

strategic directions

strategic DIRECTIONS
2009-2012

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STATEMENT OF RECOGNITION

NAPWA recognises and values the unique status of Aboriginal and Torres Strait Islander people as the original owners and custodians of the land and waters of Australia.

NAPWA believes it is important that the historical and cultural position of Aboriginal and Torres Strait Islander peoples is recognised and incorporated in the organisation's official protocols.

PRESIDENT'S FOREWORD

It is with pleasure that I introduce this Strategic Directions document 2009–2012 for NAPWA. This document builds on the successful previous strategic plan for the organisation (2004–2008) and evolved through consultation and review of that plan. The progress that the organisation has made to date in representing and advocating for the needs of people living with HIV in Australia has also been considered in setting these Strategic Directions.

As the HIV epidemic in Australia moves into a third decade, the complexities and challenges faced by people living with HIV increases. NAPWA faces the challenges of responding strategically to these changing needs and engaging purposefully with the national HIV response, to help achieve the best-possible quality of life for people living with HIV. NAPWA works in an inclusive and collaborative way to address the many issues faced by people living with HIV in all aspects of their lives – this Strategic Directions document reflects and embodies that approach for the organisation into the future.

This Strategic Directions document guides the activity of the organisation, Board and Secretariat in the forthcoming years, and articulates the collective vision that NAPWA Members have for the direction of the organisation. Over the life of this document the Board, Secretariat and networks will develop subordinate documents based on the priorities identified, which address operational matters – such as annual work plans for teams and individual employees, contractors and external consultants. This supplementary documentation will focus more closely on the specifics of the activities that NAPWA will undertake and will more accurately reflect funding contracts and resource allocation decisions made at Board level, which may vary year to year in accordance with arising needs.

These supporting documents, when produced along with the reports on progress, will be made available at the general meetings of the association every six months as outlined in the Monitoring, Evaluation and Review section of this document. This will ensure that there is a continuous commitment by the organisation to a strategic engagement with the HIV response in Australia by the peak organisation representing people living with HIV. The organisation is able to be held accountable to the strategic directions that have been set.

I would like to acknowledge the valuable contributions that NAPWA Members, individuals and other sector stakeholders have made throughout the extensive review and development process. I would especially like to thank my fellow Board members and the Staff of NAPWA for the time and effort they have contributed to the development of this document, and also for their commitment to this ongoing process of strategic development for the organisation.

Robert Mitchell
President
April 2009

INTRODUCTION TO THE NATIONAL ASSOCIATION OF PEOPLE LIVING WITH HIV/AIDS

NAPWA was founded in 1988 and is the national peak body representing PLHIV community-based groups in Australia. The organisation is governed by a Board of Directors. All Directors are people living with HIV and are elected annually through the NAPWA member organisations representing every State and Territory.

NAPWA is a community-based advocacy organisation operating within a human rights and social justice framework and provides advocacy, policy, education, health promotion and outreach at a national level. NAPWA's role continues to develop and respond to a complex and ever-changing context – with the organisation functioning across a range of health and education initiatives to promote the highest-quality standard of care and support for people living with HIV.

NAPWA activities include policy development and analysis, national communication and issues coordination, representation on issues affecting people living with HIV, and health and research-based program development. The NAPWA Secretariat (based in Sydney) is responsible for operational matters. The Secretariat comprises the Health, Treatments and Research Unit, the HIV Living Unit and the NAPWA *Treataware* Project.

NAPWA is part of an international network of people living with HIV, and a member organisation of the Asia-Pacific Network of People living with HIV/AIDS (APN+). NAPWA has a set of criteria for participation in HIV Regional Programs and Activities (www.napwa.org.au).

NAPWA is a non-political, non-profit, non-government organisation incorporated under the Australian Capital Territory Associations Incorporation Act 1991.

OUR VISION

NAPWA promotes the empowerment of people living with HIV to live to their full potential by facilitating and encouraging participation at all levels of the national HIV response.

OUR MISSION

To strengthen and maintain a responsive national leadership body that is credible, informed and guided by the interests of people living with HIV. This will be achieved by fostering active national and member organisation networks who prioritise effective communication, collaboration and consultation.

OUR VALUED PRINCIPLES

These principles are fundamental to the way NAPWA maintains an environment and culture within which the organisation delivers its activities and advocates on behalf of people living with HIV.

NAPWA as the national HIV peer-based community organisation demonstrates respect, compassion and integrity in all representations. NAPWA is an incorporated organisation committed to HIV-positive governance, leadership and accountability – NAPWA is administered under a constitution and set of rules determined by the member organisations.

NAPWA engages with the direct experiences of people living with HIV, and the expertise of a diverse membership base of people living with HIV.

NAPWA is committed to reducing HIV morbidity and mortality through minimising the individual and societal impacts experienced by people living with HIV.

NAPWA promotes and strengthens the national response to the HIV epidemic by ensuring the meaningful involvement, visibility and centrality of people living with HIV.

NAPWA endeavours to build consensus, partnerships and coalitions in all decisions while respecting that alternate positions may be held.

NAPWA participates and collaborates with all people affected by HIV – inclusive of a local, state and national focus.

NAPWA is committed to the principles of the Ottawa Charter and supports the GIPA principles (The Greater Involvement of People Living with HIV/AIDS).

In 2005, NAPWA Members endorsed a Declaration of Rights for People Living with HIV/AIDS (see Appendix 2). The Declaration is inclusive of all people living with HIV from all communities, and NAPWA enthusiastically supports and operates within the principles of the 2005 Declaration.

KEY RESULT AREAS

NAPWA Strategic Directions 2009–2012 comprises seven Key Result Areas which address the organisation's internal and external activities. Each Key Result Area is accompanied by a set of objectives that NAPWA seeks to achieve during the life of the document.

Internal, supplementary documents will expand on these broad strategic domains and describe in detail how each objective will be achieved and will provide a series of performance indicators against which activity and progress will be monitored.

- 1 Meaningful participation of people living with HIV in the national HIV response**
- 2 Collaborative partnerships**
- 3 Best-practice, peer-based health promotion**
- 4 Health policy, treatments and research**
- 5 Social determinants of health framework**
- 6 Social policy, social justice and human rights**
- 7 Member organisations and communications**

KEY RESULT AREA 1

Meaningful participation of people living with HIV in the national HIV response

NAPWA supports the centrality of people living with HIV in responding at all levels of the national HIV response. The credibility and success of the organisation's advocacy work depends on the active participation of a large and diverse membership and the organisation is committed to a continuing process of membership retention, capacity building and renewal that will ensure the relevance of the organisation's advocacy efforts.

OBJECTIVES

- 1.1 Demonstrate and encourage meaningful representation and advocacy that is unique and singular for people living with HIV.
- 1.2 Ensure there is engaged, informed and strategic leadership located within the peak body for people living with HIV.
- 1.3 Engage with and support the national membership and networks of people living with HIV and coordinate their active and effective participation within the national HIV response.
- 1.4 Ensure that NAPWA representatives are recognised as essential partners to the activities of other organisations involved in the national HIV response.
- 1.5 Ensure that there is equity of engagement and representation of the diverse groups and populations of people living with HIV, including: Aboriginal and Torres Strait Islanders, women, positive heterosexuals and people from culturally and linguistically diverse (CALD) backgrounds.

KEY RESULT AREA 2

Collaborative partnerships

NAPWA works collaboratively with stakeholders across the community to maximise the effectiveness of its advocacy and policy work. The organisation engages with government bodies to ensure the effective development and implementation of the successive National Strategies.

As the peak body representing people living with HIV, NAPWA is responsible for the coordination of HIV issues and collaborates with members and other professional organisations, government, pharmaceutical industry, civil society and the media to advocate for the rights of all people living with HIV.

OBJECTIVES

- 2.1 Identify, liaise and build formal strategic partnerships and working relationships which enhance the organisation's network activity.
- 2.2 Collaborate with a range of professional agencies across community, government, pharmaceutical and regulatory bodies, welfare and disability organisations, and research and education institutions to maximise the efficiency of the organisation's activities.
- 2.3 Maintain and consolidate partnership activities with appropriate agencies including: ACROSS, AFDO, AHRC, ASHM, CHF and other relevant professional institutions and community groups.
- 2.4 Monitor partnerships to ensure they are appropriate and effective for NAPWA and its membership in delivering favourable outcomes for all HIV-positive populations.
- 2.5 Develop key and strategic partnerships through the National HIV/AIDS Strategy and relevant Australian government departments and structures.

KEY RESULT AREA 3

Best-practice, peer-based health promotion

NAPWA's work in HIV-positive health promotion and education assists and supports the membership to promote the importance of a 'whole of life' approach to health and wellbeing. The involvement and engagement of NAPWA representatives within a wide range of national education and health promotion forums contributes to the informed development of HIV prevention efforts and adheres to best-practice, peer-based education and health promotion principles.

OBJECTIVES

- 3.1 Continue to engage in collaborations with the Australian Federation of AIDS Organisations (AFAO) through the National Education Program to develop and implement education and health promotion activities for people living with HIV.
- 3.2 Engage with other peak national organisations, such as Scarlet Alliance and the Australian Injecting and Illicit Drug Users League (AIVL) as partners in advancing best-practice, peer-based health promotion approaches.
- 3.3 Continue to develop and enhance innovative peer-based health promotion activities across the *Treataware* Project and the Health, Treatments and Research Unit of NAPWA.
- 3.4 Maintain and strengthen the skills and expertise of NAPWA and member organisations in best-practice and peer-based health promotion practices for people living with HIV.
- 3.5 Continue the production of the national broadsheet *Positive Living* as an important communication medium for people living with HIV.

KEY RESULT AREA 4

Health policy, treatments and research

The core work of NAPWA has consistently focused on the areas of health, treatments and research. The organisation has established partnerships with other HIV sector organisations, government bodies and committees, research institutions and the pharmaceutical industry. These relationships have been instrumental in streamlining access to the latest treatments for those who need them.

NAPWA continues to play an active role in health policy development through advocating for the health needs of people living with HIV. The advocacy encompasses a broad view of health and well-being and therefore includes areas such as mental health. The Health, Treatments and Research Unit's overarching focus remains one of advocacy – and is closely supported by HIV-positive representatives with a high level of expertise and treatments experience.

OBJECTIVES

- 4.1 Strengthen and maintain the skills and expertise base for effective representation in treatments advocacy and in research collaborations.
- 4.2 Maintain existing relationships and establish new partnerships with professional bodies, regulatory authorities and the pharmaceutical industry.
- 4.3 Maintain existing relationships and establish new partnerships Australia wide with professional and research institutions, including: the Australasian Society for HIV Medicine (ASHM), the National Centre in HIV Epidemiology and Clinical Research (NCHECR), the Australian Centre for HIV and Hepatitis Virology Research (ACH²), the National Centre in HIV Social Research (NCHSR) and the Australian Research Centre in Sex, Health and Society (ARCSHS).
- 4.4 Ensure the national leadership of NAPWA across health policy and research domains is more broadly recognised and resourced.
- 4.5 Participate in critical analysis of international HIV clinical research to promote and advance the development of domestic strategies for HIV programs and service delivery.
- 4.6 Ensure that NAPWA remains central to national discussions on health, treatments and research for people living with HIV and demonstrates leadership in the coordination of health, treatments and research issues.

KEY RESULT AREA 5

Social determinants of health framework

NAPWA recognises that health is a broad concept involving many social and medical factors. The HIV Living Unit provides informed representation, advice and advocacy on relevant social research and policy issues. NAPWA supports the involvement of a number of representatives who actively participate in a wide range of committees, working groups and reference groups that seek to address social issues and policy responses.

OBJECTIVES

- 5.1 Maximise and demonstrate opportunities to promote meaningful social participation of people living with HIV.
- 5.2 Support and enable representations from the diversity of HIV-positive lives and experiences.
- 5.3 Maintain existing relationships and establish new partnerships with social research institutions including: the National Centre in HIV Social Research (NCHSR) and the Australian Research Centre in Sex, Health and Society (ARCSHS).
- 5.4 Promote the development of evidence-based policy responses that address the social impacts of HIV diagnosis – utilising a social determinants of health framework.

KEY RESULT AREA 6

Social policy, social justice and human rights

NAPWA members have developed and endorsed a Declaration of Rights for People Living With HIV (see Appendix 2) and the organisation works within a human rights framework.

People living with HIV continue to experience stigma and discrimination in the community and the workplace. NAPWA plays a key role in responding to these particular social dynamics of the epidemic through the organisation's advocacy activity. Individual and network activity and representations across all levels of the organisation aim to promote and protect the rights of people living with HIV. Through advocacy NAPWA aims to achieve social change and promote the social inclusion of all people living with HIV.

OBJECTIVES

- 6.1 Articulate HIV-positive issues and priorities in national social policy discourse and policy development.
- 6.2 Maintain expert and valued policy capacity (particularly social and legal policy) to advocate effectively for improvement to the lives of all people living with HIV.
- 6.3 Develop and maintain strategic alliances and effective collaborations across the broader social policy sector.
- 6.4 Advocate for equity across the HIV-positive community and equity for people living with HIV within the broad community.

KEY RESULT AREA 7

Member organisations and communications

NAPWA is a member-based organisation. The legitimacy of the organisation is dependent upon effective engagement with member organisations and the diverse communities and populations that comprise member jurisdictions. In 2008 NAPWA members endorsed the NAPWA Communications Pathways Document (www.napwa.org.au). The document details the avenues and mechanisms that facilitate effective communication within the organisation, membership and affiliated networks across the HIV sector and broader community.

OBJECTIVES

- 7.1 Promote and ensure that mutual support is nurtured across member organisation strategies, goals, agendas and partnerships.
- 7.2 Facilitate effective and consultative communication pathways across and within the organisation, the membership and broader community networks.
- 7.3 Develop, foster and utilise broad and effective consultation with member organisations on key issues.
- 7.4 Enhance and facilitate membership engagement within the structures and networks of the organisation – at all levels.
- 7.5 Develop, facilitate and respond to regular membership review of organisational activity at Annual General Meetings of the Association.
- 7.6 Encourage a continuing process of engagement, revitalisation, renewal and retention of HIV-positive advocates.

MONITORING

The Executive Director will provide a quarterly report against Key Result Areas. This is to be considered at Board meetings and additional summary and narrative will be added.

EVALUATION

Each six-monthly evaluation will consider the Executive Director and Board monitoring reports. A worksheet will be used to track and record progress in relation to the Key Result Areas.

The worksheet will be read in conjunction with the Strategic Directions document to track any changes agreed by the Membership at the Special General Meetings or the Annual General Meetings. The regular completion and dissemination of this worksheet represents the evaluation by members.

REVIEW

The review process will begin at the end of 2011, feedback and comments will be sought from external stakeholders and the membership. Consultation and development will continue in 2012 with a new document to be released in 2013.

APPENDIX 1

LIST OF ACRONYMS

ACH2	Australian Centre for HIV and Hepatitis Virology Research
ACOSS	Australian Council of Social Services
AFAO	Australian Federation of AIDS Organisations
AFDO	Australian Federation of Disability Organisations
AHRC	Australian Human Rights Commission
AIVL	Australian Injecting and Illicit Drug Users League
APN+	Asia-Pacific Network of People living with HIV/AIDS
ARCSHS	Australian Research Centre in Sex, Health and Society
ASHM	Australasian Society for HIV Medicine
BBVSS	Blood Borne Virus and Sexually Transmitted Infections Sub-committee
CALD	Culturally and Linguistically Diverse
CHF	Consumer Health Forum
DoHA	Department of Health and Ageing
GIPA Principles	Greater Involvement of People Living with HIV/AIDS
MACBBVS	Ministerial Advisory Committee on Blood Borne Viruses and Sexually Transmissible Infections
NCHECR	National Centre in HIV Epidemiology and Clinical Research
NCHSR	National Centre in HIV Social Research
PL	<i>Positive Living</i> (magazine)
PLHIV	People Living with HIV/AIDS

The following documents, referenced in Strategic Directions, can be found on the NAPWA website www.napwa.org.au

APPENDIX 2

NAPWA Declaration of Rights of People Living with HIV/AIDS, 2005 Life • Love • Participation

The National Association of People Living with HIV/AIDS (NAPWA) is Australia's peak non-government advocacy organisation representing PLWHA community based groups from each of Australia's States and Territories.

Worldwide, approximately 40 million people live with the human immunodeficiency virus (HIV), which causes AIDS. Half of all adults living with HIV/AIDS are female and in sub-Saharan Africa, the most affected region, the figure is nearly 60 percent¹. Twenty million people have died from AIDS since the first cases were identified in 1981. More than 14 million children have become AIDS orphans, and despite antiretroviral therapy that has significantly reduced AIDS-related deaths, the HIV population has expanded alarmingly, increasing by more than 50 percent since 1991².

The need to find effective ways to deal with the transmission of HIV, in all nations, rich and poor, is now greater than it is has ever been. And with more people living with HIV than at any time in our past, the need to protect their health and human rights is also greater than it has ever been.

Human rights are fundamental to the response to HIV, for three reasons: ethical, because all human beings have a right to health, to life and all other human rights; legal, to implement the International Declaration on Human Rights and the many other international and national laws and guidelines on human rights, and for pragmatic reasons, because it is beyond doubt that a human rights based response, which empowers our whole community to avoid infection, and which treats those with HIV with respect and inclusion and aims to properly manage their health, is significantly more effective in reducing the spread of HIV than a response of silence, discrimination or exclusion³.

The Rights we now declare uphold not only the rights of those with HIV and AIDS, but are made for the greater good of our community in their promotion of its ethical and physical health. These Rights implement the self-evident precepts, embraced in international law, ethics and basic common sense, that no one human is more human than another, that no one human being has more worth than another, and that all human beings have equal human rights.

These Rights are declared to improve the quality of our Life and the Life of the community at large. They are centred in Love, as this is the ultimate foundation of all human rights. They will be carried out through our Participation in all aspects of the consultative and decision making processes in relation to them.

These Rights are firmly anchored within existing human rights laws and guidelines, and adopt, in large measure, the International Guidelines on HIV/AIDS and Human Rights of the United Nations Commissioner for Human Rights (ONHCR) and the Joint United Nations Program on HIV/AIDS (UNAIDS), revised in 2002 after extensive worldwide consultations and chaired by eminent Australian jurist, Mr Justice Michael Kirby⁴.

¹ United Nations Population Fund, International Conference on Population and Development, Program of Action, September 1994

² UNAIDS 2004 Report on the Global AIDS Epidemic, July 2004.

³ Dr Peter Piot, UNAIDS Executive Director, Speech to the 59th Session of the UNHCR, Geneva, 19 March 2003; see also Ralf Jürgens, Human Rights for People Living with HIV/AIDS, Partnership to fight HIV/AIDS in Europe and Central Asia, Dublin, 24 February 2004, with numerous references.

⁴ UNAIDS and UNHCR, HIV/AIDS International Guidelines on HIV/AIDS and Human Rights 1998.

We, the peoples in Australia living with, and affected by HIV/AIDS, through our National and State representative bodies, CONFIRM our Right to Life, Health and the other Rights enshrined in the Universal Declaration of Human Rights, and DECLARE, for ourselves and for the good of our Society in general, our RIGHTS as follows:

1 (Full Rights) The full complement of human rights under international law, those most relevant to HIV/AIDS -including the Right to:

- life
- participate fully in public and cultural life, including freedom to practice spiritual and cultural beliefs
- share in scientific advancement and its benefits
- freedom of movement
- freedom of association
- marry, form relationships and have a family
- a reasonable standard of living
- be free from torture and cruel, inhuman or degrading treatment or punishment.
- liberty and security of person
- the highest standards of physical and mental health
- non-discrimination, equal protection and equality before the law
- freedom of opinion and expression
- privacy and confidentiality
- work
- equal access to education
- social security, assistance and welfare
- seek asylum

2 (Co-ordinated Response) The Right to a coordinated and effective response from all levels of government in Australia to the HIV/AIDS pandemic.

3 (No Discrimination) The Right to live free from harmful discrimination or stigma which in any way relates to our positive HIV status, and to be treated with respect and dignity.

4 (Sex) The Right, as consenting adults, to a full and satisfying sex life.

5 (Participation) The Right to:

- participate at every level of consultation, decision making and implementation regarding HIV/AIDS advice, policy, laws, treatments, funding, research, education, resourcing and financing, and all other matters relevant to the HIV/AIDS response;
- be represented in the governance of all organisations that are involved with HIV/AIDS or which provide any service in that regard; and
- form autonomous, self-governing organisations of people living with HIV/AIDS and for those organisations to be consulted and listened to in all levels of HIV/AIDS decision making.

6 (Testing) The Right to confidential and comprehensive pre- and post-test counselling and to give informed consent. The Right to HIV testing and monitoring without coercion. This includes an enabling environment for the upholding of privacy and the protection of confidentiality.

7 (Treatment) The Right to the highest quality and standards of specialist medical treatments of our choice. The Right to refuse treatments if we so choose.

8 (Care) The Right to any quality and specialist medical care, palliative care and support services suitable and acceptable to the individual including:

- the Right to life-saving and life-prolonging health care;
- the Right to have our psycho-social needs addressed as well as our biomedical needs, and in particular, the Right to quality and specialist psychological and mental health services;
- the Right to make fully informed and voluntary decisions about our participation in clinical trials, to access quality care regardless of our agreement or refusal to participate in HIV/AIDS research;
- and in each case we have these Rights without regard to our ability to pay or the absence or type of health insurance and coverage.

9 (Medications) The Right to access HIV/AIDS medications and treatments as and when we need them, and regardless of our capacity to pay. This includes the Right, protected through legislation, to access and advocate for new and emerging medications, as clinically necessary and through emergency access measures.

- 10 (Family and Relationships)** The Right to marry, to form and maintain family and partnership arrangements, and care arrangements as we choose, including:
- the Right of HIV positive women and HIV positive men to have children and to make fully informed decisions in that regard;
 - the Right to adopt children, and to maintain custody of our own children; and
 - the Right to require that Australian Governments protect and promote these Rights in the legal system and create supportive and enabling environments for women, men, children and the family and the partnership arrangements we have described herein.
- 11 (Housing)** The Right to acceptable standards of housing, including the Right for people with life- threatening HIV/AIDS to have priority access to public housing.
- 12 (Education)** The Right to education, at all levels within the community, unrestricted on the basis of HIV status.
- 13 (Prisoners)** The Right to community standard health and treatments for those with HIV/AIDS in custodial settings. The Right to health for those in custody. This includes the Right to access, treatment prevention technologies, condoms, clean needles and the like free of charge.
- 14 (Injecting Drug Users)** The same Right to health as any other Australian. Access to programmes which protect the health of people who inject drugs and reduce HIV transmission (such as needle syringe programmes, substitution and rehabilitation therapies) are a human right. Laws must be enacted by Australian Governments to protect that right and in so doing the public health of the community.
- 15 (Indigenous)** The same Right to health as any non-indigenous Australian, and the same Right to the same standards of health as any non-indigenous Australian, delivered in a culturally appropriate way, which reflect the differing and particular needs of indigenous Australians.
- 16 (Multicultural)** The Right to receive all information and services, and to attain all of the Rights which we now declare, provided in a culturally acceptable manner and spoken and written in the language of their choice, and through an interpreter if necessary.
- 17 (International)** The Right to require that all governments, organisations, corporations and other bodies in Australia share their knowledge and experience regarding HIV/AIDS issues and promote and protect our Rights at the national and international level. This includes the fulfilment of Australian international commitments through specific HIV/AIDS programs and in the programs of all groups involved in the Australian international HIV/AIDS response.
- 18 (Freedom of Movement)** The Right of people living with HIV/AIDS to freedom of international movement and migration privilege, as accorded any other individuals. This also includes the Right to seek asylum and not be refused on the basis of their HIV status.
- 19 (Death)** The Right to die with dignity and in the manner the individual chooses.
- 20 (Implementation)** The Right to secure, through policy and legislation, protection in both the public and private sectors for those with HIV/AIDS. This should be achieved through enforceable codes of conduct and professional practice.
- 21 (Accountability and Enforcement)** The Right to require that Australian Governments enact and adopt monitoring and enforcement mechanisms to implement our Rights, with appropriate penalties where that is not done, together with affordable and effective administrative and civil remedies to enable and ensure our Rights are appropriately enforced. The Right to require Australian Governments to review, enact and reform legislation to protect and promote each of our Rights which we now declare.

Declared by people in Australia living with HIV/AIDS, through their National, State and Territory representative bodies at the Tenth Biennial NAPWA Conference, Adelaide, South Australia on Friday November 18, 2005.

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