

NAPWA CARE+SUPPORT AUDIT

transitions

Sharpening our lens on experience

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EXECUTIVE SUMMARY

The Care and Support Snapshot Survey (CSSS) prepared by NAPWA is new, important work for NAPWA to undertake because it asks and then listens to the perceptions of a range of positive people. It includes a number of questions about service needs, constituency and representation, geography and the policy and advocacy work of NAPWA through the lens of positive people.

The survey was mailed out to approximately 100 HIV positive delegates attending the NAPWA Tenth Biennial Conference in Adelaide in 2005. Completed survey instruments were accepted until the closing date of January 27, 2006. A total of 64 surveys were completed and returned by mail to NAPWA.

The comments and issues raised spoke to a number of concerns positive people wanted to communicate about what life is like for them and their HIV positive friends. They directly name problems and in some cases propose solutions. The needs and experiences of many people are expressed as a series of transitions, sometimes interrelated, and cover a diversity of experience. The final section of the report arrives at thematic approaches in summarising peer experiences reported by this group of HIV positive respondents including:

- 'Burden' of HIV
- 'Cost burden' of HIV
- Certain vulnerabilities
- Essential services
- Work
- Peer support
- Building resilience
- HIV awareness

The results indicated there are 'transitions' or 'zones' that HIV positive people are managing as they make changes to their personal circumstances and continue to move towards embracing improved health outcomes. Some people are able to benefit from opportunities as a result of the effectiveness of treatments and improved health monitoring and management. For others, it is important to understand that having their HIV 'controlled' by treatments does not equate with chronic manageable illness in HIV. There is still no cure for HIV and 'chronic manageable illness' does not mean a good quality of life, way of life, existence, or standard of living for many people. The report also identifies that there are still many areas requiring targeted ongoing advocacy and policy responses.

The survey was never intended to be representative of Australia's HIV population. Instead, it was conducted among a group of positive people attending the NAPWA conference, which is a vehicle to draw together HIV positive people from around the nation. The results from this analysis should be seen as a starting point for discussion and may be indicative of issues warranting further exploration or understanding through a variety of means including research, case studies or HIV sector discussion.

NAPWA National Care and Support Audit Critical Reference Group (CRG)

Members of the NAPWA National Care and Support Audit Critical Reference Group (CRG) who have provided feedback on the report include:

Gabe McCarthy Director, NAPWA

Katherine Leane Director, NAPWA; HIV Peer Support Worker, Women's Health Statewide, South Australia

David Menadue Education Convenor, NAPWA

Rob Lake Care and Support Convenor, NAPWA; Chief Executive Officer, PLWHA (NSW)

David Barton former Program Coordinator, Heterosexual HIV/AIDS Service, NSW

David Wallace former Positive Futures Team Leader, Bobby Goldsmith Foundation

Cipri Martinez former HIV Positive Peer Educator, WA AIDS Council

John Daye Health and Treatments Convenor, NAPWA

John Rule Deputy Director, NAPWA

Bill Whittaker Health and Treatments Convenor, NAPWA

Ian Rankin President, AFAO

The findings acknowledge the complexity of needs around treatment and care issues directly arising as a result of improved health outcomes post-1996. These changes affect service direction, highlighting gaps in services or difficulties in access, which requires the formulation of solutions when projecting on care and support needs and service responses.

The CRG supports further consultative efforts by NAPWA to gain insights into HIV positive people's needs, quality of life and service utilisation experiences. Further, the CRG believes that this report has spoken on a range of specific issues and their effects, providing the organisation with a powerful lobbying tool as NAPWA refines its work and collects more information about HIV social policy.

Significant assistance in preparing the report has also been received from the Australian Research Centre in Sex, Health and Society (ARCSHS), especially Jeffrey Grierson and Rachel Thorpe. Jo Watson, the Executive Director of NAPWA was also instrumental in shaping the report.

NAPWA thanks the CRG members, ARCSHS and the survey participants for their contributions.

THE SURVEY INSTRUMENT

The survey instrument was six pages in length and asked thirteen questions around the issues raised in the four survey sections as follows:

SECTION 1: WHO ARE WE?

Where we're from – gender, age, place of residence (state or territory), region as defined by capital city/inner or outer suburban, regional centre (population 5,000 or more) or rural, Aboriginal and Torres Strait Islander (ATSI) background, staff, volunteer, client or no involvement in PLWHA organisations and AIDS councils, and length of involvement in the HIV/AIDS sector.

Who we represent – in what representative capacity (if any) the respondent was attending the conference (20 options were provided covering major NAPWA representative networks and other HIV/AIDS sector capacities).

How we identify – twelve options were offered seeking information on the group that the respondent feels most strongly connected to or the group whose concerns they are most likely to speak on behalf of. Options included a range of positive communities, gay and general community, and health and medical communities.

Who we connect with – the degree to which people felt connected with six groups (other positive people, their state PLWHA organisation, NAPWA, AIDS organisations, AIDS councils, AFAO) was canvassed using a six point scale from 'very well' to 'not at all' or 'not applicable'.

SECTION 2: CARE AND SUPPORT SERVICE ISSUES

In this section five questions were asked (with room for comments on each question) about the significance of a range of care and support service issues for the respondent, their friends, their organisation, their region and their constituency.

The service issues canvassed were grouped under the headings of 'HIV Health' and 'HIV Living' as follows:

'HIV Health' – services provided by general practitioners (GPs), hospitals and clinics, including specialist and ambulatory services, counselling, dental care and health management and monitoring.

'HIV Living' – housing, community support services (transport, food networks, and financial management), personal needs such as peer support and opportunities for social participation, and employment and income support (pre-employment and ongoing employment support, accessibility of Job Network services and services to support people returning to work or study.)

Respondents were asked to rate how great that service need (e.g., GP care) is currently for each group (e.g. 'you personally' or 'your friends who are HIV positive') from six options ranging from 'very well' to 'not at all' or 'not applicable'. A rating of 'very well' could mean that the respondent felt that they or another group is spending a lot of time trying to address it, that there are a lot of people with that need, or that that need has a major impact on their life at the moment.

SECTION 3: POLICY AND ADVOCACY

In this section, respondents were asked two questions to rate how relevant the following six current areas of policy and advocacy work – identified and undertaken by NAPWA – were to the needs in 'their region' or 'for their constituency'.

1. Improving access to health services
2. Addressing discrimination in insurance industry
3. Achieving affordable long term and supported housing
4. Improving the range and quality of plwha return to work services
5. Arriving at a 'true' cost of living with HIV
6. Ensuring the implementation of the 5th National HIV/AIDS Strategy at state level

This section explored how well the care and support issues around the country are represented in the policy and advocacy work that NAPWA undertakes. Policy and advocacy refers to the building of healthy public policy within a health promotion framework. Six areas of policy work were used as starting points and respondents were asked to rate each of the six areas (e.g. 'discrimination in insurance') on a seven option scale from 'very' to 'not at all', 'not applicable' or 'don't know'. Space was provided for comments on each question.

SECTION 4: PEER EXPERIENCES

In this section two open-ended questions were asked:

1. Respondents were invited to freely express anything else they wanted to note in relation to care and support needs or their particular experiences.
2. Respondents were invited to talk about their own lives and the lives of their friends and invited to make any final comments on their care and support needs and experiences.

THE SURVEY RESULTS

SECTION 1: WHO ARE WE?

- Gender: of the 64 respondents, 14 identified as female and 49 as male.
- Age: participants ranged from 27 to 67 years with a mean of 47 years.
- Place of residence: state or territory

Table 1: State or territory: respondents' residence

STATE/ TERRITORY	FREQUENCY	PERCENTAGE %
ACT	6	10.5
NSW	13	22.0
NT	1	2.0
QLD	5	9.0
SA	11	19.0
TAS	3	5.0
VIC	13	22.0
WA	6	10.5
<u>Total</u>	<u>58</u>	<u>100</u>

Table 2: Respondents' region*

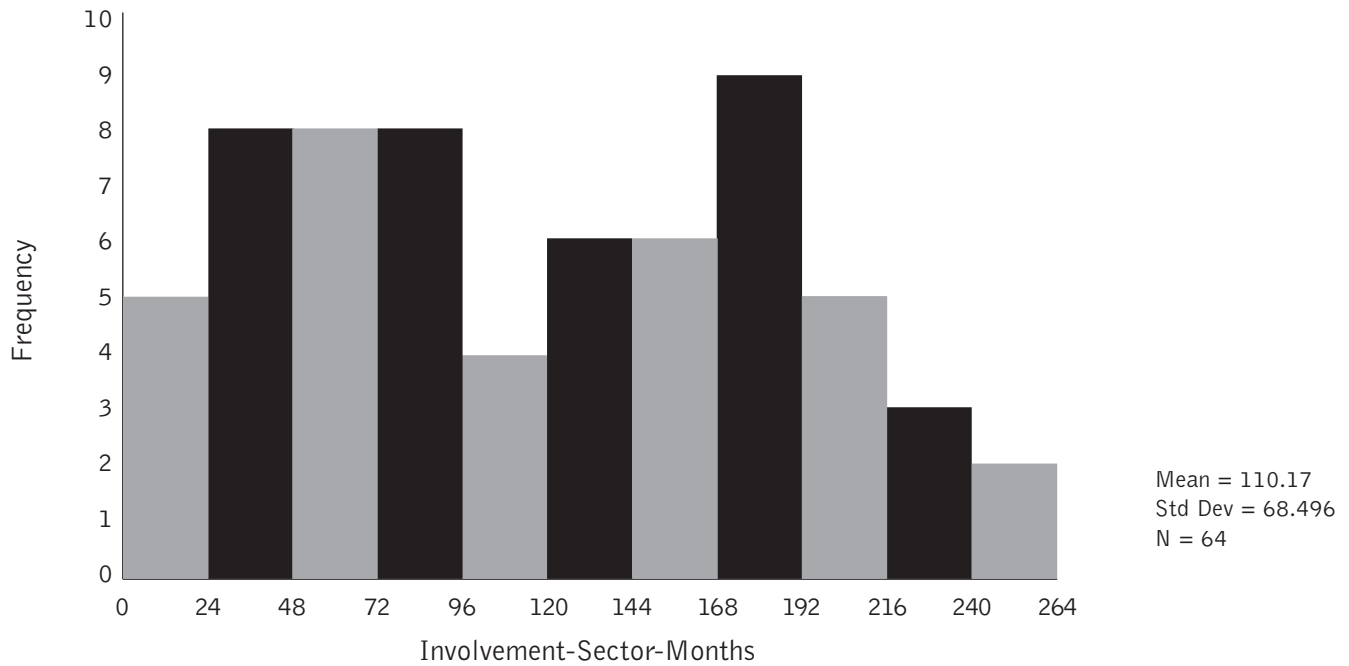
REGION*	FREQUENCY	PERCENTAGE %
Capital city	38	67
Outer suburbs	8	14
Regional centre	8	14
Rural	3	5
<u>Total</u>	<u>57</u>	<u>100</u>

* region as defined by capital city/inner or outer suburban, regional centre (population 5,000 or more) or rural

- ATSI background: three respondents identified as Aboriginal and Torres Strait Islander
- Staff, volunteer, client or no involvement in both PLWHA organisations and AIDS councils: more people cited volunteer work with their PLWHA organisation than their AIDS council.
- Involvement in PLWHA organisations: of the 65 respondents, six (9.4%) held a staff position, 34 (53.1%) undertook volunteer work within PLWHA organisations and 25 (39.1%) identified as a client. Eleven (17.2%) indicated that they had no contact with PLWHA organisations.
- Involvement in AIDS councils: of the 65 respondents, nine (14.1%) held a staff position, 20 (31.1%) undertook volunteer work within their AIDS council and 26 (40.6%) received services as a client. Twenty (31.3%) indicated that they had no contact with their AIDS council.
- Length of involvement in the HIV/AIDS sector: the length of time that respondents indicated their sector involvement varied from nil to 240 months (20 years), with the mean time being 110.17 months or 9.16 years.

This identifies the respondents as a particular population of plwhas and as having a long involvement in the HIV/AIDS sector. It suggests that an issue for possible investigation is the extent to which involvement as volunteers and advocates in the work of NAPWA and its networks impacts on social well-being and broader community participation opportunities.

Figure 1: LENGTH OF HIV SECTOR INVOLVEMENT



WHO WE REPRESENT

Respondents were asked in what representative capacity (if any) they were attending the conference (20 options were included covering major NAPWA representative networks and other HIV/AIDS sector capacities). Respondents could tick as many as apply.

As this was the biennial NAPWA conference, it would be expected that this group would include people who were there in some representative capacity which was linked into the NAPWA processes of governance and representation.

Apart from directly linked representatives (Representative Committee, Board, convenors, working group members, Indigenous Positive Network (IPN+) members) and indirectly linked NAPWA representatives (local PLWHA organisations), NAPWA provided scholarships to over 50 people from around Australia to attend the conference and 23 respondents indicated that they were attending in that capacity. The scholarship recipients were not linked into the NAPWA processes of governance or representation and some of these people took part in the survey.

Respondents reported attending the NAPWA conference in the following capacities:

Table 3: WHO WE REPRESENT

REPRESENTATION	FREQUENCY	PERCENTAGE %
Local PLWHA organisation	24	38
Local AIDS council	9	14
NAPWA Representative Committee	6	9
NAPWA Board of Directors	3	5
National portfolio convenors	4	6
NAPWA working group	2	3
National women's meeting	5	8
Indigenous Positive Network IPN+	3	5
Private individual	16	25
Positive womens' organisation	6	9
Scholarship recipient	23	36
NAPWA staff	0	0
AIDS council staff	5	8
Positive Living Centre	8	13
Positive heterosexuals organisation	1	2
Multicultural CALD (culturally and linguistically diverse) organisation	1	2
Indigenous organisation e.g., IPON	2	3
Health worker	4	6
Government sector/AFAO Board or staff	1	2
Other	7	11

HOW WE IDENTIFY

Respondents were asked who they mostly identified with, or, if they were representing a particular group, who they felt they were speaking on behalf of. Options included a range of positive communities, gay and general community, as well as health and medical communities.

The survey results indicate that this population of positive people clearly see themselves as firstly identifying as HIV positive, followed by identification based on their sexuality, gender, race or work.

Thirty-six (56.3%) respondents indicated that their primary constituency, when thinking of the group that they most strongly belong to or speak on behalf of, was plwha generally, followed by both gay and heterosexual HIV positive men (20 people or 31.3%), and HIV positive women (12 people or 21.9%). Thirteen respondents (20.3%) indicated their primary constituency as being gay men.

Table 4: WHO WE IDENTIFY WITH

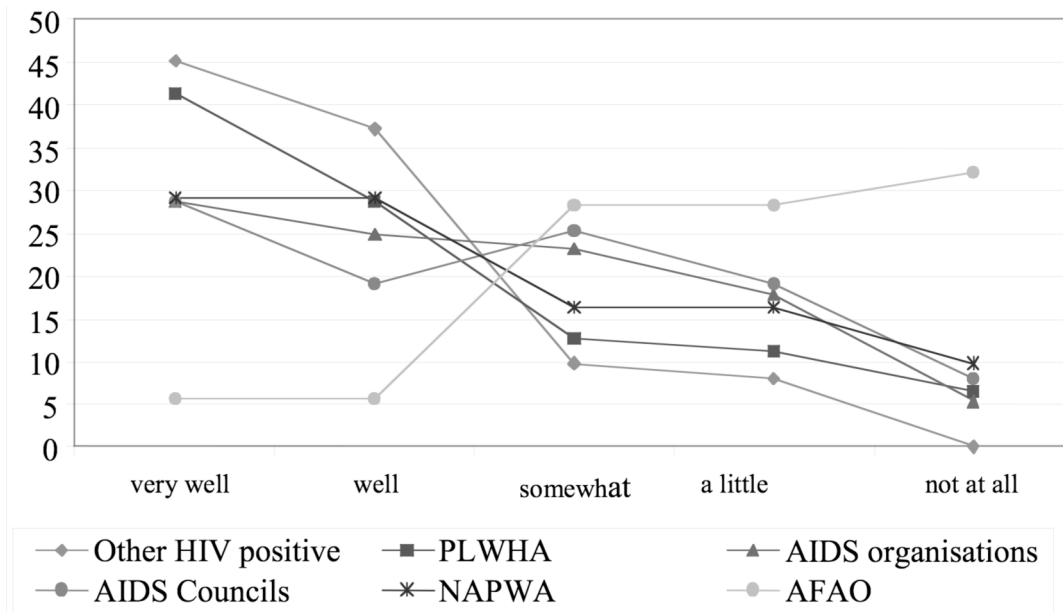
CONSTITUENCY	FREQUENCY	PERCENTAGE %
Plwha generally	36	56
Positive gay men	17	27
Positive women	9	14
Indigenous	2	3
Positive female heterosexual	5	8
Positive male heterosexual	3	5
Gay men	13	20
General community	9	14
Health consumers	3	5
Allied health	1	2
Medical community	1	2
Community health	2	3

WHO WE CONNECT WITH

The connection or identity association with six groups was canvassed rating connection from six options ranging from 'very well' to 'not at all' or 'not applicable'. Overall, as can be seen by the connectedness graph (Figure 2), respondents stated that in order of connectedness, they felt most connected to:

1. other positive people
2. their representative PLWHA state organisations
3. NAPWA
4. AIDS organisations
5. AIDS councils
6. AFAO

Figure 2: WHO WE CONNECT WITH



Specifically in order of connectedness:

1. Other positive people: 51 respondents (82.3%) indicated they were 'well or very well' connected, with five (8.1%) being 'a little' connected.
2. Their representative PLWHA state organisations: 44 respondents (69.8%) indicated they were 'well or very well' connected, with 11 (17.4%) being 'a little' or 'not at all' connected.
3. NAPWA: 36 respondents (58.1%) indicated they were 'well or very well' connected, with 16 (25.8%) being 'a little or not at all' connected.
4. AIDS organisations: 30 respondents (53.6%) indicated they were 'well or very well' connected, with 13 (23.3%) being 'a little' or 'not at all' connected.
5. AIDS councils: 30 respondents (47.6%) indicated they were 'well or very well' connected, with 17 (26.9%) being 'a little' or 'not at all' connected.
6. AFAO: six respondents (11.3%) indicated they were 'well or very well' connected, with 32 (60.4%) being 'a little' or 'not at all' connected.

IS THIS THE SAME FOR ALL OF US?

State differences. An analysis by state needs to be read with caution due to the small numbers of respondents in some states. While these individual state differences may not represent meaningful differences between the states, they do warrant further understanding. For this reason, the following comments have been based on the results of the three states with the largest numbers of respondents – NSW, Victoria and South Australia.

Looking specifically at organisational connectedness, in terms of peak bodies, respondents are more connected to NAPWA than AFAO and to PLWHA organisations than AIDS councils. A closer analysis of NSW, Victoria and South Australia using the ratings of 'very well' and 'well' reveals that respondents are more connected to NAPWA (66.7%-70%) than AFAO (0%-15.4%) and more connected to PLWHA organisations (53.9%-91.6%) than AIDS councils (25%-72.8%).

While respondents consistently rated more connectedness to NAPWA than AFAO, when analysing the connectedness to AIDS councils and PLWHA organisations more closely by state, it can be observed that in NSW there is a more moderate and even sense of connectedness to PLWHA organisations (53.9%) and AIDS councils (38.5%). In contrast the results from Victoria and South Australia show that in South Australia there is a very high sense of connectedness to both PLWHA organisations and AIDS councils (91.6% versus 72.8%), whereas in Victoria there appears to be a disconnect (91.6% versus 25%).

Of interest is the moderately high connectedness in NSW to NAPWA (69.3%) compared with the state PLWHA organisation (53.9%) and AIDS council (38.5%). This relatively strong sense of connectedness could have something to do with the presence of NAPWA within NSW compared to the rest of Australia. (See appendix for cross-tabulations of state results.)

Regional differences. Comments represent an aggregation of rural and regional responses. Once again, looking at connectedness and engagement with groups and organisations in South Australia, Victoria and NSW, in both capital city and regional locations, respondents indicate a greater connection with NAPWA (66% versus 15%) than AFAO (15% versus 7%) and again with PLWHA organisations (75% versus 58%). However, the connection appears to be more even with AIDS council engagement (46% versus 47%) between capital and regional centres. (See appendix for cross-tabulations of regional results.)

Importantly, it needs to be understood that it is the role or 'job' of NAPWA to have a national reach, so the above results are not surprising in this context. On the other hand, NAPWA is not charged with a service delivery role and so it may be that the physical presence of the AIDS Council of NSW outside of Sydney, together with its statewide charter for service delivery, has a role in this understanding.

Of importance is the sense of engagement and connection to NAPWA reported by respondents living in regional areas. This provides an important insight into a difference between NAPWA and the PLWHA state-based organisations, where NAPWA's reach into regional areas on advocacy and policy briefs is possibly greater than most PLWHA state-based organisations, which in the main do not have the organisational resource capacity to affect a statewide reach.

Differences for gay men and women. When analysing the responses by constituency groupings, further understandings of the modes of engagement operating nationally for gay men and women is apparent. For reasons of sample size, positive gay men and gay men are added together, as well as adding female heterosexual women and positive women together. The comments below therefore relate to gay men and women using the 'very well' and 'well' ratings.

For both gay men and women, the connectedness to organisations follows the national trend with more connection to NAPWA (52% versus 41.6%) than AFAO (0% versus 9.1%), and to PLWHA organisations (65.4% versus 66.6%) than AIDS councils (38.5% versus 50%).

Of interest is the relatively strong connection expressed by women to NAPWA and when considered along with the strong state analysis of connection to NAPWA, it appears that there may be a politically different mode and frequency of engagement by women than men. One possible reading of this, is that women may have a different process of engagement with organisations and the politics of HIV than gay men.

Importantly, the sense of engagement and connection by women to the NAPWA processes says something useful about structural access and governance arrangements for women within NAPWA where there is a dedicated national women's network, national female president (at the time) and other key director or portfolio engagement by women.

The development of a positive women's organisation in Victoria (Positive Women Victoria), may have occurred precisely because there was a critical mass of women in that state. On the other hand, the establishment of a National Women's Network by NAPWA has occurred in spite of a critical mass of women in all states and speaks to the importance and power of a national organisation assisting women by providing a national voice, peer support and education opportunities for women under the NAPWA umbrella. The National Women's Meeting coincided with the NAPWA conference and is another example of this facilitation through the NAPWA processes.

SUPPORTING THE HIV POSITIVE WORKFORCE

The survey involved people who are reasonably 'connected' into processes of influence and politics within AIDS organisations at both state and national levels. A significant number of participants report being actively involved with AIDS organisations and in the local, state and national responses, to the prevention and management of HIV around the nation.

Many respondents are unpaid workers or volunteers for organisations who have been involved for long periods of time. It is worth thinking about a significant part of this group as being part of the national HIV workforce and in doing so, consider how the health of this workforce can best be maintained and strengthened.

The questions that could be asked include:

1. What particular needs are required to maintain capacity to participate in a beneficial way in the national response to HIV?
2. What health issues are there for this group that require attention?
3. How does participation in advocacy, or as a representative speaker, help or hinder a person's sense of their own resilience?
4. What are the best models for opportunities for participation, workforce re-entry and the future models of positive governance and representational work?

As the culture of volunteerism in the HIV sector has changed as a result of a number of factors, including improved health outcomes for positive people, the rise of individualism and the deconstruction of the gay community. It is useful to think about the implications of these changing cultural forces on opportunities for participation, workforce re-entry and the future models of positive governance and representational work. It may be appropriate to think further about the future role of identity and organisational structural politics for HIV positive groups and organisations.

Improved understandings of the shifts in the HIV positive workforce and organisational workplace management issues could be usefully positioned alongside an understanding of the importance of positive governance to the outcomes of positive organisations. For example, if there is a reduction in the volunteer time and commitment of positive people to their positive advocacy groups due to return to work or other shifts, maintaining a positive governance model for groups and organisations is the surest way of achieving policy and advocacy objectives in the absence of a positive volunteer workforce to the level of that enjoyed to date.

CONCLUSION

This section offers insights into 'who we are', providing a detailed look into the very different nature of our backgrounds and into the ways that representation, identity and our speaking voices come together and are organised.

The analysis reveals that respondents do represent a diverse cross section of the Australian body positive although not proportionately representative of national epidemiology, particularly in CALD, Indigenous and the more recently-diagnosed subpopulations.

Through these results, we see that at the NAPWA biennial conference there were many people who wanted to speak of their lives, connections, work and experiences; that the conference is an important national social participation and peer support opportunity; and that there is a history of continuing commitment to the ongoing advocacy efforts of NAPWA and our national response spanning a mean of 9.16 years of volunteer work and involvement for each respondent.

NAPWA acknowledges the significance of this enormous positive contribution by many dedicated and passionate individuals who are actively participating in the national response in a variety of important ways. NAPWA sees that it is now critical to ensure that this unpaid workforce is supported appropriately to maximise both individual and organisational health and well-being.

Participants spoke about how they choose to identify and have told NAPWA that an HIV positive identity is important to them, in some ways even more important than other identities related to sexuality, race or gender. Significantly, they have reaffirmed the importance of being in relationship with other positive people as they feel most connected to or are likely to speak on behalf of other positive people.

NAPWA has learnt about the significance of organisational and interpersonal connections and these intersections with positive people's lives. Respondents have told us about the relative importance and intersection of connections with other positive people and both service and representative policy organisations at national and state levels. NAPWA has learnt from this analysis that there is more to be done to strengthen opportunities for social participation through strategies which enhance connectedness. This analysis raises important issues about relationships and the ways that positive networks currently operate. NAPWA considers that it is very important to understand more about the impact of both organisational 'role' and 'reach' through exploration of the factors and dynamics that affect opportunities for connections with positive people.

In summary, this section has talked about the power and the significance of relationships and their critical role to understanding some of the dimensions that underpin social policy responses and opportunities for positive engagement and response.

RECOMMENDATIONS

1. NAPWA believes that more needs to be done to create opportunities for the participation of HIV positive sub populations, including CALD and indigenous, in areas of social policy and organisational response.
2. NAPWA recommends that the biennial conference be resourced by the Commonwealth through the Department of Health and Ageing at an adequate level to support an enhanced scholarship program for positive people to participate, with specific targets set for subpopulations and those who are financially disadvantaged or on low incomes.
3. NAPWA recommends that further research, case studies and HIV discussion occur with members of the HIV positive volunteer workforce with the aim of understanding how best to support their individual health and well-being as volunteers through identifying organisational processes and other structural or programmatic enhancements.
4. NAPWA recommends that research be conducted to further understand the dynamics and relationships of HIV positive networks to HIV organisational life and national responses with the aim of identifying any structural enhancements to the HIV positive networks which may assist the capacity and processes for participation in HIV social policy responses through NAPWA.

SECTION 2: CARE AND SUPPORT SERVICES

In this section, the results of specified HIV health and HIV living needs and services are rated according to their significance to the respondent, their positive friends, their organisation, region and their stated constituency and summarised in figures 3.

KEY PRIORITIES

An analysis of these responses reveals a consistent and very high significance rating given to all of the service areas.

GP CARE AND HOSPITAL SERVICES

In a hierarchical list of service needs, respondents rated GP care (including health management and monitoring) and hospital services (including specialist and ambulatory services and counselling) consistently the highest of all service needs. The respondents consistently rated GP care and hospitals as top priority, whether in terms of region or other identification.

PEER SUPPORT AND OPPORTUNITIES FOR SOCIAL PARTICIPATION

GP care and hospital services was closely followed by personal needs (peer support and opportunities for social participation), community services (including the availability of community support services e.g. transport, food networks and financial management) and allied health (including nutrition, mental health and dental health). Income support and employment (includes pre-employment and ongoing employment support, accessibility of job networks) followed, with only a minimal gap. It should be noted that personal needs was about other notions of 'closeness' and 'connection' through peer support and social participation opportunities. There were no significant regional differences and the responses followed the national results.

By region using ratings of 'very well' and 'well'

GP	91.1%
Hospital	91.1%
Allied health	88.6%
Housing	87.4%
Income support	87.3%
Community services	87.1%
Employment	81.0%
Personal needs	80.5%

When results are considered for gay men and women they are similar to national results.

For gay men using the ratings of 'very well' and 'well'

GP	91.6%
Hospital	91.7%
Income support	87.5%
Personal needs	83.4%
Community services	82.6%
Allied health	82.6%
Housing	79.1%
Employment	77.3%

For women using the rating of 'very well'*

GP / hospital / income support (all 90%)

Allied health / housing / community services / personal needs / employment (all 80%)

Income support highlighted

Significantly, GP care, hospital services and income support were rated as consistently high needs, regardless of where the respondents lived or to which constituency group they belonged. This was further articulated in the peer experiences about essential services and the cost of living.

Among a larger sample of men, there was more differentiation, but with all services rating in the top quartile.

Figure 3: SIGNIFICANCE OF HOSPITAL NEEDS

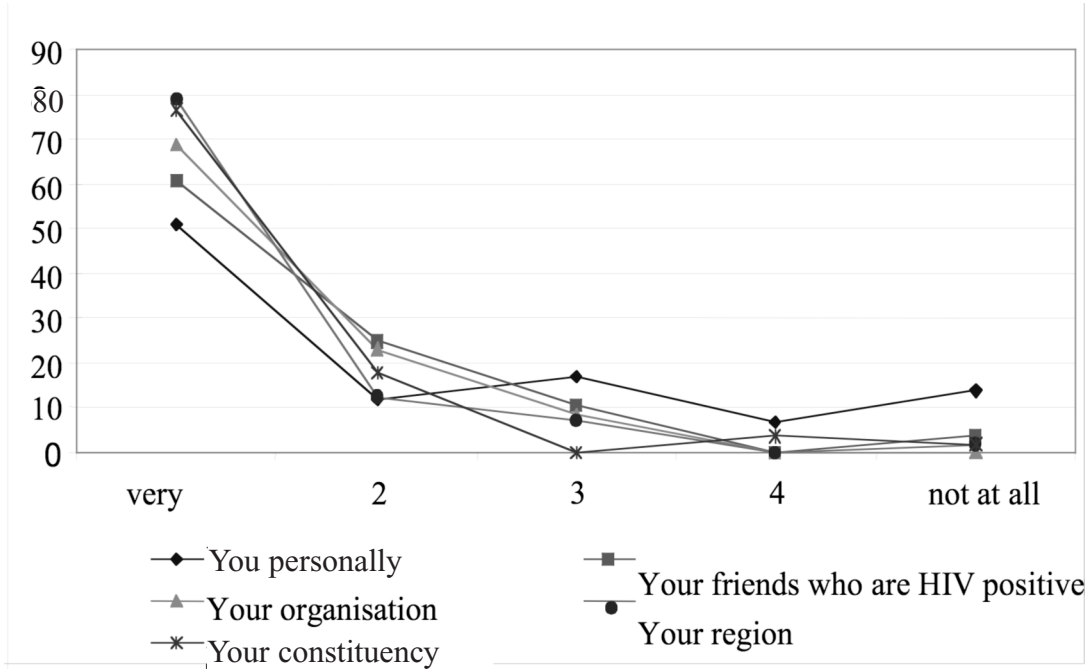


Figure 4: SIGNIFICANCE OF GP NEEDS

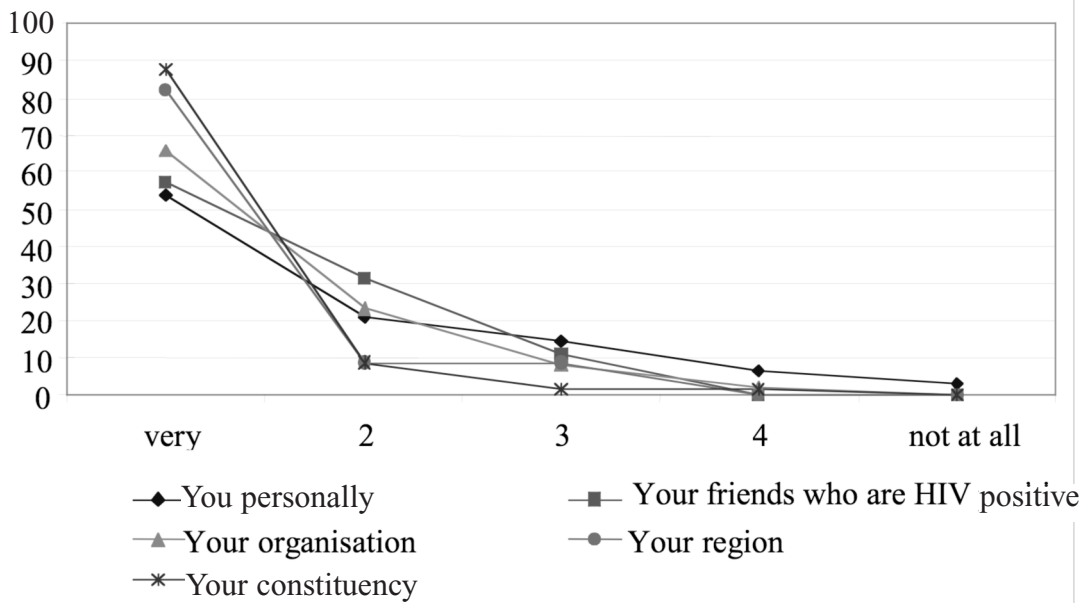


Figure 5: SIGNIFICANCE OF ALLIED HEALTH NEEDS

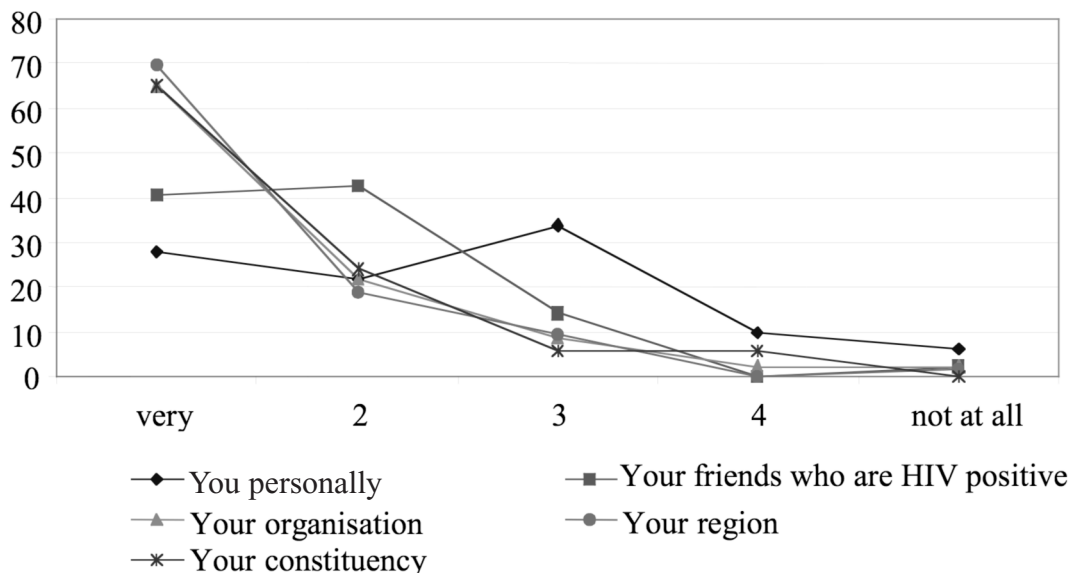


Figure 6: SIGNIFICANCE OF HOUSING NEEDS

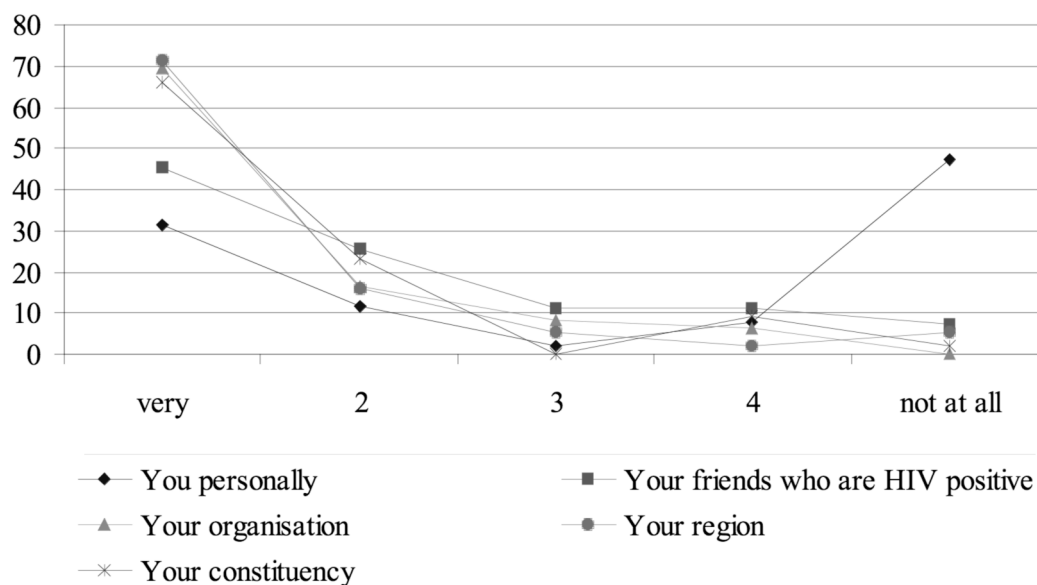


Figure 7: SIGNIFICANCE OF COMMUNITY SERVICES NEEDS

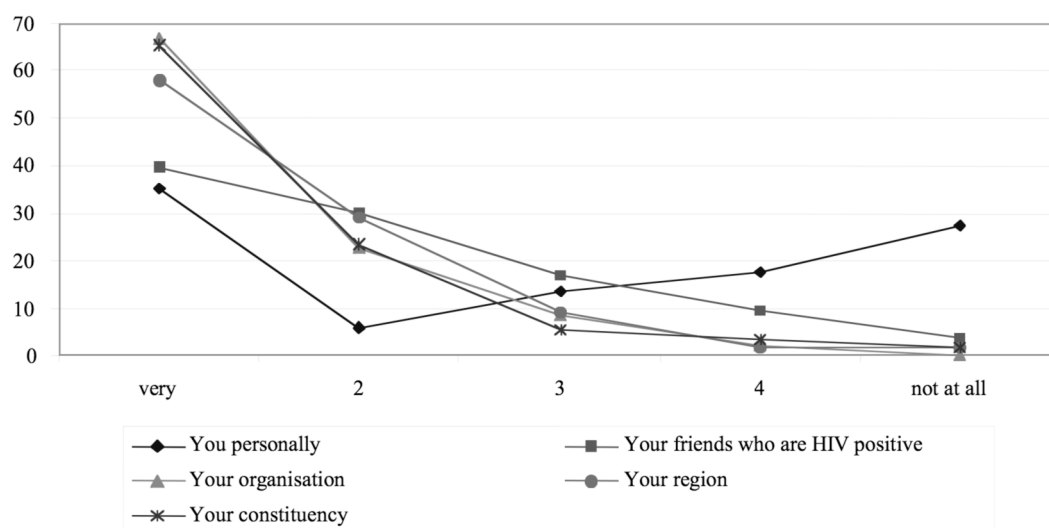


Figure 8: SIGNIFICANCE OF PERSONAL NEEDS

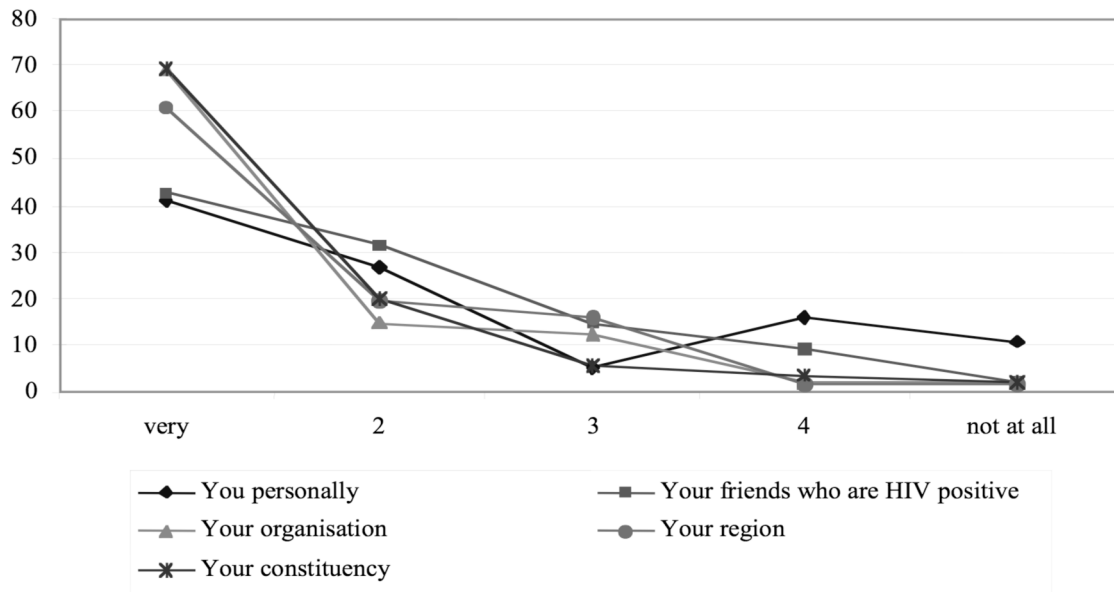


Figure 9: SIGNIFICANCE OF EMPLOYMENT NEEDS

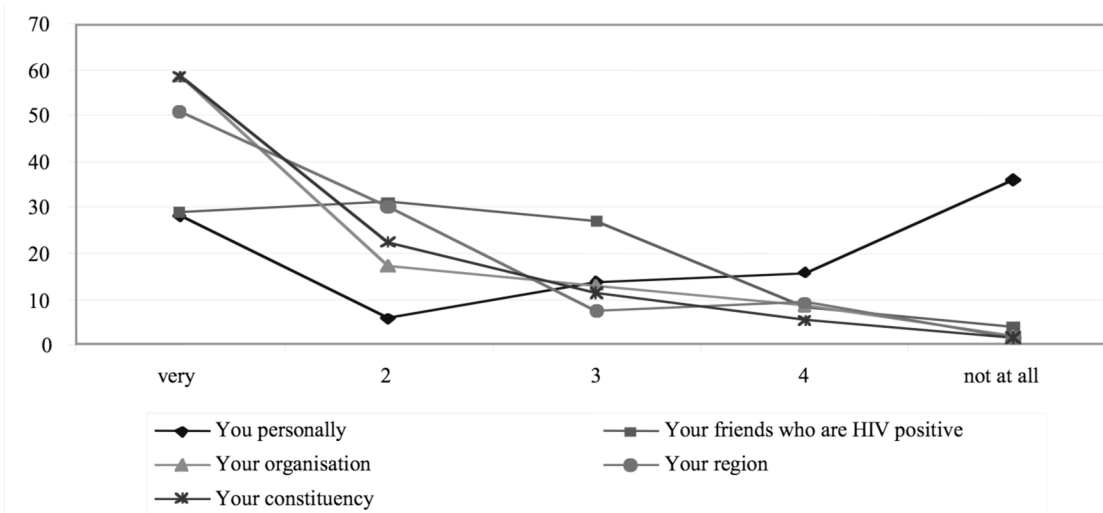
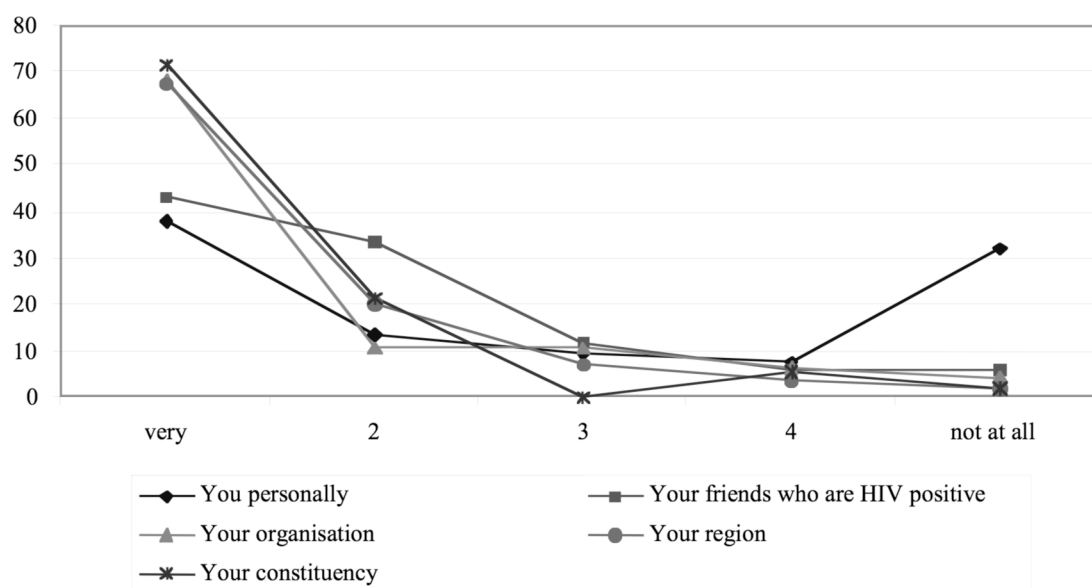


Figure 10: SIGNIFICANCE OF INCOME SUPPORT NEEDS



Perceptions of 'need'

Applying a hierarchy of significance to each one of the eight service need areas against a different perspective of who the need is significant for, reveals an interesting relationship between the 'personal' perspective of need and the need of 'the other'. 'The other' refers to the respondents' perception of the needs of their positive friends, their organisation, their region and their constituency. The ratings given to the significance of need for 'the other' is in every instance higher than the perception of personal need.

It would be interesting to explore further the place or importance that the assumed role an advocate has to play in the positioning of personal needs. This could examine whether or not there was a 'holding back' or reluctance to speak of personal need by the positive advocate who is frequently in the position of 'arguing the case' for others living with HIV. As a result, there needs to be an examination of whether or not there are any implications for support of positive advocates who are often stigmatised by their role as representative speakersⁱ.

Research from the HIV Futuresⁱⁱ studies suggests that people generally see themselves as being more resilient than the 'anonymous other' and this is reflected here throughout the analysis of significance of need.

CONCLUSION

In this section respondents have identified two critical priorities for national service needs as being GP care (including health management and monitoring) and hospital services (including specialist and ambulatory services and counselling) services.

NAPWA is not surprised by these priorities as the HIV medical response is in the main managed through these settings, including through a range of clinics. However, this means that these key medical response sites need to be appropriately resourced, held accountable for practice and able to provide best practice care which complies with HIV models of clinical care for positive people, now and into the future.

Peer support and opportunities for social participation were clearly identified as a key priority and income support was a consistent need expressed. 'Peer support' and 'cost of living' are key areas emphasised within the peer experiences of Section 4.

Whilst key priorities were identified, all service needs rated very highly and it is clear that all eight service needs are seen by respondents as important to the care and support service package.

Analysis of perceptions of personal need in relation to the need of others reveals an opportunity to understand more about the role that volunteer advocates assume as part of the national HIV workforce and the effect of this participation on their own perceptions of personal need.

RECOMMENDATIONS

1. NAPWA recommends that MACASSH through the Commonwealth Department of Health and Ageing (DoHA) investigate the appropriateness and completeness of current HIV models of care to the current and future service needs of HIV positive people.
2. Further, NAPWA recommends that this investigation involve research and analysis on service utilisation and quality of life issues for positive people involving case studies and targeted HIV sector discussion to inform any change to service direction and address any important gaps or difficulties within the current HIV models of care.
3. NAPWA recommends that the small body of current research into HIV and identity be expanded to include understandings of the relationships between HIV positive identity, participation in the national or state HIV responses, and the effects of HIV related stigma on HIV positive participation.

SECTION 3: POLICY AND ADVOCACY WORK

One survey objective was to understand the relevance of NAPWA's policy and advocacy work on the range of care and support issues around the nation. While the processes used by NAPWA to determine national priorities for policy and advocacy work undertaken are robust, this survey was an opportunity to further promote these issues and formally assess the relevance of issues to the perceived needs.

The responses have been analysed by region and constituency for both gay men (including positive men) and women (including heterosexual women). All of NAPWA's current care and support policy and advocacy areas were found to be relevant, all rating in the top third and fourth quartiles.

Of no surprise was the very high relevance given to "improving access to health services (mental health, dental services, equity in regional and non-regional areas, the audit of care and support needs, mapping of care and support services and anti-discrimination in health services)." This was followed by "arriving at the true cost of living with HIV (research and funding for modeling and chronic illness card)." Ensuring the implementation of the 5th National HIV/AIDS Strategy at a state level was the clear third priority.

The importance of these issues is further articulated in Section 4 where respondents provide comments on their own service experiences. Many commented on the personal difficulty of meeting the cost of living with HIV and a range of experiences with health services, which may indicate that these are areas of NAPWA's work which are more easily identifiable as relevant to respondents.

CONSTITUENCY

GAY MEN

Table 5: RELEVANCE OF NATIONAL POLICY AND ADVOCACY AREAS TO THE NEEDS OF GAY MEN*

NAPWA policy and advocacy areas	VERY (%)	2 (%)	3 (%)	4 (%)	NOT AT ALL (%)	TOTAL
Health services	84.6	7.7	3.8		3.8	100
Discrimination in insurance	56.0	24.0	8.0	8.0	4.0	100
Long term and supported housing	56.0	12.0	12.0	4.0	16.0	100
Return to work services	54.2	12.5	4.2	20.8	8.3	100
Cost of living with HIV	69.2	15.4	7.7		7.7	100
Implementation of 5th National Strategy	66.7	12.5	8.3	8.3	4.2	100

*Note: 'positive gay men' and 'gay men' were recorded in the one category

WOMEN

Table 6 RELEVANCE OF NATIONAL POLICY AND ADVOCACY AREAS TO THE NEEDS OF WOMEN*

NAPWA policy and advocacy areas	VERY (%)	2 (%)	3 (%)	4 (%)	NOT AT ALL (%)	DON'T KNOW	TOTAL
Health services	90.9					9.1	100
Discrimination in insurance	70.0		10.0			20.0	100
Long term and supported housing	72.7		9.1			18.2	100
Return to work services	63.6	18.2	9.1			9.1	100
Cost of living with HIV	81.8	9.1				9.1	100
Implementation of 5th National Strategy	63.6	27.3				9.1	100

*Note: positive women and heterosexual women recorded to one category

REGION

Table 7: RELEVANCE OF NATIONAL POLICY AND ADVOCACY AREAS TO NEEDS OF REGION

NAPWA policy and advocacy areas		VERY (%)	2 (%)	3 (%)	4 (%)	NOT AT ALL (%)	DON'T KNOW	TOTAL
Health services	CAPITAL	74.3	22.9				2.9	100
	OTHER	83.3	5.6		5.6	5.6		
	TOTAL	77.4	17.0		1.9	3.8		
Discrimination in insurance	CAPITAL	60.0	17.1	20.0		2.9		100
	OTHER	44.4	5.6	16.7	11.1	5.6	16.7	
	TOTAL	54.7	13.2	18.9	3.8	3.8	5.7	
Long term and supported housing	CAPITAL	68.6	17.1	8.6	2.9	2.9		100
	OTHER	61.1	11.1	16.7	5.6	5.6		
	TOTAL	66.0	15.1	11.3	3.8	3.8		
Return to work services	CAPITAL	57.1	20.0	14.3	2.9	5.7		100
	OTHER	50.0	11.1	22.2		11.1	5.6	
	TOTAL	54.7	17.0	17.0	1.9	7.5	1.9	
Cost of living with HIV	CAPITAL	77.8	16.7	2.8	2.8			100
	OTHER	72.2	22.2			5.6		
	TOTAL	75.9	18.5	1.9	1.9	1.9		
Implementation of 5th National Strategy	CAPITAL	72.2	16.7	8.3		2.8		100
	OTHER	61.1	5.6	11.1	5.6	5.6	11.1	
	TOTAL	68.5	13.0	9.3	1.9	3.7	3.7	

CONCLUSION

This process of checking the relevance of NAPWA's work has proved to be most useful. Through this survey, respondents have issued a clear message that the identified areas of systematic policy and advocacy work by NAPWA are important and of considerable relevance around the nation.

There is universal agreement that the top three policy and advocacy areas of most relevance are strengthening access to health services, the true cost of living with HIV and seeing a strategic national implementation of the 5th National Strategy.

The validation of NAPWA's policy and advocacy work speaks to the importance of these issues being addressed in a broad and systemic manner through the national and state partnerships.

RECOMMENDATIONS

1. NAPWA utilises future biennial conference opportunities to promote and canvass significant policy and advocacy issues.

SECTION 4: PEER EXPERIENCES

From the comments received a range of themes emerge around a series of 'transitions; that people living with HIV or AIDS are taking or making. These transitions are experienced at an individual level, but collective dialogues and themes also surface which speak to the positioning of the 'place of HIV' in the lives of the respondents. In addition, the 'place of HIV' is experienced as being 'on the move' as people encounter and acknowledge a series of life and living challenges or circumstances related to the changing nature and outlook of HIV.

THE 'BURDEN' OF HIV

"Life is alright, however, there is the constant worry . . ."

Respondents talked about life experienced as a 'burden', 'it's hard', 'it's a struggle', 'there are many worries' and 'it's not easy'. This speaks to the range of complex psycho-medical-social challenges many positive people face in living with HIV or AIDS and in doing so, speaks of a complexity associated with HIV that affects people differently.

As one participant puts it:

"All people living with HIV and AIDS face considerable psycho-medico-social challenges. However, individuals have different challenge mixes and they change over time."

As a result of effective treatments and improved health outcomes for positive people, HIV is increasingly being positioned and spoken of as a chronic manageable illness for many people. Positive people acknowledge there is change and are grateful for their improved prospects but sitting alongside this new found hope for the present and future is genuine unease about a range of 'disease burdens' related to living with HIV and treatments.

"Life is alright. However, there is the constant worry of new ARVs (antiretrovirals) to fight chronic resistance. The long-term effects of HIV or ARVs on health is also a worry. Perhaps the worst part is the physical changes that HIV brings about to body shape. Not at all sure that care and support can address these, but there may be implications as we get older."

This respondent speaks of being worried about developing resistance to currently available treatments and gaining access to newer improved treatments in time to keep the virus controlled and stabilised. As well, he talks of the worrying longer-term treatment side effects of lipodystrophy and other metabolic complications. Almost in a melancholic way, he muses that he's not sure what difference care and support can or will make to living with the physical changes he experiences to his body shape and that he is worried about the implications of ongoing treatment and ageing.

Treatments related side effects are mentioned by another respondent:

"For most, it is one big struggle due to stigma and drug side effects."

While not specifically naming the source of stigma as treatments, it is known from existing researchⁱⁱⁱ that lipodystrophy experiences can and do accompany feelings of poor self esteem and people speak of feeling unattractive, visible or obvious. So whether or not stigma is related to having HIV or a manifestation of treating HIV, it is a real and worrying experience for many positive people.

Naming stigma in this context highlights the need for appropriate care and support strategies to sit alongside treatment management strategies in providing emotional support and assisting plwhas to develop personal coping strategies into the uncertain future. The characterisation of HIV as a chronic manageable illness and assisting plwhas to make this transition is a continuous challenge given the complex nature of HIV disease manifestation and the diversity of experience.

It is important to remember that positive people, who have experienced HIV through the lens of a palliative framework, may not have the same understanding of their illness state as those who have not shared that experience. It may be that even in the context of a treatments-controlled virus, HIV is not embraced or understood as a chronic illness for them today, precisely because they come from somewhere else, have different personal experiences and an epidemic history which has formed their lived experience and is part of today's HIV realities.

This has implications for the way that our health system engages with people with HIV across the spectrum of disease experience. A good health system will acknowledge personal difference and work with a range of needs and experiences, implementing approaches and providing supports to assist people move towards optimal health and well-being. This involves being prepared to embrace the range of experience that HIV illness now spans and in appreciating that illness has many levels, manifests differently and resolves differently in individuals. A good health system will respect these differences and deal with and treat the individual, respecting their strengths and vulnerabilities, and work to heal.

Recent research from Futures IV^{iv} provides evidence and insight into the additional burden of illness that plwhas carry as they age and live longer with HIV and treatments. This additional illness burden is expressed by one respondent as follows:

"My experience with dentists, oral surgeons and specialists including dermatologists and head and neck surgeons has all been positive. I should add that these health professionals are all located in the inner city."

What is interesting about this response is the matter-of-fact way the respondent describes the range of services required to address a variety of health issues. It is uncertain to what extent HIV has been of direct impact, but the point is that complexity and added illness exist. It should be noted that the respondent's experience of these services has been a positive one. Although almost as a throw away line, the respondent notes the inner city location of services and leaves it as an almost clinical and removed description of experience without further comment on the personal impact of this illness burden. It's as if the respondent has developed an approach to illness that avoids problematising the physical, but rather sees the physical problem as something else to be addressed. It would be interesting to explore this disconnect between the physical and emotional states further.

The disconnect between the physical and emotional or between the way that HIV is experienced as opposed to the way that personal experience is recorded and described to others is an overarching theme throughout the survey results.

"Mental health is a major issue for plwhas."

"Fortunately my physical health overall is good. I have encountered dental health problems in the last two years and significant mental health issues as well."

From a variety of research^v over a number of years it is known that HIV and mental or cognitive health is an issue. For example, this has been well documented in HIV Futures surveys and the pH survey,^{vi} which clearly indicate that plwhas experience significantly higher rates of depression and anxiety than the general population and are prescribed anti-depressants and anti-anxiotics at a high rate.

It is interesting to note that only a few respondents mentioned the significance of mental health as an issue for positive people generally or depression or mental health issues as a personal issue directly affecting their emotional health. A question arises over whether there is an internalising of emotional responses to living with HIV and why this would be the case. Questions arise over why positive people would do this and if some positive people are embarrassed to talk about their emotional response to HIV.

One person noted positively that:

"I am lucky to have supported accommodation. Without it I don't know what I would have done."

Other people noted that life is hard regardless of whether they work or not:

"My life is hard even though I have a job."

"Whether we are working or not, HIV has placed a burden on our lives . . ."

Another in talking about life in a regional centre said:

"Being positive in regional Australia, at times is not easy, there is discrimination etc. in and out of the queer scene."

While many positive people have and many others continue to make a successful transition to positioning HIV as a controllable illness in their life, there are still vulnerabilities introduced by the complexity of HIV and the burden of illness that will require acknowledgement that HIV can, and does, occupy a prominent place in the lives of many plwhas.

"I don't have many positive friends but certainly the ones that I do have, have needed to spend time in hospital this year."

In talking of the future, one respondent captured the uncertainty of living with HIV:

"Although my own care and support needs are not high, I do worry about the future and what my care and support needs might look like in 10 or 20 years."

"Budgeting for my health, living alone, eating properly and educating myself has made my life hard."

THE 'COST BURDEN' OF HIV

"Life is poor – financially it's a struggle to keep things afloat."

This peer dialogue was about costs: the costs of additional support and living costs that are part of people's lives because of HIV or AIDS. The word 'costs', 'costs of living' and 'expenses' kept coming up. 'Affordability', 'costs', the 'extra burden', 'financial hassle' and 'just scraping through' were among the comments raised and these have been grouped into discrete sections below. What is clear is that the cost of living associated with HIV is an issue that is felt by a substantial number of positive people across a wide range of social determinants associated with health and well-being outcomes.

'Scraping by'

"Life is poor – financially it's a struggle to keep everything afloat."

"Budgeting for my health, living alone, eating properly and educating myself has made my life hard."

"I am trying to raise my capacity to cope with the cost of living with HIV by education and work but sometimes I wish I had stayed on the pension in the bush!"

"Income support – most are just scraping by particularly as single parents or single people with little family support."

"The extra burden that living with HIV puts onto our existence must be noted and addressed."

"I would support some sort of national benchmarks so we can work out if we are achieving 'quality of life.' Perhaps 'No plwha should live below the Henderson poverty line' might be a starting point!"

"I personally do not have significant unmet care and support needs. However many people I know do have. They relate to a very decreased financial and material level of comfort compared to what the situation would be if they were not positive. Part of this is to do with having sustained well-paid employment. Part of it is to do with the cost of HIV if you are in the workforce."

Impact of HIV medications and food

"But the financial hassle has impacted on my health, both mental and physical."

"Cost of living with HIV is a major issue for me. I have to work to pay for my health care regime e.g. gym, vitamins, naturopath, but in doing so have no energy to live life. Do I work less, not affording treatments and get sick?"

"Friends live in constant poverty and in the endless round of hospital and doctors queues."

"I just think it would be good if all medication was paid for as it might only be almost \$5 with a concession, but it can add up when you have about four others as well."

"My needs are mainly in the cost of pharmaceuticals. I would appreciate a chronic illness card to offset the price of my monthly chemist bill for antiretrovirals and PBS items (increasing every month due to side-effects). I am not entitled to a Healthcare Card but have a low income. My friends on a Healthcare Card have trouble existing and need pantry services, food vouchers, help with costs from David Williams Fund, etc., to survive each week. Cost of HIV is a major problem for them."

"Positive people constantly share their struggles managing on the DSP (Disability Support Pension) or low incomes. Access to food store (HIVE) has seen an increasing need; stock is limited but demand and need continue to grow."

Costs of transport and housing and holistic health services

"Moving into a new house as I have just done is very expensive with phone, power, food, etc . . . then there is medication on top. It would help if there were some sort of help with new house moves to help to get on your feet. Although my HIV/AIDS organisation has helped heaps, it's just not enough."

"I personally do not have significant unmet care and support needs. However many people I know do have. They relate to a very decreased financial and material level of comfort compared to what the situation would be if they were not positive. Part of this is to do with having sustained well-paid employment. Part of it is to do with the cost of HIV if you are in the workforce."

What is clear is that many survey respondents clearly experience financial difficulty in meeting the costs of living with HIV and are worried about their financial survival and future options.

Over time, the financial and social capacity of some positive people may be affected and there may be additional financial challenges directly related to their illness and disease including the cost of medications and supportive health care options and difficulty in meeting the costs for essential items such as food, transport, accommodation and utilities.

The results show that income support and other benefits from Government are necessary and important, that paid work does not resolve the financial burden for those in low income generating employment, and that community sources supplement and assist in relieving financial burden.

Attention needs to be given to assessing the cost of living with HIV, both in and out of the workforce. This should include assessments of the impact of costs for those who are not working and in receipt of income support and those on low incomes and with family commitments.

CERTAIN VULNERABILITIES

"Without these needs being met – be it just one of them – my chain is broken and I am unable to function as independently as I do now."

The survey included open-ended questions and respondents were encouraged to talk about their experiences of living with HIV. Many talked about their 'lack of connection', 'withdrawal and isolation', 'being loners', 'lack of confidence in future support systems', 'seeing no evidence of state based planning' and 'fearing a loss of peer support'.

"I have no confidence that there will be the necessary support systems in place as the government will have progressively dismantled them."

"Discrimination is very much out there. Depression is overwhelming at times, withdrawal and isolation takes over I wish there was more access and support financially for alternative medicines."

"Efforts seem concentrated on education and not towards support of positive people when they are in need of some real hands-on support at times of not being in good health."

"All services need constant monitoring and (there are) some threats, particularly income support is of particular concern."

"Cost of living with HIV is a priority but, people are worried about future needs in care and support and we need to see planning happening on state basis."

"Social isolation is a big issue for positive persons (with a) large percentage living outside of metro areas."

"I wonder if gay men sometimes get lost in competing disadvantage claims by various groups i.e. the assumption is that all the HIV services meet the needs of positive gay men. I think that is an assumption open to question."

"Often enough there is no contact from ATSI (Aboriginal and Torres Strait Islander) workers until you're extremely ill in hospital or dying."

What is clear is that there is concern and worry over a range of issues that have the potential to impact negatively on personal health and well-being.

It is worth noting in this context of vulnerabilities and the need for supportive environments that the improved health outcomes seen for many HIV positive people in recent years also brings challenges to the communities in which they live, work and play. This is particularly important now that many plwhas are moving back to work and making the transition back to community living in line with their own health improvements.

It is worth considering what this means for current health services and their future planning as plwhas hopefully continue to require less traditional institutional care and potentially more community care arrangements, such as the Home and Community Care (HACC) programs existing in some states or brokered supported housing arrangements. It is also worth considering just how this transition from institutionalised care to community living can be made as seamless as possible for all concerned. Further discussion with HIV positive people on what assistance may be required to facilitate the transitions to full and rewarding community lives is required.

ESSENTIAL SERVICES

"We have all fought for what and where we are and maintaining these things is the concern – as we know Government can change our position – just like that."

The respondents validated the absolute essential nature of HIV health and HIV living services especially hospital, GP and sexual health services for positive people.

Respondents were very clear that the services listed were considered essential to them in maintaining health and well-being and that maintaining these services should be a high priority for health advocacy nationally. Many cited 'service shortage' issues with particular services and highlighted difficulties in accessing services in smaller capital cities and regional areas. Mental health and counselling services were mentioned as high priorities needing attention as was the need for oral health services and specific supported accommodation services for positive people.

Overall, this section highlights the vulnerability of positive people living regionally and in smaller capital cities to appropriate HIV services including GP and hospital care. It validates the need to ensure that any mainstreaming of HIV services occurs with the input of the HIV community and that appropriate mechanisms for input and consultation are in place to avoid poor health and quality of life outcomes.

IMPORTANCE OF MAINTAINING SERVICES

"Everyone I know has the same concerns as me. We have all fought for what and where we are and maintaining these things is the concern – as we know Government can change our position – just like that."

"All these services are essential to keep and have available when required."

"These identified services, issues and strategies are important to our lives and the quality of our living standards."

"For all it is health services (accessibility and survival) and cost of living."

NEED FOR MORE GP, HOSPITAL AND SEXUAL HEALTH CENTRE SERVICES INCLUDING MORE HOSPITAL SPECIALISTS

"The major concerns I have for the Darwin area is there is only one sexual health clinic that positive people are able to access for HIV care. And, the specialist is only employed on a part-time basis. This is while at the same time having no other GPs in the area that have any HIV experience and case loads."

"Many comment on the difficulty finding appropriate GPs, experienced HIV GPs and Section 100 prescribers."

DIFFICULTIES WITH HOSPITALS

"In the Bulli community there is limited care available. In Wollongong there are limited services but I found GPs to access through ACON. It's easier to go to St Vincent's for bloods etc."

"Having the one area to deal with, Canberra, if things go wrong, turning to other services can be a bit tricky. There's not a lot of choice as there are only two centres to go for a Section 100 prescribing doctor."

UNAVAILABILITY OF ORAL HEALTH, MENTAL HEALTH AND DRUG AND ALCOHOL SERVICES

"I do believe there needs to be more dental care available and counselling services need to be maintained."

"Dental care is very hard to get because of waiting lists."

"From my volunteer work I believe priority must be given to mental health, drug and alcohol services for positive people."

"Mental health is a major issue for plwhas – independently addressed in most states. Supported accommodation, dementia care, physical impairment and the need for appropriate 'in-house' supports need to be addressed much better in most states; NSW only state doing much in this area. Health promotion needs of plwhas living longer needs to be addressed by state PLWHA groups – with Government funding."

DIFFICULTIES AND DIFFERENCES FOR REGIONAL AREAS

"Most of the above (service needs) are important, even if I don't access or use them. It is worth noting that in the Northern Territory a number of these services – community services, HIV housing, peer support – are just not available."

"Living in an area with a much smaller population and lower numbers of positive people has a major impact on the level of services available. For example: there really are no care and support services in the (Northern) Territory. There is a lack of supported accommodation services and no return to work services for HIV positive people."

"Shortage of hours (that) hospital services (are) available, i.e., prescriptions pick up only Mon-Fri, 9am-5pm with one hour closed at lunchtime. How does an employed person have time to collect then? Shortage of openly positive people, no nutritional advice, no health management advice, discrimination in some of the regions' medical units (private practices). Only three S100 prescribing doctors in all of Cairns, Cooktown, Tablelands, Mission Beach region with over 150 positive clients."

"It has not been easy acquiring services in the general community services sector."

"Staff in hospitals are not discreet and openly make you feel bad by their behaviour. The sector itself is mainly geared for gay guys and positive heterosexuals are not very well represented."

WOMEN

"Care and Support needs for positive women are about their children's care, welfare and future. Secure housing is vital. Access to family support and counselling is valued and programs that support children and young adults (camps, outings, holiday events). Unfortunately Centrelink and Housing Trust rules have become very rigid – individuals find dealing with these mainstream services disempowering, hard and there is pressure to disclose just to receive a basic service. Hence upskilling peer support workers within PLWHA organisations and AIDS councils is important."

WORK

"My main concern is returning to work and getting little reward for part-time work."

No respondent talked about working full-time. Part-time work or not working at all was a big feature and 'volunteer' work kept appearing. Housing was part of this dialogue, with uncertainties around housing services, including supported housing, mentioned.

"My main concern is returning to work and getting little reward for part-time work."

"Few of my positive friends are in a position where they can contemplate returning to work."

"Working part-time is no reward. Only punishment."

"In South Australia, a better coordinated approach to return to work is needed. By this I mean that state PLWHA organisations need to be better resourced to pick up. As Centrelink criteria tightens, PLWHA organisations need to be strong advocates for the concerns and voice of positive people."

"I am disabled [and] unable to work but volunteer my time."

With the welfare reform agenda of the current federal government firmly in place, it will be important to put emphasis on the individual capacity for work which takes into account personal circumstances, the episodic nature of HIV illness and the resultant need for flexibility in workforce participation requirements and eligibility arrangements for realistic welfare support and ongoing supports in the workplace. For people who have been out of the workforce for some time or who have lost either some functionality through illness or the confidence to participate fully in suitable paid or volunteer work, will most likely require training and re-skilling.

PEER SUPPORT

"I was a loner and stuck to myself when I was first diagnosed as HIV positive in 1991."

The importance of peer support was repeatedly mentioned along with the importance of connection to other HIV positive people.

"I am concerned about the trend of services to mainstream us and downplay the role of peer support."

"For a heterosexual male living in Tasmania it is very difficult with no peer-support available."

"I was a loner and stuck to myself when I was first diagnosed as HIV positive in 1991. But over the last four to five years I have joined and helped start up positive groups for gay positive men and found the friendship and support very fulfilling and I am more outgoing now because of it."

"Ultimately, positive women's support groups are my main inspiration in coping."

"I need more peer support, email exchange, get-togethers and social activities."

"We need our social needs attended to – a drop-in place for plwha or peer support groups to deal with isolation. Somewhere where we can come together as a family and look at ways to maintain health and wellness."

"Don't have any friends who are positive."

"Myrtle Place and BGF (Bobby Goldsmith Foundation) are very important to my needs."

"I have very little contact with agencies and am only beginning to link in with other positive women."

"I don't feel very connected to other plwhas, am concerned that too high a percentage of plwhas have negative concurrent issues going on in their lives, apart from being HIV positive. Turns me 'off' many HIV positive persons so don't feel as though I get a lot of support from other plwhas."

One of the challenges for positive people in maintaining a healthy sexual life, in taking responsibility for their own health and in supporting the health of others, is to have safe and confidential opportunities to communicate freely with other positive people and gain the communication skills for disclosure of HIV status. Ideally, disclosure of HIV status should be a mutually beneficial and safe arrangement for all concerned and not lead to further discrimination, ostracising or demonising of the HIV positive person.

Traditionally in the HIV sector, HIV peer support (and counselling) arrangements have been a very important way for positive people to address concerns or fears about a range of issues which can present in living with HIV or AIDS including peer education about safe disclosure.

In addition to the public health and safety concern, many positive people often deal with quite profound manifestations of isolation relating to their diagnosis and illness. Many seek access to other HIV positive people in order to hear about how life is for them, to share personal successes and to gain support through difficult times. Given that there are increasing numbers of HIV positive people, peer support and peer education services have the potential to provide and meet important additional health promotion challenges in facilitating transition from illness to social well-being and health maintenance in the context of community living.

BUILDING RESILIENCE

"Although disabled I have a fairly good quality of life and now am moving on with my life and making good friends."

In this section, respondents spoke of 'moving on', of being in 'good health', 'living fairly well', 'treatments working' and 'decreased dependence'. For some, these comments acknowledge a journey and a return – or the beginnings of one, from a place where personal health was affected by living with HIV.

The respondents talk about having moved or moving to 'this place', that treatments do work, that life can be normalised and that this is possible even if you are living life with a disability or a controllable illness.

"Although disabled I have a fairly good quality of life and now am moving on with my life and making good friends."

"I have been living fairly well of late in good health and not currently on treatment."

"Happy that my treatments are working and my life is relatively uncomplicated."

"Being HIV positive is just one part of my make-up, and that's a really good thing. An interest in politics/history/archeology probably takes up more of my thought time than being HIV positive – a lot more!"

"My treatments health is quite good. I have decreased dependence on medical systems and services. I am fortunate to have secure housing and income."

"Fortunate to have a superannuation pension. Health is relatively well so not an acute need for services."

"Life's great for me :-)"

"Life is fairly good for me in general except I don't like having to move to new doctors when my doctor moves on to other areas."

"I personally do not have significant unmet care and support needs."

"Things are much better now health wise. My current support needs services are satisfactory."

HIV AWARENESS

"While the general community are getting better educated – still lots of work to be done."

In this section, respondents spoke of areas where they have identified issues or problems and the need for more HIV education work to be done in health and medical services areas.

"More education for medical persons e.g. doctors/nurses, etc., around who are asking: "how did you get it?" when it has no medical relevance at that time."

"More education needed in some medical areas."

"We need more education of health services on HIV."

"While the general community are getting better educated – there is still lots of work to be done."

"Staff in hospitals are not discreet and openly make you feel bad by their behaviour. The sector itself is mainly geared for gay guys and heterosexuals are not very well represented."

"Need more in the way of making holistic healthcare more affordable and access to practitioners who are HIV aware."

"Rural Victoria needs more GPs upskilled around HIV."

This section highlights the ongoing need for workforce development to maintain skilled health and medical services that sensitive to the medical, health, legal and social issues related to HIV to ensure that positive people can have equitable access to non-discriminatory quality services.

CONCLUSION

This section on peer experience tells an important story about the lives of this group of 64 positive people today. Whilst the sample size is small, it provides important insights through the lens of positive experience.

The report and its findings are of importance to all who work in the HIV and mainstream health sectors with policy, advocacy and service responsibilities for the health and well-being outcomes of HIV positive people. This includes the Commonwealth, through the Department of Health and Ageing (DoHA), AFAO and the state and territory AIDS councils, and NAPWA and our membership of PLWHA organisations.

The report focus is care and support. In exploring these areas, the report has examined both the areas of HIV Health and HIV Living in some detail and 'drilled down' to expose levels of personal experience and impact.

In the section on peer experiences, there are some contradictory remarks made by respondents. These highlight the range of experience and the ways that health and well-being outcomes are being felt and experienced today. Importantly, one of the reports strengths is in questioning this range and difference of experience and in proposing recommendations to understand these contradictions further through ongoing discussion, case studies and further research.

RECOMMENDATIONS

1. NAPWA recommends that funding be made available to support the formation of a small HIV positive cohort to enable further qualitative research aimed at extending the knowledge about living with HIV/AIDS in Australia.
2. NAPWA recommends that urgent action is needed to improve referral pathways and access to mainstream health services, particularly mental health, housing and for education aimed at reducing stigma and discrimination in health care settings.
3. NAPWA recommends that work be undertaken to arrive at a true cost of living with HIV which reflects the additional cost burden associated with living with HIV /AIDS.

CONCLUDING COMMENTS

The CSSS and the survey represents an important new direction for NAPWA in providing a narrative on how policy and advocacy work is represented through its national structures. The report underscores the importance of continuing with the 'centrality of positive people' as one of the fundamental principles of the Australian approach to developing and responding to the national HIV effort at all levels. It is clear from this report that if and when asked, positive people have understandings and knowledge about living with HIV or AIDS that they are prepared to share, which complements available research by Australia's national HIV centres. These positive perspectives add 'colour' to research data and support qualitative findings, whilst providing insights into current and future care and support service needs and their impact.

BUILDING RESILIENCE

The survey reveals it is important to recognise the high level of HIV/AIDS sector engagement and workforce contribution by this HIV positive population in a largely voluntary capacity over a lengthy and extended period. In addition, it is reasonable to suggest that participants have responded to various demands and challenges over time in the management of their personal health and well-being in living with HIV or AIDS.

It is also reasonable to suggest that individual health and well-being responses involve variable processes and occur at different rates of adjustment for individuals. It is this HIV adjustment process that speaks to the building of resilience, and further work could investigate ways to strengthen personal resilience. In the context of this report it could be useful to further explore the place of volunteer participation in the development of personal resilience.

SOCIAL PARTICIPATION

Arguably, the NAPWA conference is an important national exercise in peer support and in providing a major contribution to social participation opportunities for positive people. This valuing of peer social participation as an opportunity was further described in the NAPWA conference evaluation report and in the peer dialogues.

Further work could be undertaken to ascertain the place of peer social participation opportunities as a mechanism to foster social well-being and as a health promotion tool.

NAPWA NETWORKS

The survey was conducted among a unique and particular sample of people, with a significant number connected into the networks, processes and work of NAPWA and its members.

It would be useful to have a more detailed understanding of the NAPWA network activity and dynamics that operate, and through this process seek to implement approaches to network governance and management which both increases individual participation and improves channels of communication, advocacy and policy response. The aim is to foster both organisational and personal acuity and to focus on network enhancements which continue to provide good health outcomes for volunteer participants.

UNDERSTANDING OF NEEDS IN CONTEXT: PEER EXPERIENCES

The results from this analysis should be seen as a starting point for discussion and may be indicative of issues or provocative points warranting further exploration or understanding through a variety of means including research, case studies or HIV sector discussion.

One of the aims of this survey has been to 'drill into' a range of care and support service issues by exploring and tapping into the expressed needs and experiences of positive people in relation to particular service needs. These issues included HIV health (services provided by GPs, hospitals, etc.) and HIV living (housing, personal needs, employment, etc). In speaking about these areas, several themes emerged and are referred to as a number of 'peer dialogues'. These peer dialogues which are about the daily realities of living with HIV captured a range of experiences. Further work exploring these peer dialogues is required and could assist in further understanding needs in context.

Australia's National HIV/AIDS Strategy states that "*the success of the National Strategy is dependent on sustaining a supportive social, legal and policy environment . . .*" and further that: "*This strategy gives priority to the development of approaches to reduce stigma and discrimination experienced by plwhas in Australia, aimed particularly at improving their access to clinical care and health services . . . Policies and laws of governments at all levels should be reviewed to ensure that all areas support improved health outcomes and that they combat and resolve, rather than compound, stigma, discrimination and social exclusion.*"

It is important to plan for further changes to community living arrangements given that one of the unwanted barriers to full participation and integration by HIV positive people into community living is HIV related stigma and the resultant discrimination. Today's task is one which must combine the challenges of living with HIV together with living in the community.

Some of the challenges raised by the respondents may require service and social policy solutions to better align physical improvement and improved social opportunity and outcome as these challenges interact dynamically with social policy responses.

REPORT RECOMMENDATIONS

Recommendations at the end of each section address some of the ways that NAPWA feels are useful for many positive people who are clearly in states of transition in their health, well-being, life engagement and development.

SECTION 1: WHO ARE WE?

1. NAPWA believes that more needs to be done to create opportunities for the participation of HIV positive sub-populations, including CALD and Indigenous, in areas of social policy and organisational response.
2. NAPWA recommends that the biennial conference be resourced by the Commonwealth through the Department of Health and Ageing at an adequate level to support an enhanced scholarship program for positive people to participate, with specific targets set for subpopulations and those who are financially disadvantaged or on low incomes.
3. NAPWA recommends that further research, case studies and HIV discussion occur with members of the HIV positive volunteer workforce with the aim of understanding how best to support their individual health and well-being as volunteers through identifying organisational processes and other structural or programmatic enhancements to assist.
4. NAPWA recommends that research be conducted to further understand the dynamics and relationships of HIV positive networks to HIV organisational life and national responses with the aim of identifying any structural enhancements to the HIV positive networks which may assist the capacity and processes for participation in HIV social policy responses through NAPWA.

SECTION 2: CARE AND SUPPORT SERVICES

1. NAPWA recommends that MACASSH through the Commonwealth Department of Health and Ageing (DoHA) investigate the appropriateness and completeness of current HIV models of care to the current and future service needs of HIV positive people.
2. Further, NAPWA recommends that this investigation involve research and analysis on service utilisation and quality of life issues for positive people involving case studies and targeted HIV sector discussion to inform any change to service direction and address any important gaps or difficulties within the current HIV models of care.
3. NAPWA recommends that the small body of current research into HIV and identity be expanded to include understandings of the relationships between HIV positive identity, participation in the national or state HIV responses, and the effects of HIV related stigma on HIV positive participation.

SECTION 3: POLICY AND ADVOCACY

1. NAPWA utilises future biennial conference opportunities to promote and canvass significant policy and advocacy issues.

SECTION 4: PEER EXPERIENCES

1. NAPWA recommends that funding be made available to support the formation of a small HIV positive cohort to enable further qualitative research aimed at extending the knowledge about living with HIV/AIDS in Australia.
2. NAPWA recommends that urgent action is needed to improve referral pathways and access to mainstream health services, particularly mental health, housing and education aimed at reducing stigma and discrimination in health care settings.
3. NAPWA recommends that work be undertaken to arrive at a true cost of living with HIV which reflects the additional cost burden associated with living with HIV /AIDS.

ACRONYMS USED IN THIS REPORT

ACON	AIDS Council of NSW
AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
ARCSHS	Australian Research Centre in Sex, Health and Society
ARV	Antiretroviral (therapy)
ATSI	Aboriginal and Torres Strait Islander
BGF	Bobby Goldsmith Foundation
CALD	Culturally and Linguistically Diverse (background)
CRG	NAPWA National Care and Support Audit Critical Reference Group
CSSS	Care and Support Snapshot Survey
DSP	Disability Support Pension
GP	General Practitioner
HACC	Home and Community Care
HIV	Human Immunodeficiency Virus
IPN+	Indigenous Positive Network
IPON	Indigenous Project Officers Network
NAPWA	National Association of People Living With HIV/AIDS
PEP	Post Exposure Prophylaxis
PLWHA	People living with HIV/AIDS

APPENDIX

SURVEY INSTRUMENT

CSSS feedback survey available from
NAPWA
PO Box 917
Newtown NSW 2042 Australia
Tel: 02 8568 0300

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GROUP AND ORGANISATIONAL CONNECTIONS: CROSS-TABULATIONS FOR STATE RESULTS

Table 8: RESPONDENTS CONNECTIONS WITH NAPWA

STATE/TERRITORY	VERY %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
ACT	16.7	50.0	16.7	16.7		100
NSW	30.8	38.5	7.7	15.4	7.7	100
NT		100.0				100
QLD	20.0	20.0	40.0	20.0		100
SA	60.0	10.0	10.0		20.0	100
TAS		33.3	33.3		33.3	100
VIC	41.7	25.0	16.7	16.7		100
WA	16.7	16.7	16.7	33.3	16.7	100
TOTAL	32.1	28.6	16.1	14.3	8.9	100

Table 9: RESPONDENTS CONNECTIONS WITH AFAO

STATE/TERRITORY	VERY %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
ACT	20.0		60.0		20.0	100
NSW	7.7	7.7	38.5	7.7	38.5	100
NT				100.0		100
QLD		25.0		50.0	25.0	100
SA		11.1	22.2	33.3	33.3	100
TAS				33.3	66.7	100
VIC			36.4	54.5	9.1	100
WA	25.0				75.0	100
TOTAL	6.0	6.0	28.0	28.0	32.0	100

Table 10: RESPONDENTS CONNECTIONS WITH PLWHA ORGANISATIONS

STATE/TERRITORY	VERY %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
ACT	50.0	16.7		33.3		100
NSW	23.1	30.8	46.2			100
NT		100.0				100
QLD	20.0	40.0		40.0		100
SA	72.7	18.2		9.1		100
TAS		33.3			66.7	100
VIC	58.3	33.3	8.3			100
WA	50.0		16.7		33.3	100
TOTAL	43.9	26.3	14.0	8.8	7.0	100

Table 11: RESPONDENTS CONNECTIONS WITH AIDS COUNCILS

STATE/TERRITORY	VERY %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
ACT	66.7		16.7	16.7		100
NSW	15.4	23.1	23.1	30.8	7.7	100
NT			100.0			100
QLD	40.0	20.0	20.0	20.0		100
SA	45.5	27.3	9.1	9.1	9.1	100
TAS		66.7			33.3	100
VIC	25.0		58.3	16.7		100
WA	33.3	33.3		33.3		100
TOTAL	31.6	19.3	24.6	19.3	5.3	100

GROUP AND ORGANISATIONAL CONNECTIONS: CROSS-TABULATIONS FOR REGIONAL RESULTS

Table 12: RESPONDENTS CONNECTIONS WITH NAPWA BY REGION

REGION	VERY WELL %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
CAPITAL	41.7	25.0	13.9	5.6	13.9	100
OTHER	15.8	31.6	21.1	31.6		100
TOTAL	32.7	27.3	16.4	14.5	9.1	100

Table 13: RESPONDENTS CONNECTIONS WITH AFAO BY REGION

REGION	VERY WELL %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
CAPITAL	9.4	6.3	31.3	25.0	28.1	100
OTHER		6.7	26.7	26.7	40.0	100
TOTAL	6.4	6.4	29.8	25.5	31.9	100

Table 14: RESPONDENTS CONNECTIONS WITH PLWHA ORGANISATIONS BY REGION

REGION	VERY WELL %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
CAPITAL						
OTHER	31.6	26.3	10.5	26.3	5.3	100
TOTAL	44.6	25.0	14.3	12.5	3.6	100

Table 15: RESPONDENTS CONNECTIONS WITH AIDS COUNCILS BY REGION

REGION	VERY WELL %	WELL %	SOMEWHAT %	A LITTLE %	NOT AT ALL %	TOTAL %
CAPITAL	32.4	13.5	27.0	16.2	10.8	100
OTHER	31.6	15.8	31.6	15.8	5.3	100
TOTAL	32.1	14.3	28.6	16.1	8.9	100

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