
Making it real: Activating our Care and Support Response

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The care and support needs of positive people are changing and remain poorly understood. A landmark NAPWA project aims to improve our knowledge in this important area, writes PETER CANAVAN.

The Fifth National HIV/AIDS and [STI](#) [1][Sexually Transmissible (or Transmitted) Infection] Infections spread by the transfer of organisms from person to person during sexual contact. Also called venereal disease (VD) (an older public health term) or sexually transmitted diseases (STDs). Strategy, launched July 2005, identifies three priority areas in responding to the changing care and support needs of people living with HIV/AIDS:

- Ensure that positive people can access appropriate treatments, care and support, including appropriate income support, disability support and carer allowances;
- Improve collaboration between mental health, [clinical](#) [2]Pertaining to or founded on observation and treatment of participants, as distinguished from theoretical or basic science. and welfare services to address the care and support needs of positive people living with cognitive illness and drug and alcohol dependency issues;
- Develop long term support for HIV-positive people who are ageing or have chronic illness.

The increasing complexity of the lives of positive people will require a variety of responses from all partners to the Fifth National Strategy and NAPWA has begun to activate our responses to these changing needs.

Redefining care and support

NAPWA has launched a national audit of the changing care and support needs of people living with HIV/AIDS, examining both the current situation and future projections.

This national audit is not intended as a mapping exercise with the function of 'following the money trail' or of services delivered, but rather as a measurement of the care and support issues or needs, including gaps as identified by HIV-positive people.

The audit will acknowledge that within the spectrum of positive people's experience, needs are experienced differently by different groups. Some people need high levels of support while others require only limited or occasional support services. Care and support services need to be placed in the context of existing PLWHA networks, and need to be appropriate for people from different cultural and linguistic backgrounds, indigenous people, and women and families.

In addition, changes within the HIV sector, health and welfare service patterns and other external factors are affecting the needs of people in our communities.

NAPWA is examining the care and support needs of positive people under the headings of 'HIV Health' and 'HIV Living'.

'HIV Health' includes services provided by GPs, hospitals and clinics, including specialist and ambulatory services, counselling, dental care and health management and monitoring.

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

This comprehensive audit will collect data and document the experiences of positive people using current services, identify best practice and make recommendations to facilitate services adapting to changing needs within a continuum of care.

For NAPWA one of the important factors in developing a response from 2005 onwards is that national work includes the ability to project some of these future needs based on the experience of positive people today.

Any further consultation around the changing care and support needs is something that NAPWA is in a unique position to facilitate and encourage; NAPWA is positioned as the link between consumers and health and support care providers.

NAPWA anticipates this will be a long-term project and will inform and suggest some models for delivery of care and support services into the future.

This national audit promises to greatly assist in the formulation of a strategic review process of current models of care and support and based upon the findings identified could make recommendations on future service delivery models.

NAPWA is collaborating with the various national HIV research centres in a number of ways to collect information to assist with the audit.

The Australian Centre in Sex Health and Society ([ARCSHS](#) [3] Australian Research Centre in Sex, Health and Society, part of La Trobe University in Melbourne. For further information see <http://www.latrobe.edu.au/arcshs/> [4]

An analysis of the data from the Positive Health ([PH](#) [5][Potential of Hydrogen] A measure of acidity or alkalinity. pH levels are expressed on a scale from 0 (most acid) to 14 (most alkaline). A pH level of 7 is neutral.) study conducted by the National Centre in HIV Social Research ([NCHSR](#) [6] National Centre in HIV Social Research. Located at the University of NSW in Sydney, NCHSR conducts research which describes and analyses the social understandings, meanings and practices of peoples, institutions and communities in relation to HIV, Hepatitis C and other communicable diseases.) at the University of NSW is also being conducted.

Following discussions held at the [ASHM](#) [7] Australasian Society for HIV Medicine. The peak Australasian organisation representing the medical and health sector in HIV/AIDS and related areas. Conference in Hobart in August 2005, this review will examine some of the issues covered by the PH study including access to services and information, personal support networks, the health of people living with HIV/AIDS, access to treatment services and other strategies employed by positive people to improve their health.

Most positive people will be aware of the two major social research projects focusing on the lives of people living with HIV/AIDS – *PH* and *HIV Futures*. Work has started on identifying the crossover between these two important research efforts and working towards a comparative analysis between the two studies to build a comprehensive picture of the lives of positive people.

Discussions and preparations are underway include some additional care and support-focused questions in the 2006 PH survey with the aim of strengthening the current care and support related questions and data collected through PH.

Sharpening our lens on experience

NAPWA is currently conducting the Care and Support Snapshot Survey (CSSS). This survey will record a 'snapshot' of positive people's experience and need of care and support services and will begin a new process for the NAPWA membership in seeing our networks and representative systems as a dynamic and essential peer voice.

The survey will canvass people on their own needs in this area as well as those of their peer group and organisations. Analysis of this survey will feed into NAPWA's work on the audit of care and support services.

An intended outcome and development from this survey will be to begin the formation of a small HIV-positive research [cohort](#) [8] In epidemiology, a group of individuals with some characteristics in common. A cohort study is a special kind of clinical trial which looks at a treatment or treatment strategy in a cohort of people. to enable further qualitative research to extend our knowledge about living with HIV/ AIDS.

While [ethics](#) [9](In clinical trials) The process of determining that a proposed clinical trial conforms to a wide range of moral, scientific and ethical standards, to ensure that participants in the trial are not abused, mistreated or unfairly taken advantage of. Before a clinical trial can go ahead, it must be given approval via an independent ethics process. approval for this secondary stage needs to be given before proceeding, NAPWA envisions conducting face-to-face qualitative research interviews exploring particular care and support needs and experiences in context and exploring the barriers experienced by positive people in accessing appropriate and relevant services.

We hope this will provide opportunity for active participation of positive communities in research. Research which is conceived, designed, analysed, interpreted and managed by positive people.

We are aiming to include positive perspectives in our experiences – to build upon our partnerships and relations with researchers, community-based organisations and positive people and to contribute to a robust future of research into the lives of positive people.

This is an edited version of a presentation to the 2005 NAPWA Conference. For further information contact peter@napwa.org.au [10] or call 1800 259 666.

- [Centrelink reviews](#)
- [Disability Support Pension](#)
- [Social and emotional support](#)
- [social research](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/188>

[2] <http://www.napwa.org.au/glossary/term/475>

[3] <http://www.napwa.org.au/glossary/term/406>

[4] <http://www.latrobe.edu.au/arcshs/>

[5] <http://www.napwa.org.au/glossary/term/105>

[6] <http://www.napwa.org.au/glossary/term/407>

[7] <http://www.napwa.org.au/glossary/term/382>

[8] <http://www.napwa.org.au/glossary/term/477>

[9] <http://www.napwa.org.au/glossary/term/498>

[10] <mailto:peter@napwa.org.au>