

# napwha national association of people with HIV australia

# Reflections on the practice of partnership

A decade of collaboration between the National Association of People With HIV Australia and Igat Hope, the national association for people living with HIV in PNG

Tim Leach and Dr John Rule 2013



This report acknowledges the extraordinary efforts of people living with HIV (PLHIV) in PNG and their supporters, especially their work in establishing a national representative organisation for PLHIV in PNG, Igat Hope. Many individuals in PNG have made important contributions to the establishment of a national organisation that is governed by — and represents the interests of — PLHIV. NAPWHA hopes these individuals and other stakeholders will see their efforts reflected positively and accurately in this report.

#### **About the authors**

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Dr John Rule has a background in building community organisations and community education. He has degrees in economics and education and completed his PhD at the University of Technology, Sydney in 2006. He has worked as the Deputy Director of NAPWHA and recently as a Research Associate at the School of Public Health and Community Medicine, University of New South Wales. John has recently published work about the effects of HIV criminalisation (in *New Political Science*) and about HIV and human resources in Papua New Guinea and the Pacific Islands (in the *Western Pacific Surveillance and Response Journal* and in the *Pacific Health Dialog*).

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### **Acronyms and abbreviations**

ADB Asian Development Bank

AHAPI AusAID HIV/AIDS Partnership Initiative
AIDS Acquired immunodeficiency syndrome

ART Antiretroviral therapy
ARV Antiretroviral

AusAID Australian aid and development agency

CBO Community-based organisation

CHPNG Collaboration for Health in Papua New Guinea

FBO Faith-based organisation
FHI Family Health International

GIPA Greater involvement of people living with HIV/AIDS

HIV Human immunodeficiency virus

Igat Hope Translation — 'I have/we have/there is' hope

MoU Memorandum of understanding

NACS National AIDS Council Secretariat (PNG)

NAPWHA National Association of People Living With HIV Australia

NCD National Capital District (PNG)

NDoH National Department of Health (PNG)

NGO Non-government organisation

PLHIV People living with HIV
PNG Papua New Guinea

UNAIDS Joint United Nations Programme on HIV/AIDS
UNDP United Nations Development Programme

WHO World Health Organization



### **Executive summary**

This report has been produced as an official account of the collaboration between the National Association of People With HIV Australia (NAPWHA) and Igat Hope, the national positive people's organisation in PNG. The report was commissioned by NAPWHA to record the outcomes of the decade-long partnership and to document the lessons NAPWHA has learned from the experience.

The report is partly a reflection on the part of the authors, but is also based on NAPWHA's extensive records and archives of its work in PNG. The report draws on various evaluative documents that have been produced over the period of the partnership.

NAPWHA's earliest collaboration with the positive people's movement in PNG predated the formal establishment of Igat Hope. Before there was any formal group for people living with HIV (PLHIV) in PNG, individual HIV-positive advocates in that country had begun to seek support and advice from positive advocates in Australia. Many of these Australian advocates were representatives or associates of NAPWHA and the institutional links were thereby established.

NAPWHA's work with lgat Hope has occurred within an environment characterised by uncertainty and rapid change. The work commenced at a time when little was known of the PNG epidemic, but a lack of reliable data and some troubling early indicators were generating considerable fear within PNG and beyond. An epidemic of catastrophic proportions was feared and governments, aid agencies and communities scrambled to prepare for its anticipated impact.

Working in partnership with lgat Hope required working in a country where not only was the epidemic very different from the epidemic in Australia, but where the resources available to respond to the epidemic were vastly inferior to those made available to the Australian response.

The partnership work took place within a very particular HIV treatments context. While research was suggesting that recent advances in antiretroviral therapy (ART) could be sustained, PLHIV in PNG were confronted with multiple barriers making universal access to ART impossible. Problems with drug procurement, supply and distribution were common backdrops to NAPWHA's work.

The PNG health system has at all times during the life of the partnership struggled to meet the country's most basic needs. Lack of financial resources, skills deficiencies and poor systems of practice have combined to leave Papua New Guineans with poor-quality health services. Even before HIV arrived in PNG, the health system was struggling to meet a high disease burden resulting from malaria and tuberculosis (among others), so its capacity to meet the emerging demands of an HIV epidemic was always very limited. In this context, PLHIV demands were often seen as unreasonable, unrealistic or of insufficient priority.

The capacity of the National Department of Health (NDoH) and the National AIDS Council Secretariat (NACS) to drive the PNG response was inadequate. The intense support required to build and sustain Igat Hope was not available within PNG and had to be sourced from Australia.

Extremely high levels of stigma and discrimination directed towards PLHIV made it especially difficult to establish and maintain a national positive organisation. Instead of being respected for their courage in being advocates, many PLHIV activists were ridiculed, threatened and/or abused. Physical violence against PLHIV was common.

AusAID's policy and program approach to combating HIV in PNG changed significantly during the partnership work. Its recent focus on delivering aid through global partnership programs (such as with the World Bank and

Asian Development Bank) has meant less interest in funding Australian community-based organisations (CBOs) to work in PNG. AusAID's new preference for funding Australian volunteers to work in PNG has also meant less support for Australian CBOs.

From 2005 to 2008, NAPWHA's work with Igat Hope was funded through the AusAID HIV/AIDS Partnership Initiative (AHAPI project). The overall aim of the project was to build community and counterpart organisation participation, capacity and knowledge in priority countries within the Asia-Pacific region through formal collaborations and partnerships with likeminded organisations. The focus of work with Igat Hope was the provision of support for the Igat Hope Coordinator (later to become the Executive Director), Secretariat structure and Board processes with the aim of enabling Igat Hope to act independently within PNG. Specifically, NAPWHA sought to provide assistance with strategic planning, governance training, peer support for new members, expansion of the PLHIV network beyond Port Moresby, promotion of Igat Hope in an attempt to address stigma and discrimination, and building skills of positive speakers.

NAPWHA arranged for its AHAPI work to be externally evaluated and participated in an internal process of program review via interviews with the lgat Hope Board. NAPWHA concluded at the time that its partnership with lgat Hope 2005–2008 had successfully contributed to the building of that organisation's institutional integrity and capacity.

From 2009 to 2012, NAPWHA was funded to work with Igat Hope under yearly contracts with the HIV/AIDS program of AusAID (PNG), Sanap Wantaim. While there were some variations between these annual contracts, NAPWHA's primary goals were to:

- Support the governance structure of the organisation
- Strengthen the Secretariat
- Enhance the organisation's treatments advocacy capacity.

During this period, NAPWHA and Igat Hope worked together successfully in relation to a range of key programs:

- Strengthening the Secretariat
- Igat Hope Board elections and constitutional reform
- Building an expanded national network of PLHIV
- National summits
- The Stigma Index project
- Treatments advocacy
- Maintaining positive governance, especially in times of crisis.

Through its partnership work with Igat Hope, NAPWHA has learned some important lessons.

NAPWHA's decision to pursue work in PNG has had a very significant impact on the organisation. NAPWHA had to learn the new discipline of international development. While its history of community development served as a solid foundation for its international work, NAPWHA had to rapidly learn the practice of development. Even though NAPWHA had been applying many development principles for years, it had to learn (fast) that development is a unique discipline with its own philosophies and frameworks, its own 'hot topics' and a language all of its own.

A significant portion of NAPWHA's inputs was not funded. While AusAID was a strong supporter, its preference for funding project activities rather than salaries meant that many NAPWHA contributions were unfunded. NAPWHA relied heavily on volunteer contributions from its staff and constituents.

NAPWHA had to manage a tension within its membership around the right balance between international and domestic work. While there was strong support for international work from within the NAPWHA membership, some felt that it should not be pursued at the expense of NAPWHA's important domestic responsibilities, particularly in light of declining funding available to support the Australian response.

To conduct its work in PNG, NAPWHA was reliant — to a very significant degree — upon volunteers from within its membership. Working in PNG took its toll on many of these volunteers. NAPWHA volunteers were confronted by the extreme poverty experienced by many PLHIV, by the levels of violence and discrimination directed towards PLHIV in PNG, by the systematic gender violence, and by the lack of access to treatments for HIV and opportunistic infections or basic health care. NAPWHA had a responsibility to support staff and volunteers to manage the personal impacts of working in PNG, and this had resource implications for the organisation.

The profile of the Igat Hope constituency and Board membership, specifically the poverty and the health issues (due to HIV and other opportunistic infections) with which members were struggling daily, made it difficult to achieve consensus on the organisation's primary goal. While many within Igat Hope were keen for the organisation to take on a national advocacy role, others wanted the organisation to provide 'services' (food, medicines or cash grants) to members.

Igat Hope has been built through the hard work of its volunteers. The issue of remuneration of volunteers has caused a range of challenges. Many volunteers (Board members and others) have had an expectation that engagement with the organisation would bring some benefits and that participation and effort should be rewarded, particularly given the comparative wealth of the organisation and the poverty experienced by Igat Hope members. This has generated ongoing problems in ensuring no funds have been applied for the personal benefit of members. A lack of consistency in approach across donor and development agencies in PNG has complicated matters.

Supporting Igat Hope to properly manage its funding has been a priority for NAPWHA. It has been a challenge for Igat Hope to apply a higher standard of financial management than is seen in politics or business across PNG. While there have been some significant problems along the way, Igat Hope has managed to attain an organisational audit for each of the years it has been operating, and retains an organisational surplus.

NAPWHA acknowledges that there are cultural and contextual factors that shape the way Board members think about organisational funds. But AusAID's zero tolerance approach to fraud and corruption has required NAPWHA to insist that Igat Hope take a very Australian approach to money management.

NAPWHA invested significant resources in trying to build the governance capacity of successive Boards, with some but limited success. Upon reflection, it would have been preferable for the Boards to meet more often and to be given more frequent governance trainings (rather than one-off training events), and for NAPWHA to have facilitated a more intensive in-country governance-mentoring program for Board members. While NAPWHA did attempt to build such a mentoring program for Igat Hope, these attempts were mostly unsuccessful.

The notion of *peer* has been central to NAPWHA's work. The personal connections of HIV-positive peers have greatly facilitated the partnership between NAPWHA and Igat Hope. But NAPWHA's commitment to peer linkages has extended beyond the personal. From the outset, NAPWHA felt strongly that only a positive organisation could understand Igat Hope's challenges. NAPWHA believes that time has shown this to be true. Many of the challenges that Igat Hope has had to face are specific to positive organisations, and NAPWHA has been well placed to assist with these.

In all of its dealings with Igat Hope, NAPWHA maintained that it was working with Igat Hope in partnership. In using this term, NAPWHA meant more than just collaboration. It was not just working with another organisation, but was working with that organisation in a particular way that was inclusive of shared goals, involved respect for the institutional integrity of the other party and, more contentiously, some notion of equality.

NAPWHA acknowledges that there was a power imbalance between the two organisations that may occasionally have resulted in something that was not quite a partnership of equals. But NAPWHA also considers that the organisations managed this imbalance in a collaborative spirit and with a shared commitment to working together in pursuit of shared goals and in accordance with shared values.

NAPWHA and Igat Hope have struggled to build treatments advocacy capacity within PNG. NAPWHA regrets that there has not been more success on this front. While the two treatments advocacy forums in 2010 and 2012 were successful events, and the <u>Waigani Statement on HIV Treatments Action</u> (2010) was a good blueprint for future work, progress has been undoubtedly slower than anticipated or desired.

Many factors have contributed to the slow rate of progress in relation to treatments advocacy, including lgat Hope's internal capacity issues, structural health system deficiencies in PNG, the approach to ARV rollout taken by the government and other stakeholders in PNG, and the loss of individual treatments activists in PNG. NAPWHA might also have tried some different strategies that may have had more success. A more focused mentoring program for lgat Hope's treatments staff would have made sense, and NAPWHA should have developed a 'Plan B' for those times when lgat Hope's internal capacity issues prevented it from taking the lead on treatments advocacy.

NAPWHA and AusAID enjoyed a very good working relationship during the life of the NAPWHA—lgat Hope partnership. AusAID demonstrated admirable flexibility in its approach to both NAPWHA and lgat Hope, in recognition of the obvious difficulties in building a national positive organisation in PNG.

There may have been some value in having, from the outset, clearer performance indicators for the NAPWHA—lgat Hope partnership.

The absence of clear performance measures has made it difficult to demonstrate lgat Hope progress and the value of NAPWHA support.

NAPWHA has developed a set of indicators for application in future capacity building programs. These would help demonstrate the utility of any future partnerships aimed at building the institutional strength of a developing country community organisation.

NAPWHA has sought to reflect on the success or otherwise of its partnership with Igat Hope. To assist in the process, NAPWHA has used a number of tools (or frameworks) for assessing its partnership work:

- NAPWHA's global perspective on PLHIV rights
- Assessment in the context of memoranda of agreement or understanding
- Assessment by reference to a 'values in practice' approach and the notion of 'mutual accountability'.

When NAPWHA began its work in PNG, it was relatively new to international development work. But it was not new to thinking and acting globally. NAPWHA had already signed on to a number of international declarations on the rights of PLHIV, developing its own declaration as early as 2005. These declarations outlined the rights that PLHIV should have regardless of where they lived, and NAPWHA had a responsibility to promote these rights through its partnership work in PNG. One way of assessing NAPWHA's work is by reference to the extent to which its partnership efforts in PNG were consistent with its commitments to promote global PLHIV rights. There is evidence that NAPWHA's work was conducted in ways consistent with its global commitments.

A second means of assessing NAPWHA's work is by reference to partnership agreements such as memoranda of understanding. Such memoranda often include indicators of proper partnership, greatly facilitating subsequent assessment of collaborations. A memorandum can act as a kind of contractual undertaking to behave in a particular way, and performance can be measured in terms of contractual compliance. While NAPWHA did not have an MOU with Igat Hope — a regrettable error — consideration of other relevant partnership agreements (such as the one involving the Australian Federation of AIDS Organisations, the Queensland Association for Healthy Communities and the Poro Sapot Project of Save the Children in PNG) is instructive. Using these tools, there is evidence that NAPWHA's work was conducted in a true partnership manner.

A third means of assessing NAPWHA's work may be by considering the extent to which NAPWHA and Igat Hope worked together through a set of shared values. There is evidence that, despite the power imbalances between NAPWHA and Igat Hope, the organisations shared a set of values that enabled them to work together in a spirit of true partnership.

There is also evidence that some of Igat Hope's most important achievements resulted from both organisations working together towards shared goals in a spirit of mutual accountability. Not surprisingly, both NAPWHA and Igat Hope were committed to the same key outcomes. First among these was the establishment of an independent, viable and national PLHIV organisation. There is ample evidence that both organisations worked towards this goal. It is also the case that many of Igat Hope's greatest strengths, as identified by a 2011 independent audit of the organisation, have been built through valuable contributions from NAPWHA.



### 1. Introduction

This report has been produced as an official account of the collaboration between the National Association of People With HIV Australia (NAPWHA) and Igat Hope, the national positive people's organisation in PNG. The report was commissioned by NAPWHA to record the outcomes of the decade-long partnership and to document the lessons NAPWHA has learned from the experience.

NAPWHA's earliest collaboration with the positive people's movement in PNG predated the formal establishment of Igat Hope. Before there was any formal group for people living with HIV (PLHIV) in PNG, individual HIV-positive advocates in that country had begun to seek support and advice from positive advocates in Australia. Many of these Australians were representatives or associates of NAPWHA and the institutional links were thereby established.

One of the earliest collaborations was via NAPWHA support for a study tour undertaken in 2001 by PLHIV advocates from PNG. Links were strengthened through meetings between PLHIV from both countries at events such as the 2001 International Congress on AIDS in Asia and the Pacific in Melbourne, where NAPWHA hosted a delegates forum specifically for PLHIV from the Region. In 2003, links were made stronger when, for the first time, a group of HIV-positive people from PNG attended the NAPWHA biennial conference in Cairns. Through these events, personal and institutional links were forged.

Igat Hope began as an informal group in 2001. By 2003, the group had become more formalised through regular meetings of PLHIV in Port Moresby. The organisation received two small capacity building grants in 2004 — but the nascent organisation struggled to effectively manage and acquit these two grants. The first membership list was compiled in August 2005 and the first Igat Hope annual general meeting was held in September 2005. NAPWHA provided the technical support necessary to facilitate these two important developments.

NAPWHA's earliest work with Igat Hope was largely unfunded, but from 2005 to 2012 NAPWHA received funding from AusAlD (in Australia and/or PNG) to support this work. In 2012, AusAlD decided to conclude its support for NAPWHA's work in PNG. NAPWHA opposed this AusAlD decision, arguing that further support for Igat Hope was required and that NAPWHA was still the agency best placed to provide this support. While maintaining that the decision to defund this work was wrong, NAPWHA acknowledges that AusAlD has been a steadfast and generous supporter of Igat Hope and that its direct support for Igat Hope continues through AusAlD activities and programs in-country.

NAPWHA has always enthusiastically supported AusAID proposals to evaluate NAPWHA's work in PNG. Unfortunately, AusAID never undertook or funded a formal evaluation of the partnership program. Of course, in negotiating contracts between NAPWHA and AusAID, the partnership program was routinely reviewed, but it has never been reviewed in its entirety. This report has been produced in part to fill this unfortunate gap.

NAPWHA and Igat Hope did conduct systematic evaluation of all partnership activities. Evaluation was both formative<sup>1</sup> and summative.<sup>2</sup> Formative and summative evaluations are found in project documentation of events such as the:

- Healthy Living Workshop for Positive Peers (December 2005)
- Hungry for Learning/Diba Bona Goada Abia Workshop (March 2007)
- Positive Speakers Training (March 2008)
- Good Governance Training Workshop (March 2009)
- Treatment Advocacy Workshops (2010 and 2012).

In writing this report, many of these source documents have been reviewed.<sup>3</sup> Documentation such as consultant reports and formal reports to the NAPWHA Board, the lgat Hope Board and lgat Hope membership meetings also include an evaluative component, and many of these documents have been re-read and reviewed in preparing this report.

NAPWHA sees itself as having contributed very significantly to the positive response in PNG. It views the formal establishment and continuing operation of Igat Hope as the primary indicator of the utility of NAPWHA's support. NAPWHA was integral to some of the organisation's most important achievements. NAPWHA played a very important role in assisting the organisation to gain and maintain legitimacy in PNG. While the members of Igat Hope initially received some support in-country, there NAPWHA sees itself as having contributed very significantly to the positive response in PNG. It views the formal establishment and continuing operation of Igat Hope as the primary indicator of the utility of NAPWHA's support. NAPWHA was integral to some of the organisation's most important achievements. NAPWHA played a very important role in assisting the organisation to gain and maintain legitimacy in PNG. While the members of loat Hope initially received some support in-country, there were also many who questioned that such an organisation was needed, or whether indeed positive people were able to manage an organisation themselves. NAPWHA was often called upon to broker relationships between lgat Hope and other organisations working in the HIV response in PNG. It was also a key contributor to organisational stability – or survival – at various times when lgat Hope struggled to remain functional. These are contributions of which NAPWHA is very proud.

At the same time, NAPWHA acknowledges that some things could have been done better. In documenting the lessons it has learned through its work in PNG, NAPWHA hopes to offer some useful guidance for other agencies working with community HIV responses in PNG. It has been NAPWHA's experience that there is too little information sharing and reflection among international non-government organisations (NGOs) working in PNG. NAPWHA hopes this report will contribute to a greater shared understanding among NGOs of what works and what does not.

Many, many people have been a part of NAPWHA's work in PNG. Some have been paid (as staff or consultants) and some have been volunteers. Most have been HIV-positive and some have been HIV-negative. All have made an important contribution to the positive response in PNG and the strength of Igat Hope. These contributors include (in alphabetical order): Robert Baldwin, Kenn Basham, Brent Beadle, Peter Canavan, Bev Greet, Barry Horwood, Robert Langdon, Suzanne Lau-Gooey, Tim Leach, Lou McCallum, Gabe McCarthy, Jenny McDonald, Anne Mijch, Wilo Muwadda, Max Niggle, Simon O'Connor, Susan Paxton, Elizabeth Reid, John Rock, John Rule, Andrew Timmins, John Trigg and Jo Watson. A significant contribution has also been made by many of NAPWHA's administrative staff.

This report seeks to outline some of NAPWHA's major achievements in its work with Igat Hope. To a degree, this reads as a list of Igat Hope's organisational achievements, but NAPWHA is specifically not claiming sole responsibility for all the achievements of Igat Hope. Indeed, NAPWHA recognises that Igat Hope's achievements are primarily attributable to the hard work of PLHIV and others in PNG who have made Igat Hope a reality. NAPWHA's funders have also played an important role. But NAPWHA does claim some credit for many of Igat Hope's biggest achievements, particularly in the areas of governance capacity, secretariat strengthening and national networking.

NAPWHA acknowledges the courage and hard work of those PLHIV in PNG who have built and sustained Igat Hope. NAPWHA has been inspired by these efforts. While NAPWHA's contract to provide Igat Hope with support has now concluded, the organisation looks forward to continuing its close working relationship with Igat Hope, albeit in a new way.

This report has been written by Tim Leach and John Rule. Tim and John have been working with Igat Hope since the early phases of the organisations' collaboration. Tim's work with Igat Hope has been conducted as a consultant for NAPWHA. John's work with Igat Hope was originally conducted in his capacity as Deputy Director of NAPWHA. More recently, his inputs have been as a NAPWHA consultant.

The report is partly a reflection on the part of the authors, but is also based on NAPWHA's extensive records and archives of its work in PNG. It has been endorsed by the NAPWHA Board. The report is being published as NAPWHA's own reflections on its experiences and it does not purport to be a joint NAPWHA—lgat Hope account — although, as noted above, many of the source documents consulted have been produced jointly by NAPWHA and lgat Hope. One example of such source documents is lgat Hope's report of its 2008 conference, 4 produced by lgat Hope with technical support and input from NAPWHA. Another example is the <u>Systems and Organisational Audit of Igat Hope Inc.</u> (December 2011). 5 This audit was activated by AusAID PNG's HIV/AIDS program, Sanap Wantaim, and conducted by UNAIDS PNG. The report notes the significant contribution of NAPWHA and NAPWHA consultants in providing information on the history and development of Igat Hope; indeed, many of the documents sighted and used by the auditors had been developed or maintained by NAPWHA.

NAPWHA hopes that various stakeholders involved in the HIV response in PNG will benefit from reading this community partnership report. This report attempts to provide a critical reflection on an important community partnership activity carried out in response to the HIV epidemic in PNG.

- ¹ Evaluation conducted in the process of developing a project. NAPWHA undertook formative evaluation prior to applying for funding. This involved scoping/seeing what needed to be done, etc. NAPWHA did formative evaluation before each workshop or activity that is, it gathered information, assessed what was needed and what was not and, on that basis, proceeded with some things and did not proceed with others. NAPWHA had feedback mechanisms in place through ongoing discussions with the lgat Hope Board and Igat Hope staff, and through reporting to the NAPWHA membership at least annually. These mechanisms encouraged the sharing of formative evaluations, as NAPWHA was often required to justify why it was proposing to undertake certain activities rather than others.
- <sup>2</sup> Evaluation that assesses work that has been done. NAPWHA did summative evaluation by asking workshop participants to fill in questionnaires what they learned/liked/wanted more of, etc. Sometimes this was done through discussion and in debriefs with lgat Hope staff and Board after events. Evaluations were undertaken for most workshops, and one of the best examples was the first national PLHIV conference. Each year, NAPWHA created a plan, as requested by AusAID, which listed aims, inputs and outputs. It also required staff and consultants to report on their in-country work. NAPWHA reported on its PNG program regularly to its Board and membership. Thus it was ensured that systems were in place for summing up work as it was conducted.
- <sup>3</sup> Evaluative reports of workshops were prepared by NAPWHA staff, partly for the purpose of reporting on activities held in PNG to the NAPWHA Board. Copies of reports on the Healthy Living Workshop for Positive Peers 2005, Hungry for Learning Workshop 2007, Good Governance Training 2009 and Treatment Advocacy Workshops 2010 and 2012 are held in NAPWHA files.
- <sup>4</sup> <u>Igat Hope Inc. Conference Report</u>, 2008, available from Igat Hope or NAPWHA.
- <sup>5</sup> Le Mesurier, R., and Dee, C., <u>Systems and Organisational Audit of Igat Hope Incorporated</u>, <u>Port Moresby, PNG (Audit period: 24 November to 16 December 2011)</u> – <u>Wok bung wantaim bilong yumi olgeta</u>, available from Igat Hope or AusAID.



## 2. Background and contexts

NAPWHA's work with lgat Hope has occurred within an environment characterised by uncertainty and rapid change. The work commenced at a time when little was known of the PNG epidemic, but a lack of reliable data and some troubling early indicators were generating considerable fear within PNG and beyond. An epidemic of catastrophic proportions was feared and governments, aid agencies and communities scrambled to prepare for its anticipated impact.

The first case of HIV was reported in PNG in 1987. PNG now has the highest incidence of HIV in the Pacific region: an estimated 0.9% of the general adult population is HIV positive, over 34,100 Papua New Guineans were living with HIV in 2009, and HIV has spread across the entire country, although its spread has been uneven across PNG provinces. In 2010, a total of 138,581 HIV tests were reported to have been conducted in PNG, with 4,208 returning positive results.

PNG has a population of about 6.4 million, over 30% of whom are under the age of 15 and about 80% of whom live in rural areas. The country has enjoyed rapid economic growth in recent years; however, this growth has not been reflected in the health status of the population. PNG has some of the worst health indicators in the Asia-Pacific region. Between 1980 and 2012, Papua New Guinea's Human Development Index<sup>8</sup> rose by 1.3%, but the country still ranks 156 out of 187 countries with comparable data. PNG's Human Development Index is the lowest within the region. Life expectancy in PNG is 63.1 years and average years of schooling per adult is only 3.9 years.<sup>9</sup>

These facts give some indication of the complicated conditions in which partnership work was carried out. Working in partnership with Igat Hope required working in a country where not only was the epidemic very different from the epidemic in Australia, but where the resources available to respond to the epidemic were vastly inferior to those made available to the Australian response. The extent and nature of the epidemic in PNG, and the limited resources available within PNG, have always combined to indicate that effective partnership work would require significant resources and inputs from an Australian counterpart.

In 2005, the HIV Epidemiological Modelling and Impact (HEMI) Study was commissioned by the Australian government for the governments of PNG, Indonesia and East Timor. 10 For PNG for the period 2005–2025, mathematical modelling predicted there would be a generalised epidemic with over 500,000 people living with HIV, with HIV prevalence of over 10% of the adult population and with an estimated 300,000 adult deaths. These estimates were later revised downwards, but policy and decision making by AusAID and the Australian government around 2005 — when NAPWHA's first work in PNG was being commenced — were informed by some of this earlier modelling. The experience of NAPWHA and other organisations in Australia was sought by AusAID to assist in what was predicted to be an HIV epidemic of alarming and costly proportions.

It should also be understood that the partnership work took place within a very particular HIV treatments context. It occurred during a period when research was suggesting that recent advances in antiretroviral therapy (ART) could be sustained, but only if multiple barriers to making ART universally available were properly addressed. These barriers were being experienced in PNG as much as in any developing country. The challenges of developing national HIV and sexual health programs in PNG, and of rolling out ART in a country already struggling to manage a high disease burden due to malaria and tuberculosis, were daunting.

The PNG health system has been struggling for some time and any attempt to build organisations and responses to support PLHIV and access to ART was always going to confront significant challenges. In PNG there has been:

Deteriorating availability and performance of many public and some private health facilities, persistently poor health outcomes across the population, and worsening trends on some indicators such as maternal health.<sup>13</sup>

There were very significant barriers to be faced in terms of the cost and availability of antiretroviral drugs, drug procurement and establishing drug distribution systems. PNG has long-running problems in the procurement and distribution of drugs, with stock-outs extending for several months and including essential items. <sup>14</sup> Major problems have continued to occur and have threatened to paralyse the ART supply system, as in 2010 when the PNG application to The Global Fund to Fight AIDS, Tuberculosis and Malaria failed. <sup>15</sup>

There were additional barriers faced in terms of the capacity of local PNG institutions to respond effectively. This may have been a result of limited capacity or resources. It is clear that over the time of the partnership work, the National Department of Health (NDoH), the National and Provincial AIDS Council structures and other institutions were experiencing difficulties in responding to the emerging epidemic. The 2008 <u>UNGASS Country Progress Report for PNG</u> noted that one of the major challenges requiring remedial action in PNG was the capacity of the secretariat of the National AIDS Council to take on an effective role in coordinating the national response. <sup>16</sup> In 2008 and 2009, the Independent Review Group on HIV/AIDS in PNG had recommended strategies for better coordination, capacity development and training for both the National AIDS Council Secretariat (NACS) and NDoH, and especially at the provincial level, in order to better support programs that were not being implemented effectively due to limited capacity. <sup>17</sup>

Problems with ART access and adherence and stigma and discrimination in PNG have been documented through recent PNG research.<sup>18</sup> The severity of some of these problems would, of course, impact the success of the partnership work.

For example, while stigma and discrimination continued in PNG with such intensity, the ability of NAPWHA to assist PLHIV to meet together and

<sup>6</sup> National AIDS Council Secretariat and National Department of Health, 2010, Papua New Guinea HIV Prevalence: 2009 Estimates, NDoH and NACS, Port Moresby,

<sup>7</sup> National Department of Health, 2011, The 2010 STI, HIV and AIDS Annual Surveillance Report, National Department of Health STI, HIV and AIDS Surveillance Unit, Port Moresby.

The index is a multi-component assessment of a country's human development and is used by the United Nations Development Program. It measures life expectancy, education and income. See http://hdr.undp.org/en/statistics/hdi/.

<sup>&</sup>lt;sup>9</sup> See http://hdrstats.undp.org/en/countries/profiles/PNG.html.

<sup>10</sup> See www.ausaid.gov.au/Publications/Documents/impacts\_hiv.pdf.

<sup>11</sup> MacDonald, T., 2007, The Global Human Right to Health, pp.132-152.

<sup>12</sup> WHO, 2006, Towards universal access by 2010: How WHO is working with countries to scale-up HIV prevention, treatment, care and support, World Health Organization, Geneva, retrieved from www.who.int/hiv/pub/advocacy/towardsuniversalaccess.pdf.

<sup>13</sup> McKay, J. & Lepani, K., 2009, Health System Strengthening in Papua New Guinea, Lowy Institute for International Policy, www.lowyinstitute.org.

<sup>&</sup>lt;sup>14</sup> AusAID, 2009, <u>Australian Aid to Health Service Delivery in PNG, Solomons and Vanuatu</u>.

form organisations was always going to be challenged. This is a critically important element of the background. PLHIV who were prepared to make themselves known in public were often placed at risk; rather than being respected for the courageous work they were undertaking, they were often treated with gross disrespect because of their HIV status. Their own belief in their potential to form and run a national organisation was often met with cynicism.

It was also clear that neither the NDoH nor NACS was in a position to provide the intense support needed to develop a national representative organisation of PLHIV. This support would need to be sourced externally.

In the context of competing health demands in a resource-limited context, when Igat Hope advocates drew attention to their HIV health needs their requests were often countered with claims that theirs was only one set of needs among many serious health issues being faced in PNG. Igat Hope members were told that they needed to be patient, for example, with their demand for access to second-line ART, and that they should not be demanding special treatment from an already burdened health system.

NAPWHA consultants and staff representatives were often told by people working in PNG that Igat Hope members were, among other things, self-interested, uneducated and incapable of establishing (let alone managing) a national organisation to represent PLHIV. Unfortunately, PLHIV connected to Igat Hope were sometimes seen locally as the problem, not part of the answer. NAPWHA had to work with Igat Hope to change this attitude.

Other barriers experienced by PLHIV included:

- Continued experience of the denial of treatment and care on the grounds of HIV status or for other reasons
- Delays in treatment without apparent reason
- Cessation of ongoing treatment due to interrupted drug supplies
- Differential treatment according to gender and other factors
- Segregation of PLHIV in community and health settings
- Negative attitudes of healthcare workers in relation to HIV infection
- Breaches of confidentiality
- Insufficiently trained staff and poor working conditions
- Uneven geographical distribution of trained and supportive staff. 19,20

These problems are noted not because the partnership between NAPWHA and lgat Hope was meant to address all of these factors, but because they are important to an understanding of the context in which the partnership activity was occurring.

In 2009, AusAID published the report Intensifying the response: Halting the spread of HIV (Australia's international development strategy for HIV). In that report, there were predictions of a dramatic increase in HIV prevalence in PNG, with the suggestion that as many as one in 20 adults might be living with HIV by 2012, mostly in rural locations. When this report was published, AusAID specifically recommended a strategy drawing on Australian expertise to support the 'twinning of Australian organisations with counterparts in the region', including community-based groups. It was

in this context and with reference to this recommendation that the second phase of NAPWHA's work in PNG formally commenced. As noted, these predictions were later revised downwards in light of HIV surveillance data, but AusAID remained greatly concerned about the PNG epidemic for most of the decade over which NAPWHA's inputs occurred.

In 2011, the <u>AusAID Review of Aid Effectiveness</u> heralded the reprioritisation of some aid issues. The review suggested that investment in responding to HIV/AIDS within the region, and in PNG in particular, should be seen in a different way and as requiring the deployment of a different set of strategies. The document foreshadowed a new type of aid program for 2015–2016 that would be less focused on investment through NGOs in favour of more delivery through global partnership programs such as those operated by the World Bank and Asian Development Bank. Of particular relevance to NAPWHA and its work was the recommendation that the Australian Volunteers for International Development program be strengthened.

Soon after the release of this report, AusAID PNG started to suggest that contracts with NAPWHA would, in all likelihood, not be renewed. AusAID began to argue that NAPWHA's inputs could perhaps be replaced by volunteers from the Australian Volunteers for International Development program.

Recently, the AusAID HIV program in PNG has been delivered under a new model of operation. The HIV program no longer operates as a stand-alone set of activities, but is, rather, subsumed within the general health program. AusAID will need to ensure that this merger does not result in a loss of proper focus on HIV.

Given these changes in the way that AusAID supports the HIV response in PNG, and the PLHIV response in particular, it is especially important that lessons learned by NAPWHA through its partnership work with lgat Hope be documented and shared.

As noted, there have been significant changes in predictions about the epidemic in PNG over the last 10 years and significant changes in how AusAID has determined to implement its programs. NAPWHA, in its partnership work with Igat Hope, has had to manage these wild changes in epidemic expectations and correspondingly large shifts in the AusAID policy environment. This was one of the strengths of the partnership – that the partnership approach was sustained within these rapidly changing and complicated contexts.

The partnership also needed to deal with significant barriers to achieving equitable access to ART and rights for PLHIV in PNG. The NAPWHA partnership aimed to position an organisation of PLHIV firmly at the centre of the national response in PNG. To do this, the partnership often had to work against the accepted local and social norms. <sup>21</sup> The lessons from the lengthy NAPWHA experience of being involved in the epidemic response in PNG, when the contexts in which the partnership work was taking place were complex and continually changing, deserve to be noted. They should be used to inform future HIV development work in PNG and, perhaps, in other countries as well.

<sup>&</sup>lt;sup>15</sup> Callick, R., 'PNG refused further AIDS drugs', The Australian, 24 February 2010.

<sup>&</sup>lt;sup>16</sup> Papua New Guinea UNGASS 2008 Country Progress Report — Reporting Period January 2006 — December 2007, www.data.unaids.org/pub/report/2008/papua\_new\_guinea\_2008\_country\_progress\_report\_en.pdf (see p. 64).

<sup>17</sup> Independent Review Group on HIV/AIDS — Report from an assessment visit 28 April—13 May 2011, www.aidsdatahub.org/dmdocuments/Independent\_Review\_Group\_on\_HIV\_AIDS\_2011\_2nd\_Mission.pdf (see recommendations).

<sup>18</sup> Kelly, A. et al., 2009, The Art of Living: the social experience of treatments for people living with HIV in Papua New Guinea, Goroko, Papua New Guinea Institute of Medical Research.

<sup>19</sup> Buchanan-Aruwafa, H. & Amos, A., 2010, HIV Prevention in Rural Economic Enclaves: A Health Workers Baseline Survey, NRI Specific Publication No. 60, National Research Institute, Port Moresby.

<sup>20</sup> Worth, H. et al., 2012, HIV and Human Resources Challenges in Papua New Guinea: an Overview, Human Resources for Health Knowledge Hub, Sydney.

<sup>21</sup> It is not possible to explore all the details of this statement here, but a good reference point is the collection of papers published by the Asian Development Bank: Cultures and context matter; Understanding and Preventing HIV in the Pacific, Manila (2006). This collection of papers suggests that HIV responses in PNG cannot be separated from complex social and cultural processes. The authors argued that 'the multiplicity of ordinary peoples' voices remains unheard and unheeded [in the HIV response]' (p. 67). The voices of PLHIV and members of Igat Hope were among those struggling to be heard.

# 3. The AusAID HIV/AIDS Partnership Initiative 2005–2008

From 2005 to 2008, NAPWHA conducted a development project entitled the AusAlD HIV/AIDS Partnership Initiative (more commonly known as the AHAPI project). The overall aim of the project<sup>22</sup> was to build community and counterpart organisation participation, capacity and knowledge in priority countries within the Asia-Pacific region through formal collaborations and partnerships with like-minded organisations. Partner organisations for this project were:

- Igat Hope
- Timor AID, an organisation based in Dili, Timor-Leste
- Asia Pacific Network of People Living With HIV/AIDS (APN+), a regional organisation based in Bangkok.

The project aimed to build the capacity and visibility of PLHIV organisations and groups through collaborative partnerships. These partnerships were intended to help develop and support PLHIV to provide representation for their peers and to participate in their country's HIV/AIDS response.

The focus of work with Igat Hope was the provision of support for the Igat Hope Coordinator (later to become the Executive Director), support to implement the Secretariat structure, and assistance with Board processes. The overall aim of this work was to enable Igat Hope to act independently within PNG.

Specifically, NAPWHA sought to provide the following forms of assistance:<sup>23</sup>

- <u>Strategic planning</u>: NAPWHA aimed to support Igat Hope to conduct its own consultative and inclusive strategic planning process, resulting in an organisational strategic plan and clear public vision.
- Governance training: NAPWHA aimed to build on its earlier provision of governance training to the Board through additional training on specific governance issues at regular intervals.
- <u>Peer support for new members</u>: NAPWHA planned to address the isolation experienced by PLHIV in PNG via peer support from the NAPWHA membership.
- <u>Expand networks beyond Port Moresby</u>: NAPWHA planned to support lgat Hope to reach out to PLHIV around the country and to support regional PLHIV responses, even where these were developing independent of lgat Hope.
- Promoting lgat Hope to address stigma and visibility issues: NAPWHA
  perceived that communication was critical to lgat Hope's capacity to
  reach out to and advocate for PLHIV, so aimed to help build the
  organisation's capacity to reach out, consult and inform.
- <u>Building skills of positive speakers</u>: NAPWHA aimed to support PLHIV to speak for themselves, but also to train PLHIV in representative skills, in advocacy, and in how to provide technical advice.

NAPWHA arranged for its work to be externally evaluated and participated in an internal process of program review via interviews with the lgat Hope Board. NAPWHA concluded at the time that its partnership with lgat Hope had successfully contributed to the building of that organisation's institutional integrity and capacity.

NAPWHA's project proposal was developed at a time of growing interest in supporting Pacific HIV responses. It was also developed at a time when the projections regarding the HIV epidemic in the region and PNG particularly were quite alarming. In the lead-up to AHAPI, NAPWHA had been asked to participate in a national meeting to discuss the <u>AusAID Analytical Response Report on HIV/AIDS in Asia and the Pacific Region</u>. <sup>24</sup> The meeting was part of the preparation for the larger and very significant policy document, <u>White Paper on Australia's Overseas Aid Program</u>, <sup>25</sup> being prepared at that time. NAPWHA had welcomed AusAID's general approach to HIV in the Asia-Pacific, <sup>26</sup> but had urged AusAID to support:

- A greater role for PLHIV in treatments rollout the PLHIV role needed to extend beyond just advocacy to engagement in the delivery of treatments and the provision of adherence support
- A package of supports for positive leaders so that they might be offered peer support, structural supports (in terms of peer-based organisations) and community support
- A role for PLHIV in prevention education.

These themes were reflected in NAPWHA's first submission for AHAPI funds.

Key NAPWHA achievements during AHAPI included the following.

### 3.1 Assistance with strategic planning

This was provided through regular supportive visits to the lgat Hope offices, participation at Board meetings, and support in the planning and conduct of annual general meetings. Initially, the 'strategic planning' was ad hoc, as it was a major achievement for the Board to even meet when the organisation did not have a Coordinator or an office, or the tools with which to convene Board meetings. In the later phases of the project, strategic planning occurred through twice-yearly governance trainings delivered by NAPWHA. NAPWHA supported lgat Hope to engage with other organisations in PNG with a view to establishing for itself a place within national HIV planning processes.

### 3.2 Provision of governance trainings

These were provided by a NAPWHA consultant who was on each occasion assisted and advised by senior NAPWHA staff and NAPWHA positive representatives (from the NAPWHA Board or volunteer networks). This support was provided to affirm that positive people needed to be central to the development of any program activities. A major outcome was the development of the <u>lgat Hope Governance Kit</u>, which outlined the organisation's objectives and the roles of the Board and Secretariat. The <u>lgat Hope Governance Kit</u> was circulated to donors and partner organisations and became a public document within PNG. It was updated every six months.

<sup>&</sup>lt;sup>22</sup> National Association of PLWHA (NAPWHA), 2008 Annual and Final Report for the AusAID HIV/AIDS Partnership Initiative (AHAPI), 'Strengthening the PLWHA Response – HIV Peer Support and Capacity Building'.

<sup>&</sup>lt;sup>23</sup> NAPWHA proposal for funding part 2.3 Statement of how the project will address development & counterpart needs/issues.

<sup>&</sup>lt;sup>24</sup> AusAID, 2005.

<sup>&</sup>lt;sup>25</sup> AusAID, 2005.

<sup>26</sup> See NAPWHA presentation for the launch of the White Paper on the Australian Government's Overseas Aid Program: 'Australian Aid – Promoting growth and sustainability', available from NAPWHA.

# 3.3 Development of PLHIV representation beyond Port Moresby and organisational capacity for newly established groups

In the initial phases of the AHAPI project, NAPWHA support was focused on establishing a base in Port Moresby for Igat Hope, setting up a functioning office, recruiting a Coordinator (later to become the Executive Director role) and ensuring that processes for financial and contract accountability were established. This support aimed to establish a central location for lgat Hope. At the same time, positive organisations were emerging across PNG – Tru Warriors in Mount Hagen, Good Samaritans and Higher Aims in Madang, the Mendi PLHIV Group, Alotau lgat Hope, West New Britain Group, East New Britain Group, Morabe Group in Lae, Wapennamanda in the Eastern Highlands, and Friends Ministry and Positive Care Foundation in Port Moresby. These groups were supported by various agencies, including Provincial AIDS Councils, faith-based organisations (FBOs) and the Red Cross. Some groups developed close relationships with Igat Hope and others did not. It was not clear during the AHAPI project whether these other organisations would be supportive of a central role for a national PLHIV organisation; indeed, it was clear that some organisations were not prepared to be actively supportive of the emergent lgat Hope. Some in-country organisations were very critical of the actions of individual lgat Hope members and were not prepared to offer the support they were requesting. NAPWHA provided information to the lgat Hope Board about the ways in which NAPWHA operates as a membership organisation and commenced a discussion with the Igat Hope Board about how it might engage other emergent groups in creating a cohesive national PLHIV response.

# 3.4 Promoting Igat Hope to address stigma and visibility issues in PNG

A first step was to assist Igat Hope to gain a 'legitimate' position in-country. Igat Hope members had reported that other agencies operating in PNG did not recognise or acknowledge the potential of an HIV-positive peer response. NAPWHA contributed in the first instance by lobbying other NGOs to support lgat Hope, including by developing supportive relationships with workers in these other NGOs – such as the Red Cross, Anglicare and Family Health International. NAPWHA made representations to the National AIDS Council on Igat Hope's behalf, encouraging the Council to see the importance of supporting Igat Hope. During the life of AHAPI, Igat Hope attained ongoing support from AusAID and other national structures and NAPWHA assisted in brokering many of these relationships. NAPWHA helped facilitate in-country relationships with UNAIDS and WHO. It was NAPWHA, for example, that brokered the first formal meeting between the staff and Board of Igat Hope and the country director of UNAIDS. Following this formal meeting in 2006, UNAIDS began to provide direct technical assistance and support to loat Hope in-country.

## 3.5 HIV healthy living and positive peer support projects

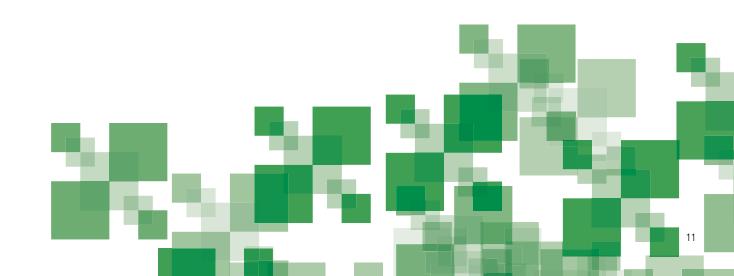
NAPWHA conducted pilot trainings with a positive peer emphasis, including:

- Healthy Living Workshop for Positive Peers (December 2005)
- Positive delegates from PNG were supported to attend the National PLHIV Conference in Australia (November 2005)
- Hungry for Learning *Diba Bona Goada Abia* Workshop (March 2007)
- Positive Speaker Training (March 2008).

A dominant theme in workshop evaluations and feedback was the lack of knowledge, still, around the basics of HIV treatments information. PLHIV wanted to better understand the role of treatments and peer support strategies for supporting treatment adherence and healthy HIV living.

NAPWHA concluded that its work under AHAPI clearly demonstrated the value of a partnership between national PLHIV organisations. Significant connections between members of Igat Hope and NAPWHA representatives had already been made prior to the AHAPI project, and these connections helped contribute to the success of the three-year AHAPI project. Conversely, AHAPI enabled the strengthening of these personal relationships, to the benefit of both organisations.

NAPWHA committed to continuing its support of Igat Hope, and arranged to do this under a bilateral Australia—PNG aid program, specifically with funding from Sanap Wantaim. This Sanap Wantaim-funded work is discussed in the next section.



# 4. Sanap Wantaim contracts 2009–2012

From 2009 to 2012, NAPWHA was funded to work with Igat Hope under yearly contracts with Sanap Wantaim. Regrettably, the 12-month contract cycle meant that a great deal of energy and time had to be devoted to short-term planning and reporting on activities.

While there were some variations between these annual contracts, NAPWHA's primary goals were to:

- Support the governance structure of the organisation
- Strengthen the Secretariat
- Enhance the organisation's treatments advocacy capacity.

Over time, there was a general shift in focus from support for the Board and its governance capacity to support for the Secretariat (especially the Executive Director and program staff) and its capacity to implement programs.

The following table lists Igat Hope's priorities from year to year,<sup>27</sup> along with the major components of NAPWHA's support for each of these years.<sup>28</sup>

	Igat Hope priorities	NAPWHA inputs
2009	Strengthen governance capacity; Build a national network of PLHIV; Strengthen Secretariat	Support to Executive Director; Provide governance training and support; Reinforce specific and distinct roles of elected Board members and paid staff; Provide directions regarding processes for financial management and accountability; Provide direct technical assistance and support to conduct Board meetings; Re-write procedure manuals; Assist in report writing; Assist in securing core funding for lgat Hope; Prepare Igat Hope representatives to participate in external committees and in international conferences and meetings; Develop communication protocols between the Board, Secretariat, regional networks and members; Assist in exploring options for a national role for Igat Hope; Provide support for a members' retreat to discuss progress towards a national organisational structure
2010	Build governance strength; Build a national network of PLHIV organisations; Build skills of the Secretariat	Support to Executive Director and Secretariat staff; Develop position descriptions for staff; Provide governance support; Assist in the development of protocols and policies for Igat Hope's external representatives; Assist in contract negotiation and management; Liaising between Igat Hope and other in-country supporters, such as UNAIDS; Provide assistance with plans to become a national organisation (constitutional reform); Train PLHIV as peer educators
2011	Establish and sustain networks and peer groups across PNG; Address stigma and discrimination; Conduct effective advocacy on treatments and related issues; Operate an effective Secretariat with strong governance, good management and excellent internal systems	Build Igat Hope capacity to be an effective advocate for treatments and care; Provide support to the Secretariat, especially the Executive Director; Consult with the Board and Funding Partners to develop key performance indicators for the Executive Director; Provide information for conflict resolution management; Conduct and manage staff performance appraisals; Assist in budgeting; Strengthen the governance of the organisation; Support the development of a healthy PLHIV workplace policy; Liaise with the Melanesian Centre for NGO Leadership to provide in-country governance support; Help Igat Hope do research in the area of stigma and discrimination; Provide support for the AGM 2012
2012	Support the establishment and sustainability of PLHIV networks and peer groups; Address stigma and discrimination; Effective advocacy on treatments and related issues; PLHIV participation in the response; Operate an effective Secretariat	Build the capacity of Igat Hope to be a better advocate for HIV treatments and care; Link Igat Hope into other national programs related to HIV health advocacy, such as the CHPNG project; Provide direct assistance in developing treatment fact sheets; Help Igat Hope undertake research in stigma and discrimination and engage in the national research agenda; Strengthen the governance of the new national structure, including through help with the AGM 2012

<sup>&</sup>lt;sup>27</sup> As indicated by Igat Hope's annual submission for National HIV and AIDS Strategy funding (Annual Implementation Plan and Budget).

<sup>&</sup>lt;sup>28</sup> As indicated by NAPWHA's annual submissions for National HIV and AIDS Strategy funding (Annual Implementation Plan and Budget).

The following sections outline some of the major NAPWHA–lgat Hope successes for the period to 2012.

### 4.1 Strengthening the Secretariat

NAPWHA retained a central role in supporting the Executive Director. This function was variously described as support or mentoring and involved the following elements:

- Regular face-to-face discussions about management issues
- Regular telephone contact and response to email correspondence
- Development of Executive Director work plans
- Identification of strengths and weaknesses and development of training/skills development plans to enhance work performance.

The Executive Director was twice supported to come to Sydney for on-site training with NAPWHA and its membership.

NAPWHA played a key role in helping the Secretariat expand its workforce. NAPWHA drafted position descriptions/duty statements and developed selection criteria for each of the following positions: Relationships/Network Liaison Officer, HIV Programs Officer, Administration Officer, Deputy Director, NCD Provincial Officer and Financial Controller. NAPWHA managed the recruitment process and also convened and was represented on the recruitment panel for many of these positions. NAPWHA took a pro-active role in these recruitment processes because it was regarded as an honest broker by all parties, including those who were funding different program activities.

NAPWHA provided sample policies and procedures for consideration and, where appropriate, adoption by Igat Hope.

## 4.2 Igat Hope Board elections and constitutional reform

NAPWHA provided technical assistance and direct staff support at each annual membership meeting from 2005 to 2010. This was an agreed partnership activity under the AHAPI project and for the duration of the Sanap Wantaim contracts. Again, NAPWHA's role as an 'honest broker' was valued by the membership, Boards and staff, and also by others involved in the PNG HIV response. NAPWHA was pleased that by 2010 a number of Papua New Guinean supporters of Igat Hope (notably NACS Deputy Director Dr Moale Kariko) were demonstrating great willingness and capacity to provide technical support in relation to member meetings and Board election processes.

In 2010, Igat Hope completed the journey begun two years earlier to become a national body representing all PLHIV in PNG. This represented the culmination of several years of NAPWHA's work to help Igat Hope position itself for national leadership, and to develop a constitutional framework and governance structure reflective of a national leadership role.

In 2010, the membership passed a series of special resolutions changing the structure and brief of the organisation. In the subsequent elections (held in association with its 2010 national summit), Igat Hope elected its first-ever national Board with a new president from the Western Highlands PLHIV group, Tru Warriors, and a vice-president from East New Britain. Other positions included a secretary/treasurer and one position for a person from each of PNG's four regions, as well as a position reserved for a person from NCD and a positive women's representative.

Igat Hope's new structure clarified that Igat Hope was now an umbrella group for PLHIV groups in PNG. It now had organisational members rather than individual members and its new structure meant that it would (eventually, ideally) have an organisational member in each province.

NAPWHA played a key role in the constitutional reform process. Igat Hope had decided to pursue change because:

- Many PLHIV groups were emerging in PNG and there was a need for national coordination
- Even though Igat Hope acted as a national body, its membership was entirely Port Moresby-based and its constitution restricted Board membership to people living in NCD
- Igat Hope was concerned that some other group, with less history and less entitlement to represent PLHIV, would claim to be the national body (for funding or other non-altruistic purposes).

The process began with NAPWHA drafting an options paper outlining different options for national PLHIV leadership in PNG. At a series of meetings and consultations, the Board and membership opted to take the lead nationally, to substitute organisational membership for individual membership, and to restructure voting and the composition of the Board.

NAPWHA drafted the new constitution and the special resolutions required to give it effect.

### 4.3 Building an expanded national network of PLHIV

As it moved towards a new national brief and structure, Igat Hope increased its focus on establishing and supporting PLHIV groups across PNG. The Relationships Liaison Officer (at other times known as the Network Liaison Officer) took the lead on this work and was ably supported by a mentor funded by the Asian Development Bank. Together, the officer and mentor helped establish several new PLHIV groups across PNG, sometimes seeking NAPWHA's assistance in developing constitutions for these groups. NAPWHA also provided advice on national networking, drawing on its own experiences as a national peak of PLHIV organisations. Some of the teething problems experienced by Igat Hope as it sought to build a national network had previously been experienced by NAPWHA, so NAPWHA's voice of experience was often appreciated.

### 4.4 National summits

A key achievement for Igat Hope has been the conduct of two national summits involving PLHIV from across the country.

The first summit was held in 2008 and represented the first time that PLHIV from across the country had had the opportunity to get together to discuss their issues. The summit was held over four days with around 87 PLHIV attending each day. A total of 41 PLHIV from outside Port Moresby were supported to attend the event. In addition, 30 local PLHIV attended sessions each day, although the 30 changed from day to day.

NAPWHA played a key role in developing the program, conducting sessions and facilitating the summit evaluation. NAPWHA funded an experienced PLHIV advocate from Australia to work with Igat Hope on developing the workshop program. Several NAPWHA representatives attended to help conduct workshop sessions. A plenary talk by NAPWHA delegate Kenn Basham, on living long term with HIV, was rated as a highlight by many who attended the summit.

The summit passed resolutions in key areas:

- A greater role for Igat Hope in shaping the HIV training agenda
- Involvement of PLHIV in home-based care
- Distribution of research findings on treatments use
- Understanding and use of the HIV/AIDS Management and Prevention Act
- Non-discriminatory health care
- Campaigning for treatment, care and support
- Availability of HIV treatments
- Church support for PLHIV and treatments
- Treatments literacy training
- Consultation with the National AIDS Council Secretariat

• The role of Igat Hope as national leader and the need to involve people from other regions in the governance of Igat Hope.<sup>29</sup>

The summit was very positively evaluated by participants.

The second national summit was held in 2010. The three-day event featured sessions on:

- Treatment, prevention, care and support
- Stigma, discrimination and human rights
- Leadership and good governance.

Many of the sessions were supported and delivered by lgat Hope staff or other local organisations. NAPWHA consultants attended the summit and assisted in the management of some sessions, but the fact that the summit was largely conducted without external support was a positive reflection of the Secretariat's enhanced capacity. This can be seen as a result of NAPWHA's efforts in helping stage the previous summit. It also reflected NAPWHA's support for the professional development of lgat Hope Secretariat staff.

The summit also enabled the conducting of a survey of all participants that aimed to develop a picture of PLHIV organisations across the country. Delegates were asked about their links to other PLHIV in their provinces, and about their connections with Igat Hope. The survey results were compiled by AusAID PNG to provide a very useful snapshot of PLHIV needs and responses across the country.

### 4.5 The Stigma Index project

Igat Hope membership support for the rollout of the Stigma Index was also assessed at the 2010 summit. As a component of the Sanap Waintaim contracts, NAPWHA had been tasked with providing technical support for this project to get under way. Direct research and consultant support was provided by NAPWHA to the Igat Hope Secretariat to ensure this would happen.

The first tranche of funding to initiate the project and conduct Phase 1 interviews was received from NACS in 2011. UNAIDS was approached to provide support for interviewer training and consultations. Data was collected in the Western Highlands in 2011 through 80 interviews conducted by the PLHIV research team. A preliminary community report was prepared in 2012. This was the first phase of a project during which it is hoped that a total of 450 interviews will be carried out in selected provinces covering the four regions of PNG. The Stigma Index project is significant because the whole project is being managed by Igat Hope and people living with HIV. The project is building PLHIV community knowledge about stigma while engaging PLHIV in the implementation of an important research project.

### 4.6 Treatments advocacy

#### 4.5.1 Treatments advocacy workshops 2010 and 2012

Igat Hope convened the country's first workshop on treatments advocacy on 22–25 March 2010. Treatments advocacy had been identified as a major need during NAPWHA's long-term mentoring work and emerged as a priority after the failure of PNG's Round 9 application to the Global Fund for AIDS, Tuberculosis and Malaria.

The workshop aimed to identify treatments advocacy priorities in PNG, increase the understanding of treatments advocacy, and support PLHIV to be treatments advocates.

The workshop was facilitated by HIV specialist Dr Anne Mijch and a team from NAPWHA, supported by Igat Hope and funded by AusAID. More than 30 participants attended, including PLHIV, policy makers, doctors, nurses and other healthcare providers, community workers and development partners such as AusAID and the ADB. Regions were represented by three regional medical officers, as well as a private general practitioner and PLHIV from each of the four regions.

Dr Mijch provided updates on the HIV epidemic in PNG, new treatments and changes in treatment guidelines such as those relating to the prevention of mother-to-child transmission. NAPWHA presented on adherence support and health maintenance. On the first day, small groups also began to explore the challenges for PLHIV taking ART, challenges confronting those involved in ART service provision, and potential solutions for these challenges.

On the second day, a map of HIV treatments in PNG was constructed from small group consultations focusing on five areas:

- Overall management and funding of the ARV program in PNG
- Prescribing and monitoring treatments in PNG
- Distribution of ARVs
- Support for PLHIV taking ARVs
- Treatments-related advocacy.

AusAID provided an update on the current status of PNG's Global Fund application.

The third day aimed at setting an advocacy agenda for PNG and identifying possible partnerships. NAPWHA drew on its own history to describe the role of advocacy in treatments access. Small groups then worked to agree on main priorities for advocacy, which were then crafted into the <u>Waigani</u> Statement on HIV Treatments Action.<sup>30</sup>

The <u>Waigani Statement</u> focuses on support to people receiving ART and those prescribing and monitoring ART and their links to care networks; supply and distribution of medicines, test kits, reagents and equipment; HIV treatments advocacy; strengthening health systems and their coordination; increasing ART prescribers and rural access; promoting the active involvement of PLHIV organisations; and the employment of PLHIV as employed peer educators in clinics.

On the fourth and final day, the draft of the <u>Waigani Statement</u> was presented to the Acting Director of NACS.

In order to take the work forward, Igat Hope agreed to convene an alliance of treatment advocacy partners to work together with the PNG NDoH.

A smaller workshop was convened in Port Moresby by NAPWHA in December 2012. One of the reasons for this event was to try and kick-start the advocacy process that had been promised by the <u>Waigani Statement</u> but which, regrettably, had not developed as hoped.

Participants included 11 workers and volunteers from PNG clinics (from several provinces) and Igat Hope staff. The sessions included general advocacy, advocacy from an Igat Hope perspective, treatments guidelines and access policies, treatments uptake around the country, and practical exercises in building treatments advocacy capacity. The workshop was conducted by NAPWHA's Treataware Senior Project Coordinator, a doctor from Port Moresby's Hederu (HIV) Clinic, and the Igat Hope Executive Director. Twelve participants completed evaluation forms and the feedback was extremely positive.

<sup>&</sup>lt;sup>29</sup> This was the first step in Igat Hope's journey to become a national peak of PLHIV organisations.

<sup>30</sup> Waigani Statement on HIV Treatments Action, 2010, available from NAPWHA or Igat Hope.

The workshop occurred at an opportune time: lgat Hope was at that time engaged in the development of a strategic plan with the assistance of AusAID. The treatments advocacy workshop fed nicely into the development of this plan, with treatments advocacy-related goals being helpfully identified.

#### 4.5.2 Other treatments work

In the period between the two forums, NAPWHA had worked with Igat Hope to develop and publish a treatments information brochure, <u>HIV</u> <u>Anti-Retroviral Therapy (ART) and Adherence</u>. This easy-to-read brochure covered the basics of ARVs, tips for promoting compliance, issues relating to side effects, and general health maintenance. The brochure was well received by Igat Hope constituents.

NAPWHA also supported an 18-month program aimed at encouraging HIV and sexual health clinics in PNG to engage PLHIV in the delivery of services. Funded by the Collaboration for Health in PNG<sup>32</sup> and operated through Igat Hope, this HIV Health Support Project supported a number of pilot sites to employ PLHIV to work with HIV-positive patients to increase understanding of HIV treatments and promote compliance with treatments regimens.

# 4.7 Maintaining positive governance, especially in times of crisis

Arguably NAPWHA's greatest contributions to Igat Hope fell into the category of 'crisis management'. One problem with the Sanap Waintaim contracts was that there was very little flexibility for NAPWHA to respond outside of the activities as negotiated with AusAID at the beginning of the contract. So there were no budget lines, for example, to cover NAPWHA interventions to deal with unanticipated governance crises. This created significant challenges when NAPWHA was routinely asked to help resolve disputes between the Board and Secretariat staff.

The response from NAPWHA in these circumstances often involved urgent interventions and trips to Port Moresby that had not been budgeted for. Arguably, in-country organisations should have been able to provide more assistance in these circumstances, but this was not the case.

It would not be appropriate to provide too much detail regarding the events that precipitated NAPWHA's crisis interventions. Suffice it to say that they involved the following:

- Questions regarding the appropriate use of funds, specifically differences of opinion within the organisation and broader membership as to how money might be lawfully and contractually expended
- Disputes between the Board and Executive Director, which paralysed the organisation and threatened its funding
- Ill-health of staff members at critical times, preventing the organisation from meeting its core responsibilities (such as meeting deadlines for reporting to funders or submitting proposals for funding).

NAPWHA's contributions at these times were critically important. NAPWHA was able to play this role because:

- There was a level of trust between NAPWHA and Igat Hope built as a consequence of the spirit of partnership within which the organisations had been collaborating — that meant Igat Hope felt that it could turn to NAPWHA in times of crisis
- As NAPWHA was not a funder per se, its knowledge of lgat Hope's

- difficulties did not threaten Igat Hope's funding
- It was helpful for funders to have ways of resolving problems without having to involve themselves directly in the dilemma; NAPWHA enjoyed a flexibility and capacity for creative problem-solving not always afforded government departments or other agencies.

The crises that Igat Hope experienced were not unusual. Many community groups experience these challenges over time. But there were some local factors that made Igat Hope's challenge even greater:

- There were no real local models or precedents to which lgat Hope could look for guidance; lgat Hope was charting new territory in being PNG's first PLHIV group and the first national peer-based health advocacy group in the country.<sup>33</sup>
- Igat Hope was confronted with a high level of expectation from members, funders and other stakeholders – which was extremely challenging for an embryonic group. Members wanted it to be both advocacy agency and service provider.
- In the context of a country where many people have limited income and scarce resources, when funding did become available the payment of per diems or travel fares to attend meetings created a competitive environment. When paid positions became available within the Secretariat, these were highly contested.
- Resources available to respond to the HIV epidemic in PNG were scarce and hard fought for. For Igat Hope, the scarce resources and unwillingness of local agencies to fund its core activities sharpened the challenges for the organisation.
- While lgat Hope enjoyed strong and consistent support from AusAID, its support from other donors was unpredictable. Igat Hope never knew from one year to the next what funding it would receive, and this made planning extremely difficult. It also made it difficult to recruit and retain staff.
- Donors (with the exception of AusAID) were also reluctant to fund lgat Hope's core Secretariat needs. This meant that lgat Hope was constantly being loaded up with 'projects' and numerous 'requests' to provide representative PLHIV input into national planning meetings. What it actually needed was support for its core costs (such as rent, utilities, governance and management). This donor preference for funding showy projects rather than unglamorous administrative needs left lgat Hope lacking basic institutional strength. At different times, this vulnerability became extremely apparent.

Given the context, it is no wonder that Igat Hope experienced problems from time to time. But neither community organisations nor their donors tend to plan particularly well for crisis management, and crisis management is not something that donors traditionally want to fund. As a consequence, much of NAPWHA's work in this area was not funded and, for obvious reasons, it was not always widely reported. Even so, these supports were important. That Igat Hope was able to survive these periods of trauma, when many organisations would have been unable to do so, was a testament to the dedication of its staff, volunteers and members, as well as to NAPWHA's ability to respond quickly and appropriately to Igat Hope's emerging needs.

<sup>&</sup>lt;sup>31</sup> Written and published by NAPWHA in 2011 with support from Igat Hope, funded by AusAID and available from Igat Hope.

<sup>&</sup>lt;sup>32</sup> In 2001, a group of like-minded pharmaceutical companies decided they wanted to address the HIV issue in PNG. The following aims were agreed: to engage with and learn from regional and global networks involved in HIV care; to understand the factors — cultural, social, political and economic — that affect access to treatment and care; to encourage cooperation among the health providers — faith-based, private, non-government, academic and public; and to help develop healthcare capacities and systems. The Collaboration funds NAPWHA and the Australasian Society for HIV Medicine to carry out HIV development work in PNG.

<sup>33</sup> See McPherson, A. & Rule, J., 2010, Hope through positive governance, HIV Australia, vol. 8, no. 2, pp. 18–20, www.afao.org.au/library/hiv-australia/volume-8/hiv-and-png/lgat-Hope.

## 5. Issues arising and lessons learned

# **5.1 The impact on NAPWHA of running an international program**

NAPWHA experienced a range of challenges in conducting this international program. The most significant of these are outlined below.

#### 5.1.1 Learning the practice of development assistance

International development is challenging work. It requires expertise in development issues, poverty, power, gender and aid. In an international context, these were new areas for NAPWHA and they all came with their own complexities. In no sense was NAPWHA's PNG work 'just another project'. It could not be easily added to the organisation's other activities. Entirely new understandings had to be acquired and new skills developed within NAPWHA. PNG is also recognised as a difficult place to work, so the challenge confronting NAPWHA was even greater. The concerns about the size of the HIV epidemic emerging in PNG added an extra sense of urgency and responsibility to the work being carried out.

AusAID's contracts with NAPWHA referenced 'international development principles'.<sup>34</sup> In so doing, AusAID made clear that best practice approaches involved working in partnership and developing creative and trusting relationships with people in developing countries. AusAID mandated that development programs:

- Prioritise the needs and interests of the people they serve and involve beneficiaries in program design and implementation
- Promote an inclusive approach that reaches the most vulnerable, especially people with disabilities and women and children
- Encourage self-help and self-reliance among beneficiaries
- Avoid encouraging dependency by engaging beneficiaries and facilitating their contributions
- Respect and foster human rights
- Be culturally appropriate and accessible
- Seek to enhance gender equality
- Protect not-for-profit organisations
- Protect children from harm and abuse
- Integrate environmental considerations
- Promote collaborative approaches to development challenges.

While NAPWHA had been applying many of these principles in its domestic work for years, it had to learn (fast) that development is a unique discipline with its own philosophies and frameworks, its own 'hot topics' and a language all of its own.

#### 5.1.2 Funded and unfunded inputs

A significant portion of NAPWHA's input costs was not funded by the organisation's international grants. AusAlD was interested in funding project activities rather than NAPWHA's salaries, management costs or administrative on-costs. Funders were willing to 'add on' to NAPWHA's resources, but reluctant to contribute to the core costs that would enable the NAPWHA Secretariat to implement proposed project activities. The regular input of NAPWHA Board members and the significant and helpful advice of volunteer members of the NAPWHA AHAPI Reference Group were never properly supported or funded through the AusAlD grants.

At best, NAPWHA was able to attain funding for the equivalent of part of a project officer's salary (two or three days per week) to assign to this international project work. This meant that time devoted to the PNG project by NAPWHA staff was not always covered by international grants. This

was especially the case for the NAPWHA Executive Director, who had to spend a lot of time initially with contract negotiations (a task then taken up by the NAPWHA Deputy Director), as well as for NAPWHA's finance and administrative personnel.

#### 5.1.3 The international verses domestic balance

It was also difficult for NAPWHA to balance its domestic and international commitments. Not everyone within the NAPWHA membership thought it appropriate for NAPWHA to be engaged in international work. Some constituents felt strongly that NAPWHA should remain focused on domestic challenges. Given NAPWHA's very limited resources, and the multitude of challenges on the domestic front, this was a compelling argument. Indeed, NAPWHA's international work did divert resources from its domestic work, and some local issues could not be pursued because resources had to be allocated to international activities.

It was apparent to observers that AusAID was not covering all costs associated with the PNG program, so those who argued that the domestic program was propping up international work had some evidence to support their claims.

It was *not* the case that these people opposed HIV development work in PNG *per se.* Instead, they argued that NAPWHA's priority (historical and constitutional) had always been — and should remain — the Australian HIV response. They argued that international work should be pursued only if it was properly funded and did not reduce NAPWHA's effectiveness domestically.

Others within the NAPWHA membership were passionate advocates of doing *more* international work. Tensions over this were evident at different times and debated thoroughly through Board and membership meetings. The tension was exacerbated by the fact that NAPWHA was never funded to the extent that it could employ a full-time worker to focus exclusively on international work. Consequently, the NAPWHA employee with primary responsibility for PNG always had domestic responsibilities as well. The worker's struggles to achieve balance between these two areas of responsibility were mirrored in the membership's own tensions.

#### 5.1.4 Personal impacts

To conduct its work in PNG, NAPWHA was reliant — to a very significant degree — upon volunteers from within its membership. Many from within the membership gave freely of their time and expertise. But working in PNG took its toll on many of these volunteers.

NAPWHA volunteers were confronted by the extreme poverty experienced by many PLHIV, by the levels of violence and discrimination directed towards PLHIV in PNG, by the systematic gender violence, by the mistreatment of gay-identifying and men-who-have-sex-with-men, by the problems for transgenders, and by the lack of access to treatments for HIV and opportunistic infections or basic health care.

Some volunteers found the work extremely distressing. This cost, though primarily personal, had an institutional dimension in that NAPWHA needed to meet its duty of care by providing ongoing support as well as debriefing and counselling for some volunteers who had been negatively impacted by their engagement with Igat Hope.

This was also true for some staff, and in very occasional cases staff were so impacted by their work in PNG that they required periods of leave. Again, these costs had personal and organisational dimensions.

# **5.2 The Igat Hope Board and the constituency**

The volunteers engaged in the establishment of Igat Hope, and in its subsequent operations, were generally poor. Few had had the opportunity to attain educational qualifications, few were employed, and many struggled to support themselves and their families without any regular income. The struggle to survive without income is hard for any Papua New Guinean, but the struggle for Igat Hope members was exacerbated by their frequent ill-health and subsequent need for mostly unaffordable care.

Many of the earliest gatherings of PLHIV in PNG occurred via drop-in centres. These centres provided dual services — they offered free meals for hungry PLHIV as well as opportunities for peer connection. From the beginning then, there was a link between PLHIV coming together and access to welfare services. Early lgat Hope events attracted not only activists interested in a positive policy response to HIV, but also many people interested in obtaining from lgat Hope financial support or assistance with access to food and medicines. A majority of lgat Hope members were more focused on the latter.

Elected Boards tended to reflect the membership and, as a consequence, were mostly comprised of volunteers with little or no experience in governance, management or employment. Boards lacked governance capacity in terms of financial management skills, program management, employment/industrial responsibilities and advocacy. At each AGM there was a high turnover of Board members, so it was difficult to build the governance capacity of the lgat Hope Board.

It is also true that efforts to build the capacity of the Board could have been better tailored. One-off trainings were insufficient to build real governance capacity, particularly given the rate of Board turnover at each AGM. While NAPWHA did take steps to establish mentoring relationships between the Board and local providers of governance support, these were not as successful as they needed to be.<sup>35</sup> This is not a reflection on NAPWHA or lgat Hope, but an acknowledgement of the difficulties experienced in building civil society capacity in PNG.

Limited funding also meant that the Board did not meet as often as would have been required to build momentum in governance capacity.

The profile of the constituency and Board membership, specifically the poverty and the health issues due to HIV and other opportunistic infections with which members were struggling daily, made it difficult to achieve consensus on the organisation's primary goal. While many within lgat Hope were keen for the organisation to take on a national advocacy role, others wanted the organisation to provide 'services' (in fact, food, medicines or cash grants) to members. Of course, this was completely understandable. It was hard for members to focus on policy goals when they were focused primarily on feeding themselves and their children.

Donor agencies were disinclined to provide Igat Hope with any funds that could be allocated to individuals in need. For this and other reasons, Igat Hope chose in the end to focus primarily on policy and advocacy. Welfare services were left to other agencies. The unit of this decision was made by the Igat Hope Board, and confirmed by subsequent Boards, there continued to be a significant force within the membership that wanted Igat Hope to refocus on welfare services. This tension distracted the organisation from its policy and advocacy activities. The advocacy-versus-welfare debate has had a long history within the Australian HIV response, so it should not be surprising that it also arose in the PNG context. But in the context described above — of poverty, ill-health and the immediacy

of a range of needs – it was difficult to get complete agreement from Board and Igat Hope members about the organisation's priorities.

Upon reflection, NAPWHA might usefully have helped in the establishment of a PLHIV charitable trust in PNG (akin to Australia's AIDS Trust or Bobby Goldsmith Foundation), which could have sought funds for welfare services. By helping set up a charitable foundation, NAPWHA might have helped relieve lgat Hope of some of the pressure to be all things to all people. Indeed, these models were discussed but not progressed.

### 5.3 Remuneration in PNG

From its earliest moments, NAPWHA has been made possible only through the hard work of PLHIV, who may have seen themselves as activists and advocates, but who essentially volunteered their time and efforts to build the organisation. NAPWHA continues to be governed by a Board of volunteers, and many PLHIV in Australia contribute to NAPWHA's policy and project activities without the expectation of being paid for their contribution.

Those PLHIV who initiated Igat Hope and were engaged in its subsequent operations were also volunteers. While their efforts may have been similarly inspired by activist and advocacy traditions, they were also dealing on a daily basis with a range of challenges, making voluntary contribution more difficult. They were generally poor and struggled to support themselves and their families without any regular income. The absence of a proper health system and, in the early days, of access to ARVs meant that many of Igat Hope's volunteers were often very unwell. By virtue of their economic and social circumstances, many of Igat Hope's initiators had less capacity to give than their Australian counterparts.

Understandably, many of those individuals who initiated lgat Hope wanted to attain some advantage through their work. Many Board members (and organisational members) thought that their association with lgat Hope might give them access to money — to cover medical expenses, or food or school fees. They thought that this would be appropriate on the basis that they deserved some compensation for their efforts, particularly given the opportunity costs of giving time to lgat Hope — time spent helping lgat Hope was time that could not be spent working or looking for work.

This expectation generated challenges. NAPWHA had to work harder than anticipated to keep Board and organisational members from trying to access for personal benefit funds that had been allocated to the organisation for project activities. While NAPWHA did provide Board members with training in fiduciary responsibilities, this did not achieve the level of universal understanding required.

It also raised for NAPWHA and funders challenging questions about the divide between 'reimbursement for expenses' and 'remuneration'. NAPWHA was often engaged in arguments over reimbursements, per diems, sitting fees, honorariums, token payments, etc. The comparative (extreme) wealth of NAPWHA staff and volunteers made these arguments more difficult. On a personal level, it was sometimes difficult for NAPWHA representatives to argue against payments to the members of lgat Hope who had obvious need for support, yet lgat Hope funding contracts precluded such payments and they were inconsistent with the organisation's commitment to its constituency.

The matter was further complicated in the PNG context, where multilateral agencies such as WHO had comparatively generous policies regarding per diems and reimbursements. Many lgat Hope members were receiving benefits from participating in WHO-sponsored activities. This WHO approach contrasted with the approach taken by many of the FBOs active

<sup>34</sup> See 'Statement of International Development Principles' as included in (for example) 2011 Grant Agreement Deed between Commonwealth of Australia (AusAID) and NAPWHA, available from NAPWHA.

<sup>35</sup> Efforts to build an ongoing relationship between lgat Hope and the Melanesian NGO Centre for Leadership (MNCL) produced some results, but changes in MNCL personnel and other factors limited the effectiveness of the partnership.

<sup>&</sup>lt;sup>36</sup> Some Igat Hope members established the Positive Care Foundation to access welfare funds.

in HIV prevention work whose policies precluded the payment of per diems and reimbursements to PLHIV volunteers. Indeed, NAPWHA was advised by a senior officer of one such FBO that NAPWHA was wasting money in providing basic reimbursements such as bus fares to attend meetings. NAPWHA had to walk a tightrope in its management of these matters, as the partnership activities between NAPWHA and Igat Hope were being closely observed by other organisations working in HIV in PNG.

And while NAPWHA struggled to walk this tightrope, it is also true that members of lgat Hope occasionally failed to manage these challenges appropriately. These issues were highlighted in the independent audit of lgat Hope commissioned by AusAID and UNAIDS In 2011.<sup>37</sup>

These issues are common across programs in PNG and have been documented elsewhere.<sup>38</sup> For NAPWHA, it was a continual learning process. It was clear that:

- There was strong support among PLHIV for the existence of a national representative organisation
- The organisation should work for the benefit of all PLHIV in PNG
- Many PLHIV were prepared to work hard to build this organisation (and did so).

It was also clear that many PLHIV had an expectation that engagement with the organisation would bring some benefits and that participation and efforts would be rewarded, particularly given the comparative wealth of the organisation and the poverty experienced by lgat Hope members.

This tension endured for the life of the NAPWHA-lgat Hope collaboration.

### 5.4 Approaches to money and resources

As noted previously, Igat Hope Board and organisational members did not always see it as reasonable that they should be denied access to organisational funds. They often argued that their undeniable need for assistance could easily be met by an organisation that had, at its peak, over a million kina annually.

Yet donors were always very clear that lgat Hope funds were to be expended only for very specific and pre-authorised purposes, such as infrastructure/assets, staff salaries, resource production or project activities. Donors did not authorise the use of funds for the personal benefit of individual members. Even so, lgat Hope sometimes struggled to observe this restriction.

This is obviously understandable in light of the very real needs experienced by Igat Hope members. It is also understandable in the context of aid programs in PNG, where there are many 'narratives of corruption'. The notion that Board members hold money on trust for a larger constituency was quite often resisted. It was rarely accepted without argument and, often, when agreement was reached, the agreement was breached through subterfuge.

This story is not unusual in PNG and, as argued by Walton (2013), responses are often 'marked by an over-reliance on "mainstream" Western interpretations of the definition, causes and solutions to corruption'. 39 Walton argues that attitudes to the ways in which money and resources are distributed within communities in PNG require a 'critical' investigation that needs to be carried out in ways that attend to cultural contexts and traditions. In other words, it is false to assume that Board members of lgat Hope would see their relationship with and responsibility to the

organisation's resources in the same way that Board members of NAPWHA might see theirs.

Igat Hope struggled to develop internal systems for managing and reporting on money. AusAID's 'zero tolerance' approach to misuse of funding is not an approach seen in broader public life in PNG, so Igat Hope was being asked to apply standards much higher than those seen in PNG government and business.

It took some time for Igat Hope to develop appropriate money management systems. In retrospect, NAPWHA might have pushed earlier on for the recruitment of an employee with financial management skills (although this would have been difficult at the beginning, with such modest levels of organisational funding).

Despite these challenges, it was a major achievement on the part of lgat Hope to successfully attain independent audits for each year of its operation. Igat Hope retains an organisational surplus. Even so, the independent audit<sup>40</sup> called for enhanced money management policies and procedures.

Igat Hope was fortunate to have a number of different funders at various times. While AusAlD was the most reliable and generous of its donors, Igat Hope also received funding from NACS, the Global Fund, UNDP, the ADB and NAPWHA. There was a regrettable lack of coordination among donors. On occasions, different donors funded substantially the same activities at the same time. Most donors had their own unique reporting requirements. Igat Hope struggled to manage so many different sources of funding and different reporting requirements.

Igat Hope also had to manage the desire on the part of Boards to spend money on members in the lead-up to Board elections (by paying people to come to the AGM, or by hosting BBQs for the members, etc.). Board members argued that it was appropriate to encourage members to participate in elections and that there should be some tangible benefits of membership. NAPWHA argued that this was problematic and would not be acceptable to donors. NAPWHA noted that the practice is common in PNG national politics and it was not always easy to explain that what was permissible at the level of national politics was not permissible for Igat Hope.

### 5.5 Concepts of peer

Peer — A person of the same standing or rank ...; a person or thing of the same effectiveness or ability ...; a person of the same age-group or social set ...; a person who is associated with another; a companion<sup>41</sup>

The notion of peer was central to NAPWHA's work with lgat Hope. The term appears in practically all of NAPWHA's proposals for work with lgat Hope and in nearly all its reports of work completed.

From its earliest days, the collaboration between PLHIV in Australia and PNG was grounded in the shared experience of living with HIV. This was the essence of the peer connection underpinning NAPWHA's work and the foundation of many friendships between Australian and PNG PLHIV activists.

NAPWHA felt very strongly that PNG's first HIV-positive activists and advocates should receive personal support through NAPWHA's work. NAPWHA recognised that these people were exposed to high levels of stigma and discrimination, including threatened and actual violence. NAPWHA was inspired by the courage of these earliest activists and sought to provide them with a degree of peer support through its work in PNG.

<sup>&</sup>lt;sup>37</sup> Le Mesurier, R., and Dee, C., <u>Systems and Organisational Audit of Igat Hope Incorporated, Port Moresby, PNG (Audit period: 24 November to 16 December 2011)</u> — Wok bung wantaim bilong yumi olgeta, available from Igat Hope or AusAID.

<sup>38</sup> See Van Reyk, P., The Price of Wok Sol - A review of Tingim Laip Volunteer Activity, July 2011, available from Tingim Laip.

<sup>39</sup> See Walton, G., 'An argument for reframing debates about corruption: insights from Papua New Guinea', Asia Pacific Viewpoint, Vol. 54, No. 1, April 2013.

 $<sup>^{\</sup>rm 40}$  Le Mesurier, R., and Dee, C., op.cit.

<sup>&</sup>lt;sup>41</sup> The New Shorter Oxford English Dictionary (1993).

In some important respects, NAPWHA's representatives were not the peers of PNG's earliest positive activists: NAPWHA representatives tended to be older, relatively wealthier, and often in a better state of health, and were more likely to be male and homosexual than their PNG counterparts. Over time, NAPWHA developed a much more sophisticated understanding of what it meant to have peer links between Australian and PNG PLHIV.

But NAPWHA's commitment to peer linkages extended beyond the personal. NAPWHA felt strongly that only a positive organisation could understand lgat Hope's challenges. NAPWHA believes that time has shown this to be true. Many of the most difficult challenges confronted by lgat Hope were more or less specific to positive organisations, and NAPWHA was able to draw on its own experiences to offer advice and support to lgat Hope. These challenges included balancing the need for advocacy with demands for welfare services, dealing with ill-health among Board or staff numbers, and the difficulties arising for HIV-positive Boards managing HIV-negative staff. These are all issues that NAPWHA has had to deal with over the years, so NAPWHA was able to offer lgat Hope the benefits of its own experience in these complicated areas.

NAPWHA's earliest representatives in PNG were all PLHIV. Over time, NAPWHA began to send HIV-positive and HIV-negative representatives. This corresponded with a shift in the focus of NAPWHA's support from working with the Board to working with the Igat Hope Secretariat. NAPWHA took steps to ensure that the peer element of its work was never lost:

- On most occasions that a HIV-negative staff member or consultant was sent to do work with lgat Hope, she or he was accompanied by a NAPWHA representative with HIV
- The NAPWHA Board (membership of which is conditional upon being a person living with HIV) retained a keen interest in and overall responsibility for the work of all NAPWHA representatives
- Anyone working on NAPWHA's behalf, whether paid or unpaid, was required to have a solid understanding of the importance of positiveled responses and commitment to the GIPA (greater involvement of people living with HIV/AIDS) principle.



### 5.6 Concepts of partnership

Partner – a person who possesses something jointly with another; a participant who takes part with another or others in doing something; an associate, a colleague

Partnership – the fact or condition of being a partner; an association of two or more people as partners<sup>42</sup>

NAPWHA and Igat Hope often described their collaboration as a *partnership*. NAPWHA has observed that most international aid agencies claim to work in *partnership* with in-country groups. Yet the nature of these partnerships differs vastly, and some clearly have little relation to what a partnership is commonly understood to mean.

The partnership between NAPWHA and Igat Hope was multifaceted, and for this and other reasons the partnership was complex.

In using the term *partnership*, NAPWHA meant more than just *collaboration*. It was not just working with another organisation, but working with that organisation in a particular way that was inclusive of shared goals and involved respect for the institutional integrity of the other party and, more contentiously, some notion of equality.

AusAID funded NAPWHA primarily to provide technical assistance to lgat Hope. NAPWHA's role was described as *providing support* to lgat Hope through the provision of technical assistance. But decisions on how to spend AusAID funds in the partnership project were ultimately taken by NAPWHA. While lgat Hope's advice was regularly sought as to what sorts of technical assistance it might like, NAPWHA made final decisions about expenditure (consistent with its fiduciary responsibilities). It must surely have seemed to lgat Hope — at least at times — that these funds *belonged* to NAPWHA rather than them being held by NAPWHA on *trust* for lgat Hope. The NAPWHA role was also described in ways that indicated NAPWHA's comparative power, such as NAPWHA was to 'mentor', 'strengthen', 'build' lgat Hope's capacity, etc.

Igat Hope did in fact need the skills and capacities that NAPWHA possessed. Igat Hope recognised that, in order to survive and function in the ways expected by its members, it would need funding. Igat Hope further recognised that the sorts of skills and capacities that donors would require of Igat Hope — the sorts they would demand before parting with funding — were those that NAPWHA was offering to build. Igat Hope must have seen that those skills NAPWHA was offering to build — governance capacity, financial management and accountability, monitoring and evaluation — were critical to the organisation's chances of long-term survival.

But NAPWHA's influence over lgat Hope's access to funding extended beyond its possession of skills in governance and financial management. Through its very close relationship with AusAID and other funders, NAPWHA was able to shape donor views on lgat Hope's viability and sustainability, at least to a degree. AusAID and other donors would, from time to time, seek advice from NAPWHA as to the functionality of lgat Hope and it must have been apparent to lgat Hope that NAPWHA could jeopardise its access to ongoing funding from these sources. This is not to suggest that donors would rely solely on NAPWHA's views in making funding decisions, but it is fair to say that NAPWHA was able to shape some decisions by some donors as to how much funding might be provided and the conditions upon which it might be provided.

NAPWHA must also have been seen as a gateway to other benefits, offering as it did occasional opportunities for lgat Hope personnel to travel to Australia or other destinations for meetings, conferences or trainings.

And, as noted earlier, some of NAPWHA's most significant inputs occurred at times when lgat Hope was at its absolute weakest. At these times, the power imbalance between the organisations must have seemed very great. Sometimes, the partners did not always look equal.

## 5.7 Why is it so hard to build treatments advocacy in PNG?

NAPWHA tried repeatedly to build treatments advocacy capacity in PNG, with mixed results for its efforts.

The treatments advocacy forums in 2010 and 2012 were successful events and the <u>Waigani Statement on HIV Treatments Action</u> was a good blueprint for further work. But progress has been undoubtedly slower than anticipated or desired.

It is important that NAPWHA reflect on the apparent slow rate of progress in this area. The following factors may have contributed to this slow rate of progress:

- Most advocacy plans were constructed in the expectation that Igat
  Hope would play the lead role. Igat Hope experienced a number of
  (previously detailed) internal capacity difficulties over the years, and
  these reduced its ability to drive a treatments advocacy agenda. In
  retrospect, NAPWHA failed to have ready a 'Plan B' for times when
  Igat Hope was unable to lead national advocacy efforts.
- Compared with many other nations, PNG achieved ARV availability relatively early in its epidemic. But the rollout was managed by international agencies and government departments with minimal engagement of local PLHIV. Right from the start, PLHIV were cast as the passive recipients of donor programs. PLHIV were sometimes regarded as being incapable of learning the details required. This approach, regrettably common with aid programs in PNG, does little to encourage the intended beneficiaries of programs to be engaged in the design or delivery of the programs intended for their benefit. This is bad enough when the programs are being rolled out successfully, but PNG's treatments program has been plagued by supply and distribution problems, stock-outs and shortages of trained healthcare personnel. PLHIV have had to observe these problems as outsiders, and have struggled to gain access to the forums in which program decisions are made.
- The enormity of the structural health system barriers in PNG cannot be underestimated. Any advocacy plans that were developed remained contingent on factors well outside the control of Igat Hope and PLHIV.
- There are real challenges in teaching advocacy. NAPWHA and others provided training in both advocacy and treatments awareness, but these tended not to result in discernible increases in on-the-ground advocacy. NAPWHA may have needed less focus on the describing of treatments advocacy and more focus on working with lgat Hope to do treatments advocacy. It is noted that lgat Hope made great progress with its regional networking when the ADB funded a full-time mentor to work with the lgat Hope Regional Liaison Officer. If a mentor had been placed within lgat Hope to work on treatments advocacy, more progress would have been made in this area.
- Follow up from the advocacy workshops was not supported so well by in-country partners of Igat Hope. The support promised locally was often not provided after the workshop program was conducted. There was no mechanism in place whereby NAPWHA could monitor how PNG agencies fulfilled the commitments made in these workshops.
- The health of individual activists and staff members of Igat Hope has been a real barrier to progress in this area. This is a critically important factor. By way of example, in June 2006 NAPWHA facilitated a planning day in Port Moresby with the Board of Igat Hope, a focus of which was the development of a treatments advocacy program. Of the eight active and committed Board members in attendance that day, three have since died. Max Mea, Fio Lunigi and Helen Samilo were all important parts of the treatments knowledge base of Igat Hope. Their deaths, and the ongoing illness of others, have made the establishment of treatments advocacy in PNG a difficult task. The loss

of each of these and other HIV community leaders has greatly reduced the capacity of Igat Hope to engage in effective treatments advocacy. Each personal tragedy has been a tragedy for PNG.

HIV advocacy and activism have occurred in the Australian HIV
response in particular and unique ways. Individuals who have taken
on advocacy and activist roles have been shaped within particular
social and cultural contexts. It would be naive to assume that the
experience of developing a treatment advocacy program and training
skilled individuals to carry out that program in Australia could simply
be shifted into a different, and differently complicated, environment
such as PNG.

In retrospect, NAPWHA might have been more successful with a slightly different approach. It might have been better to try to source a long-term, on-the-ground mentor for lgat Hope staff — perhaps a volunteer or a paid officer, such as the one funded by ADB to support lgat Hope's regional liaison. And NAPWHA should have developed a Plan B for driving treatments advocacy at times when the capacity of the lgat Hope Secretariat was inadequate or when PNG institutions did not provide the promised support.





## **5.8 Performance Indicators for future projects**

NAPWHA and AusAID enjoyed a very good working relationship.

AusAID (PNG) had a very good sense of the difficulties associated with development work in PNG. It was careful not to expect too much from lgat Hope in its earliest years. It also appreciated that NAPWHA was learning as it went into PNG and showed patience in its dealings with NAPWHA.

Given the challenges associated with doing development work in PNG, the 'land of the unexpected', it was appropriate to demonstrate some flexibility in terms of performance indicators. It is also true that the way in which a community organisation develops can be shaped by so many different factors — so few of which the organisation can control — that it is hard to set fair indicators for performance.

But the flip side is that without proper indicators it is hard to show whether or not an organisation's strength is increasing or decreasing. It was hard for Igat Hope and NAPWHA to measure the rate at which Igat Hope was developing into a robust community-based organisation. It was hard for AusAID to make assessments as to Igat Hope improvements, or NAPWHA's success in building a strong peak in PNG.

NAPWHA believes that it may have been useful to have clearer indicators to measure lgat Hope's institutional strength. NAPWHA suggests the following as possible indicators for future similar projects.

#### Structural strength

- A constitution that is broadly reflective of aims and intended functions
- A constitution that describes the role of members and Board members (and possibly the CEO)
- Positive membership a constitutional provision or membership policy that asserts the primacy of PLHIV membership
- Some verifiable efforts to build/expand membership
- A register of members
- AGMs held each year, with quorum being achieved at each AGM
- Constitutional elections at regular intervals

#### **Board**

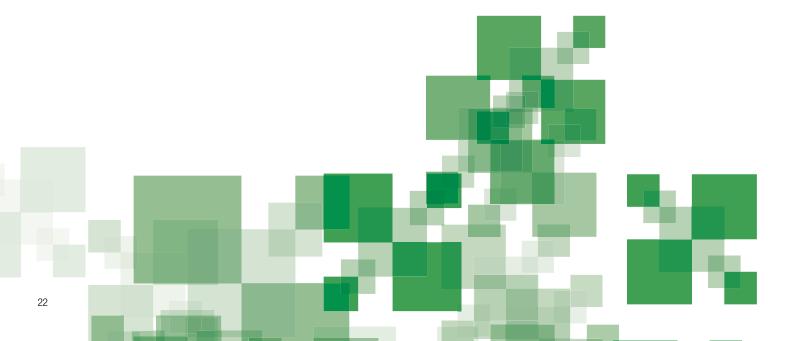
- Clear roles for Board members
- Constitutional behaviour
- Board positions filled
- Board meetings held with quorum achieved
- Board decisions as evidenced by minutes of meetings or other records
- Governance training for Board members
- Exercise of governance functions:
  - Employment/supervision of Executive Director
  - Exercise of financial oversight
  - Holding of meetings, etc.

#### **Finances**

- Annual audit
- Solvency (indicated by audit)
- Bank account(s) with appropriate signatories
- Books of account
- Financial management procedures/policies
- Agreements with funders/donors (such as funding contracts)
- Financial reports at regular intervals

#### **Executive Director**

- Position filled
- Contract/agreement with Executive Director, including term of employment and salary
- Position description
- Attendance
- Reporting to Board
- Exercise of Executive Director responsibilities:
  - Supervision of other staff and demonstrated capacity to discipline staff
  - Financial oversight
  - Reporting to Board and funders



#### **Staff**

- Positions filled
- Contracts/agreements with employees, including term of employment and salary
- Position descriptions
- Attendance

#### **Activities**

- Organisational goals or targets
- Work plans
- Staff reports, including reference to goals or targets
- Reports to funders, including reference to goals or targets

#### **Advocacy**

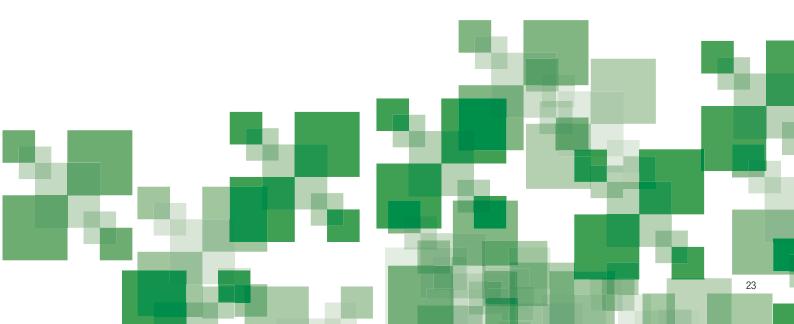
- Organisational vision/mission
- Advocacy goals or targets
- A system of review/reflection

#### Monitoring and evaluation

- Goals or targets
- A system of review/reflection
- Reporting

#### **Profile**

- Positions on inter-agency boards, relevant committees, etc.
- Funding levels plus role specified/acknowledged by funders



# 6. Reflecting on NAPWHA's overall performance

Having acknowledged the complexity of partnership as a notion, and as a goal, how then might NAPWHA begin to measure its overall achievements in this regard? This report has already noted that NAPWHA's contracts for work in PNG lacked adequate performance indicators, so how might sense be made of NAPWHA's contributions?

This report does not seek to measure NAPWHA's achievements with any great precision. Nor is this report a formal evaluation of NAPWHA's work. But NAPWHA has sought to identify some tools that could be used to evaluate its work, and to at least begin the process by which it might measure the effectiveness of its efforts in PNG.

NAPWHA contemplates use of three different tools or measurements that might ultimately generate an evidence-base from which to draw some conclusions:

- Assessing the partnership by reference to NAPWHA's global vision for PLHIV rights
- Assessing the partnership according to memorandum of understanding (MoU) models
- Assessing the partnership with reference to a 'values in practice' approach and notions of 'mutual accountability'.

# 6.1 With reference to NAPWHA's global perspective on PLHIV rights

At the commencement of NAPWHA's work in PNG, the organisation was relatively new to international development. But it was not new to thinking and responding globally. NAPWHA had always been a part of the international movement to promote the rights of PLHIV and, as such, was used to thinking about PLHIV rights in international contexts. It was used to advocating for PLHIV rights in ways that made sense in different contexts, including in the context of developing countries.

NAPWHA's vision for PLHIV in PNG was, from the very beginnings of its work with Igat Hope, shaped by its vision for PLHIV globally. This vision is articulated through documentation such as the Denver Principles and the Positive Health, Dignity and Prevention Policy Framework.<sup>43</sup> NAPWHA wanted PLHIV to enjoy the same rights and protections wherever they may live. In the relationship between NAPWHA and Igat Hope, there was an agreed objective — that being to promote a specified set of rights for PLHIV.

It makes sense then to measure the success of the NAPWHA–lgat Hope partnership by reference to the extent to which the partnership was able to progress the rights enshrined in global PLHIV declarations. This may not be the measurement of most interest to funders, but it is one of importance to NAPWHA.

In 2005, NAPWHA developed its own Declaration of the Rights of People Living with HIV/AIDS.<sup>44</sup> Included in the Declaration is the following Article:

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.

Any reflection on the NAPWHA—Igat Hope partnership must consider this Declaration, along with others adopted by NAPWHA. Having signed on to them, NAPWHA has at all times had a responsibility to promote them through the full range of its activities, including its work in PNG.

A number of rights named in the NAPWHA Declaration were clearly and conscientiously promoted by NAPWHA in its partnership work with Igat Hope. These included:

- The right to live free from harmful discrimination or stigma
- The right to access HIV/AIDS medications and treatments
- The right to form autonomous, self-governing organisations of people living with HIV/AIDS and for those organisations to be consulted and listened to at all levels of HIV/AIDS decision making.

The partnership has delivered some successful outcomes, especially in terms of the assistance provided to form an autonomous and self-governing organisation of PLHIV in PNG. Clearly, an organisation was formed where it had not previously existed. That organisation is now active in PNG in terms of addressing discrimination and stigma and pursing access to HIV medications and treatments for PLHIV.

Paul Farmer (2005) has written at length on the problems of international aid and development work, particularly in regards to HIV interventions in developing country contexts. <sup>45</sup> He is critical of donors and 'partners' who fail to acknowledge that work is being carried out in conditions where class, gender and other forms of social stratification have significant effects and consequences. He is critical of projects and programs that do not recognise structural violence as a societal condition to be managed on a daily basis by the recipients of most aid programs. He is critical of projects where the recipient partners are seeking one form of support — often at a very practical level — and the donor partner offers another response.

NAPWHA's partnership work sought always to reflect an understanding of the disempowered position from which Igat Hope members were acting. Igat Hope's membership was predominantly poor and lived with the daily challenges that poverty presents. Women and transgender members of the organisation shared many stories of their experiences of gender-based violence and discrimination, compounded by their HIV status. And all Igat Hope members had their stories of being marginalised, stigmatised and subjected to discrimination in a myriad of forms. NAPWHA tried in very practical ways to support the organisation's members to overcome the disempowered positions from which they were required to operate.

One example clearly illustrates this situation: the practical response and support that NAPWHA offered in relation to securing premises for the organisation.

<sup>&</sup>lt;sup>43</sup> See <u>Deriver Principles</u>, 1983, www.actupny.org/documents/Denver.html; also <u>Positive Health, Dignity and Prevention Framework</u>, 2011, www.gnpplus.net/en/programmes/positive-health-dignity-and-prevention/positive-health-dignity-and-prevention.

<sup>44</sup> See Life-Love-Participation. Adopted by the NAPWHA membership at the 2005 NAPWHA biennial national conference, Adelaide, South Australia. A number of Igat Hope representatives attended this conference. See http://NAPWHA.org.au/2005/11/18/declaration-of-rights-for-people-living-with-hivaids.

<sup>&</sup>lt;sup>45</sup> See Farmer, P., 2005, *Pathologies of Power*, University of California Press.

In 2006, Igat Hope signed a contract for rental of office premises, a place from which the organisation could operate. At the request of the Igat Hope Board, NAPWHA staff and consultants had commenced a search for premises, eventually finding an appropriate office in Boroko. With Board input, negotiations with the real estate agency commenced. The estate agency was not prepared to sign a contract with Igat Hope unless some guarantee could be given by another partner agency, this despite the fact that by this time Igat Hope was an incorporated and registered organisation with access to funding.

No agency in PNG was prepared to underwrite Igat Hope's lease. Instead, NAPWHA did. In this example, Igat Hope found itself in a disempowered situation, unable to run the organisation without premises and unable to secure premises without the support of other partners. NAPWHA provided the necessary guarantee.

NAPWHA understood that Igat Hope members were regarded with suspicion by partner agencies and were not trusted within the community in which they were operating. <sup>46</sup> NAPWHA appreciated that without some external support, Igat Hope would never be given the opportunity to rent the premises and establish itself as a legitimate organisation. While the Igat Hope Board was simply trying to assert its right to rent premises, the existing structures within PNG did not allow this to happen. <sup>47</sup> NAPWHA was prepared to struggle with Igat Hope against the prevailing power dynamics to ensure that the organisation and its members were able to pursue the right to rent premises. At the core of this issue was the right to operate as an autonomous and self-governing organisation.

# 6.2 With reference to partnership agreements such as memoranda of understanding

It is not uncommon for organisations that intend to work together to strike some type of formal agreement, such as a memorandum of understanding. These can be useful tools for assessing the success or otherwise of the partnership. For one thing, they often set out goals for the partnership, thereby setting a standard by which partnership performance can be measured. They also act as a kind of contract — albeit less specific and less enforceable than a proper contract — and so encourage assessment of partnership via some notion of contractual compliance.

In 2006, Igat Hope developed a standard memorandum of understanding (MoU) for use in proposed collaborations with other agencies. Oddly, there is no record of any MoU between NAPWHA and Igat Hope; however, yearly negotiations over a set of collaborative activities did occur. <sup>48</sup> Each year NAPWHA and Igat Hope would discuss what joint activities to pursue over the next 12 months. The agreed list was duly inserted into NAPWHA's annual proposal to AusAID. These proposals were generally accepted by AusAID and became the contractual basis for NAPWHA's ongoing work in PNG. <sup>49</sup>

It is instructive to consider the MoU developed by the Australian Federation of AIDS Organisations (AFAO), the Queensland Association for Healthy Communities (QAHC) and the Poro Sapot Project (PSP) of Save The Children in PNG. The document (included as an annexure) was developed partly through a reflection on the successes of NAPWHA's partnership with Igat Hope. The principles underpinning this agreement<sup>50</sup> were:

- That partners respect each other's integrity
- That partners maintain open and transparent communication about the relationship
- That partners undertake a development approach.

The AFAO/QAHC/PSP MoU is an excellent model for application in PNG and beyond, seeking, as it did, to wrestle with notions of power and respect.

While NAPWHA maintained at all times a commitment to working in partnership with Igat Hope, a partnership of equals was not necessarily what AusAID was seeking to purchase. Instead, AusAID wanted NAPWHA to help make Igat Hope stronger. AusAID probably expected that in order to make Igat Hope stronger, NAPWHA would have to use a combination of approaches, not all of which might be described as partnership. NAPWHA should have anticipated this expectation, and may have benefited from a deeper reflection as to what was required.

NAPWHA's ways of working may not always have looked exactly like partnership. To achieve its goals, NAPWHA sometimes played the role of a funder, making decisions about whether or not to support an lgat Hope initiative (such as a treatments forum or a governance training). Sometimes it played the role of assessor/adjudicator, deciding whether or not lgat Hope had reached a milestone or satisfied a criterion. Sometimes NAPWHA played the role of critic, occasionally raising with lgat Hope issues of underperformance (at least as perceived by NAPWHA).

Despite these different approaches, NAPWHA's work consistently involved application of the following commitments, all of which are consistent with a true partnership approach:

- A commitment to enhancing the HIV-positive response in PNG
- A commitment to consulting respectfully with Igat Hope
- A commitment to acknowledging and respecting cultural difference
- A commitment to strengthening lgat Hope, even where this might come at a cost to NAPWHA.

With reference to the AFAO/QAHC/PSP MoU, NAPWHA could reasonably claim:

- Respect for the integrity of each other's work
   NAPWHA did respect the integrity of lgat Hope's work. Igat Hope's
   experience was respected, as were the cultural differences between
   the experiences of Australian and PNG PLHIV. Both organisations
   shared a commitment to the centrality of community participation
   and empowerment.
- Open and transparent communication about the relationship NAPWHA endeavoured, with mixed success, to maintain open and transparent communication about the relationship. This was made difficult at some points because of the friction between the Board and the Executive Director. NAPWHA often found itself stuck between these two (frequently) opposing forces, and this made open and honest communication problematic. The intensity and complexity of the conflict between Board and staff was not (and could not reasonably have been) anticipated, so it is hard to imagine how any pre-agreed communications protocols could have resolved the problems.

<sup>&</sup>lt;sup>46</sup> The only other agency to offer some form of support at this time was Family Health International (FHI). FHI kindly offered some assistance with office refurbishment.

<sup>&</sup>lt;sup>47</sup> This is a clear example of what Paul Farmer (2005) refers to as 'symmetries of power' (following the ideas of Amartya Sen). In this case, the symmetry of power, due to bureaucracy and stratification in society, kept lgat Hope members in a powerless position. Their powerlessness was shown because they were unable to rent premises in their own right. The intervention by NAPWHA attempted to redress or change that power arrangement.

<sup>&</sup>lt;sup>48</sup> What was never in doubt was NAPWHA's intention to provide support for the establishment of a functioning national organisation of PLHIV in PNG. The aim was for this organisation to represent the interests of PLHIV through advocacy and engagement in national HIV policy.

<sup>&</sup>lt;sup>49</sup> It is to AusAID's credit that it generally accepted the joint advice of NAPWHA and Igat Hope regarding proposed collaborations. AusAID occasionally tweaked the proposed program of activities, and in some cases declined to fund some components, but in general supported the program as proposed.

<sup>&</sup>lt;sup>50</sup> AFAO/PSP/QAHC partnership agreement, 2009.

#### A development approach

NAPWHA demonstrated a commitment to taking a development approach and to an ongoing dialogue about the pace at which Igat Hope might be expected to grow. There was also significant flexibility within the collaboration. NAPWHA did not always see the pace of progress as appropriate, and NAPWHA was no doubt seen from time to time as being pushy. Despite this, the collaboration undoubtedly resulted in a strengthened Igat Hope.

## 6.3 With reference to shared values and mutual accountability

Another way to talk about the partnership approach is to talk about shared values. HIV development practitioner Elizabeth Reid has written about this in her article on the Poro Sapot Project in PNG.<sup>51</sup> Reid writes of how partners — despite apparent power imbalances such as between NAPWHA and Igat Hope — may have shared values that enable them to work together in ways that could be described as a genuine partnership.

Organisations that work on HIV from a values and human rightsbased approach have as their primary focus the physical, social and moral well-being of those they work with. They follow the moral conflicts and systems of structural violence that mark their lives. They journey with them as they endure and resist hardships, discrimination and oppression in their daily lives. They work with them in their quest to create better lives for themselves and their children.

The partnership between NAPWHA and lgat Hope could conceivably be described as a 'journey with' in which many of the difficulties noted by Reid were present and honoured. These difficulties became the focus of partnership activities.

Reid also places high value on creating spaces for reflection and learning in partnership work. To this end, the peer-based workshops conducted as part of the NAPWHA—Igat Hope partnership have been very important. The content of all workshops was evaluated by participants. After-event assessments were also conducted by the Igat Hope Board and staff, and by NAPWHA staff and consultants. All workshops were co-facilitated, with local PLHIV playing a key role in content delivery, interpretation and discussion. There was always a commitment to conducting workshops via the best possible mixture of English and Tok-Pisin, subject to the capacity of NAPWHA representatives to speak Tok-Pisin.

Some workshops were assessed by participants as providing an opportunity for peer reflection and sharing that would not have been available otherwise. Other workshops were valued because of the content and information shared.<sup>52</sup> The treatments-related workshops, where PLHIV, members of the medical community, and HIV health service planners were brought together to discuss issues of common concern, were highly valued by participants as unique opportunities to sit together and discuss matters of the greatest importance. This speaks to the shared values of the two organisations — a common belief in PLHIV having a 'place at the table', engaging in national HIV policy development, and having the right to engage as equals with other partners in national HIV programs.

Reid notes the five partnership commitments outlined in the Paris Declaration (2005), affirmed and further described in the Accra Agenda for Action (2008) and localised through the Kavieng Declaration (2008).<sup>53</sup> Reid argues that these five commitments can be used not only to measure the success of partnerships between donor and recipient countries, but also to

assess other sorts of aid partnerships. How might NAPWHA's performance be assessed with reference to these five commitments — to ownership, alignment, harmonisation, results and mutual accountability?

A quick assessment suggests:

- There is good evidence of strong ownership of collaborative activities on the part of Igat Hope and its members. Activities were determined jointly and Igat Hope made a genuine effort to pursue activities as agreed.
- There is ample evidence that NAPWHA's work has been aligned to PNG's national HIV strategies and to AusAlD's regional and PNG priorities. There has been a genuine attempt to make sure that NAPWHA's work has been part of a broader national effort in PNG.
- There were attempts to coordinate NAPWHA inputs with those being made by other agencies, although more could definitely have been done in this regard.
- There were good results achieved through the partnership, although there is some argument that greater attention to setting goals and establishing indicators would have been useful.
- The partners were mutually accountable to each other (see below).

This last notion of mutual accountability deserves some further consideration.

A particular feature of the Paris Declaration (2005), Accra Agenda for Action (2008) and Kavieng Declaration is this principle of mutual accountability. As Reid has noted, it is a matter of being committed to *power with* others rather than *power over* others.

How can NAPWHA provide evidence of this mutual accountability within the partnership? How can NAPWHA demonstrate that it was through *power with* lgat Hope that it achieved its outcomes, rather than working with *power over* lgat Hope?

The fact is that gathering such evidence is not really possible at this stage. Perhaps testimonials could be gathered from lgat Hope Board, staff and organisational members to indicate the ways in which mutual accountability was or was not demonstrated. Other NGOs or agencies in PNG might also provide useful information. Perhaps the question could be subject to a longer research project and analysis.

There is some evidence though that NAPWHA met the principle of mutual accountability through its work in helping lgat Hope reach one of its primary goals — to establish itself as the national peak PLHIV organisation. A 2010 press release from lgat Hope, extracted below, announced that an organisation with a system of national representation had been established. The new national structure was achieved through a challenging national consultation process and via a complex special general meeting. NAPWHA provided the technical support that lgat Hope needed to conduct the special general meeting. NAPWHA also provided technical support for drafting of the new constitution. A key goal of the partnership activity was thereby met.

Igat Hope Press Release [Thursday, 8 July 2010]

At a special general meeting of Igat Hope 30 June 2010 over seventy members made some important decisions about the future of the organisation. The meeting unanimously agreed that Igat Hope will be the national peak organisation for people living with HIV/AIDS (PLHIV) and that a new governance structure will should take effect from November 2010. The new structure

<sup>51</sup> See Reid, E., Putting Values into Practice in PNG: The Poro Sapot Project and Aid Effectiveness, ejournal of the Australian Association for the Advancement of Pacific Studies, Issues 1.2 and 2.1, April 2010.

<sup>&</sup>lt;sup>52</sup> Evaluative reports for workshops were prepared by NAPWHA staff, partly for the purpose of reporting to the NAPWHA Board on activities held in PNG. Copies of reports on the Healthy Living Workshop for Positive Peers 2005, Hungry for Learning 2007, Good Governance Training 2009 and Treatment Advocacy Workshops 2010 and 2012 are kept by NAPWHA.

<sup>53</sup> Signed by the PNG government and development partners in 2008. NGOs were seen by the PNG government as playing an important role in implementing the Kavieng Declaration. See www.forumsec.org/resources/uploads/attachments/documents/PNG\_Paris\_Monitoring\_Survey\_2008.pdf.

means that Igat Hope has an organisational membership, with a PLHIV organisational member in each province. Igat Hope will be governed by a new national 9-member Board. The Board will include 3 general members, 1 member from each of PNG's four regions, 1 member from NCD and 1 member representing HIV-positive women in PNG. Elections for the new Board will take place in November 2010 at the national PLHIV conference in Port Moresby.

The meeting also agreed that a new Provincial Coordinating Mechanism for NCD be set up before November. This Provincial Coordinating Mechanism will include Ita Gini Mosbi, Friends Ministry, Positive Care Foundation and Women Affected by HIV/ AIDS. Igat Hope also agreed to help HIV-positive women in HIV work together to nominate the women's representative on the new Board. This will probably be done by bringing representatives of HIV-positive women's groups together for a satellite meeting attached to the national conference.

This is an exciting time for Igat Hope as it becomes the national representative body for all PLHIV in PNG. The decisions taken by the members at the special general meeting are some of the most important the organisation has ever taken.

As the organisation agreed to such significant changes, it also looked back over its history. Igat Hope began in 2003 with a meeting of 22 PLHIV. At the special general meeting there was

a presentation to seven members of this original group of Igat Hope founders. They were congratulated for their part in Igat Hope's history.

The final agreement to go national was supported unanimously and everyone joined in a round of applause to mark the special occasion.

The launching of a national organisation, finally, demonstrated that technical inputs and capacity building from NAPWHA over many years had helped generate the intended outcome — an autonomous, self-governing organisation of PLHIV had been established in PNG. To a certain extent, this exemplifies the condition of mutual accountability. The goal that NAPWHA had set out to achieve, the goal that Igat Hope had continually asked for help in achieving — that is, establishing a national organisation, had been attained.

The 2011 independent audit of Igat Hope<sup>54</sup> can also be read as providing evidence of the ways in which NAPWHA has been mutually accountable and has systematically assisted in the development of Igat Hope. The audit reviewed extant documentation and reported on information gathered from 69 interviews conducted in November and December 2011 in PNG. The audit report usefully identified some of Igat Hope's greatest strengths. While Igat Hope members, Board members and staff would rightly claim credit for these strengths, it can also be easily demonstrated that these have been built partly as a consequence of mutual contributions from NAPWHA over many years.

#### Strengths Identified in the 2011 audit

- a) Overall there was clear and consistent recognition of the significant achievements of Igat Hope since it began as an informal group in 2001. Many audit participants noted that the growth in the number of people living with HIV (PLHIV) who had 'come out' publicly as HIV positive and the recent emergence of local, district and province-wide networks/groups of PLHIV could be directly attributed to the hard work of Igat Hope over the last 9–10 years.
- b) The majority of participants were similarly clear in their belief that Igat Hope was best placed to be the national network/coordinating body for local/district and province-wide groups and networks of PLHIV in PNG.
- c) The new Igat Hope Incorporated (IHI) Constitution 2010 is a strong foundation document and provides the needed basis for other core documents to develop.
- d) Key staff in the Secretariat at Igat Hope were acknowledged by many participants as having contributed significantly over the last few years in improving the environment for PLHIV in PNG.
- e) The recent appointment of the Financial Controller has been well received by donors, the Board and the Secretariat. The AusAlD audit affirmed the resulting improvement in the quality of the financial controls and the technical abilities of the lead financial management now within lgat Hope.

#### NAPWHA mutuality contributions

- \* NAPWHA supported individual members of the informal group through a study tour in 2001 and subsequent mentoring of individual Igat Hope members
- \* NAPWHA supported positive speakers and PLHIV peer-based training in PNG
- \* NAPWHA supported regional network development
- \* There have been many criticisms of Igat Hope over the years, but NAPWHA has always supported Igat Hope as the national representative organisation
- \* NAPWHA assisted in the drafting of the first (2005) and second (2010) lgat Hope Constitutions
- \* NAPWHA drafted all versions of the <u>Governance Kit</u> used by Igat Hope from 2006 to 2012
- \* NAPWHA drafted position descriptions for Secretariat staff
- \* NAPWHA assisted in the recruitment of Secretariat staff
- \* NAPWHA provided mentoring for all roles within the Secretariat, especially the Executive Director and senior project staff
- \* NAPWHA assisted in the funding negotiations to secure the Financial Controller position
- \* Prior to the Financial Controller position being placed within the Secretariat, NAPWHA provided direct support and advice regarding budgeting, financial accountability, finance management and financial reporting within Igat Hope

<sup>&</sup>lt;sup>54</sup> Le Mesurier, R., and Dee, C., op.cit.

### 7. Conclusion

The report has sought to detail the primary achievements of the decadelong partnership between NAPWHA and Igat Hope. Clearly, much has been achieved.

The report has not sought to be a joint NAPWHA—Igat Hope account. It has been drafted to present NAPWHA's perspectives on the collaboration and to detail the lessons NAPWHA has learned through its experiences.

The continued existence of a national PLHIV organisation is the best indicator of the partnership's success, but there have been countless lesser achievements of which both organisations can also be proud. NAPWHA is confident that it has provided valuable support to Igat Hope, greatly enhancing its capacity to operate as an effective national peak.

NAPWHA acknowledges the efforts of Igat Hope members and staff in building a national PLHIV organisation. In documenting the achievements of the NAPWHA—Igat Hope partnership, NAPWHA recognises that nothing could have been achieved without the inspiring contributions and leadership of PLHIV activists in PNG. The important role of AusAID and other donors is also acknowledged.

The partnership was not without its faults and, if NAPWHA were able to have its time over, it would do some things differently. Some of the strategies that NAPWHA sought to utilise turned out to be less effective than anticipated. NAPWHA failed to foresee and plan for some of the challenges that arose. By sharing these experiences — the misses as well as the hits — NAPWHA hopes to build a better understanding of how organisational partnerships can be used to build the capacity of community responses in developing countries.

It will take some time to fully understand the success of the NAPWHA–Igat Hope partnership, and more reflection and assessment will be required to make sense of it all. NAPWHA believes that in pursuit of this deeper understanding, this report will be a useful first step.



### **Annexure**

### Principles underpinning AFAO/QAHC/PSP Memorandum of Association 2009

The principles were as follows:

#### a. Partners respect the integrity of each other's work

- Acknowledge Save the Children Poro Sapot Project's PNG experience
- Acknowledge AFAO's experience in supporting community development across the Asia and Pacific regions
- Respect the cultural differences between PNG and Australian MSM experiences
- Recognise that genuine partnership is respectful, mutually beneficial and non-exploitative
- Integrity of core organisational values and/or vision statements will underpin the relationship
- Share a commitment to the centrality of community participation and empowerment

### <u>b. Partners maintain open and transparent communication about the relationship</u>

- Expectations and goals of the relationship are clearly articulated and realistic
- Real consultation, which is honest and open, is ongoing and conducted in a constructive manner
- A communication process and follow-up mechanism is agreed upon and implemented
- A clear process and structure for discussing difficult issues is agreed upon and formalised

#### c. Partners undertake a development approach

- Both parties recognise that partnerships develop and are strengthened over time
- Expectations and outcomes of the partnership develop in a realistic time frame
- When working on collaborative initiatives, partners will work at a pace that suits all parties, particularly at a pace agreed by Save the Children Poro Sapot Project as the local implementing partner
- Work undertaken by the parties results in benefits for MSM communities in PNG, while ensuring both partners are not weaker as a result of the partnership
- Save the Children Poro Sapot Project's capacity is strengthened as a result of the partnership
- Adequate resources are invested which reflect and support both partners' ability to undertake new work
- The partnership will allow for flexibility in all aspects of the relationship, and encourage reflection as a necessary step for moving forward.



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