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Regional HIV Forum for the Pacific Island Countries and Territories 2018

SUMMARY

From 29 to 31 October 2018, the United Nations Development Programme (UNDP) in partnership with the Fiji Network for People Living with HIV (FJN+) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) held the Regional HIV Forum 2018 for the Pacific Island Countries and Territories.

The forum was the first event of its kind in the Western Pacific, bringing together people living with HIV and health care workers from across the region to meet, discuss and share their experiences working with and living with HIV. It provided a platform for open dialogue for both groups, enhancing HIV and antiretroviral therapy (ART) literacy, and self-empowerment, while aiming to catalyse coordination across HIV care, treatment and prevention programmes in the Pacific islands.

The forum was attended by 55 participants, including 31 people living with HIV, and health workers from the Federated States of Micronesia, Fiji, Kiribati, Nauru, Palau, Republic of Marshall Islands, Samoa, Tonga and Vanuatu, as well as development partners and civil society organizations (CSOs) working on the response to HIV. A range of experts, including from the World Health Organization (WHO), were invited to speak and give presentations during the forum.

Before the official forum, FJN+ organized a side meeting with all of its members, as well as with people living with HIV from the region who had come to attend the forum, to provide them with support and preparation for the meeting ahead.

Background

The forum was supported by UNDP through the Multi-Country Western Pacific Integrated HIV/TB Programme, in collaboration with UNAIDS and FJN+.

The objectives of the forum were to:

1. Provide an opportunity for dialogue among people living with HIV in the Pacific region.
2. Facilitate, implement and maintain strategic engagement of people living with HIV in ongoing programmes for action.
3. Increase awareness and understanding on the definition, nature, side effects and effects of antiretroviral therapy treatment and adherence.
4. Develop advocacy strategies and recommend effective processes for change.
5. Develop strategies and create space to discuss the set-up of local support groups for people living with HIV in Pacific countries.

In addition, the forum sought to achieve the following objectives for health care workers and clinicians:

Health care workers

1. Provide space for health care workers to discuss and talk about ways of improvement to attain 100 percent of treatment intake.



Towards zero new HIV infections, zero discrimination and zero AIDS-related deaths —we need to reform our way of doing business. Access to antiretroviral therapy for every person living with HIV is paramount and important. We will continue to advocate to ensure everyone receives fair access to health services including antiretroviral therapy – and no one should be left behind.

**– HIS EXCELLENCY RATU EPELI NAILATIKAU,
UNAIDS GOODWILL AMBASSADOR FOR THE
PACIFIC**

2. Run a face-to-face meeting with health care workers and share individual views to strengthen services at the country level.
3. Document best practices and lessons learned, and for health care workers to embrace treatment adherence and the process of prevention of parent-to-child transmission of HIV (PPTCT).
4. Discuss confidentiality issues and find ways to counter such situations in the future.

Clinicians

1. Increase awareness and understanding on the latest trends in antiretroviral therapy and opportunistic infections (OI) treatment and side effects management.
2. Discuss treatment initiation, adherence and barriers to treatment.
3. Provide counselling to patients and clinicians on a case-by-case basis.
4. Provide recommendations to the Multi-Country Western Pacific Integrated HIV/TB Programme and clinicians on the improvement of patients' adherence.

The intended outcomes described in the *PLHIV Forum Concept Note* were to:

1. Boost the rate of people living with HIV on antiretroviral therapy to 100 percent.

2. Increase understanding about the perspectives of people living with HIV as well as those of health care workers.
3. Discuss workable interventions at the policy level to eliminate confidentiality breaches.
4. Report on best practices and lessons learned from health care workers in the Pacific.

Together, the forum's objectives and intended outcomes support country efforts to achieve the UNAIDS 90–90–90 treatment targets by 2020: 90% of all people living with HIV know their HIV status; 90% of all people diagnosed with HIV are on ART; and 90% of all people receiving antiretroviral therapy have viral load suppression.

Participants

The workshop was attended by 55 people, of which 31 were HIV positive people, including 7 co-facilitators from FJN+. Also in attendance were the UNAIDS Goodwill Ambassador for the Pacific, His Excellency Ratu Epeli Nailatikau, an adviser from the WHO Regional Office for the Western Pacific, Dr Derek Chan, a consultant from Albion Street Centre, Sydney,

Australia – WHO Collaborating Centre for Capacity Building and Health Care Worker (clinicians and nurses) Training in HIV/AIDS Care, Treatment and Support, a specialist from the UNDP Multi-Country Western Pacific Integrated HIV/TB Programme and FJN+ members. Dr Sophaganine Ty Wilson facilitated the meeting.

Planning

The three-day regional forum was planned according to the objectives described above, aiming to meet the needs of people living with HIV and health care workers (including clinicians) in the Pacific islands and promote dialogue between and within groups.

Each day was planned according to a theme. Each topic included a short presentation followed by open discussion and group work. Sessions were dedicated to promoting dialogue between participants to identify lessons learned and best practices. Breakout group discussions provided the opportunity for engaging and speaking in smaller groups than the larger forum and for informal discussions.

Following the presentations, time was available for questions and answers. Participants had the opportunity to have

private conversations and receive confidential counselling from the facilitator or consultant if they wished to do so privately.

The meeting was organized to encourage active engagement by all participants, particularly in the dialogue related to the most appropriate and feasible approaches countries can use to support the care and retention of people living with HIV on treatment.

Participants had the opportunity to share their experiences and to provide leadership in doing session recaps, and were encouraged to share their experiences in both large and small groups.

Workshop proceedings and activities

The pre-meeting with people living with HIV was held the day before the official proceedings, on 28 October, and provided support to those attendees who had never attended a meeting such as this, or of this size. They shared their expectations with each other, and in some cases, shared their HIV status for the first time with other people besides their close families and physicians.

Change begins from home. We encourage people living with HIV to step forward, share their stories, speak up for themselves and their colleagues, and fight back against stigma and discrimination. We all can make the difference. You are the agent for change.

– MR EMOSI RATINI, BOARD MEMBER AND CHAIR OF FJN+





HIV is a unique disease which involves an emotional sense of being, carrying stigma and discrimination unlike other diseases. This is the first gathering in the Pacific that allows health care workers and people living with HIV to sit together to discuss the needs of people living with HIV. It allows health care workers and people living with HIV to establish a dialogue and work together to address the issues related to management of people living with HIV in their country.

– MS ANNA CHERNYSHOVA, PROGRAMME MANAGER, UNDP

Each of the three days had a theme. Day 1 was ‘Stigma and Discrimination’. Day 2 was ‘Treatment Adherence & Education’. Day 3 was divided into two parallel sessions – for the community of people living with HIV, the theme was ‘Advocacy & Positive Community Conception’. For clinicians, there was a ‘Treatment Capacity-Building Session’.

The forum was opened by His Excellency Ratu Epeli Nailatika, UNAIDS Goodwill Ambassador for the Pacific, Ms Anna Chernyshova, Programme Manager for the Western Pacific HIV, TB and Malaria Programmes, and Mr Emosi Ratini, Board member and Chair of FJN+.

Day 1 on ‘Stigma and Discrimination’ included a review of the agenda and an introduction to the participants of the forum. Its key sessions were:

- Global HIV epidemiology, the HIV treatment cascade and the need to monitor the related new WHO recommendations
- Highlights of the Regional Stigma Index Findings
- Me and my country – telling my story and my specific country situation
- Dealing with stigma and discrimination

- Confidentiality and human rights

The key sessions of Day 2 on ‘Treatment Adherence & Education’ were:

- Treatment literacy and adherence (including PPTCT)
- Dealing with treatment issues (stock outs, side effects and PPTCT)
- Documenting best practices based on the experiences of people living with HIV
- Treatment monitoring
- Developing recommendations on treatment

Day 3 was divided into parallel sessions. For the community of people living with HIV, the key sessions with the theme of ‘Advocacy & Positive Community Conception’ were:

- Advocacy
- Taking action – Setting up local people living with HIV support groups at the country level
- Mentorship
- Public speaking and the media
- Advocacy areas identified and the development of a work plan

For clinicians, the key sessions of the 'Treatment Capacity-Building Session' were:

- Overview of treatment, including antiretroviral therapy and pharmacology initiation
- ART guidelines
- ART
- Clinical management
- Retention in care

Outcomes

UNDP, working with FJN+, UNAIDS and other partners in the region, successfully created an environment to facilitate productive dialogue between people living with HIV and health care workers on issues relating to the health and welfare of people living with HIV.

The majority of the forum's attendees were people living with HIV, 31 out of 55 people, a successful reflection of the principle to meaningfully involve those who are affected by HIV in the response.

Among the most significant achievements of the forum was the successful counselling of several people living with HIV by their clinicians to confidently commence ART upon returning to their respective countries.

Ongoing support from UNDP through the Multi-Country Western Pacific Integrated HIV/TB Programme, which provides education on HIV medicine, ART pharmacology and the relevant WHO guidelines, empowers clinicians to improve the lives of people living with HIV and expands the professional expertise of clinicians. Getting people living with HIV on treatment also moves countries towards meeting their UNAIDS 90-90-90 targets and curbs HIV infections in the Western Pacific.

Other key outcomes from the forum were not necessarily captured in official proceedings but are worth noting:

- Strengthening the capacity of FJN+ to support the organization of the forum.

- Building capacity and leadership among people living with HIV in the region.
- Building the capacity and knowledge of clinicians and health care workers in the region.
- Strengthening formal and informal bonds between health care workers and people living with HIV in the region.
- Strengthening the bonds between health care workers in the region so they can support each other and continue to share and build knowledge.
- Strengthening the bonds between people living with HIV in the region so they can support each other and share success stories and challenges for setting up peer support groups, and improving treatment access and adherence.

As part of forum sessions, country activity plans were created for each participating Pacific island country, which identified key areas (such as setting up peer support groups, increasing treatment access, and addressing stigma and discrimination). It then matched the areas with concrete activities, a timeline and the stakeholders who should provide support for the activities.

Another key set of planning was identifying the activities required in relation to setting up local peer support groups for people living with HIV in five of the Pacific island countries and territories that do not have existing peer support groups, and activities to strengthen the existing peer support group in Kiribati.

Feedback from the evaluation of the forum was extremely positive, with a large majority of attendees finding the facilitation excellent or effective (90%), the facilitators' performance as excellent or effective (96%) and the logistical arrangements very satisfactory or satisfactory (90%). The session on treatment adherence was considered the most useful session by the most participants, and the pre-meeting for people living with HIV, clinicians' parallel session, and the session on stigma and

discrimination were considered most often as those that provided the most new knowledge.

A detailed internal report was completed and distributed to stakeholders. This summary captures the key recommendations and describes the outcomes and activities of the forum. The summary will be made widely available.

The insights and information gained from the forum should be used in countries by Ministries of Health and persons living with HIV, civil society organizations working in this field, grant managers and regional partners to plan and develop more effective strategies around HIV advocacy and addressing stigma and discrimination while providing a continuum of care for people living with HIV in the region.

Recommendations

The following recommendations came out of the forum's sessions, breakout groups and discussions. They are grouped according to stakeholder and topic.

1. **Accountability:** Promote accountability at all levels for the effectiveness of community and peer-led interventions which includes recommendations to the following stakeholders:
 - a. **Government** – To ensure legislation and policies that support and address the specific needs of people living with HIV and their families and address stigma and discrimination, and for the implementation of this legislation and these policies to be held accountable with metrics regarding their effectiveness.
 - b. **Medical facilities** – To ensure the appropriate supply of medical products and proper training of health care workers to provide health care services for people living with HIV.
 - c. **Families and communities** – To enable a positive and proactive environment that not only supports people living with HIV but is free of stigma and discrimination.
- d. **People living with HIV** – To be accountable for their health, adhere to HIV medication and treatment, and make use of available counselling and support groups when required.
2. **Supporting interventions:** Make available support groups for mothers that have taken part in prevention of parent-to-child transmission interventions, as this has been shown to reduce new transmissions and increase retention in health care.
 - a. Provide peer-to-peer meetings for women who have taken part in PPTCT to come together to provide support for women taking part in PPTCT for the first time.
 - b. Promote a continuum of care for PPTCT, including pre-delivery, during delivery and post-delivery.
3. **Women and adolescents living with HIV:** Involve them in every decision regarding their sexual and reproductive health, including HIV treatment and care.
4. **Peer support interventions for people living with HIV:** Include these as part of National Action Frameworks:
 - a. Clearly define the concept of peer-to-peer support, adapting this globally successful approach to the context of each country.
 - b. Identify and support peer mentors and their continued work through appropriate documentation, stipends, training, clear standard operating procedures, linkages between community and facilities, integration in other sectors, and scaling up, among other measures.
 - c. Improve coordination of peer support groups including through planning, implementation and monitoring data and quality.

- d. Consider how to measure community participation and integration with other sectors (e.g. poverty, food access, school access and violence).
5. **Funding:** Ensure that funding is available to support government accountability, address fragmented health systems and reduce stigma and discrimination for people living with HIV and their families.
6. **Development partners:** Continue technical and financial support to countries to create effective peer support groups for people living with HIV.
7. **Scaling up HIV testing:** Conduct community education on HIV testing, care and support, while linking HIV testing with broader efforts to achieve universal access to HIV prevention, treatment, care and support by integrating provider-initiated counselling and testing in all health service delivery, especially at the primary health care level.
8. **ART guidelines**
 - a. Health care workers should reach out to their respective health ministries and bodies in charge of HIV to endorse national ART guidelines as soon as possible.
 - b. Health care workers should consider establishing a guidelines committee that can readily update changes and ensure guidelines are up to date.
 - c. Guidelines currently in draft form and those that have not been endorsed should include the addition of Dolutegravir (DTG) as the third agent in first-line ART as per the WHO recommendation.
 - d. The WHO recommendation about the use of DTG in women of reproductive age should be included in all national ART guidelines.
9. **Antiretroviral therapy:** All doctors managing people living with HIV should:
 - a. Undergo training in HIV medicine and ART.
 - b. Link to the available clinical support and mentoring programme provided by the Australian Society for HIV Medicine (ASHM) or other UNDP-accredited training providers.
 - c. Educate nurses, peers and other clinical staff about ART and HIV.
 - d. Provide people living with HIV with dosette boxes (also known as pill organizers) to improve ART adherence.
 - e. Provide required ART treatment uptake data and reports to the UNDP ARV Procurement and Supply Chain Management System in a timely manner.
10. **Clinical management:** All clinics managing people living with HIV should:
 - a. Provide education such as general factsheets and online resources on HIV, opportunistic infections, co-infections, ART, PPTCT and living well with HIV.
 - b. Implement algorithms outlining patient flow in the clinic, i.e. steps in ART initiation, monitoring and required blood tests, appointment schedules and confidentiality guidelines for clinical staff to follow. This is especially important for when a doctor is absent.
 - c. Provide factsheets and online resources for people living with HIV outlining the basics of HIV including prevention, transmission, advantages and disadvantages of ART including side effects, PPTCT and breast-feeding advice, the importance of adherence, warning symptoms to look out for and report, and the need to adhere to ART and attend clinics for monitoring at regular intervals or as necessary.

- d. Provide factsheets and online resources about methods known to maintain the immune system in addition to ART (i.e. general health information about nutrition, exercise, sleep, alcohol and drug use).

11. Cascade of care:

- a. Implement patient recall systems to prevent people living with HIV being lost to follow-up. Consider delegating a team member (e.g. nurse or counsellor) to undertake follow-up and monitor non-attendance.
- b. Appoint a second clinician (e.g. nurse or counsellor) who is available for people living with HIV when the doctor is not available in order to maintain engagement in care. A multidisciplinary approach to patient care is best.
- c. Countries to liaise with UNDP for support with increasing retention in care, e.g. supporting travel costs to clinics for people living with HIV.
- d. Provide accurate Global AIDS Monitoring statistics to UNAIDS in a timely manner for country reports. These data are essential in monitoring the success of the cascade of care in countries, as well as in identifying gaps and opportunities to build on patient care.

Acknowledgements

The UNDP Pacific Office in Fiji is grateful to the participants who contributed to this forum, in particular the people living with HIV and health care workers who shared their personal experiences and perceptions on the stigma that is attached to HIV in their countries. Addressing and countering stigma and discrimination is paramount for a successful response to HIV in Pacific island countries and everywhere.

UNDP would also like to thank FJN+ for the mammoth task of organizing and mobilizing the community of people living with HIV for a high turnout at the forum and embracing the principle of the Greater Involvement of People living with HIV/AIDS and the practice promoted by the Sustainable Development Goals of leaving no one behind.

Our sincere thank you to UNAIDS and WHO for the technical and administrative support provided during the forum.

In addition, UNDP acknowledges the work of the workshop facilitators, Dr Sophaganine Ty Wilson and Dr Derek Chan, for their perseverance and hard work, which made the forum a success.

UNDP would also like to thank His Excellency Ratu Epeli Nailatikau, UNAIDS Goodwill Ambassador for the Pacific, for his contributions to the forum.

The Multi-Country Western Pacific Integrated HIV/TB Programme, which seeks to strengthen the control of HIV and TB in 11 Pacific island countries, is supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria.

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