41.3% said they would 'document HIV as high clinical risk'. Only 21% said they would use 'no special measures' although this is all that is required in HIV nursing care.

20.1% said they would 'wear double gloves' and over 18% said they would 'wear gloves during every aspect of a client's care (including history taking and physical examination)'. Nearly 15% of staff said they would 'advise pregnant staff not to visit'.

Staff were asked to provide more information if they responded 'yes' to the question regarding pregnant staff.

45 comments were made, providing rich contextual data on respondents' reasoning around this issue. 15 referred appropriately to Standard Precautions.

Themes identified from the comments are summarized in Table 8 (9 responses were 'unsure', 'depends' and uncategorized).

Table 12: Rationale given for advising pregnant staff not to visit HIV clients

Risk of other infections (7)	'The possibility of infections that could harm the baby e.g. CMV'.
	'Some of the infections HIV client have can impact on pregnant women i.e. certain drugs'.
	'Only related to CMV in pregnancy'.
	'Except if infected with CMV or other infection that may be detrimental to pregnant staff'.
Cytotoxic drugs or other medications (7)	'Maybe due to the medications used would need to ascertain if the client is on chemo'.
	'Clients may be on cytotoxic medication'.
Risk to mother and/or baby (3)	'Avoid care which could potentially result in needle stick injury, especially at advanced stage of pregnancy as some procedures can become more awkward at this time'.
	'Possible risk to get infection and possible risk to pass to child'.
Right to know (2)	'I think it would be that staff member's right to know if they were attending a client with HIV'.
	'Although we should use standard precautions with all clients, I think it is still good to know those who have HIV or hepatitis etc. so that we can be extra careful in our work'.
Need for alerts (5)	'I would make alert HIV positive. This may not be required but I would err on the side of precaution with pregnancy'.
	'CSC process is to identify clients with infectious disease via alert; it is terrible'.

Each of these matters raised in responses to the staff survey require addressing in RDNS education at a basic level and can be utilised immediately in education programming.

Q17 The final question to be reported on here from the staff survey asked them their opinion of ways to improve access to care for PLHIV and the care provided. This question was the same as one asked of clients (see **Q10** of Client survey).

Figure 37: Staff opinion on importance of ways to improve care and access to care for HIV clients (1)

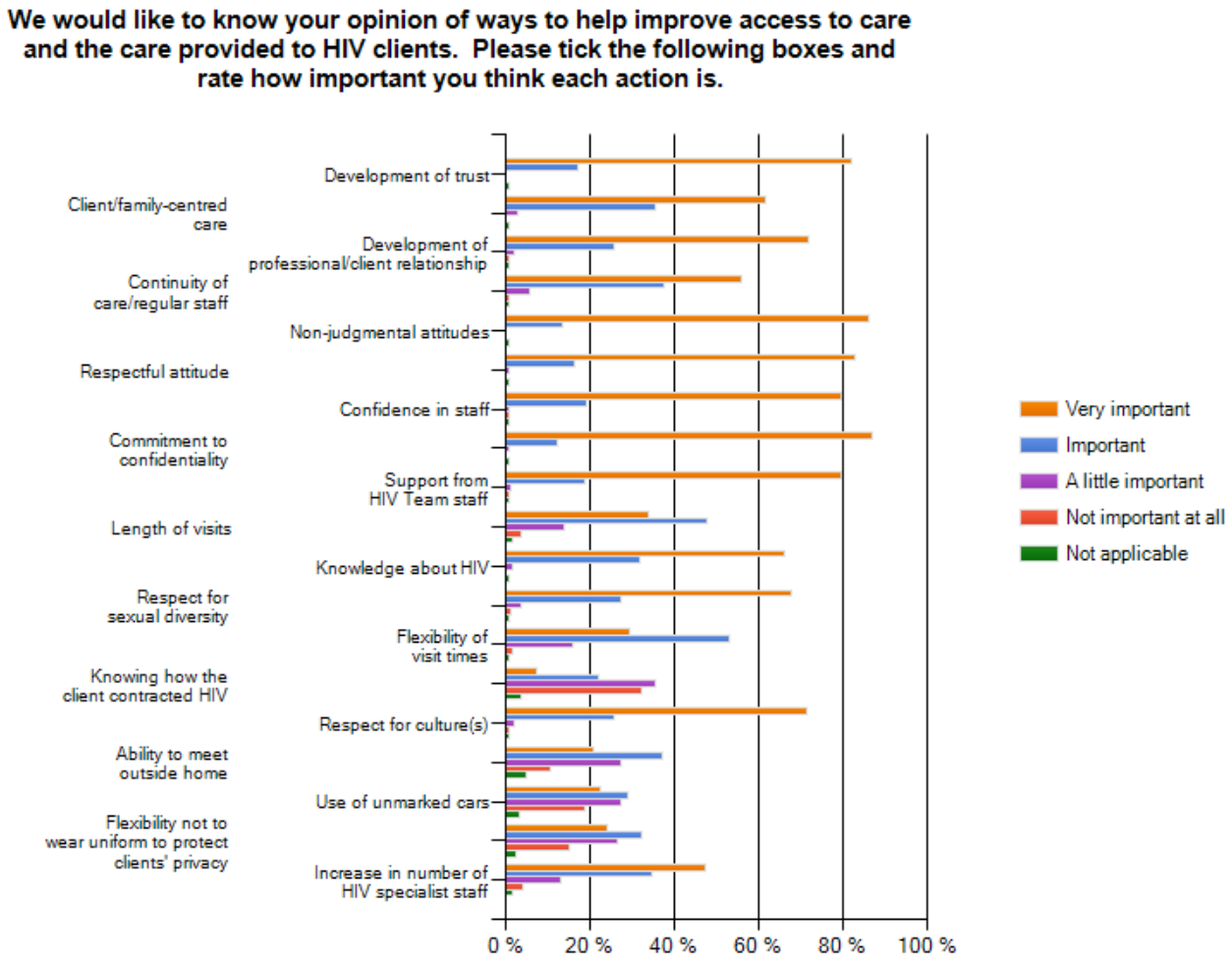


Figure 38: Staff opinions on importance of ways to improve care and access to care for HIV clients (2).

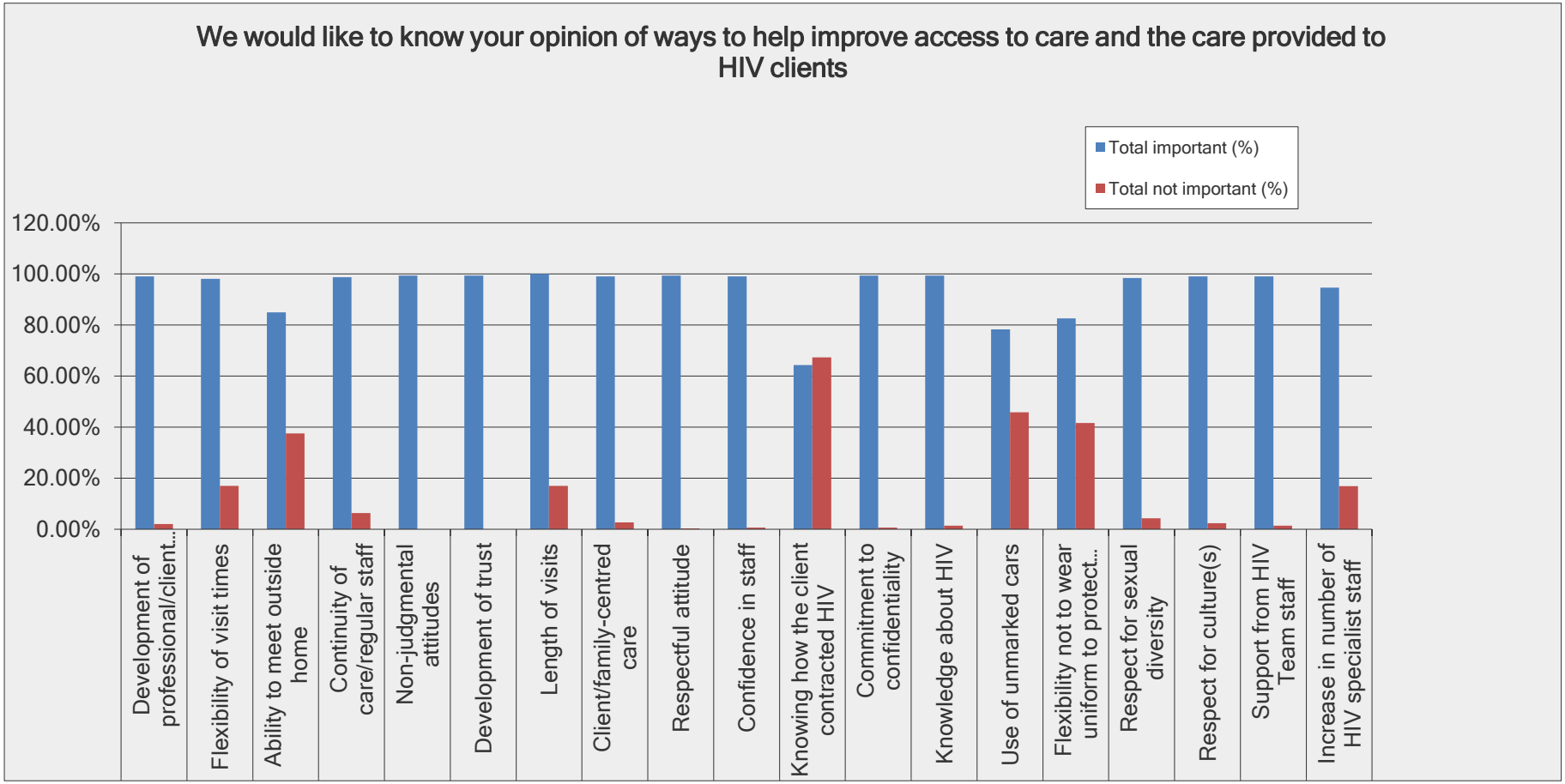


Figure 37 shows complete responses, and in Figure 38, the range of responses was collapsed into three categories – Total important ('very important' or 'important' and Total not important ('Not important at all' or 'a little important'), and 'not applicable'. There was significant congruence between what staff and clients saw as important, with trust, respect, confidence in staff, non–judgmental attitudes, commitment to confidentiality, level of HIV knowledge. 100% of clients and 99% staff rated trust as the most important value. 98% saw client– and family–centred care as important.

Use of unmarked cars and flexibility not to wear uniforms (51.2%; 56%) were considered less important, though this means over half do recognise that marked cars and uniforms can be a barrier for this client group. A majority saw a need for an increase in HIV specialist staff (82%), though some disagreed.

29 comments were made:

> *'Increasing the "specialist staff" removes this client group further from staff, thus no development in the area' (*Management role).
>
> *'Cars & uniforms, I don't see where what people drive or wear as important, it needs to be promoted as "normal" to the client, if the clients have an issue can they access a clinic, LMO or pharmacist?'* (Management role).
>
> *'If we are to use unmarked car and not wearing uniform for HIV clients we should do the same with other clients too' (Grade 3 RN).*
>
> *'Knowing how the client contracted HIV could be important e.g. if sexually assaulted, or if it affected relationships in family etc. to help provide appropriate support'* (CNC).

Q 18 Staff were asked whether they believe RDNS or other agencies have a duty to disclose a client's HIV status to nursing staff who will provide care. The majority (71.9%) responded in the affirmative, with 14.2% saying No and 13.9% unsure.

45 Open–ended responses were made, many mentioning Standard Precautions, however some emphasizing the need to know HIV status

> *'to ensure they practise usual precautions';*
>
> *'yes, despite the importance of universal protection, some staff may not practise as they should';*
>
> *'Sometimes it's important to be extra careful […] we can't always operate at the same level of awareness. […] I see it as a duty of care to staff […] we aren't machines'.*

These comments illustrate persevering doubts about standard precautions.

Others emphasized the need to know in order to provide the best care:

'Why not tell someone who is involved in someone's care, so care can be specific for that client?'

A few identified that this is not a legal duty:

'Client has the right to confidentiality'.

'Not legal'

'Clients have the right not to disclose their own health status to service providers'.

Q19 Staff were asked whether they would disclose a client's HIV or other BBV status to a council for services (e.g. cleaning). 7.3% responded Yes, 28.7% said No, 52.1% responded Yes, but only with the client's informed consent. 11.9% were unsure.

24 comments were made.

'I would seek the advice of the RDNS Specialist staff'.

'I don't think I would as I'm not sure of others' reaction to client, I like to protect'.

'It would depend on whether there was an identified risk for staff (e.g. IV drug user)'.

'Yes if for hygiene'.

Q20 Finally, staff were asked if they had any further comments or suggestions about the HIV Program and their educational needs. Comments on the program and roles included:

*'The leadership and compassion shown by the HIV Team is really inspiring (*Clinical Nurse Specialist).

*'There is too much of a focus on GLBT issues and I have been told by an educator that the Catholic church is wrong for opposing use of condoms. Unprofessional and irrelevant. It should be about treatment, not sexual behaviour' (*Division 2 Nurse).

'The role of CNCs within RDNS needs to be reviewed. I would include the HIV Specialist in that review'.

'HIV Team should operate from one site to provide better team work'.

The other main theme concerned staff wanting and needing more education, and to see more HIV clients:

*'Ability to see more HIV clients to ensure our knowledge and skills are relevant and up to date' (*District Nurse Grade 2).

'Would like to attend the Pre and Post Test counselling 5 day course at Latrobe'

'Short education sessions for staff'. 'In–service would be beneficial'. 'Whole day on HIV'.

'Higher demands in all areas of health care. More complexity and co–morbidities. This is just another area of growing need. Something has got to give'.

> *'refresher would be appreciated on legal/alerts/staff awareness/responsibilities vs confidentiality/rights i.e. moral vs. legal issues' (*Grade 2 District Nurse).
>
> *'HIV should be standard and automatic for all orientation of new staff (including graduates)' (*Management role).

HIV clients not being treated as 'special' was also raised:

> *'I think we need to start removing the "special" focus on this client group, start bringing them into the general area of care for staff […] we treat all clients as equal and deserving of our care and expertise' (*Management role).

Some of the challenges arising for RDNS staff in relation to HIV client care are captured in this quote below, from an HIV Specialist Nurse:

> *'These clients are incredibly complex, they are going to need care for a long period of time, the care that is provided is deeply personal, there has to be opportunity to have dialogue around risky behaviours, whether that be unsafe sex, or sex, or whether that's around injecting and safe injecting, and currently I believe that for the majority of primary nurses this falls outside their scope of practice, or their "comfort zones" of practice'.*

Chapter 6: Discussion

This chapter discusses the implications of the results for the development of the HIV Program in relation to the evaluation questions.

HIV clients' current and future needs

HIV Program data

Through examination of current HIV epidemiological data and literature, the review of HIV Program data and the client survey, this evaluation first identified and described the profile of current RDNS HIV clients and in the sample who responded to the survey. In context, this group is on average 10 years older than PLHIV in Victoria overall, has multiple co–morbidities, and includes a very diverse range of people. Over–represented in the RDNS HIV Program are indigenous people, women, and people from diverse cultures including refugees/asylum seekers, homeless people and long–term survivors, mainly gay men. Mental health problems and cognitive impairment along with other co–morbidities are prevalent in this group.

The high proportion of indigenous clients (~8%) in comparison to RDNS general clients, and Culturally and Linguistically Diverse clients (nearly 40%) are testimony to the team's ability to engage these groups who historically have reduced access to services, particularly if they have HIV infection. Furthermore, these groups notoriously present late in infection, with higher rates of death and disease and are priority target groups of the National and Victorian HIV/AIDS Strategies[5, 6].

Human resources use

HIV–related human resource use (nursing hours) has increased significantly over the past 10 years, peaking in 2009, with no funding growth. Additional HIV nursing roles were implemented in 2003 at two high case load sites which have increased the Program's capacity. Several sites have high case–loads with inequitable specialist resource allocation.

Evidence of likely increasing demand on human resources, and subsequent educational needs of staff, is supported by the literature, HIV Program data, client and staff surveys, qualitative data from interviews with key informants, staff and clients' comments.

Client survey

Age–related issues, cancer, dying of AIDS and non–HIV related illnesses were all concerns to clients. Many clients were concerned about housing and financial issues, and were

socially isolated, a finding that has been reported in other Australian studies as well[65]. These are all supported by the literature and reaffirmed by key informants, including medical specialists, nursing specialists, peer support workers and executives in the HIV sector. There is strong evidence for changing epidemic dynamics, including increasing numbers of women, people from diverse cultural backgrounds, homeless people and heterosexuals, through HIV Program data, survey respondent demographics, literature review and interview themes.

Key informants highlighted that stigma and discrimination are still prevalent, especially fear of stigma, self– or internalised stigma which primes people to avoid services and lack trust. Themes of premature ageing, increasing numbers of women requiring reproductive services and subsequent support, refugees, mental health/drug and alcohol and cognitive issues, and protection of public health were all raised as issues that would affect RDNS HIV client cohort in the future. These are consistent with current literature[27, 34].

Model of care, service description and strengths

The model of care was described in the background to this report in Chapter 1 and depicted in the Program Logic model (Figure 1). A detailed description of the service was obtained through analysis of the client questionnaire.

The care provided encompassed 6 domains of care – Health monitoring, mental health support, psychosocial, medication management, health promotion and prevention, care coordination. This is important to answer the questions about reach and effectiveness of the Program, to what extent clients are receiving comprehensive care, and quality care. Each domain encompasses several aspects of care and can be multifaceted. For instance, medication management and assistance with adherence can involve ensuring consistent supplies, organising prescriptions, checking those dispensed are correct, assisting with funding to pay for medications, educating about adherence/side effects, and even directly administering, whilst assisting clients to self–manage wherever possible. Many of these tasks are required due to clients' cognitive, mental health or language problems and indicate significant support needs.

The intervention acknowledged by the greatest proportion of clients fit with the 'Mental health support' domain, which included 'help with emotional issues', 'when my mood is low or I feel stressed', and 'help me cope with my situation'.

Clients' comments added richness to the Program description. Practical and moral support, information and health education were also described.

There has been a significant gap in the literature which articulates models of HIV care in Australia which include community nursing roles. One recent study in New South Wales omits evidence of the role of district nurses in HIV care in Australia [66], though the intention to examine nursing roles more broadly is mentioned in the appendix. It is important to understand these roles in caring for those with complex community nursing and support needs in particular.

A report produced by RDNS South Australia (SA)[14] provides a description of its HIV Program and philosophy of care: the SA model is similar to the one reported here, with clients describing similar values amongst the nurses – notably their appreciation of respect, trust and not feeling judged. In the SA report, clients' involvement with the HIV Nursing Team was instrumental in counteracting the impact of negative prior and current experiences with other services or people (p. 22). The authors found that connecting with the HIV Team marked a point in which some clients began to see a future, to take stock of past negative or risky behaviours. The impact of such services to empower people to 'turn their lives around' may be difficult to measure; however, there is room to suggest that it can have an effect on risk–taking behaviours and subsequent HIV transmission.

Engagement and retention in HIV care and 'the treatment cascade'

Community–based nurses can play an influential role in engaging and retaining some of the most marginalised PLHIV in clinical care, a growing concern. There is evidence from over 40 studies that marginalised groups experience enormous disparities 'across every step of the treatment cascade' – for example, black MSM in the USA are 'are less likely to be diagnosed, linked to care, retained in care, prescribed ART, and virally suppressed'[67]. Conversely, retention in care is critical for PLHIV for a range of reasons – they are more likely to be prescribed ART, to achieve an undetectable viral load, and improve in mortality and morbidity; moreover, retention in care is directly linked to decreased HIV transmission[68]. Whilst there are no systematic Australian studies on this issue, and the health care systems are vastly different, there are likely to be some similarities; there is

[14] Unrelated to RDNS in Victoria, and now known as Silverchain.

evidence that CALD clients, for example, present late in infection and experience worse outcomes in the Australian setting [40].

The comprehensive role that the HIV Program plays in coordinating community –based care, ensuring clients can attend appointments, ensure a continuous supply of antiretrovirals, monitor and promote adherence and assertively outreaching to those most marginalised, are all key elements of engaging and retaining PLHIV in clinical care and therefore improving their chances of viral suppression and improved health outcomes in the long term[68].

A recent systematic review of interventions to assist to retain PLHIV in care in the USA [69], p. 313 found that 'strengths–based case management that encourages clients to recognize and use their own internal abilities to access resources and solve problems offered strong evidence for retention in care', as does reducing structural and systemic barriers. Some of these elements are evident in the HIV Program.

Client satisfaction

Care provided by the HIV Program is highly valued by clients and other service providers. Clients expressed a high degree of satisfaction with the service. Accessibility and communication, and all aspects of quality of care (visit duration and frequency, knowledge and skills, continuity of care, ethical practices, need and expectations for support, and cultural competence) were all rated highly.

Cultural competence/sensitivity

Cultural competence has been defined as:

> *'A set of congruent behaviours, attitudes and policies that come together in a system, agency, or amongst professionals and enables that system, agency or those professionals to work effectively in cross–cultural situations'*[37], p. iv.

Further, Cross notes that

> *A cultural competent system of care acknowledges and incorporates—at all levels—the importance of culture, the assessment of cross–cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally–unique needs* [37], p. iv.

Cultural competence in the HIV sector is understood to be essential for the care of people from culturally and linguistically diverse backgrounds as well as GLBTI people. Cultural and sexuality–related issues are often compounded for PLHIV.

Clients overwhelmingly reported getting services in the language they wanted (98%) and 100% of those for whom this was relevant said they felt nurses 'respected their culture'. 98% said nurses were accepting of their life and health care choices.

Gaps in services

The client survey and key informant interviews identified lack of continuity of care, need for better care coordination across services, and the need for mental health expertise as gaps in the service (and services more generally).

Two HIV sector managers expressed views about the 'vulnerability' of the HIV Program within RDNS, suggesting it be removed from RDNS and auspiced by a community–based organisation such as VAC which has its own medical and nursing services. Throughout Australia, HIV specialist nursing teams are attached to community health centres, hospitals and general practices[70, 71]. It is beyond the scope of this project to examine different models of providing HIV nursing services in the community or to debate their merits, however, the sense of 'ownership' of the HIV Program by the community it serves is noted.

RDNS Staff survey – Workforce development needs

The Staff survey results helped answer the questions about workforce development needs and supplementary questions (Table 13).

Knowledge

Most staff reported very low levels of HIV knowledge in all domains explored: HIV pathophysiology, medical management, prevention, specific populations/vulnerable groups. A majority reported few skills in HIV care. A majority see no or only a few HIV clients; this is related both to the low prevalence of HIV generally, and their widespread geographical location across Melbourne[72].

Evidence regarding knowledge gaps can be immediately incorporated into RDNS internal education programs with focused attention on topics most pertinent to RDNS' role, including medication management/drug toxicities and side effects, neurological/cognitive issues, mental health, and the specific needs of vulnerable populations, to name a few.

Staff's level of willingness and eagerness to learn about HIV is very high, though their comfort level relatively low. Many indicated ambivalence about Standard Precautions, the cornerstone of safe nursing practice.

Attitudes

A number of staff, principally at management level, expressed lack of understanding of and support for the HIV Program, suggesting that having specialist staff 'de–skills' other staff, and that clients should be (or already are) treated 'the same' as all others, effectively 'mainstreamed' into RDNS.

> *'Having an HIV Resource nurse takes opportunities away from primary nurses – they then become deskilled'.*
>
> *'HIV clients should be seen and treated as every other client not discriminated or made to appear "special"'.*

However, according to key informants in the sector and current literature, stigma and discrimination are still prevalent.

> *'…stigma, less so discrimination, but stigma, profoundly affects the lives of every single person living with HIV. There is no one I know with HIV who has not experienced some form of stigma that makes them feel bad, unworthy, ashamed and then of course all that stuff that that raises for them.[…]* (Senior Manager, HIV agency, HIV+ gay man).

HIV sector workers, especially those who are HIV positive themselves, are wary about calls for mainstreaming:

> *'I actually choose services that are HIV savvy, I won't go outside of that'* (Peer support worker, HIV agency, HIV+ woman).
>
> *'It would bother me if it was mainstreamed [into RDNS] because you've got a whole bunch of people who aren't educated and you don't know what their response is going to be. If they're educated, we don't have that issue, we can go to one of you guys and it's all OK, we have that confidence in you and we don't have to speak up. If there's any discrimination that goes on (laughs) you guys DEAL with it. You bear the brunt of it FOR us'* (Peer support worker, HIV agency, HIV+ve woman).

Practice

Some staff are concerned about contracting HIV in the workplace, even in 'no risk' situations. 68 respondents (21.6%) were concerned about contracting HIV from 'drinking from a cup in a client's home'. Unease about whether pregnant staff should visit HIV clients was expressed. A significant number of staff, including managers, support the use of computer 'alerts' regarding HIV clients, justifying their reasoning in terms of infection

prevention. Nearly 20% said they would 'use special measures with HIV clients that they would not use with other clients', and over 18% said they would use gloves during every aspect of client care (including history–taking).

> *'I would make alert HIV positive. This may not be required but I would err on the side of precaution with pregnancy'.*

Specific HIV Program practices, such as use of an unmarked car/no uniform to protect privacy and reduce barriers to access were not supported consistently:

> *'Cars & uniforms, I don't see where what people drive or wear as important, it needs to be promoted as "normal" to the client, if the clients have an issue can they access a clinic, LMO or pharmacist?* (Management role).

Some of these practices amount to active discrimination; others (such as generic intake policies and practices) result in indirect or passive discrimination if they pose a systematic barrier to access to some groups.

There is incongruence between the views of field staff, most of whom report low levels of skills and knowledge yet are interested to learn more and partake in care of PLHIV, and managers suggesting that they have been 'deskilled' by having and HIV Team. Field staff acknowledge the supportive role of the HIV Team and the need for expertise. A few report negative attitudes towards the Program itself, some questioning its existence. Whilst some staff felt that having unmarked cars, a confidential code for HIV clients and an HIV Program per se, perpetuated discrimination and stigmatisation, conversely, others indicated that they would place an alert on a client's computer file and advise pregnant staff not to visit HIV clients. Others suggested that HIV should be treated like any other chronic illness. These contradictory stances can present barriers to providing sensitive, continuous, targeted, skills–based care to HIV clients.

The underlying problem (perhaps under–recognised) is that stigma and discrimination persist in the lives of PLHIV [41], whilst some health professionals consider stigmatisation no longer occurs. As demonstrated in this report, the cohort at RDNS has a range of mental health issues and specific cultural issues where fear of disclosure of their HIV status, and

feelings of shame can be overriding factors affecting their access to, and engagement with health care[15].

Key informants present contrasting views. They emphasise apprehension about mainstreaming, ongoing negative experiences of clients within health care services, reluctance to disclose HIV status, fear of discrimination, and the importance of advocacy by HIV CNCs. It was mentioned several times that HIV is 'not just a chronic illness' by HIV sectoral staff including medical, nursing and peer support workers, each illustrating this claim with powerful anecdotes. HIV peer support workers emphasized the reassurance provided by knowing there is a specialist team within RDNS, that they will not have to fight for their rights when unwell. Clients mentioned RDNS being there 'when no family was'.

These divergent views point to the RDNS HIV Program being a recognised 'safe haven' within the health care system but one that is at risk of erosion within the wider organisation.

From the staff survey, and considering the data from interviews and literature reviews, four key issues were identified that require decisive action: a persistent level of fear around infection, issues concerning pregnant staff and need for 'alerts', laws around disclosure of HIV status; and HIV–related discrimination. These will be discussed in turn.

Infection prevention

Fear of infection

A surprising number, over 20% of staff across all categories reported concern about contracting HIV by drinking from a cup in a client's home; many were ambivalent about Standard Precautions even when they profess to use them. Fear of contracting HIV from needle–stick injuries was common [73], in line with reports in international literature [74, 75]. A recent Victorian study also indicated that staff in nursing homes have expressed fear of contracting HIV from caring for an HIV–positive resident and that staff might use excessive infection control precautions or avoid PLHIV [37]. A study in New South Wales found that gay men in particular were concerned about nurses' lack of HIV knowledge, lack of experience and potential discrimination[70]. The provision of targeted information

[15] One client who had her status disclosed in 2012 to people in her community by the arrival of mail to her home was threatened with murder by relatives and had to move away from her community.

and education have been shown to be effective in reducing fear[37]. Basic information needs to be provided at all levels for RDNS staff on HIV and infection prevention.

Pregnant staff visiting HIV clients

There is no evidence that pregnant nurses attending to the care of HIV clients are at increased risk of occupational HIV infection yet many staff (nearly 15%) said they would advise pregnant staff not to visit HIV clients.

Concerns regarding cytotoxic medications are valid and would be considered for each client and many staff recognised that this was not a concern specific to HIV clients.

The risk of other infections (mostly cytomegalovirus – CMV) that an HIV client may have was mentioned frequently. CMV can cause foetal abnormalities if the mother is newly infected (or has a reactivation of infection) during pregnancy so there is legitimate concern for pregnant women about avoiding CMV. However, Standard Precautions protect against CMV (as for other infections). Most CMV infections in pregnancy are reportedly contracted through sexual contact or contact with the urine of a young child [76]. Pregnant nurses should be advised to undertake thorough hand washing with soap and water when dealing with CMV positive clients [77].

Legal and ethical

'Right to know' HIV status

It is a concern that over 70% of staff agreed that they had a 'duty to disclose' HIV status to other nurses, with most justifying this with reference to the need to protect staff, whilst acknowledging Standard Precautions in theory. It is well–established that there is legally no 'right to know' a diagnosis and that the best way to protect staff in occupational settings is through the use of Standard Precautions [77]. In most cases HIV clients do provide consent to disclose to relevant staff for the purposes of providing care. There is no requirement for a nurse to disclose to another nurse for the purpose of protecting staff.

The Victorian Health Services Act (1988) allows disclosure only 'with the consent of the person; as expressly authorized, permitted, or required by law, in relation to criminal proceedings; in the public interest; or in relation to health care where the information is required for the further treatment of a patient'. The Health Records Act 2001 also addresses this issue as does RDNS Information Privacy (SP–L04) Policy. This issue should be prioritised in education for RDNS staff.

Some topics addressed in the staff survey do not relate just to HIV, especially legal issues around disclosure, privacy and legal rights – they are applicable to clients across the organization and within health care. It can be argued that breaches usually have greater implications in the context of HIV and other blood borne viruses and thus this knowledge gap needs to be addressed across the organization.

Stigma and discrimination

HIV–related discrimination has been defined as:

> *unfavourable treatment on the basis of known or imputed HIV status; action or inaction that results in people being denied full or partial access to otherwise generally available services or opportunities because of known or imputed HIV status (*49) p (vii).

It can be further described as direct and active (proactive and reactive); or indirect and passive.

Direct discrimination is based on an individual's real or attributed characteristics and proactive discrimination is intentional and planned [78]. The use of 'alerts' and 'advising pregnant staff not to visit' are examples of direct (proactive) discrimination.

Reactive discrimination occurs when a person is confronted by an HIV positive person and reacts negatively. An example is the adoption of excessive infection control precautions or avoidance upon disclosure of HIV status {NSWADB, 1992 #71. There is some evidence that this might occur within RDNS, given the proportion of staff who responded that they would wear gloves during every aspect of care with an HIV–positive person. 3o years since the epidemic was first recognized, this is a surprising finding.

Indirect discrimination is based in 'the establishment of rules, policies or conditions which in themselves do not appear discriminatory', but which result in discrimination against people who are less able or unable to meet the required conditions {NSWADB, 1992 #71}p. 9. Indirect discrimination within RDNS can occur when policies and practices which purport to treat all equally (generic intake practices, use of car logo and uniforms, not meeting outside the home) can result in discrimination against this highly vulnerable group by reducing their access to RDNS' services. For some, assertive outreach is an important component of the HIV model of care[79]. There is evidence in comments that some RDNS staff, in professing to want to treat all clients 'the same' could inadvertently exclude

some PLHIV from services[16]. For a client who is not engaged with health services, where the HIV Program might be their sole link into HIV services and subsequent retention in care, this stance could further marginalise them and lead to loss of engagement.

There is evidence that direct discrimination against PLHIV occurs within RDNS, especially with respect to the use of 'alerts' regarding their HIV status and unnecessary infection control precautions. Indirect discrimination is also likely in relation to practices that might pose barriers to access for some clients. Currently, in spite of policies being in place that support specific practices for HIV Program clients, these are not consistently supported by management and are therefore at risk of being dismantled or undermined.

The contradictory viewpoints discussed above can lead to systemic barriers and discrimination. In seeking to address this concern, it is helpful to draw from the concept of 'the AIDS Paradox', first espoused by former Justice Michael Kirby.

> *My basic thesis is simple. It is that, paradoxically, the protection of the human rights of persons at risk is the most effective way of arresting or slowing the spread of the virus. This is the AIDS paradox. Only by recognising this paradox can the confidence and attention of the relevant audience be won and held. Only by doing this can the behaviour modification, necessary to containing the epidemic, be achieved* [80].

Similarly, it is only by recognising the specific needs of clients with HIV, including their experiences of discrimination/stigma, mistrust of health services, and fear of disclosure, that we will gain their confidence and reduce barriers to access to services that ultimately will enable us to treat them 'the same' as everyone else. Paying attention to paradoxes such as these calls for 'divergent, rather than convergent' thinking, according to Rappaport where both sides of a contradiction need to have attention paid to them[81]. He states 'when we pay attention to paradox, we are more likely than otherwise to find ourselves useful'. Pursuit of paradox, he states, is 'finding those places' in institutions that have become one–sided and turn them around (recognising that many problems are inadvertently created by the 'helping' organisations). It can only be accomplished by those with 'a sense of urgency' because organisational and professional pressures ask workers to 'ignore the paradox and keep doing what is "acceptable" ' [81], p. 148.

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[16] For instance, the suggestion that if clients don't want a nurse to visit in a marked car (with logo), they should attend a different service such as GP, and that the marked car should be seen as 'normal'.

Countering 'we treat everyone the same'

The view that RDNS staff 'treat everyone the same' was common amongst staff survey respondents. This view suggests that staff are committed to 'formal equality' (that people all have the same rights), yet this must be distinguished from 'substantive equality'. Discrimination, rights violations and negative outcomes can occur even where there is formal equality.

As Hunt comments,

> *[F]ormal equality treats discrimination as if it were an aberration which can be eliminated by extending the same rights and entitlements to all. [It is] blind to entrenched structural inequalities, it ignores actual social and economic disparities. By constructing standards which appear to be neutral, it embodies a set of particular needs and experiences which derive from a socially privileged group. In this way formal equality may actually reinforce inequality.* p. 133.

Substantive equality, on the other hand

> *'demands an examination of the actual conditions experienced by groups and individuals, and requires the elimination of discriminatory structural barriers'* [82]p. 136.

Thus, the actual experiences, social situation and conditions of RDNS clients living with HIV need to be proactively addressed by the HIV Program and RDNS overall if equity is to be achieved.

One group disproportionately affected by HIV, gay men and MSM, demands particular attention as they are ageing. The invisibility of GLBTI people, especially those who are older, within mainstream society, and the lack of understanding and awareness of 'their specific needs, histories and life experiences, and their experiences of discrimination throughout the life course' from a wide range of agencies and service providers, has been poorly understood[83] and is only now being examined. Recent research into the care of GLBTI people in community settings found that community workers often said they 'we do that already, we treat everyone the same'[7]. Their belief often shifted, however once evidence about the poorer health and wellbeing of GLBTI people and an explanation of what 'GLBTI–inclusive practice' is. Further, using narratives about experiences of GLBTI people within healthcare was the most successful strategy to shift awareness[7]. Whilst not all RDNS HIV clients belong to GLBTI communities, many do, and the strategy of providing targeted education to staff about HIV and vulnerable communities, along with the use of narratives and HIV positive speakers, have proven useful. It may also be of

benefit for RDNS to collaborate with Gay and Lesbian Health Victoria to deliver the 'How2 create a GLBTI inclusive service' within RDNS. The program aims to make improvement within organization in relation to six standards: Access and intake procedures; consumer consultation; cultural safety; disclosure and documentation; professional development and organizational capacity.

Several other documents exist which help to promote culturally sensitive care for ageing GLBTI people are available including 'Well Proud': a guide to gay, lesbian, bisexual, transgender and intersex inclusive practice for health and human services[84] and the new National LGBTI Ageing and Aged Care Strategy[85]. RDNS' own 'Diversity Strategy' also aims to promote cultural/diversity competence and explicitly includes PLHIV. The HIV Program can collaborate with the Diversity Team on such initiatives.

The final matter to be discussed concerns 'mainstreaming'. This developed as a theme of concern to many throughout the project and relates strongly to many of the issues discussed above.

HIV Program versus 'mainstreaming' HIV care within RDNS

As discussed earlier in this chapter, there was a view amongst some respondents that 'mainstreaming' of HIV care (within RDNS) is preferable to the current model of care. Related to this, some staff, largely managers, said that having an HIV Program or specialist staff 'de–skills' other nurses. Policies, procedures and practices that treat PLHIV 'differently' (such as use of a code for HIV diagnosis, intake procedures, use of unmarked cars and optional uniforms) are not supported by some staff, particularly at management level.

HIV Team 'deskilling' RDNS staff

The view of some staff survey respondents that the HIV Team 'deskills' other nurses indicates awareness that knowledge is limited amongst staff, but attributing this to the presence and practices of HIV specialists underestimates the impact of systemic impediments to the provision of quality care to PLHIV. It assumes that staff were already skilled in this area, and that their skills are being made obsolete. The other suggestion made is that specialist staff retain clients and do not share their expertise. Both suggestions deserve further exploration.

1. First, knowledge gaps around HIV are evident across all levels of staff. Staff reported low levels in HIV knowledge, but particularly in those areas most critical to this client cohort – knowledge of the needs of specific populations or vulnerable groups (gay men, injecting drug users, refugees).

Knowledge deficits around basic infection prevention were identified in this project. The effect on HIV clients can be devastating, including the use of excessive infection prevention precautions, use of 'alerts', avoidance, and even denial of service. Understanding and education of infection prevention is a basic expectation of all health care workers. It cannot be argued convincingly that the HIV Team 'deskills' staff in this area. On the contrary, HIV Team staff are both proactive and reactive in responding to frequent instances of discrimination in the form of unnecessary 'alerts', excessive infection control precautions or reluctance to provide service. Along with this, they frequently explain basic infection prevention to staff, including one–on–one informal education with staff, clients and carers.

2. The second suggestion, that 'deskilling' results from HIV Team staff retaining clients and expertise, again reflects limited appreciation of constraints on HIV client care within RDNS. Rather than being the cause of deskilling, the necessity for HIV Team staff to provide ongoing care to individual clients is related to low baseline skills across the agency, and very limited organisational capacity to ensure continuity of care from appropriately skilled staff. As evidence from this project shows, this client cohort requires regularity and continuity of staff, and often has needs that require assessment by, and sometimes management by, a member of staff with expertise in HIV and accompanying socio–cultural and ethical complexities. Constant advocacy and vigilance by HIV Team staff is required externally but even within RDNS to ensure care is appropriate and their rights are upheld.

In summary, the notion that the HIV Program results in 'deskilling' staff diverts attention from deeper systemic and structural capacity concerns that affect Program sustainability.

Building capacity through specialist roles and education

It has been recognized that in tailoring individualized and holistic services to PLHIV in Australia, there is a need to balance expanding access to mainstream services, and developing or building the capacity of HIV services[40]. RDNS is in a fortunate position of being both a mainstream service, with aged care and many other areas of expertise, and

having an HIV specialist service. Capacity building through HIV Program support and development is likely to be the most useful option.

Organisational capacity for continuity of skilled HIV care has been improved in high case–load areas through the use of HIV Resource Nurses who are able to cross all areas within a given site's boundaries[17].

It is evident that where HIV Resource Nurses and CNC are based, there is a slow but steady increase in knowledge and skills across the whole site. HIV specialist staff, including HIV Resource Nurses have undertaken further education and training. These roles are appropriately located at high case load sites, where there is critical mass of clients. Awareness, understanding and capacity building occur. Additional HIV Resource Nurse hours or roles are warranted at higher caseload sites. Data indicates that Heidelberg, Moreland, and Essendon require additional HIV Resource Nurse hours immediately.

Program improvement and sustainability

It has been recognized that caring for marginalised groups, in particular PLHIV, does have additional costs in primary health care. RDNS HIV client care needs may conflict with RDNS local sites' priorities, e.g. short, technical intervention and fee–for–service, and HIV clients require a high level of care, responsiveness, and use of human resources for a relatively small number of clients. If support visits are cancelled or postponed to prioritise other visits, it can lead to fragmented care and put clients at risk of disengagement and poor adherence, and even risks to public health.

There are sustainability challenges throughout the sector due to difficulties maintaining a 'diversity–competent' workforce who are also skilled in HIV, and the sector is politically and financially vulnerable[71], p. S59. Factors that improve sustainability include a service 'being part of the community it serves'; 'the creation of deeply integrated networks of diversity–competent service providers' and '"the virtuous non–adaptability" of service providers in refusing to compromise care standards' despite pressures to do so[71], p. S62. These issues are relevant to the HIV Program at RDNS.

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[17] Responsiveness and continuity of care by HIV Resource Nurses has been compromised recently with the closure of Yarra site which has resulted in the splitting of Resource Nurses hours between two large catchments, Moreland and Heidelberg, so that neither are is adequately covered. This is unsustainable and quality of care is compromised.

HIV clients experience stigma and discrimination and engagement is a significant issue for RDNS staff. Many are fearful of services and have had traumatic experiences within health care system; many are survivors of trauma and abuse. Engagement can therefore take a very long time with intermittent visits. This means flexibility with visit times and locations is essential. Many HIV clients first access health care services during a health crisis and assertive outreach and responsiveness to immediate need at the first point of contact are critical components of the HIV Team role. Knowing that RDNS has a specific HIV Team enables clients to develop trust with the HIV nurses. The risk of disengagement of HIV clients from RDNS can have significant consequences for their health outcomes and can affect their willingness to access care in the long term. Often clients are referred to RDNS HIV Program due to other services within the sector's inability to engage them, and the HIV Team has a high success rate with engagement, but it requires intensive resourcing. Organisational support for the HIV Program's model of care, highly valued by the HIV sector and clients, is essential.

Key informants suggested mental health expertise, better continuity of care by additional HIV nursing roles, a supportive environment for HIV Team staff, removing the Program from RDNS and placing it firmly within the HIV sector, the use of Telehealth for isolated rural clients, and ongoing HIV education for all health care workers.

Heidelberg, Essendon, Caulfield, Altona, and Moreland have recorded the greatest number of visits and utilise the greatest hours of care. Following the closure of Yarra site in 2012, Moreland in particular has grown significantly. Frankston, Diamond Valley, Koonung, and Sunshine are sites to monitor. The HARP Program through Royal Melbourne Hospital and RDNS is also growing and likely to have a flow–on effect to the HIV Program, especially in the North Western Region. The need for backfilling of CNC leave has been identified – for capacity building, succession planning and client care – to help prevent loss to follow up of those who are hard to engage, or who have complex mental health/drug and alcohol issues.

Restructuring of the management of the HIV Program including the development of a Team Coordinator, Senior Clinical Nurse Advisor (or similar) role to enhance Program development and expansion has been recommended by HIV Team staff [17].

The potential impact of the new rapid testing facility should be considered and monitored. Similarly, the impact of the HARP HIV CNC role at the Royal Melbourne Hospital on

numbers of new referrals to RDNS' HIV Program needs to be monitored. Closer, formal integration of the HARP role with the HIV Program is also recommended, including in relation to streamlining documentation and referral processes.

Leadership and management

Dale Fisher, Australian nurse and hospital Chief Executive Officer has pointed out that:

> *'specialist care requires particular attention, leadership and management'*[86].

Furthermore, she has observed that:

> *'to ensure equity for marginalised groups, services need to invest more'.*

Given that HIV clients, through HACC funding, generate additional funding for the RDNS, extra budget allocation could allow for HIV Program development and expansion to ensure that the specific needs of this diverse and vulnerable group can be met.

In March, 2012, the HIV Team developed a discussion paper on the management of the HIV Team which outlined difficulties with its management structures – inconsistent lines of reporting, lack of support for a cohesive team approach affecting productivity and quality of care and a lack of resources tied to Program planning, growth and development[17]. Whilst a Clinical Support Manager has recently been appointed, the HIV Team currently has 6 additional line managers. Thus there are now 8 managers for this small team (including the Program Manager), all with different roles and expectations of the Team, the Program itself, and the individual staff. This is unworkable and adds an enormous administrative workload to clinical staff.

Effective leadership structures in HIV care have been recognised as essential to strengthening social justice and human rights in all aspects of the global HIV response[3]. Good leadership structures help ensure the needs of all affected (especially those most disenfranchised) are recognised and reflected – this helps protect the interests of vulnerable groups and promotes equitable distribution of services[3]. The development of a Senior Clinical Nurse Advisor HIV for the HIV Program is proposed to enable ongoing Program development, evaluation, seek funding opportunities and so on. Program development requires a long term commitment from RDNS to its HIV Program.

Through this evaluation, in addition to the primary evaluation questions, most of the supplementary evaluation questions have also been partially answered (see Table 13).

Strengths and limitations of the study

This study had several strengths:

- Being an internal evaluation, the expertise of the RDNS HIV Team was extensively drawn upon, in designing the project, in the analysis and in developing recommendations that are likely to be utilised.
- The use of existing data sets (HIV Program data) was efficient and cost–effective.
- There has been significant capacity building within the HIV Team for evaluation, with nurses participating in recruitment and administration of the client questionnaires and data analysis.
- The broad range of clients who completed the survey and the high response rate to both surveys help to minimise response bias. Both clients and staff survey samples can be considered representative, supporting the data's validity.
- The anonymity afforded to staff allowed for comprehensive data collection. Staff were able to express their views frankly without risk of identification, and many did.

Limitations of internal evaluation include:

- The potential for bias:
    - Analysis was performed by the HIV Team staff and Project Consultant from VAC/GMHC, all of whom have significant interests in the HIV Program and could present a biased perspective, either critical or exceedingly positive. This was minimised by triangulation of methods.
    - Some clients might have been reluctant to provide negative feedback about the HIV Program, especially since they are in a dependent relationship with staff. Staff sought to minimize this by assuring clients that the results were for Program improvement so that all opinions were valued.
    - The staff survey may have been responded to by staff with a particular interest or point of view to advance, hence the polarised responses to some questions.

- It was not possible within the confines of this project to undertake qualitative interviews with clients, which could have provide additional in–depth information about their needs. However, opportunity to make comments within the questionnaires helped to provide contextual and explanatory data.
- Statistical analysis has not been performed on large amounts of data which could assist more rigorous and comprehensive analysis.
- Cross–checking the analysis of qualitative data from the interviews with respondents was not performed; this is recommended by Patton to help strengthen, validate and verify conclusions[47] but was beyond the scope of this project.

An unexpected outcome?

In **Q10,** Clients expressed strong concern about 'a service like RDNS HIV Team not being available to me'. It is possible that the evaluation itself provoked anxiety amongst clients that the service was under review and that they may lose it. Whilst reassurance was provided that this was not the case, it may have resulted in an inflated number of clients expressing concern about this item in the questionnaire.

Table 13: Answers to evaluation questions

Evaluation question	Response
1. To what extent are HIV clients receiving high quality, comprehensive care? Are they satisfied?	1. Clients are evidently receiving comprehensive care and are mostly very satisfied.
2. To what extent does staff have current knowledge and skills in HIV?	2. Most RDNS do not have current knowledge and skills, most are interested to undertake further education.
3. What proportion of staff is educationally prepared to care for PLHIV?	3. Only a small proportion of staff is educationally prepared to care for PLHIV with confidence.
4. What proportion has accessed RDNS HIV education?	4. Surprisingly, nearly half of the respondents had accessed RDNS HIV education, however the question did not addressed recency and type of course. Short courses (2 days) are the only ones now available through RDNS, having been reduced from 5 day intensive course.
5. Does the Program achieve effectiveness across different subgroups including those most at risk, those with fewest resources and from culturally diverse backgrounds?	5. The program caters to a diverse range of client including many from CALD backgrounds who are believed to be difficult to engage. The HIV Team nurses have substantial skills in engaging indigenous clients, injecting drug users and CALD and gaining their trust.
6. In what ways are HIV knowledge and positive attitudes incorporated into the core business of RDNS?	6. The HIV Program is not seen as 'core business' and it cannot be said that HIV knowledge and positive attitudes are universally respected across the organisation.
7. Is the Program flexible to changes and responses that may be required?	7. The Program has shown itself to be flexible to changes, especially in working with a diverse clientele. There is little capacity now for expansion.
8. What factors would assist Program development and sustainability?	8. Review of the management structure is the key factor requiring addressing for Program development and sustainability. This has been addressed in a separate document by the HIV Team. A Senior Clinical Nurse Advisor (or similar) role with expertise in HIV could facilitate research, quality improvement and education. Other factors that will help Program development include the review of HIV–related policies and procedures.
9. What are plans for sustainability? Will additional funding be needed?	9. Renewal of VAC Partnership and strengthening of other sectoral partnerships. Additional funding may be needed but the contribution of HIV clients to HACC funding received by RDNS should be examined. Some of this could be utilised to develop the HIV Program.

Chapter 7: Conclusions and Recommendations

HIV clients receiving care from RDNS are a very diverse group, and have a range of co–morbidities that render their care in the community complex and challenging. Evidence of likely increasing demand on service, and subsequent educational needs of staff, is supported by the literature, Program data, client and staff surveys, qualitative data from interviews with key informants, staff and clients' comments.

RDNS Staff report significant knowledge deficits in all areas of HIV care, but especially those most pertinent to this client group – the special needs of specific populations/vulnerable groups, HIV prevention (including basic infection control), medical management, legal and ethical issues, psychosocial and mental health. Overall, staff's level of willingness and eagerness to learn about HIV is very high, though their comfort level is low. They report ambivalence about Standard Precautions, the foundation stone of safe clinical nursing practice.

The following recommendations are made for RDNS for the development of the HIV Program. These align with the priorities of the 6th National HIV Strategy[5] including emerging issues (ageing, co–morbidities) focusing on priority populations, models of care and workforce development, and the Victorian HIV Strategy)[6]. The evaluation will be reported to stakeholders, through community meetings of summary findings and recommendations, a more detailed presentation for RDNS Program managers. Journal articles will be written for publication with additional statistical analysis.

It has been recognised that the role of HIV specialist nurses in the community is central to bridging the gaps between clinics, other specialist services and generic community services, especially in low HIV prevalence settings such as Australia[4]. They help facilitate transition from hospital to home and establish communication and networking between hospital and community teams. They work with family, carers and other community health workers for the benefit of PLHIV and their assessments in the home can identify issues affecting adherence, welfare and well–being that may not have been identified before. They educate the community as well as other services about HIV and provide holistic care[4]. This project demonstrates that the RDNS cohort of PLHIV requires special attention, expertise and resources for the Program to have a sustainable workforce, develop and meet the needs of PLHIV into the future.

HIV Program Evaluation Recommendations

Organisational	Next 12 months	1–3 years
Capacity building	1. Implement role of Senior Clinical Nurse Advisor (.5 EFT) to enable Program development and better resource utilisation (see Draft Position description, Appendix 9). 2. Adjust HIV Resource Nurse hours as detailed in footnote[18]. *Consider HIV Resource Nurses to cross site boundaries.* 3. Implement backfilling of HIV Team staff for any more than one week with 'permanent reliever' position • for succession–planning, skill development and to build capacity in engaging marginalised clients, reducing barriers to access. 4. Recognise and streamline relationship between HARP RDNS/HIV and RDNS HIV Program to facilitate seamless referral and integration of services, efficient resource use, documentation and accurate data collection for improved Program reporting and planning.	5. Review management of HIV Team with a view to reducing number of line managers to one. 6. Model HIV Program on Homeless Person's Program and consider partnership with HPP to foster Program development, research, staff support, education, shared resources, capacity building. (E.g. outreach to high and low HIV case load GPs, co–locations at other services). 7. Reconsider funding of mental health nursing role within the HIV Team; support for mental health training for HIV Team staff. 8. Implement Professional supervision for HIV Team staff. *Consider expansion of RDNS HIV service into rural areas (with a view to Telehealth consultations with CNCs, local Resource nurses and clients).*
Workforce development	9. Reinstate RDNS HIV Program into staff orientation program. HIV prevention information made explicit in the context of Standard Precautions and information provided on staff safety and pregnant staff visiting HIV clients to demystify misconceptions and fear.	10. RDNS participate in 'Rainbow Tick' campaign and 'How2'[7, 8] through Gay and Lesbian Health Victoria to enhance cultural competency. *Consider reinstating dedicated HIV educator position or incorporate into Senior Clinical Nurse Advisor role.*

[18] Heidelberg – increase from 16 hours to 32 hours per week; Moreland – increase to 40 hours per week; Essendon – new position, 24 hours per week. Re–assess hours at Caulfield and Altona.

Policy and procedure	11. Policy review – recommit to relevant, specific HIV policies in consultation with HIV Team (intake, assessment and care plan, referral). • Promote across RDNS to foster recognition and understanding of the impact of stigma, fear and prejudice for those infected/affected by HIV to this day that results in barriers to access to services. 12. Review and provide education on RDNS policy on computer 'alerts' to prevent discrimination and further stigmatisation.	
Marketing and branding	13. Provide banner to be used at community events (including Rainbow Tick approval once achieved), to promote RDNS as HIV and GLBTIQ–friendly	14. Improve marketing and profile of the RDNS HIV Program internally and externally, through dedicated webpage. • Review brochures at regular intervals with HIV Team
Partnership Strengthening	15. Review and recommit to Partnership Agreement with Victorian AIDS Council/Gay Men's Health Centre HIV Services with HIV Team and identify and formalise other HIV sector Partnerships. 16. Invite representative of PLHIV organisation(s) to participate in RDNS consumer reference group.	

HIV Team	Next 12 months	1–3 years
Workforce development	1. Utilise evaluation data in reviewing internal and external education – in particular, for sessions on HIV and ageing, psychosocial issues, prevention, specific populations, legal and ethical issues, stigma and fear, health literacy, engagement and retention in HIV care. *Collaborate with Diversity Team, Quality Manager, Education department, Safety, Health and Environment*	2. Implement regular educational 'road shows' to sites 3. Revise and update RDNS HIV Manual for RDNS staff – 'Caring in the Community' and carers' booklet, 'Positive Caring' to promote the HIV Program model of care and education role.
Policy and procedure	4. Policy review – recommit to relevant, specific HIV policies (intake, assessment and care plan, referral) (see also 11 above).	5. Develop HIV assessment tool and nursing care plan. 6. Revise HIV staff position descriptions utilising national competency standards to promote understanding and recognition of roles [9].
Model of care	7. Further develop HIV holistic model of care, document. 8. Presentations and promotion of model of care.	
Partnership Strengthening	9. Review and recommit to Partnership Agreement with Victorian AIDS Council/Gay Men's Health Centre HIV Services and identify and formalise other HIV sector Partnerships (see 15 above).	
Research and evaluation		10. Develop research and evaluation plan, conference presentations, publications (pending support of and implementation of Senior Clinical Nurse Advisor or similar role).

Appendix 1

Supplementary evaluation questions

Supplementary questions	Rationale
1. To what extent are HIV clients receiving high quality, comprehensive care? Are they satisfied?	• Obtain evidence regarding 'felt' needs.
2. To what extent do staff have current knowledge and skills in HIV 3. What proportion of staff is educationally prepared to care for PLHIV?	• Establish whether the HIV Program is meeting its goal of providing appropriate education in the context of a changing epidemic
4. What proportion has accessed RDNS HIV education?	• Establish whether personnel have been exposed to current HIV education.
5. Does the Program achieve effectiveness across different subgroups including those most at risk, those with fewest resources and from culturally diverse backgrounds?	• Help identify 'comparative needs' and gaps in services
6. In what ways are HIV knowledge and positive attitudes incorporated into the core business of RDNS?	• Determine the extent of HIV awareness across the agency in view of likely increase in demand for resources and needs of client group, increasing pressure on HIV Team and RDNS overall.
7. Is the Program flexible to changes and responses that may be required?	• Determine stakeholders' views on HIV Program responsiveness to changing needs.
8. What factors would assist Program development and sustainability?	• Obtain innovative ideas from program staff and others for future planning.
9. What are plans for sustainability? Will additional funding be needed?	• Gain an understanding of economic implications of increasing needs.

Appendix 2

RDNS Human Research Ethics Committee – Ethics approval letter

RDNS
Helen Macpherson Smith
Institute of Community Health

15 October 2012

Liz Crock
Clinical Nurse Consultant HIV
Northern/Eastern Regions
RDNS Heidelberg

Dear Liz

RE: RDNS Human Research Ethics Committee (HREC) Project No. 133
The RDNS HIV Program in a changing epidemic – an action evaluation

Thank you for your application for ethics approval of the above research project. Your project was reviewed by the RDNS HREC on 9 October 2012 and approved with the following condition:

- A withdrawal without prejudice clause be included in Attachment 4 Withdrawal of Consent form.

The HREC members would like to pass on the following suggestion:

- Face-to-face interviews be conducted instead of telephone interviews. There was concern that people being interviewed would be unable to take in the content of the plain language statement when it is read over the phone and that it may set up barriers and concerns prior to the interviewer making contact.

Please find enclosed a Research Progress Report which needs to be completed and sent to the RDNS HREC secretariat on an annual basis as per Section 11 of the RDNS Guidelines for Researchers Seeking Ethics Approval for Research Projects. Please advise a date when the project will commence for our records.

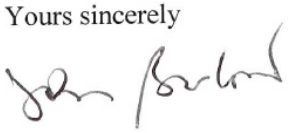
Upon completion of the project, as per Section 13 of the RDNS Guidelines for Researchers Seeking Ethics Approval for Research Projects, you are required to immediately send to us three copies of the full report and 12 copies of a study summary (no more than three pages), prior to its release to other parties. Furthermore, you are requested to immediately report to the Chair of the RDNS HREC verbally and in writing, anything that might warrant review of the ethical approval of the project. This includes serious or unexpected adverse effects on participants, proposed changes in the project and unforeseen events that might affect continued ethical acceptability of the project.

...../2

Royal District Nursing Service Limited ABN 49 052 188 717 | 31 Alma Road St Kilda VIC 3182 | Telephone 03 9536 5222 | Fax 03 9536 5333 | www.rdns.com.au

We wish you well with the project and look forward to learning of your outcomes. If you have any queries regarding the above, please contact me on 9536 5243 or email jbarlow@rdns.com.au.

Yours sincerely



John Barlow
Interim Chair
RDNS Human Research Ethics Committee

Enc

Appendix 3

HIV Program Evaluation Research project budget

Timeline for major activities

Stage 1 – August – September 2012; Stage 2 – October 2012 – August – October 2012; Stage 3 – November 2012 – March 2013; Stage 4 – April – July 2013

Budget

Costings			Charge ($)
Establishment Costs			
Research project worker (HIV CNC)	Rate	Days/Hours	
Project Staff #1	$40.63/hr plus PhD allowance $2.04/hr = $42.67	40 hours/fortnight for 14 weeks	$11,947.60 plus on costs $4,000 = $15,947.60
Project Staff #2, #3 Project Staff #4	No charge costed for. $42.67/hr X 3 days	9 days total	$1,024.08
Travel – $600 Stationery – $300			$900
Equipment costs – digital recorder			$400
Data processing			$2,075
Refreshments			$90
Total budget			**$20,436.68**

Justification of budget items

A. Personnel

a) Researcher: the chief investigator will be seconded from a clinical role to undertake the evaluation and will be responsible for:

1. Overall evaluation coordination,
2. Preparing and submitting the RDNS Human Research and Ethics committee approval application
3. Conducting the literature review
4. Organising and conducting interviews
5. Receiving, indexing, filing and ensuring secure storage of digital and other files;

6. Keeping account of receipts and other budget items, tracking expenditure, reporting, preparing budget reports.
7. Preparing progress and final evaluation reports.
8. Facilitating communication between participants throughout the project
Salary at .5 Clinical Nurse Consultant Grade 4B rate:

5 days per fortnight, with on costs: $42.67 plus on costs $4,000 =
$ 15,947.6 for 14 weeks.

b) Project Consultants: Ms Nalla Burk and Mr. Oscar Morata – CNC Grade 4B (40.63/hr) – 6 days over course of project – to provide expertise in HIV and community care, assistance in recruiting participants – time allocated without cost as both full–time.

c) Project Consultant: Ms Judy Frecker CNC Grade 4B plus qualification allowance ($42.67/hr) – 3 days over course of project – to provide expertise in community and acute care, consultation and assistance in recruiting participants – $1,024.08

d) Project Consultant Mr. John Hall – reciprocal arrangement through Partnership Agreement (no fee) – to provide expertise and advice on the project, particularly regarding long term survivors with HIV, volunteer support services and assistance with recruitment.

B. Equipment

Digital recorder – $400 based on

Olympus Recorder DM–3 recommended by Pacific Solutions

C. Data analysis and processing

Transcription – the transcription of audio–recorded interviews using an experienced transcriber is a critical component of the data processing stage. Estimate $180 per 60–minute focus group interview (groups of five people or more) or individual interview. There will be 5 key informant interviews.

5 X 1.5 hr X $180 = $1,350
5 X 1 hr X $145 = $725
Total = $2075

D. Travel and parking

Travel costs will be reimbursed during the course of the project (eg when the researcher is arranging and conducting interviews). Costs shown are at 2012 reimbursement rates per kilometre for travelling to and parking at community based sites (Living Positive Vic, Positive Women, Straight Arrows). Travel: average 40km return trips X 10 @ 75c/km = $300, parking @ $30 X 10 = $300, total $600.

E. Stationery, duplicating, printing, postage etc

Questionnaires – 10 pages total (4 for clients and 6 for RDNS staff)
Questionnaires will be emailed to staff at no cost.
Questionnaires to clients/PLHIV – 50 X 4 pages @ 20 cents per page to 125 clients = $50
Printing of participants information and consent forms; data storage; distribution of progress and final reports (Progress and Final reports – 50 pages each @ 20 cents per page, 5 copies = $50) – $300

F. Miscellaneous

Refreshments for participants $10 X 8 – $90

Appendix 4a

RDNS HIV Client questionnaire

RDNS A100 Program Survey

This survey will help us to understand what you need, to plan for the future and improve our service to you and other clients.

All information you provide is confidential and you cannot be identified from this survey. You can choose not to answer any question. Your help is very much appreciated.

To answer, please tick in the box like this √

In general, would you say your health is now:

Excellent	
Very good	
Good	
Fair	
Poor	

In general, how would you say your health was 2 years ago?

Excellent	
Very good	
Good	
Fair	
Poor	

3. How confident are you that you can maintain your health over the next 5 years?

Very confident	
Confident	

Unsure	
Not confident	
Very unconfident	

4. How often does an RDNS nurse/other RDNS staff member visit you?

Twice a day	
Once a day	
Once a week	
3 times per week	
Once a fortnight	
Once a month	
Less than monthly	

Other (please explain)

How long have you been an RDNS client?.....

5. Which of the following do RDNS nurses and/or other RDNS staff **(**e.g. social worker, mental health nurse) do for you, or with you? Please tick Yes, No or Not Applicable for all items.	**Yes**	**No**	**N/ A**
Ask me about how I am and how I am feeling			
Help me if I feel unwell			
Help me avoid getting sick			
Help me if I have diarrhoea, fever, nausea			
Help me avoid going to hospital			
Help with Hepatitis C treatments			
Give me mental health support			
Give me health advice e.g. about food, staying healthy			
Give me health education			
Suggest ways to remember to take my medications			
Explain side effects of my medications in ways I can understand			
Organise my prescriptions			
Check the medications I have been given are correct			
Make sure I have enough medications			
Explain to me the importance of taking medication as prescribed			
Help me understand what doctors have told me			
Talk to me about how to avoid passing HIV to others			
Talk to me about how to avoid getting Hepatitis C or other infections			
Talking to my doctors and other health workers			
5. Which of the following do RDNS nurses and/or other RDNS staff do with you? Please tick Yes, No or Not Applicable for all items.	Yes	No	N/ A
Coordinate my care in the community			
Refer me for peer support (meeting other HIV positive people)			
Help me remember appointments			
Help me with emotional issues. When my mood is low, or I feel stressed			

Help me cope with my situation			
Help when I go home from hospital			
Train volunteers from VAC who help me			
Organise respite for me when I need it			
Refer me for other services I need (e.g. dentist, physio, dietitian)			
Organise transport to appointments			
Help me manage my financial issues			
Help me to sort out any housing problems			
Listen to me when I need to talk (counseling/support)			
Work with VAC to provide support			
Support my family/carers			
Help me to become independent			

6. What else do RDNS nurses and/or other RDNS staff (e.g. social worker, mental health nurse) do for you? Please explain in short sentences

7. The following statements relate to your care by RDNS nurses and other RDNS staff in the past 12 months.

	All the time	Most times	Sometimes	Rarely	Never	Not relevant for me
Finding information about RDNS and making an appointment was easy.						
It is easy to contact RDNS nurses						
The nurses visit for a good length of time (not too long, not too short)						
The nurses visit as often as I need						

The response time when I need an urgent visit is good						
After hours phone support is easy to get						
The nurses who visit me know me well.						
RDNS staff should spend more time with me						
My home nursing visits are interrupted						
Care meets my expectations						
The support provided meets my needs						

	All the time	Most times	Sometimes	Rarely	Never	Not relevant for me
RDNS nurses' skills in HIV care are of a high standard						
RDNS nurses are sensitive to my situation						
RDNS nurses respect confidentiality						
RDNS nurses respect my culture						
RDNS nurses are accepting of my life and health care choices						
RDNS nurses stand up for my rights						
I feel uncomfortable talking about personal or intimate matters with the nurses						
When I ask questions, I can understand the RDNS nurses' responses						
I am involved in making decisions about my RDNS care at home						
There are questions I would like to ask the nurse but have not asked						
If I had a complaint about my care by RDNS, they would ignore it						
I got services in the language I wanted						

8. We would like to know your opinion of ways to help improving care. Please rate how important you think each of the following is:

	Not important at all	Somewhat important	Important	Very important
Enough time to establish professional/client relationship				
Flexibility of visit times				
Ability to meet outside home if I prefer				
Continuity of care/regular staff				
Non–judgmental attitudes of staff				
Development of trust				
Length of visits				
Staff listen to what help I would like and care is based upon what I see are my needs (client–centred care)				
Respectful attitude of staff				
Confidence in staff				
Commitment to confidentiality				
Knowledge about HIV				
Respect for sexual diversity				
Respect for cultural diversity				
Not asking how I got HIV				
RDNS staff working with my family and me				

Other (please specify)

9. Is there anything you value most about RDNS HIV service? If so, please explain in a few words.

10. Thinking of the next 5 to 10 years, are you concerned about any of the following for yourself? Please provide an answer for each line.	**Not concerned at all**	**A little concerned**	**Somewhat concerned**	**Very concerned**
Getting older				
Getting care that is GLBTIQ–friendly (Gay, Lesbian, Bisexual, Transgender, Intersex, Queer).				
Mental health problems				
Memory problems				
Dementia				
Drug or alcohol use				
HIV–related illnesses				
Non HIV–related illnesses				
Pain				
Developing AIDS				
Dying				
Dying of an illness not related to HIV				
Heart problems				
Cancer				
Being forced to leave my home				
Needing more help at home				
Finances				

10. Thinking of the next 5 to 10 years, are you concerned about any of the following for yourself? Please provide an answer for each line.	Not concerned at all	A little concerned	Somewhat concerned	Very concerned
Housing/homelessness				
Losing mobility/difficulty walking				
Transport				
My own caring responsibilities				
A service like RDNS and HIV Team not being available to me				
Being able to get the health care I need				
Having to go to a nursing home				
Friends dying				
Having no one to look after me				
People not believing me when I am sick				
Being sad				
Being anxious				
Getting back to work/study/independence				

Other (please specify)

11. How important is it for you that RDNS helps you with the following in the next 5 – 10 years?	Very important	Important	Somewhat important	Not important at all	Not relevant for me
Stay in my own home (e.g. organising services)					
Help with personal care (e.g. someone to help me showering)					
Advise me on what I need to be cared for at home					
Prepare Advanced Care Plan – end of life care					
Manage other illnesses					
Keep me out of hospital					
Social or family problems					
Understand my changing condition and health needs					
Becoming independent of RDNS and other services					

Other (please specify)

12. Are you aware of RDNS working closely with the Victorian AIDS Council/Gay Men's Health Centre? Please tick Yes or No. If your answer is No, skip to Question 14.

Yes	
No	

13. If you receive care from RDNS and VAC, how would you rate the following aspects of care?

	1 = Very satisfied	2 = Satisfied	3 = Unsatisfied	4 = Very unsatisfied	5 = Not applicable
Communication between RDNS and VAC staff					
Coordination of my care					
Assistance with appointments					
'Tuckerbag' meals					
Referral from RDNS to VAC					
Referral from VAC to RDNS					
Response time when I have problems					

Comments

14. What would you change to make RDNS service better for yourself and other HIV clients?

A LITTLE INFORMATION ABOUT YOU.

These questions are being asked to make sure we hear from diverse RDNS clients.

15. What is your age?

Less than 10 years (if parent/guardian completing)	
Less than 20	
21–30	
31–40	
41–50	
51–60	
61–70	
71–80	
Over 80	

16. What is your gender identity?

Female	
Male	
Intersex	
Transgender	
Other (please specify)	

17. Sexuality. Please tick.

Gay	
Lesbian	
Heterosexual	
Bisexual	
Queer	
Other (please specify)	

18. Country of origin. Please tick.

Indigenous Australian	
Australia	
New Zealand	
Africa (name country)	
South Africa	
Asia	
Eastern Europe	
Western Europe	
United Kingdom	
USA	
Pacific Islands	
Other (please specify)	

19. Language(s) spoken at home…….……..…….

20. Year of diagnosis……...

21. I have completed this survey....

By myself, with no help	
With some help from an RDNS staff member	
With someone reading the survey to me and filling it out based on my answers	

Other (please specify)……

Thank you for helping to improve our service.

Appendix 4b

Client cognitive capacity checklist

CLIENT COGNITIVE CAPACITY CHECKLIST

CAN THE CLIENT PROVIDE HIS/HER OWN CONSENT?

Please tick 'yes' or 'no' to each statement based on your knowledge of the client:

The client would be able to understand what the project is about when it is explained to him/her?	Yes	❑	No	❑
The client would know that it is up to him/her only to decide to be in the project?	Yes	❑	No	❑
The client would understand what benefit s/he might have from being in the project?	Yes	❑	No	❑
The client would understand the risks and inconvenience involved in being in the project?	Yes	❑	No	❑
The client would understand that s/he can complain about the project to any one of the following people: a member of the Project Team or the Chair of the RDNS Research Ethics Committee?	Yes	❑	No	❑

If you answered 'no' to any of these or are uncertain about any of these, do not invite the client to participate in the survey.

Appendix 4c

HIV Client Plain Language Statement

Plain Language Statement – RDNS Clients

The RDNS A100 Program in a changing epidemic – an action evaluation

Names of researchers: Dr. Elizabeth Crock and Rosemary McKenzie

Project Consultants: Ms. Judy Frecker, Ms. Nalla Burk, Mr. Oscar Morata, Mr John Hall.

What is the project about?

We are conducting an evaluation of the *Royal District Nursing Service A100 Program* in relation to clients' current and future needs so that we can identify what is helpful in our service, any gaps or needed improvements and plan for the future care of people living with A100 in the community.

We would like you to complete a survey that will take about twenty minutes of your time. The survey asks questions about your needs at home, what you think of RDNS service, your likely future needs in relation to your health, and any other concerns or suggestions you may have to help improve our service. Your A100 Team nurse or someone else who you choose can help you complete the survey if you wish.

Your nurse will give you a copy of the survey and an envelope to return it to the project worker, or you can give it back to your nurse if you prefer. Completing the survey and sending it back will mean that you consent to participate. You can say 'yes' or 'no' to take part in this project and it will not affect your care or your relationship with RDNS staff.

How will my privacy be maintained?

The survey is anonymous – no information that identifies you will be recorded. During the project, surveys will be kept in a locked filing cabinet at the RDNS Heidelberg and on password protected computer files at RDNS.

What are the benefits and risks?

The information you provide in the survey should help improve our service so that we can meet the needs of the Program's clients into the future. It may provide direct benefit to you if you raise any new issues for RDNS staff to address while completing the survey. We do not see any risk to you of completing the survey. If any questions cause you worry or upset, you can talk to your nurse about them and you can choose not to answer every question.

How will the information be used?

The information from this project will be written up in a report. Recommendations will be made to help improve our service. Journal articles and conference papers may be written based on the report.

If you have any questions about this project please contact:

Liz Crock

RDNS Heidelberg
100 Oriel Rd.,
Heidelberg 3081
Phone: 0410 560 314

If you have any concerns or complaints about the conduct of this research project please contact:

Chair

RDNS Human Research Ethics Committee
RDNS Institute of Community Health,
31 Alma Road, St. Kilda, Victoria, 3182
Phone (03) 9536 5382, Fax (03) 9536 5300
Email getinfo@rdns.com.au

Appendix 5a

RDNS Staff HIV Questionnaire

RDNS Staff HIV Questionnaire

We are conducting this survey to identify RDNS staff's HIV education needs, to help improve our service and to plan for the future. Please respond as openly and honestly as you can. Your responses are anonymous and you cannot be identified from your answers.

***1. Please indicate your role - tick all that apply if more than one:**

- ☐ Division 2 Nurse
- ☐ Graduate Nurse
- ☐ District Nurse Grade 2
- ☐ District Nurse Grade 3
- ☐ District Nurse (Specialist)
- ☐ Clinical Nurse Specialist
- ☐ Clinical Nurse Consultant
- ☐ Clinical Coordinator Grade 4
- ☐ Customer Service Centre Operator RN Grade 3
- ☐ Customer Service Centre Operator RN Grade 4
- ☐ Management role (includes CSM, OM, GM DON, Clinical Support/Innovation etc)
- ☐ Social Worker
- ☐ Allied Health (Physio, OT, etc.)
- ☐ Other (specify)
- ☐ Community Care Aide

Other (please specify)

***2. What area of RDNS do you work in? Tick all areas that apply if you work in more than one.**

- [ ] Head Office
- [ ] South/Eastern
- [ ] North/Eastern
- [ ] North/Western
- [ ] Homeless Person's Program
- [ ] Customer Service Centre

Other (please specify)

***3. How many clients with HIV-infection have you visited in the past 12 months?**

- ◯ 0
- ◯ 1-5
- ◯ 5+
- ◯ 10+
- ◯ 20+
- ◯ N/A (e.g. I do not work in a clinical role)

Other (please comment)

***4. Considering each of the clients you have visited, on average, on how many occasions have you visited them in the last 12 months?**

- ◯ Never
- ◯ Less than 5 times
- ◯ 5 or more than 5 times
- ◯ Less than 10 times
- ◯ 10 or more than 10 times
- ◯ N/A

Other (please specify)

***5. Have you ever received any HIV education in the following settings?**

	Yes	No	Not applicable
At school	◯	◯	◯
Hospital-based course	◯	◯	◯
Tertiary institution	◯	◯	◯
Post graduate	◯	◯	◯
RDNS courses	◯	◯	◯
Other facilities e.g. hospital-run short courses	◯	◯	◯
Informal education on-the-job	◯	◯	◯
Self-education	◯	◯	◯

***6. Have you used information/knowledge from HIV training in your daily work?**

◯ Yes

◯ No

◯ N/A (please comment)

***7. How willing are you to provide care for HIV clients? Please rate by ticking on the scale.**

1 - Very willing	2	3	4	5	6	7	8	9	10 - Very unwilling
◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

Other (please specify)

***8. How would you describe your skill level in caring for HIV clients in the home or community setting?**

◯ I am very skilled

◯ I have moderate skills

◯ I have few skills

◯ I have never worked with HIV clients but have some skills

◯ I have no skills

◯ I would like to know more and become more skilled

Other (please comment)

***9. If you were to see several HIV clients in your area, tick the number that best represents your level of knowledge and/or skill on each topic listed below.**

1 - Have no knowledge at all on this topic

2 - Would like more education on this topic

3 - Satisfied with my level of knowledge on this topic

4 - Have very good knowledge on this topic

5 - Have expert knowledge on this topic

	1	2	3	4	5
Natural history of HIV Infection	○	○	○	○	○
Clinical diagnosis of HIV/AIDS	○	○	○	○	○
Sexually transmissible infections and HIV/AIDS	○	○	○	○	○
Hands-on care of HIV/AIDS clients	○	○	○	○	○
Standard Precautions (previously known as Universal Precautions) and Infection Prevention	○	○	○	○	○
Prevention of Mother-to-Child-Transmission (PMTCT)	○	○	○	○	○
Global scenario of HIV/AIDS	○	○	○	○	○
Australian scenario of HIV/AIDS	○	○	○	○	○
Australian National HIV Testing Policy	○	○	○	○	○
Medical management of HIV/AIDS	○	○	○	○	○
Antiretroviral Therapy	○	○	○	○	○
Ageing and HIV	○	○	○	○	○
Specific issues for injecting drug users with HIV	○	○	○	○	○
Hepatitis C and HIV co-infection	○	○	○	○	○
Specific issues for gay men living with HIV	○	○	○	○	○
Common co-morbidities and HIV	○	○	○	○	○
Privacy Laws pertaining to HIV and health care	○	○	○	○	○
Disclosure of HIV status	○	○	○	○	○
Legal rights of people with HIV	○	○	○	○	○
Specific issues for asylum seekers with HIV	○	○	○	○	○
Hepatitis B and HIV co-infection	○	○	○	○	○
Specific issues for people who have been living long term with HIV	○	○	○	○	○
Specific issues for families living with HIV	○	○	○	○	○
Pregnancy issues	○	○	○	○	○
Specific issues for women with HIV (other than pregnancy)	○	○	○	○	○
Supports for carers of people living with HIV	○	○	○	○	○
Gender and sexual diversity issues (e.g. lesbian, gay, bisexual, transgender, intersex, queer health)	○	○	○	○	○
HIV medication toxicities	○	○	○	○	○
Specific issues for heterosexual men living with HIV	○	○	○	○	○
Physical effects of living long term with HIV	○	○	○	○	○
Mental health and HIV	○	○	○	○	○
Post-Exposure Prophylaxis (e.g. treatment to prevent infection after occupational or non-occupational exposure)	○	○	○	○	○
Opportunistic infections	○	○	○	○	○
HIV-related cancers	○	○	○	○	○

N/A (Not in a clinical role)

***10. How comfortable are you in caring for HIV clients? Please rate by ticking on the scale.**

1 - Very uncomfortable	2	3	4	5	6	7	8	9	10 - Very comfortable
◯	◯	◯	◯	◯	◯	◯	◯	◯	◯

Other (please comment)

11. How are HIV clients and the RDNS HIV Program perceived in your workplace? Positive and negative examples would be welcomed, in the interests of quality improvement.

***12. What do you see as potential concerns relating to caring for HIV clients at RDNS? Select as many as you think are applicable.**

- ☐ Don't know enough about HIV to provide care for them
- ☐ Don't see enough HIV clients in my area for me to be aware of any problems
- ☐ Organisational obstacles
- ☐ Concern about client's lifestyle or background
- ☐ Risk of contracting HIV infection
- ☐ Risk of contracting other infections from clients
- ☐ Lack of time
- ☐ Geographical allocation
- ☐ Inadequate specialist nursing support within RDNS
- ☐ Inability to provide continuity of care
- ☐ Travel time
- ☐ Complexity of HIV clients' problems
- ☐ Clients' mental health issues
- ☐ Clients' drug-related issues
- ☐ HIV is a relatively low priority
- ☐ Clients' behaviours
- ☐ Concern for the client's health i.e. clients' risk of contracting other infections from me due to immunosuppression

Comments

***13. To what degree do you think any of the following are important in HIV care provision within RDNS? In your answer, consider from point of diagnosis to end of life.**

	Important to consider at all stages of care	Important to consider in most stages of care	Maybe important to consider at some stage	Not very important	Irrelevant, I treat all clients the same regardless of this.
Social isolation	◯	◯	◯	◯	◯
HIV-related stigma	◯	◯	◯	◯	◯
Complex medication regimes	◯	◯	◯	◯	◯
Discrimination against people living with HIV in general	◯	◯	◯	◯	◯
Cultural background	◯	◯	◯	◯	◯
HIV-associated cognitive impairment	◯	◯	◯	◯	◯
Discrimination experienced by gay men with HIV	◯	◯	◯	◯	◯
Sexuality	◯	◯	◯	◯	◯
Discrimination experienced by women with HIV	◯	◯	◯	◯	◯
Clients' experiences of discrimination in health care	◯	◯	◯	◯	◯
Lack of disclosure of HIV status to family or close friends	◯	◯	◯	◯	◯

Comments

***15. How concerned do you think your partner or family would be about you caring for clients with HIV? Please tick.**

- ◯ Not concerned at all
- ◯ A little concerned
- ◯ Concerned
- ◯ Very concerned
- ◯ Not applicable

Other (please comment)

***16. Which of the following measures, if any, would you use when providing care or services for a client living with HIV?**

	Yes	No	Not applicable
a. Wear double gloves	◯	◯	◯
b. Avoid touching them	◯	◯	◯
c. Wear gloves during all aspects of the client's care (history-taking, physical examination, etc.)	◯	◯	◯
d. Use masks during all aspects of the client's care	◯	◯	◯
e. No special measures	◯	◯	◯
f. Wear goggles during all aspects of the client's care	◯	◯	◯
g. Use any other special measures with patients living with HIV that you do not use with other patients	◯	◯	◯
h. Document HIV on the computer as an alert. e.g. 'high clinical risk'	◯	◯	◯
i. Use Standard Precautions at all times in my work	◯	◯	◯
j. Advise pregnant staff they should not attend care of an HIV client	◯	◯	◯

If you answered Yes to j, please provide more details.

***17. We would like to know your opinion of ways to help improve access to care and the care provided to HIV clients. Please tick the following boxes and rate how important you think each action is.**

	Very important	Important	A little important	Not important at all	Not applicable
Development of professional/client relationship	◯	◯	◯	◯	◯
Flexibility of visit times	◯	◯	◯	◯	◯
Ability to meet outside home	◯	◯	◯	◯	◯
Continuity of care/regular staff	◯	◯	◯	◯	◯
Non-judgmental attitudes	◯	◯	◯	◯	◯
Development of trust	◯	◯	◯	◯	◯
Length of visits	◯	◯	◯	◯	◯
Client/family-centred care	◯	◯	◯	◯	◯
Respectful attitude	◯	◯	◯	◯	◯
Confidence in staff	◯	◯	◯	◯	◯
Knowing how the client contracted HIV	◯	◯	◯	◯	◯
Commitment to confidentiality	◯	◯	◯	◯	◯
Knowledge about HIV	◯	◯	◯	◯	◯
Use of unmarked cars	◯	◯	◯	◯	◯
Flexibility not to wear uniform to protect clients' privacy	◯	◯	◯	◯	◯
Respect for sexual diversity	◯	◯	◯	◯	◯
Respect for culture(s)	◯	◯	◯	◯	◯
Support from HIV Team staff	◯	◯	◯	◯	◯
Increase in number of HIV specialist staff	◯	◯	◯	◯	◯

Other (please specify and provide details)

Touch the clothing of a client living with HIV	◯	◯	◯	◯	◯
Perform a physical examination on a client living with HIV e.g. bladder palpation	◯	◯	◯	◯	◯
Give an injection to a client living with HIV	◯	◯	◯	◯	◯
Manage a central line/IV drip in a client living with HIV	◯	◯	◯	◯	◯
Draw blood from a client living with HIV using standard precautions	◯	◯	◯	◯	◯
Care for a client with HIV who has been incontinent of urine	◯	◯	◯	◯	◯
Take blood glucose level measurement	◯	◯	◯	◯	◯
Attend wound care	◯	◯	◯	◯	◯
Drink from a cup in client's home	◯	◯	◯	◯	◯
Support a client who is vomiting	◯	◯	◯	◯	◯
Care for client who has been faecally incontinent	◯	◯	◯	◯	◯
Administer eye drops	◯	◯	◯	◯	◯
Shower or bathe a client	◯	◯	◯	◯	◯

Comments

***19. If you were referring a client to council for services (e.g. cleaning) would you disclose the client's HIV or other BBV status?**

- ◯ Yes
- ◯ No
- ◯ Yes, but only with client's informed consent
- ◯ Unsure

Other (please specify)

20. Please provide any other suggestions or comments about the RDNS HIV Program and your educational needs in relation to this client group, in the box below

Appendix 5b

Staff Plain Language Statement

Plain Language Statement – RDNS Staff

The RDNS HIV Program in a changing epidemic – an action evaluation

Names of researchers: Dr. Elizabeth Crock and Rosemary McKenzie

Project Consultants: Ms. Judy Frecker, Ms. Nalla Burk, Mr. Oscar Morata, Mr John Hall.

What is the project about?

We are conducting an evaluation of the *Royal District Nursing Service HIV Program* in relation to HIV clients' current and future needs so that we can identify what is helpful in our service, any gaps or needed improvements and plan for the future care of people living with HIV in the community.

We would like you to complete an on–line survey that will take about ten minutes of your time. The survey asks questions about your educational needs, attitudes and practices in relation to HIV clients at RDNS. The survey will be sent to all clinical staff, allied health and nursing managers.

Completing the survey and sending it back will mean that you consent to participate.

You can say 'yes' or 'no' to take part in this project and it will not affect your care or your relationship with other RDNS staff.

How will my privacy be maintained?

The survey is anonymous – no information that identifies you will be recorded. During the project, survey results will be kept on a password protected computer files at RDNS.

What are the benefits and risks?

The information you provide in the survey should help improve our service so that we can provide appropriate staff education and meet the needs of people living with HIV into the future. We do not anticipate any risk to you of completing the survey. If any questions cause you concern, you can call the researcher or one of the HIV Team staff for support, and you can choose not to answer every question.

How will the information be used?

The information from this project will be written up in a report. Recommendations will be made to help improve our service. Journal articles and conference papers may be written based on the report.

If you have any questions about this project please contact:

Liz Crock
RDNS Heidelberg
100 Oriel Rd.,
Heidelberg 3081
Phone: 0410 560 314

If you have any concerns or complaints about the conduct of this research project please contact:

Chair
RDNS Human Research Ethics Committee
RDNS Helen Macpherson Smith Institute of Community Health,
31 Alma Road,
St. Kilda, Victoria, 3182
Phone (03) 9536 5382, Fax (03) 9536 5300
Email getinfo@rdns.com.au

Appendix 5c

Email information request to managers and staff survey email

I N T E R N A L M E M O

RDNS HEIDELBERG

100 Oriel Rd, HEIDELBERG 3081

Telephone: 9499 4237 Fax: 9499 7648

TO:	Client Services Managers, Operations Managers, Manager CSC, Manager Liaison
FROM:	Liz Crock – Clinical Nurse Consultant HIV Northern/Eastern Regions, Janeen Kupsch, Manager Clinical Support
RE:	Staff survey – HIV
DATE:	4/03/2013
COPIES:	Victorian General Managers, Manager Clinical Support , Manager Clinical Innovations, Director, RDNS Institute.

The RDNS HIV Program in a changing epidemic – an action evaluation

Researchers: Dr. Elizabeth Crock and Rosemary McKenzie

Project Consultants: Ms. Judy Frecker, Ms. Nalla Burk, Mr. Oscar Morata, Mr John Hall.

PURPOSE:

We request that you kindly notify your staff about an upcoming online survey, regarding HIV care at RDNS. The survey will be conducted in early March and we encourage all nursing staff, Community Care Aides, Allied Health staff and nursing managers to complete it. The survey will take about 10 minutes and all staff's input and contributions are highly valued. Up to two reminders will be sent throughout March.

BACKGROUND:

We are conducting an evaluation of the RDNS HIV Program in relation to HIV clients' current and future needs so that we can identify what is helpful in our service, any gaps,

improvements and plans for the future care of people living with HIV in the community. The staff survey is part of the project which has been approved by RDNS Human Research Ethics Committee.

How will staff privacy be maintained?

The survey is anonymous – no information identifying staff will be recorded. During the project, survey results will be kept on a password protected computer file at RDNS.

What are the benefits and risks?

The information that staff provide in the survey will improve our service so that we can provide appropriate staff education and meet the current and future needs of people living with HIV. We do not anticipate any concerns for staff in completing the survey. If any questions cause concern, staff can call the researcher, Liz Crock, for support and can choose not to answer every question. Contact details are included in the Plain Language Statement for staff which will be attached to the email that contains the survey link.

For further information, please contact:

Liz Crock, Clinical Nurse Consultant HIV, RDNS Heidelberg (0410 560 314 or email lcrock@rdns.com.au).

If you have any concerns or complaints about the conduct of this research project, please contact:

Chair
RDNS Human Research Ethics Committee
RDNS Helen Macpherson Smith Institute of Community Health,
31 Alma Road, St. Kilda, Victoria, 3182 Phone (03) 9536 5382, Fax (03) 9536 5300
Email getinfo@rdns.com.au
Page 1 of 1

From: Crock, Liz
Sent: Wednesday, 6 March 2013 9:02 AM
Subject: Staff survey – HIV – for all staff

Dear Colleagues,

We are conducting an evaluation of the RDNS HIV Program in relation to HIV clients' current and future needs so that we can identify what is helpful in our service, any gaps, suggested improvements and plans for the future care of people living with HIV in the community. The staff survey included here via survey monkey link is part of the evaluation, which has been approved by RDNS Human Research Ethics Committee (see the Plain Language Statement below for more details).

We would appreciate if you could complete this on–line anonymous survey – it will take about ten minutes. https://www.surveymonkey.com/s/Z789J35

Your input will be highly valued in the planning and development of the HIV Program at RDNS.

Yours sincerely,

Liz Crock
Clinical Nurse Consultant
Northern/Eastern Regions
Heidelberg Site 100 Oriel Rd Heidelberg Victoria 3081
Ph: 03 9499 4237 Fax: 03 9499 7648
Mobile: 0410 560 314
Email: lcrock@rdns.com.au

Appendix 6a

Key informant interview question guide

Key informant interview question guide

1. What do you see as the future needs of PLHIV/Women/Straight Arrows/VAC/GMHC/RDNS HIV Program clients?

2. Concerns about future needs for home–based and community services?

3. What kind of supports do you see will be needed in the next 5–10 years and beyond?

4. What would you like RDNS HIV Program to provide for your members into the future?

5. Suggestions for service improvements/changes?

6. Strengths and weaknesses of the RDNS HIV Program

Appendix 6b

Key informants Plain Language Statement

Plain Language Statement – Key Informants

Title of research project: The RDNS HIV Program in a changing epidemic – an action evaluation

Dr. Elizabeth Crock and Rosemary McKenzie

Project Consultants: Ms. Judy Frecker, Ms. Nalla Burk, Mr. Oscar Morata, Mr John Hall.

You are invited to participate in the above project. We are conducting an evaluation of the *Royal District Nursing Service HIV Program* in relation to HIV clients' current and future needs so that we can identify any gaps in our service and plan for the future care of people living with HIV in the community who need home based care and support. We would like to conduct an interview with you as a representative of HIV Team/Positive Women/Straight Arrows/People Living with HIV/AIDS/ or VAC/GMHC.

With your written consent, the interview will be digitally recorded. We will ask you several broad questions about what do you see as the future needs of PLHIV/Women/Straight Arrows, what kind of home– and community–based supports do you see will be needed in the next 5–10 years, concerns you may have about future needs for home–based and community services, and any suggestions you may have for service improvements/changes.

How will my privacy be maintained?

The digital recording will be saved to a password protected file accessible only by the researchers. The digital recording will then be immediately deleted from the recorder. Transcriptions of interviews will not be made. Any identifying information you provide will be treated as strictly confidential, identifying details changed and pseudonyms used on any written reports.

What are the benefits and risks?

The information you provide in the survey should help improve our service so that we can provide appropriate staff education and meet the needs of people living with HIV into the future. We do not anticipate any risk to you of completing the survey. If any questions cause you concern, you can call the researcher or one of the HIV Team staff for support, and you can choose not to answer every question.

How will the information be used?

The information from this project will be written up in a report. Recommendations will be made to help improve our service to respond to the needs of people living longer with HIV. Journal articles and conference papers may be written based on the report.

If you have any questions about this project please contact:

Dr. Liz Crock
RDNS Heidelberg
100 Oriel Rd.,
Heidelberg 3081
Phone: 0410 560 314

If you have any concerns or complaints about the conduct of this research project please contact:

Chair
RDNS Human Research Ethics Committee
RDNS Institute of Community Health,
31 Alma Road,
St. Kilda, Victoria, 3182
Phone (03) 9536 5382, Fax (03) 9536 5300
Email getinfo@rdns.com.au

Appendix 6c

Key informants Informed consent form

INFORMED CONSENT FORM

The RDNS HIV Program in a changing epidemic – an action evaluation

Example: HIV Services representative Victorian AIDS Council/Gay Men's Health Centre
Positive Living Centre
51 Commercial Rd.,
South Yarra 3141

I hereby consent to participate in the above research project.

- The details of this research project have been explained to me verbally, and
- I have received a copy of the Plain Language Statement, and
- Any questions I have asked in regard to this project have been answered to my satisfaction.

I agree to participate in this research project as a key informant and to have an interview digitally recorded. I understand that I may withdraw from participation at any time. If I withdraw from the project any data previously collected will be destroyed. I agree that research data provided by me may be used in a report, presented at conferences or published in journals on the condition that neither my name nor any other identifying information is used. I understand that any information I provide will be treated with the strictest confidence.

Signature of participant:
……..

Print
name……..

Date……

Witnessed by: …….

Print name……

Appendix 6d

Key informants – Withdrawal of consent form

Withdrawal of consent form

Project Title: The RDNS HIV Program in a changing epidemic – an action evaluation

Participant's name: HIV Services representative Victorian AIDS Council/Gay Men's Health Centre (or other key informant as applicable).

Positive Living Centre
51 Commercial Rd.,
South Yarra 3141

I hereby withdraw my consent to participate in the above research project. I understand that all data collected from me will be destroyed and will not be used in the study report, publications or presentations.

Signature of participant:
……..

Print name……..

Date……

Witnessed by: …….

Print name……

Appendix 7

Coding – client questionnaire

Which of the following do RDNS nurses and/or other RDNS staff (e.g. social worker, mental health nurse) do for you, or with you? Please tick Yes, No or Not Applicable for all items.					
Answer Options	YES	NO	NOT APPLICABLE	Response Count	
Ask me about how I am and how I am feeling	84	0	0	84	A
Help me if I feel unwell	79	0	4	83	A
Help me avoid getting sick	73	5	5	83	B
Help me if I have diarrhea, fever, nausea	50	7	24	81	A
Help me avoid going to hospital	54	10	19	83	B
Help with Hepatitis C treatments	10	10	63	83	C
Give me mental health support	63	7	13	83	D
Give me health advice e.g. about food, staying healthy	73	7	3	83	B
Give me health education	67	9	7	83	B
Suggest ways to remember to take my medications	55	11	16	82	C
Explain side effects of my medications in ways I can understand	63	13	7	83	C
Organise my prescriptions	40	27	16	83	C
Check the medications I have been given are correct	58	16	10	84	C
Make sure I have enough medications	61	10	13	84	C
Explain to me the importance of taking medication as prescribed	74	7	2	83	C
Help me understand what doctors have told me	67	8	6	81	F
Talk to me about how to avoid passing HIV to others	49	20	13	82	B
Talk to me about how to avoid getting Hepatitis C or other infections	34	21	28	83	B
Talking to my doctors and other health workers	82	0	2	84	F
Coordinate my care in the community	59	11	14	84	F
Refer me for peer support (meeting other HIV positive people)	42	28	14	84	F

Help me remember appointments	57	17	9	83	F
Help me with emotional issues. When my mood is low , or I feel stressed	69	8	6	83	D
Help me cope with my situation	76	3	4	83	D
Help when I go home from hospital	48	11	23	82	A
Train volunteers from VAC who help me	21	19	41	81	F
Organise respite for me when I need it	27	12	42	81	F
Refer me for other services I need (e.g. dentist, physio, dietitian)	54	16	13	83	F
Organise transport to appointments	21	30	32	83	F
Help me manage my financial issues	14	46	22	82	E
Help me to sort out any housing problems	25	25	34	84	E
Listen to me when I talk (counselling/support)	81	0	3	84	D
Work with VAC to provide support	42	10	30	82	F
Support my family/carers	38	23	23	84	E
Help me to become independent	50	7	22	79	B
Comments				12	

Appendix 8a

Categories of HIV Knowledge with codes

Pathophysiology	25	160	105	32	12	334	A
	36	185	83	19	12	335	A
TOTAL	61	345	188	51	24	669	
%	9%	52%	28%	8%	4%		
Medical Management	9	138	131	43	10	331	B
	27	170	88	33	16	334	B
	51	210	50	13	10	334	B
	62	203	46	9	10	330	B
	76	206	32	8	8	330	B
	56	201	57	10	10	334	B
	55	201	53	12	10	331	B
	67	208	39	10	6	330	B
	93	202	22	10	6	333	B
	56	215	42	9	10	332	B
	60	207	44	13	10	334	B
	79	196	38	12	6	331	B
TOTAL	691	2357	642	182	112	3984	
%	17%	59%	16%	5%	3%		
Prevention	7	60	120	92	58	337	C
	74	192	44	15	8	333	C
	86	200	36	9	5	336	C
	71	192	43	14	14	334	C
TOTAL	238	644	243	130	85	1340	
%	18%	48%	18%	10%	6%		
Epidemiology	49	197	67	14	7	334	D
	56	196	63	13	6	334	D
TOTAL	105	393	130	27	13	668	
%	16%	59%	19%	4%	2%		
Specific populations or vulnerable groups	72	191	52	7	11	333	E
	63	199	52	10	10	334	E
	120	181	19	8	4	332	E

	68	208	43	10	6	335	E
	71	214	33	7	7	332	E
	78	186	53	8	8	333	E
TOTAL	472	1179	252	50	46	1999	
%	24%	59%	13%	3%	2%		
Legal and ethical	62	175	68	17	11	333	F
	60	173	69	16	15	333	F
	62	182	58	15	14	331	F
TOTAL	184	530	195	48	40	997	
%	18%	53%	20%	5%	4%		
Psychosocial	63	205	49	8	8	333	G
	81	210	30	7	6	334	G
	68	195	55	9	9	336	G
	60	187	66	15	6	334	G
	74	193	48	10	9	334	G
TOTAL	346	990	248	49	38	1671	
%	21%	59%	15%	3%	2%		

Appendix 8b

Explanation of HIV Knowledge codes and results

	No Knowledge	More Education	Satisfied	Moderate	Expert	Total	
Natural history of HIV Infection	25	160	105	32	12	334	A
Clinical diagnosis of HIV/AIDS	36	185	83	19	12	335	A
Sexually transmissible infections and HIV/AIDS	9	138	131	43	10	331	B
Hands-on care of HIV/AIDS clients	27	170	88	33	16	334	B
Standard Precautions (previously known as Universal Precautions) and Infection Prevention	7	60	120	92	58	337	C
Prevention of Mother-to-Child-Transmission (PMTCT)	74	192	44	15	8	333	C
Global scenario of HIV/AIDS	49	197	67	14	7	334	D
Australian scenario of HIV/AIDS	56	196	63	13	6	334	D
Australian National HIV Testing Policy	86	200	36	9	5	336	C
Medical management of HIV/AIDS	51	210	50	13	10	334	B
Antiretroviral Therapy	62	203	46	9	10	330	B
Ageing and HIV	76	206	32	8	8	330	B
Specific issues for injecting drug users with HIV	72	191	52	7	11	333	E
Hepatitis C and HIV co-infection	56	201	57	10	10	334	B
Specific issues for gay men living with HIV	63	199	52	10	10	334	E
Common co-morbidities and HIV	55	201	53	12	10	331	B
Privacy Laws pertaining to HIV and health care	62	175	68	17	11	333	F
Disclosure of HIV status	60	173	69	16	15	333	F
Legal rights of people with HIV	62	182	58	15	14	331	F
Specific issues for asylum seekers with HIV	120	181	19	8	4	332	E
Hepatitis B and HIV co-infection	67	208	39	10	6	330	B
Specific issues for people who have been living long term with HIV	63	205	49	8	8	333	G
Specific issues for families living with HIV	68	208	43	10	6	335	E
Pregnancy issues	81	210	30	7	6	334	G
Specific issues for women with HIV (other than pregnancy)	71	214	33	7	7	332	E

Supports for carers of people living with HIV	68	195	55	9	9	336	G
Gender and sexual diversity issues (e.g. lesbian, gay, bisexual, transgender, intersex, queer health)	60	187	66	15	6	334	G
HIV medication toxicities	93	202	22	10	6	333	B
Specific issues for heterosexual men living with HIV	78	186	53	8	8	333	E
Physical effects of living long term with HIV	56	215	42	9	10	332	B
Mental health and HIV	74	193	48	10	9	334	G
Post-Exposure Prophylaxis (e.g. treatment to prevent infection after occupational or non-occupational exposure)	71	192	43	14	14	334	C
Opportunistic infections	60	207	44	13	10	334	B
HIV-related cancers	79	196	38	12	6	331	B

Appendix 9

Draft position description

Position Description

Royal District Nursing Service (RDNS) is the largest and oldest provider of home nursing and healthcare services in Australia. Grounded in the principles of care and compassion, RDNS is a not-for-profit organisation, delivering 24 hour a day nursing care to people in their homes, schools and workplaces.

Vision Statement

To be the provider of choice for home and community nursing and healthcare services

(DRAFT) For help on developing Position Descriptions, please access the guidelines

Position Title	Senior Clinical Nurse Advisor HIV
Support site	As appointed
Department	n/a
Position reports to	GM DON Southern Metropolitan Region
Direct reports	N/A

Job Purpose

- To provide clinical consultancy and expert care and support for clients living with HIV at all stages of the infection.
- To facilitate and provide support to the RDNS HIV team.
- To actively co-ordinate and resource the teams and Manager of RDNS HIV Program initiatives.
- To provide support to the Program Manager of RDNS HIV Program.
- To facilitate and actively assist RDNS HIV Team in the development of internal and external operational policies/protocols.
- To offer expert advice and assistance to external service providers on HIV and BBV related issues and to participate in the development of appropriate service models/responses.
- To promote the work of RDNS HIV Team across the health, welfare, housing sector and educational institutions.
- To actively advocate to service providers on behalf of people living with HIV and those at risk
- To undertake research and program evaluation

Key Position Functions

The Senior Clinical Nurse Advisor will provide consultancy across RDNS and externally in relation to the care of people living with HIV and will be an advanced practice nurse across the following domains:

- **Effective communication**
- **Assessment, care planning and Clinical management**
- **Health Promotion and client education**
- **Research**
- **Legal and ethical nursing practice**
- **Collaboration and Partnerships**

- **Leadership and development**

In addition, the Senior Clinical Nurse Advisor will:

Team Coordination and communication

- Facilitate the orientation and the provision of support for new staff.
- Facilitate communication and support strategies between RDNS HIV Team staff as individuals, as a team and as a whole.
- Support team individuals in meeting required quality improvement strategies and occupational health and safety standards.
- Co-ordinate and maintain the Partnership Agreement(s) (Victorian AIDS Council/Gay Men's Health Centre) with other agencies in conjunction with the RDNS Legal Officer as necessary.
- Inform and update the RDNS HIV Program Manager of service and/or project issues impacting on the individuals and/or a regional RDNS HIV team/s.
- Maintain relationships/communication with RDNS support site, RDNS Education and Research Departments, Head Office and key external stakeholders.

Program Development

- Lead and develop the HIV Team Health Promotion Plan and Clinical Care and Support funding documents.
- Within a collaborative framework, co-ordinate a response to the clinical and sectoral issues requiring change or impacting on RDNS HIV Program.
- Advocate on behalf of people living with HIV, by establishing, maintaining and participating in networks in community service providers, Public Hospitals, educational institutions, key stakeholders, the Department of Health etc.
- In collaboration with RDNS HIV Team staff and/or team, take lead responsibility for designated HIV service initiatives, research and project work.
- Assist the team in the developing strategies that enable and support program/service reflection.
- Coordinate project and administration tasks with the HIV Program Manager.
- Develop publications in the speciality area of HIV nursing.

Health Promotion and Education

- Facilitate and support professional development for RDNS HIV staff.
- Co-ordinate and supervise the placement of students and observers.
- Provide specialised tuition/lectures and advice on HIV and related issues to internal RDNS, external service providers, public hospitals and educational institutions.

Other

This position description is not intended to be all-inclusive. The employee may perform other related duties as required to meet the ongoing needs of the department and/or organisation.

Skills/Knowledge/Attributes

- In depth knowledge and experience of HIV/AIDS and the impact on an individual and the wider community (within social justice framework).
- A commitment to the principles of primary health care.
- A high level of expertise and knowledge of the health and welfare systems.
- Ability to work as an independent practitioner, which incorporates reflective practice.
- Highly developed management, communication and interpersonal skills, including experience in public speaking and conference paper presentation.
- A thorough understanding of quality management and how it impacts on every aspect of the organisation (program development, implementation and evaluation).

- Demonstrates knowledge of contemporary ethical issues impinging on nursing practice, education and research and in relation to HIV in particular.
- Functions in accordance with legislation and common law affecting nursing practice.
- Leadership and motivational skills.
- Acts to enhance the professional development of self and others.
- Minimum 5 years experience working in community health and/or similar role

Qualifications

- Registered Nurse (Division 1)

Active Service Model

The Victorian Home and Community Care (HACC) Active Service Model (ASM) is a quality improvement initiative that explicitly focuses on promoting person centred care, capacity building and restorative care in service delivery. The goal of the ASM is for frail older people and people with disabilities in the HACC target group to live in the community as independently and autonomously as possible.

Occupational Health & Safety Requirements

RDNS adheres to all Occupational Health & Safety regulations as an employer. The organisation endeavours to provide a working environment that is safe and without risk to all employees. As an employee, you also have Occupational Health and Safety responsibilities, they are as follows:

- To comply with all RDNS policies related to Occupational Health and Safety in the workplace.
- Take reasonable care of your own health and safety in addition to the health and safety of your colleagues and clients who may be affected by your acts or omissions in the workplace.

Terms and Conditions

- As per relevant award, agreement or employment contract
- Current and satisfactory National Police Record check
- Current nursing registration in state or country in which employment is based
- Current drivers licence valid in the state or country in which employment based

Reviewed/Created by	Elizabeth Crock
	Clinical Nurse Consultant HIV/AIDS
	6th September 2013
Authorised by	(Name)
	(Title)
	(Date)

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