

# Assessing the Status of Diabetes Associations in the Pacific: A Starting Point for Strengthening Associations to Manage Diabetes

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## Abstract

*This study aimed to assess the status of national diabetes associations in the Pacific Island Countries and Territories as a starting point for strengthening their development and effectiveness in the prevention and control of diabetes. This cross-sectional study was conducted in 21 Pacific Island Countries and Territories using a structured questionnaire that gathered information from national non-communicable diseases prevention and control focal persons on diabetes associations, organizational structure, funding sources, and ongoing activities to address diabetes. The overall status of national diabetes associations was assessed using standardized criteria. Of the 21 countries surveyed, 18 (86%) responded. Of these, 12 (67%; American Samoa, Northern Mariana Islands, Federated States of Micronesia, French Polynesia, Fiji, Guam, Nauru, Papua New Guinea, Marshall Islands, Solomon Islands, Tonga, and Vanuatu) have a national diabetes association. Half of the existing associations are fully functioning, while the remainder is either partially functioning or not functioning. Only 50% of existing associations have a regular funding source, and many lack clear visions and workable governance structures. This study fills a knowledge gap on the current status of associations and forms a baseline from which associations can be strengthened. It also draws attention to the need for Pacific leaders to invest and engage more in civil societies for better and effective diabetes care for all.*

## Keywords

Association, diabetes, non-communicable diseases, Pacific Islands Countries and Territories

## Abbreviations

NCD = non-communicable diseases

PICTs = Pacific Island Countries and Territories

SPC = The Pacific Community

## Introduction

Diabetes imposes a high economic cost and is a major health and development challenge globally.<sup>1,2</sup> Premature deaths and disability from diabetes are creating a socioeconomic crisis that challenges global progress to achieve the World Health Organization's Sustainable Development Goal 3 “ensure healthy lives and promote well-being for all at all ages,” particularly Target 3.4, “reduce by one third premature mortality from non-communicable diseases (NCDs) by 2030.”<sup>3</sup>

The prevalence of diabetes in Pacific Islands Countries and Territories (PICTs)—American Samoa, Common Wealth of the

Northern Mariana Islands, Cook Islands, Fiji, Federated States of Micronesia, French Polynesia, Guam, Kiribati, Marshall Islands, Niue, New Caledonia, Nauru, Papua New Guinea, Palau, Samoa, Solomon Islands, Tokelau, Tonga, Tuvalu, Vanuatu, and Wallis and Futuna—are among the highest in the world. For example, in 2018, 45.4% of adults in American Samoa<sup>4</sup> and 29.4% in the Kosrae-Federated States of Micronesia<sup>5</sup> have diabetes, which was much higher than the estimated global prevalence of 9% in 2019.<sup>6</sup> Diabetes-related complications in PICTs are also substantial; in 2013, the prevalence of amputations and diabetic retinopathies are approximately 11% and 69% respectively among people with diabetes in some PICTs.<sup>7</sup> Cost for diabetes is enormous. For example, in Nauru and the Solomon Islands, diabetes care consumed 20% of annual government health care expenditure in 2007 and 2011, respectively.<sup>8</sup> These estimates were much higher than the global average of 12% in 2019.<sup>6</sup>

Declarations and commitments aimed at addressing diabetes and other NCD consistently highlight the urgent need for a whole-of-government and whole-of-society approach.<sup>9,10</sup> It is well-recognized that stakeholders, such as diabetes associations, play an important role in tackling diabetes. However, limited information is available about the existence, establishment, structure, governance, management, activities, and effectiveness of Pacific diabetes associations. Therefore, this study aimed to assess the status of diabetes associations in PICTs as a starting point for strengthening their development and effectiveness in the prevention and control of diabetes. The findings of this survey will help identify the support needs to strengthen the function of diabetes associations, and ultimately to contribute to achieving the Healthy Island Vision—a unifying theme endorsed by the Pacific Health Ministers to guide health development in the Pacific region—particularly the vision on “people work and age with dignity by reducing avoidable disease burden and premature deaths due to NCD”.<sup>11</sup>

## Methods

This cross-sectional study was conducted in all 21 PICTs across the Pacific region to identify the existence and assess the status of their national diabetes associations. A structured self-administered questionnaire was developed by the NCD policy experts within the public health division of the Pacific Community (SPC), and contents were validated by the selective

PICTs' NCD prevention and control focal persons. The national NCD focal persons designated by their respective Ministries of Health were selected to complete the survey, given that the national NCD focal persons support and oversee the function of national diabetes associations. The self-administered questionnaire was distributed electronically via email to the national NCD focal persons of all 21 PICTs across the Pacific. If there was no initial response, follow-up by email was conducted to complete questionnaires, with initial data collection occurring between June 2017 and August 2017. The answers in the completed questionnaires were cross-checked by the SPC's NCD policy experts and PICTs' national NCD focal persons and representatives from diabetes associations who attended the inaugural Pacific diabetes association meeting in September 2017. An additional period of email follow-up was conducted with national NCD focal persons between September 2017 and January 2018 to clarify any key points. The questionnaire sought information on the existence of diabetes associations, organizational structure, funding sources, and ongoing activities to address diabetes. One open-ended question on the questionnaire also sought to identify the support needs for their diabetes associations to function effectively.

The data were compiled and analyzed using Microsoft Office Excel 2016 issued by DigiCert in Lehi, USA. Where relevant, data were reported as numbers and percentages. The overall

status of diabetes associations was assessed. Associations were categorized as "well-functioning" if they met the following 3 criteria: (1) has a formal organizational structure, (2) has a regular source of funding, and (3) is implementing 3 or more ongoing diabetes prevention and control activities. Associations meeting 1 or 2 of these criteria were categorized as "partially functioning." Associations meeting none of these criteria were categorized as "not functioning." The categories of assessment for overall functioning status were determined by the Pacific Community's (SPC) NCD policy experts. This study was conducted with approval from SPC's Scientific and Technical Expert Group.

## Results

Of the 21 PICTs surveyed, 18 responded (Table 1). The response rate is 86%. Of the 18 countries that responded to the survey, 12 (67%) have a national diabetes association, and 5 of these (Fiji, Nauru, Papua New Guinea, Tonga, and Vanuatu) are International Diabetes Federation member associations. The Cook Islands do not currently have a diabetes association; however, they plan to establish one in the next 12 months. The remaining 5 PICTs (Kiribati, Niue, Palau, Tokelau, and Wallis and Futuna) do not have a diabetes association and do not plan to establish one in the next 12 months. Some associations have been established for over 20 years (eg, French Polynesia; Table 2).

Description	n (%) (N=21)	Name of Country
Countries responded	18 (86%)	American Samoa, Commonwealth of the Northern Mariana Islands, Cook Islands, FSM, French Polynesia, Fiji, Guam, Kiribati, Nauru, Niue, Papua New Guinea, Palau, Marshall Islands, Solomon Islands, Tokelau, Tonga, Vanuatu, Wallis and Futuna

Description	n (%) (N=18)	Name of Country (Year of Establishment) <sup>a</sup>
Of the countries responded, countries with a diabetes association	12 (67%)	American Samoa (2013), Commonwealth of the Northern Mariana Islands (2002), Federated States of Micronesia (2010), French Polynesia (1990), Fiji (2012), Guam (2008), Nauru (2008), Papua New Guinea (1996), Marshall Islands (2010), Solomon Islands (2000), Tonga (2000), Vanuatu (2007)
Of the countries responded, countries which do not currently have a diabetes association, however, plan to establish 1 in the next 12 months	1 (5%)	Cook Islands
Of the countries responded, countries which do not currently have a diabetes association and do not plan to establish 1 in the next 12 months	5 (28%)	Kiribati, Niue, Palau, Tokelau, Wallis and Futuna

<sup>a</sup> The year a national diabetes association was first established in the Pacific Island Country or Territory.

Table 3 shows the statuses of existing diabetes associations regarding organizational structure, funding source, and ongoing diabetes prevention and control activities. Seven (58%) associations have established and functioning organizational structures with a specific purpose, vision and goal, and board of directors or committee for governance. Half of the existing associations have regular funding sources. The majority of the existing associations hold annual events to commemorate international days (eg, World Diabetes Day, World Health Day) and reported that they work closely with other government organizations, including the Ministries of Health in their respective countries.

The overall functioning status of the associations was assessed. Of the 12 existing associations that responded to the survey, 6 (50%) associations (American Samoa, Fiji, Federated States of

Micronesia, French Polynesia, Guam, and Marshall Islands) are reported to be functioning well but need further strengthening, 3 (25%) associations (Commonwealth of the Northern Mariana Islands, Papua New Guinea, and Tonga) are partially functioning, and 3 (25%) associations (Nauru, Solomon Islands, and Vanuatu) are not functioning and need reactivation.

Respondents were also asked to identify what support was required for their diabetes association to function effectively. Support needs identified by respondents included the need for developing organization structure, training for NCD and associated risk factors, funding to support interventions, and reactivating defunct associations. Other support needs mentioned were providing health promotion resources, information sharing, and developing a diabetes registry (Table 4).

Table 3. Status of Existing Diabetes Associations in Pacific Island Countries and Territories		
Description	n (%) (N=12)	Name of Country
<b>Organization</b>		
Functioning diabetes associations with a specific purpose, a vision and goal, and a board of directors/committee for governance	7 (58%)	American Samoa, Federated States of Micronesia, French Polynesia, Fiji, Guam, Marshall Islands, Tonga
<b>Funding</b>		
Diabetes associations with a regular source of funding (eg, donor agencies)	6 (50%)	American Samoa, Federated States of Micronesia, French Polynesia, Fiji, Guam, Marshall Islands
<b>Activities</b>		
Diabetes associations that host annual events (eg, World Diabetes Day, World Food Day, World Health Day)	9 (75%)	American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, French Polynesia, Fiji, Guam, Marshall Islands, Papua New Guinea, Tonga
Diabetes associations that organize education and awareness activities on an ongoing basis	7 (58%)	American Samoa, Federated States of Micronesia, French Polynesia, Fiji, Guam, Marshall Islands, Papua New Guinea
Diabetes associations that organize ongoing health programs (eg, physical activity program, health food cooking demonstration program)	4 (33%)	Federated States of Micronesia, Fiji, Guam, Marshall Islands
Diabetes associations that produce resources (eg, pamphlets, flyers, posters)	4 (33%)	Federated States of Micronesia, Fiji, Guam, Marshall Islands
Diabetes associations that collaborate with other organizations in their country (eg, Ministries of Health, schools, colleges, non-government organizations)	9 (75%)	American Samoa, Commonwealth of the Northern Mariana Islands, Federated States of Micronesia, French Polynesia, Fiji, Guam, Marshall Islands, Papua New Guinea, Tonga

Table 4. Support Needs Identified by the Existing Diabetes Associations in Pacific Island Countries and Territories		
Description	n (%) (N=12)	Name of Country
Developing organization structure	4 (33%)	Nauru, Papua New Guinea, Solomon Islands, Vanuatu
Training about non-communicable diseases and associated risk factors	9 (75%)	American Samoa, Federated States of Micronesia, French Polynesia, Fiji, Guam, Marshall Islands, Nauru, Papua New Guinea, Tonga
Funding to support interventions	5 (42%)	Nauru, Papua New Guinea, Solomon Islands, Vanuatu, Tonga
Reactivation of associations	3 (25%)	Nauru, Papua New Guinea, Solomon Islands, Vanuatu
Other (eg, providing health promotion resources, information sharing, developing diabetes registry)	3 (25%)	Guam, Fiji, Solomon Islands

## Discussion

This study provides information on the status of diabetes associations in PICTs and identifies areas that need to be enhanced to scale up their efforts in combating diabetes. A diverse range of diabetes prevention and care activities were supported by existing associations, including hosting annual events, running health programs, and producing information resources about diabetes.

There are very limited studies examining the existence and status of diabetes associations in PICTs, which are relevant to make comparisons with the findings of this study. However, there are examples of established and sustained robust diabetes associations that can speak up for the needs and rights of people with diabetes, such as Diabetes Australia.<sup>12</sup> However, this study identifies that only half of the Pacific diabetes associations that responded to the survey are fully functioning—the remainder are either partially functioning (n=3, 25%) or not functioning at all (n=3, 25%). Some associations faced organizational challenges, including that only half of associations have a regular funding source, and many do not have a robust governance structure or specific purpose and vision. This finding demonstrates the need to establish and strengthen diabetes associations in implementing acceptable practices to address diabetes effectively.

Capacity and resources to address diabetes and the effectiveness and sustainability of these diabetes associations are of major concern. Only 4 (33%) of associations reported that they produce health promotion resources (eg, pamphlets and flyers) and organize ongoing health programs addressing NCD risk factors (eg, physical activity promotion program and healthy food cooking demonstration program). Given that funding and capacity building through training were identified as support needs by most associations, it is critical for PICT governments and development agencies to invest more in strengthening diabetes associations to scale up diabetes prevention and control actions at the national level.

Given PICTs have some of the highest rates of diabetes in the world. Diabetes has become a major health and development challenge in the Pacific region. There have been several declarations and commitments aimed at addressing diabetes as a whole-of-government and whole-of-society approach. For example, the Pacific NCD roadmap<sup>13</sup> endorsed by Pacific leaders in 2014 recognized the need for multi-stakeholder involvement to address NCD, a commitment reaffirmed by Pacific leaders at the 2016 Pacific NCD Summit<sup>10</sup> and Pacific Health Ministers Meeting 2019.<sup>14</sup> However, there have been challenges to ensuring the response is a collaborative approach involving stakeholders including diabetes associations. These challenges include limited capacity, resource constraints, and competing priorities of stakeholders in PICTs.

Recognizing these challenges and considering the preliminary findings of this study, SPC conducted an inaugural regional meeting of Pacific diabetes associations in September 2017 in Fiji. The meeting aimed to strengthen Pacific diabetes associations and enhance collaboration to address the diabetes epidemic. The meeting was attended by representatives from 12 PICTs (American Samoa, Cook Islands, Fiji, Federated States of Micronesia, French Polynesia, Guam, Marshall Islands, Nauru, Papua New Guinea, Solomon Islands, Tonga, and Vanuatu), and development partners and stakeholders, including the World Health Organization, United Nations agencies, Fred Hollows Foundation New Zealand, Diabetes Australia, Diabetes New Zealand, and academic institutions.

Preliminary data presented at this meeting helped generate a common understanding among diabetes associations on actions needed to improve the function of their associations, the prerequisites to sustain their associations, and resources and opportunities to strengthen in-country and regional collaboration to foster their growth and development. This meeting also increased awareness, knowledge, and understanding of the role and influence of associations in addressing diabetes at the national and regional levels. More importantly, considering the

preliminary findings of this study, the participants developed an ‘action plan’ for their national diabetes association and identified future focus areas and collaborative initiatives. Following this meeting, SPC has continued to support diabetes associations to ensure associations are robust and well-functioning.

From 2018 to 2019, several important actions have been observed at the country level. For example, the Solomon Islands and Nauru have committed to reactivating their existing national diabetes associations. Fiji, Tonga, Marshall Islands, and Guam have further strengthened their association by implementing diabetes prevention and care activities in their respective countries. A follow-up study replicating the process of the current study should be considered to monitor the progress on the status of associations.

This study fills a significant knowledge gap by providing an overview of the status of associations and forms a baseline from which associations can be strengthened. More importantly, it draws attention to the need for Pacific leaders to focus and invest more in engaging and mobilizing civil societies in tackling diabetes more effectively. PICTs should be encouraged to continue to strengthen their diabetes associations, and PICTs which do not have existing diabetes associations should be encouraged to establish one, to strengthen their efforts in addressing evidence-based cost-effective diabetes intervention in a whole-of-society approach. However, this study has a limitation that needs to be improved in the future follow-up study. For example, given that SPC’s NCD policy experts solely determined the categories of assessment for overall functioning status, it may not adequately reflect the actual functioning status of the associations. Despite the limitation, the categories on functioning status are necessary to prioritize which associations need the most support from the development partners in the Pacific to enhance their efforts in prevention and control of diabetes.

In conclusion, mounting a sustainable response to the diabetes epidemic is an urgent priority. It is imperative to assess and understand the status of key stakeholders, such as diabetes associations. Engaging diabetes associations by design and not by default is key in our collaborative approach to address diabetes in the Pacific. Our shared vision of the Healthy Islands, particularly the vision on “people work and age with dignity”<sup>11</sup> through efforts to reduce avoidable disease burden and premature deaths due to NCD, will be realized when diabetes associations are sustained and no one left behind. These efforts will ensure Pacific people reach their potential and lead healthy lives.

## Conflict of Interest

None of the authors identify a conflict of interest.

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