# PACIFIC NCD SURVEILLANCE AND OPERATIONAL RESEARCH MEETING

(Noumea, New Caledonia, 6-8 February 2013)

LIBRARY

Secretariat of the Pacific Community

# REPORT OF MEETING

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Noumea, New Caledonia, 2013

#### **Contents** 1. 11. Introduction ......5 Agenda ......6 III. Proceedings......7 IV. 1. 2. Presentation on Global, regional and national agreements by Viliami Puloka ......8 3. NCD surveillance activities in Palau – presented by Karen Carter on behalf of Losii Samsel ......8 4. 5. NCD surveillance activities in Cook Islands – presented by Haikiu Taukave......9 NCD surveillance activities in Vanuatu – presented by George Worwor .......9 6. NCD surveillance activities in Tonga – presented by Sione Hufanga and Malakai Ake ......9 7. 8. Secretariat of the Pacific Community - Health Protection Programme - presented by Adam Roth......10 9. Brisbane Accord Group/Pacific Vital Statistics Action Plan – presented by Karen Carter ......11 NCD surveillance activities in New Caledonia – presented by Sylvie Laumond.......11 10. 11. National Minimum Development Indicators – presented by James Hemphill......12 12. Pacific Health Information Network – presented by Sione Hufanga......12 13. UQ – HISHub – presented by Nicola Hodge ......13 14. C-POND presented by Wendy Snowdon.....14 15. PIHOA NCD surveillance framework presented by Mark Durand.......15 16.

Pacific Public Health Surveillance Network presented by Christelle Lepers......16

NCD Observatory presented by Boyd Swinburn......16

Appendix 1 - LIST OF PARTICIPANTS ......21

Group exercise: What are the NCD surveillance needs in the Pacific? What are the NCD operational

Group Exercise: How can the identified needs for NCD surveillance and operational research be

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#### I. Executive summary

The Pacific NCD Surveillance and Operational Research meeting was held at the Secretariat of the Pacific Community (SPC) headquarters in Noumea, New Caledonia, 6-8 February 2013. Representatives from Pacific Island countries and territories and key regional organisations attended the meeting. The purpose of the meeting was to share information and discuss current NCD surveillance initiatives and frameworks in the Pacific region, and to discuss NCD surveillance and operational research needs and ways to address these needs.

Regarding surveillance, recommendations include: (1) advocate for a contact person (and back-up person) for NCD surveillance in each Pacific Island country and territory – it would be good to have one CD/NCD surveillance person and one person who is a general NCD person; (2) tailor the WHO NCD framework of indicators to the Pacific; (3) sketch out the potential structure, processes and visualisations for a regional access point for health; (4) conduct a mapping exercise of what people are currently doing regarding NCD surveillance and operational research; (5) conduct national HIS assessment – inclusive of NCD surveillance assessment – where required, identifying national gaps/needs, and then advocating the importance of NCD surveillance to national politicians; (6) at the Pacific Health Information Network (PHIN) meeting in June, do further work with countries to map out the country-specific NCD surveillance and operational research needs; (7) support the continuation of PHIN; (8) support the Pacific Vital Statistics Action Plan – work around improving vital statistics and cause of death data should continue to be coordinated through this process; (9) hold further country-level consultations on this plan.

Regarding operational research, recommendations include: (1) improve the sharing of information — to include a mechanism for bilingual information sharing, such as Inform'ACTION; another Pacific Health Dialogue issue on NCDs; a formalised communication strategy for sharing information; more sharing of research in the region; link to the regional access point; (2) ethics — support and streamline national and regional processes for ethics approval (country ministries, WHO, universities, etc.); (3) support translating research into policy and practice, identifying barriers and enablers; (4) build capacity in operational research at country and regional levels, including through courses, programmes and mentoring/supervision, and through the continuum of research planning to publication; and (5) taking stock of activities (identification/mapping of country and regional NCD operational research needs and activities).

The information in this report will be used in SPC's Public Health Division strategic planning. Further consultation of Pacific Island countries and territories will take place at the PHIN meeting in June and other key regional meetings. SPC will work with countries and key regional institutions to develop an agreed set of recommendations and a plan for strengthening NCD surveillance and operational research in the Pacific.

#### II. Introduction

The Pacific NCD Surveillance and Operational Research meeting was held at the Secretariat of the Pacific Community (SPC) headquarters in Noumea, New Caledonia, February 6-8, 2013. The meeting was hosted by SPC and chaired by Dr Wendy Snowdon from the Pacific Research Centre for the Prevention of Obesity and Noncommunicable Diseases (C-POND).

#### **MEETING OBJECTIVES**

- 1. To present current NCD surveillance initiatives/frameworks in the Pacific.
- 2. To discuss NCD surveillance and operational research needs in the Pacific.
- 3. To discuss ways forward for addressing these needs.

#### **MEETING OUTPUTS**

- 1. Mapping document/matrix of current NCD surveillance and operational research activities in the Pacific.
- 2. Recommendation report/paper for strengthening NCD surveillance and operational research in the Pacific.
- 3. Recommendation report/paper on the identified NCD operational research agenda for the Pacific.

# III. Agenda

Madhasilaz áib	February	
8.30-9.00	Meeting opening and introductions	Colin Tukuitonga
9.00-9.45	Background, outline of objectives, mapping questionnaire,	Damian Hoy
	workshop evaluation	
	Presentations on current NCD surveillance	
	initiatives/frameworks in the Pacific (each presenter to please	
	give a 10 minute overview of past/current activities, areas of need, future plans, and key policy/strategy documents, plus 5-	
	10 minutes discussion)	
9.45-10.15	Global, regional and national agreements	Viliami Puloka
10.15-10.45	Morning tea	VIII I GIORG
10110 10110	NCD surveillance activities in Palau	Losii Samsel
	NCD surveillance activities in Cook Islands	Haikiu Taukave
10.45-12.30	NCD surveillance activities in Vanuatu	George Worwor
	NCD surveillance activities in New Caledonia	Sylvie Laumond
	NCD surveillance activities in Tonga	Ake Malakai
12.30-1.30	Lunch	
	Secretariat of the Pacific Community - Health Protection	Adam Roth
	Program	
1.30-3.10	Brisbane Accord Group/Pacific Vital Statistics Action Plan	Karen Carter
1.50 5.10	National Minimum Development Indicators	James Hemphill
•	PHIN Regional HIS Plan	Sione Hufanga
2 10 2 20	Health Information Systems Hub (HISHub)	Nicola Hodge
3.10-3.30	Afternoon tea	Mark Durand (dial in)
3.30-5.00	PIHOA/CDC NCD surveillance framework Human Resources for Health Hub (HRHHub)	Mark Durand (dial-in) UNSW (TBC)
	Pacific NCD Observatory	Boyd Swinburn (dial-in)
	C-POND	Wendy Snowdon
	Pacific Public Health Surveillance Network	Christelle Lepers
Thursday 7th Fo	ebruary	
Thursday 7th Fo		Damian Hoy
	Re-cap of Day 1  NCDs in the Pacific: short presentation; exercise	Damian Hoy Facilitated by Adam Roth
8.30-9.00	Re-cap of Day 1	
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8.30-9.00 9.00-10.00 10.00-10.20 10.20-11.30 11.30-12.30 12.30-1.30 1.30-2.30 2.30-3.00 3.00-4.30	Re-cap of Day 1 NCDs in the Pacific: short presentation; exercise  Morning tea NCDs in the Pacific (cont'd): discussion Group exercise:  What are the NCD surveillance needs in the Pacific?  What are the NCD operational research needs in the Pacific?  Lunch Group exercise (cont'd):  What are the NCD surveillance needs in the Pacific?  What are the NCD operational research needs in the Pacific?  Maternoon tea Group exercise: How can the identified needs for NCD surveillance and operational research be addressed?	Facilitated by Adam Roth and Damian Hoy  Facilitated by Adam Roth Facilitated by Viliami Puloka and Jeannie McKenzie  Facilitated by Viliami Puloka and Jeanie McKenzie
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8.30-9.00 9.00-10.00 10.00-10.20 10.20-11.30 11.30-12.30 12.30-1.30 1.30-2.30 2.30-3.00 3.00-4.30 6.00	Re-cap of Day 1 NCDs in the Pacific: short presentation; exercise  Morning tea NCDs in the Pacific (cont'd): discussion Group exercise:  • What are the NCD surveillance needs in the Pacific?  • What are the NCD operational research needs in the Pacific?  Lunch Group exercise (cont'd):  • What are the NCD surveillance needs in the Pacific?  • What are the NCD operational research needs in the Pacific?  • What are the NCD operational research needs in the Pacific?  Afternoon tea Group exercise: How can the identified needs for NCD surveillance and operational research be addressed?  BBQ  Mary  Re-cap of Day 2 Group work: How can the identified needs for NCD	Facilitated by Adam Roth and Damian Hoy  Facilitated by Adam Roth Facilitated by Viliami Puloka and Jeannie McKenzie  Facilitated by Viliami Puloka and Jeanie McKenzie  Facilitated by Christelle Lepers and Adam Roth
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#### IV. Proceedings

#### 1. Meeting opening and introductions by Colin Tukuitonga

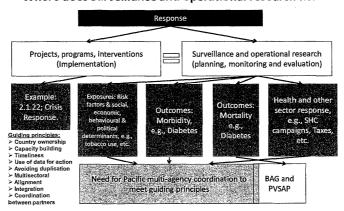
- a. SPC is currently revisiting their plans for supporting Public Health in the region.
- b. The Surveillance and Operational Research program is very much recognised and respected in the region.
- c. There are many health concerns in the region NCDs are a big part of this.
- d. Great participants are here as we want to get their input into our planning.
- e. This is an SPC and country meeting, and is part of a longer conversation on how we can improve NCD Surveillance and Operational Research (SOR) and SPC's role in that. We will meet with WHO soon as they were unable to come to the meeting.
- f. Time for countries to start analysing the information in a timely manner.

#### 2. Presentation on background and outline of objectives by Damian Hoy

- a. Non-communicable diseases (NCDs) cause an enormous and increasing global burden.
- b. In 1990, 47% of DALYs worldwide were from communicable, maternal, neonatal, and nutritional disorders, 43% from non-communicable diseases, and 10% from injuries. By 2010, this had shifted to 35%, 54%, and 11%, respectively
- c. NCDs causing the greatest global burden in 2010 are estimated to be ischaemic heart disease (1), stroke (3), <u>low back pain</u> (6), COPD (9), <u>depression</u> (11), diabetes (14), <u>neck pain</u> (21), and trachea/bronchus/lung cancers (22).
- d. Good quality health information is essential for planning and implementing health programs to address the rising NCD burden.
- e. Health Ministers meeting in Tonga (2003): Call for aspects of NCD surveillance to be incorporated into the Pacific Public Health Surveillance Network (PPHSN).
- f. Health Ministers meeting in Samoa (2005): "Establish a regional policy and coordinated mechanism for sharing of NCD surveillance data between countries and areas. This would:
  - i. Allow countries and areas to compare their data sets directly with others, with protection for confidentiality
  - ii. Seek integration with health information systems and with mortality data
  - iii. Facilitate age- and gender-specific analyses and aid the development of age- and gender-appropriate interventions
  - iv. Link to and coordinate with PPHSN mechanisms in order to extend rather than duplicate existing mechanisms."
- g. At the October 2012 Pacific Island Forum Secretariat Health and Population Working Group Meeting, SPC proposed there be a multi-stakeholder NCD surveillance meeting (this meeting) to discuss ways of improving NCD surveillance and its coordination in the Pacific.
- h. There are several NCD surveillance and operational research initiatives currently taking place or in development in the Pacific -> important that these are all harmonised.
- i. NCDs are one of the identified cross-cutting issues at SPC. A number of SPC divisions are currently involved in the NCD response.
- i. SPC PHD is revisiting their long term strategy
  - i. NCD is a priority for PHD and SPC
  - ii. Surveillance and OR will be core functions for PHD.



#### Where does surveillance and operational research fit?



#### k. Questions/comments:

- i. A need for collection of data to observe disease patterns.
- ii. Surveillance is about "early detection" to facilitate early response that is why communicable disease response has been so effective at controlling epidemics.
- iii. Important to closely link surveillance with monitoring and evaluation.
- iv. Recognition that the time frames are different for NCDs
- v. Need to have better information to act as things either get worse, or to see if the epidemic is waning due to interventions (or other).
- vi. General support for putting together a matrix of who is doing what and where with regard to NCD surveillance and operational research.

#### 3. Presentation on Global, regional and national agreements by Viliami Puloka

- a. Need for better use of data.
- b. NCD big problem contributing to disability/morbidity and premature mortality in the Pacific.
- c. Growing and young population in the Pacific ->big problem for future.
- d. Issues with Diet Imported foods 70% of food in Tonga imported.
- e. Urbanisation an issue.
- f. Need to address behavioural, environmental risk factors as a priority.
- g. 2-1-22 Pacific NCD Programme WHO/SPC partnership. Pacific NCD framework was developed as part of this Funding has finished for this.
- h. Very high prevalence of diabetes; NCDs big contribution to premature mortality; obesity very common.
- i. Pacific status need to recognise it and address it.
- i. Widespread agreement on the importance of surveillance.
- k. A number of countries have NCD plans with surveillance, monitoring and evaluation.
- 1. Different sources of NCD data surveys, vital stats, census, health system records, etc.
- m. CDC Chronic Disease Surveillance System in the North Pacific.
- n. WHO-STEPs: Three levels of assessment: interview; physical measurements; biochemical measurements. Three modules: core; expanded; optional.
- o. Pacific-specific targets for NCDs, based on the global WHO targets for 2025 these were set in Auckland in 2012 not finalised yet still a draft.
- p. Childhood obesity need greater focus on children.
- q. Three prongs of surveillance need exposures; outcomes; health sector response.
- r. Need to translate information to inform policy makers
- s. Good news: NCDs are preventable.
- t. We must dare to be brave nothing will happen if we're not willing to do something about it there is hope for the Pacific.

#### 4. NCD surveillance activities in Palau - presented by Karen Carter on behalf of Losii Samsel

- a. Most NCD surveillance sits outside the health information system.
- b. Support from US grant funding specific reporting structures are linked to this.

- c. Cancer screening -> tracking system for this. (Cancer Management System links up with CDC system). Cancer registry has been in place since the 1970s has a lot of data. Mandated (by law) to report -> they present reports. Programs get together annually to share data.
- d. Also have a chronic disease/conditions registry evolved from a diabetes registry (diabetes, hypertension, asthma, gout, cardiovascular disease). -> have standard data collection for this.
- e. Currently now at the planning and transition phases from Chronic Diseases/Conditions Registry to Chronic Diseases Electronic Management System (CDEMS) which will incorporate all the chronic diseases that are currently being captured in the Chronic Disease/Conditions Registry and will also include cancer.
- f. A form is currently being finalized. Because of limitations in connectivity and other resources, the providers would fill this out to be entered by NCD staff. A report is printed out and filed into the patient's "NCD clinic" folders so that providers and patients can easily track and monitor progress and interventions.
- g. Also do school health screening for NCDs annual collection of information (ages 6-18).
- h. Are currently developing a social media campaign on tobacco use amongst high school students as the data gathered from school health screening clearly showed that we need to intervene so that kids don't ever start using tobacco.
- i. Injuries captured through ER logbooks and public safety records.
- j. Challenges need injury surveillance system; centralised NCD data system; make sure we have NCD risk factor data that are not too outdated.

#### 5. NCD surveillance activities in Cook Islands – presented by Haikiu Taukave

- a. NCDs contribute significantly to the health burden of Cook Islands people with increasing numbers of people presenting with cardiovascular disease, diabetes, cancer, chronic respiratory disease and injury.
- b. NCDs accounted for 80% of deaths in the Cook Islands in 2010.
- c. The prevalence of NCD has steadily risen from 16.5% in 2001 to 31% in 2010.
- d. The increasing rates of cancers and the ability to intervene early and provide curative care is a major challenge to the health system.
- e. 2003- STEPS survey of chronic disease risk factors for adults 25-64yrs
- f. Package of Essential NCD (PEN) is a WHO developed program looking at non communicable disease interventions for primary health care in low resource settings. Six building blocks of the health system Service delivery, Human Resources, Finance and Social Protection, Information, Medicines and Technologies, and Leadership and governance. Currently we are integrating PEN into 3 areas where it is likely to impact the most.
- g. Have the Cook Island Tobacco Control Action Plan 2012-2016.
- h. Other activities include: Walkway in town; Weekly Zumba activity; Daily training program; Awareness programs Movember, free screening; and CHIP Coronary Health Integrated Program.

#### 6. NCD surveillance activities in Vanuatu - presented by George Worwor

- a. Various activities being undertaken to address risk factors for NCDs:
  - i. Increase alcohol tax
  - ii. Smoke-free work/public places
  - iii. Have banned tobacco advertising
  - iv. Salt reduction program.
- b. STEPs surveys in 2007 and 2011 there has been a one page summary document of the results report not yet released.
- c. Will find out more from MOH and will forward information.

#### 7. NCD surveillance activities in Tonga - presented by Sione Hufanga and Malakai Ake

- a. Health Information System is well established -> collects, analysed, disseminates information -> morbidity/mortality data, survey/screening data included in HIS.
- b. NCD Surveillance tools and approaches:
  - i. 2 STEPs SURVEYs (2004 & 2012)
  - ii. NATIONAL CENSUS (2011)
  - iii. DHS SURVEY 2012
  - iv. 2 Researchers 2012 (Mortality)
  - v. HIS Data Collection (Hospital and Community HC, ongoing)

- c. HIS data collection:
  - i. hospital plus health centre monthly reports
  - ii. 148 Health indicators; 23 annual reports.
  - iii. Stock take all health data dictionary 35 NCD indicators.
  - iv. Hospitalisations for NCD types principal and additional
  - v. Finance allocated to NCD care.
  - vi. Data from 2000-2013 ongoing (therefore timely)
- d. 25% of people screened under 25 years have diabetes (prelim data not for release only)
- e. Adult mortality 3 times higher than Australia and NZ.
- f. Revamping the Cancer registry operational for while, but now revising.
- g. Cancer registry from 2000 updating from 2009 still need some work.
- h. NCD is a focus of the MDG acceleration program started 2010. Acceleration program has own targets. Implementation targets. Outcome targets are the same as the Pacific targets.
- i. Hospital morbidity data had identified an issue that not only are diabetes cases increasing but that age of onset was getting younger. Then confirmed that in a modification of the STEPS survey
- j. STEPS 1 took 7 years to analyse and release (released in 2012) learned from mistake 2012 survey being analysed now and will be released in 2013.
- k. Need external assistance with action research as opposed to surveillance very little research done by national staff and would like some assistance with this.
- 1. Comment: the need to address the continuum from child->adult so data on risk factors for all ages.

#### 8. Secretariat of the Pacific Community - Health Protection Programme - presented by Adam Roth

- a. SPC Public Health Division (PHD) within a change process and deciding on their strategy. CD and NCDs will be priority areas within the PHD strategy (also STIs, social determinants of health). Will not be changing what's working.
- b. Core functions: Evidence and Information for Action; Planning, Policy & Regulatory, M & E; and Training & Development, Public Health Leadership
- c. Health Protection Program (HPP) of the PHD:
  - i. Disease surveillance and response
    - CDs: PPHSN priority target diseases (dengue fever, measles, rubella, influenza, leptospirosis, typhoid fever, cholera and HIV/STIs) and tuberculosis; emerging diseases; and public health emergencies (risk evaluation, surveillance, response)
    - NCDs (surveillance only, i.e., not response)
  - ii. Laboratory strengthening
  - iii. Operational research
  - iv. Focal point for the PPHSN Coordinating Body (CB)
- d. Six guiding principles:
  - i. Information of the public health decision-making process (evidence-based);
  - ii. Strengthening the PPHSN services and regional coordination mechanisms;
  - iii. Capacity building, capacity supplementation and/or capacity substitution at national and/or regional levels;
  - iv. Development of inter-PICT technical assistance;
  - v. Sustainability of health protection services at national and regional levels;
  - vi. Combination of operational research and development activities/synergies.
- e. 8-year strategy/plan for guiding HPP development:
  - i. Strengthening HIS at national and regional levels
  - ii. Develop an operational research agenda across HPP
  - iii. Prepare action plans for each of the PPHSN priority target diseases, TB, EID and PH emergencies
  - iv. Complete FETP feasibility study and plan for the Pacific FETP in coordination with WHO, FSMed and PPHSN-CB members
  - v. Develop ad hoc and/or ongoing training activities on a modular format to fit the future FETP portfolio of educational objectives, and suit the different needs of our country/territory members
  - vi. This meeting is an opportunity for ideas and input.

#### 9. Brisbane Accord Group/Pacific Vital Statistics Action Plan - presented by Karen Carter

- a. Mortality is a critical outcome indicator for NCDs in its own right, and can be a useful proxy for NCD morbidity, particularly when other elements of NCD surveillance are not well developed.
- b. WHO NCD mortality target has not been formally adopted as yet.
- c. Direct and indirect indicators for mortality.
- d. Tongan system is a good example of a well functioning vital registration and health information system. Very useful for monitoring the NCD situation in Tonga.
- e. Need minimum data deaths by age/sex/cause.
- f. There are big gaps in being able to estimate adult mortality in the Pacific.
- g. Complete vital registration is the best source of data for mortality indicators
- h. Working with countries to improve analysis and reporting of vital registration data for NCD surveillance (along with other health planning and evaluation uses) is a core component of the Pacific Vital Statistics Improvement Action Plan.
- i. The BAG group is currently working with countries under this plan. 15 countries and 3 territories have country teams working on vital statistics improvement.
- j. Brisbane Accord Group (BAG):
  - i. Multi-agency group to try to harmonise approach across region and provide a consistent, coordinated approach. including SPC, WHO, UNICEF, UNFPA, UQ HIS Hub, FNU, PHIN UNSW, QUT etc
  - ii. Country engagement through national statistics frameworks
  - iii. Have developed Pacific Vital Statistics Action Plan (2011-14), which sites under the TYPSS. The plan is country driven/focused.
  - iv. Report back to countries through Health Ministers meetings.
  - v. First step in national assessments, then development of national plans to support strengthening vital stats
  - vi. Have 4 country clusters i.e., four categories of countries each category has a different strategy.
  - vii. Working with countries to analyse and report on vital statistics.

# 10.NCD surveillance activities in New Caledonia - presented by Sylvie Laumond

- a. Generally NCD surveillance is organised 2 ways in New Caledonia: Routine collection of pathologies and NCD surveys.
- b. NCD have a major impact in New Caledonia.
- c. Many people involved in surveillance:
  - i. Three hospitals in New Caledonia 1 for aged; 2 other hospitals. Have medical information management system -> a record is made every time someone presents. There is also a computerised register currently being set up at the hospital. Pharmacy and other departments within the hospital also collect data which can be useful for monitoring NCDs.
  - ii. Health departments and health care networks involved in data collection e.g., cancer/kidney/respiratory disease.
  - iii. NGOs surveillance of environmental risk (e.g., air quality).
  - iv. Also French research institutes (Pasteur Institute).
  - v. Have done mental health studies, asthma, mercury consumption, pregnancy studies, consequences of air quality on health.
  - vi. Police department also involved (road trauma, alcohol).
  - vii. Economic Affairs data (tobacco consumption, etc).
  - viii. Statistics and demographic department.
  - ix. Articular Rheumatism, Cancer (mandatory reporting), etc.
  - x. Death certification -> registry births and deaths, also sent to public health department.
  - xi. Do social/demographic surveys on regular intervals give information on health status of the population, incl. NCDs. Also tobacco consumption surveys.
  - xii. Diabetes registry.
- d. Each year, we synthesise all of these data and prepare a State of Health report (available of website) this is used for planning, monitoring and evaluating programs.
- e. Also involved in disease outbreak and response.
- f. Infant Mortality Rate 4.6/1000 live births.
- g. Life Expectancy at Birth 77.4.

- h. Cancer has moved from second to first position in terms of Cause of Death; health and lung disease are next, followed by accidents and external causes. Communicable diseases account for <10% of deaths in New Caledonia.
- i. 35% of people from 13 to 15 years old smoke.
- j. Alcohol use is high.
- k. Main cancers: Breast Cancer, Prostate Cancer, Lung Cancer.
- 1. Short of data on obesity in children; the evolution of diabetes prevalence; and cancer survival, etc.

#### 11. Two studies from New Caledonia presented by Philippe Corsenac

- a. Barometer of Health Survey similar design to WHO-STEPs survey i.e., there are two steps interview and biometric measurement.
- b. 2010 New Caledonia Global Youth Tobacco Survey have added questions about alcohol and kava consumption.
- c. Comments:
  - i. A need for research in Tonga on the changing knowledge and attitudes in regarding to some of the risk factors for NCDs (e.g., Smoking).
  - ii. Very important to have political support for surveillance.

# 12. National Minimum Development Indicators - presented by James Hemphill

- a. Website: www.spc.int/nmdi
- b. An online database of over 200 indicators multi-sectoral.
- c. Open access no password required.
- d. In terms of NCDs: life expectancy, adult mortality, diabetes, overweight, obesity. This needs to be expanded.
- e. Country data as a priority.
- f. Very clear about the source of the data and meta-data.
- g. 15 countries so far and will follow up other countries/territories this year.
- h. Summary information can see how old the data are.
- i. Can produce summary reports/charts by country can export as pdfs and excel files.
- j. Can view indicators on a map.
- k. Are in the process of adding further NCD-specific indicators.
- 1. Also doing a lot of work as to how the data can be visualised posters, etc.
- m. WHO have recently introduced a health information and intelligence platform. SPC are currently discussing with WHO how the two databases can be better linked.
- n. PRISM a link to national level statistics websites –important for visibility and links with other sectors website: <a href="www.spc.int/prism">www.spc.int/prism</a> Key advantage of this project is that pages are country owned with SPC support and links to a regional platform.
- o. Comments:
  - i. Dr Ake recommended going to countries to strengthen country capacity to collect this information and send it through to NMDI and other regional databases. Need assistance with how to do databases like this in-country need help to lobby leaders for this. Need to have Noumea/Suva agreement for databases. For syndromic surveillance, most Pacific countries report to WHO countries happy to include SPC in this need to make sure there is just one form and not duplicate.
  - ii. Point made on the usefulness of NMDI to stimulate operational research.
  - iii. Point made about the need to lobby decision makers suggestion about the importance and usefulness of using visual aids to lobby leaders.

#### 13. Pacific Health Information Network - presented by Sione Hufanga

- a. Website: www.phinnetwork.org
- b. PHIN is a non-government, not for profit organisation
- c. PHIN was established at a Health Metrics Network (HMN) meeting in Noumea in 2006
- d. Sione is the President; UQ HISHub is the Secretariat
- e. Mission: Professionals working in health information systems in Pacific Island Countries and Territories shall promote and use reliable, complete and timely information for decision-making and for achieving greater health outcomes.
- f. Until now, our Pacific communities have understood health information systems in different ways. An incorrect but common definition is that health information systems are <u>sophisticated computer systems</u>.

- g. Health information systems refer to any system that captures, stores, manages or transmits information related to the health of individuals or the activities of organisations that work within the health sector.
- h. Health information should include determinants of health, health system inputs, outputs and outcomes as well as morbidity, mortality and well-being.
- i. A health information system is an 'Invisible Giant' with intelligent processes to move data around a health system to assist evidence-based healthcare services. Health information systems cut through the whole spectrum of health care services (bottom-up, left, right and centre)
- j. Data sources: population based (census, civil registration, surveys, etc), institution-based (records).
- k. Need for public health research to better understand the health of the community.
- 1. Importance of an <u>integrated health information system</u> emphasised it cuts across all aspects of the health system.
- m. Importance of translating data into action emphasised.
- n. "Before we ask what the HIS has done for the health system, we should ask what the health system has done for HIS"
- o. PHIN 2012-17 Regional HIS Plan to guide PHIN members to strengthen their HIS six key aspects of this:
  - i. Advocate for the recognition of and improvement to HIS with PICTs
  - ii. Enhance institutional capacity and opportunities for workforce development and training
  - iii. Strengthen the application of information and communication technologies (ICT)
  - iv. Improve data integration, quality and sharing
  - v. Develop policies, regulations and legislation on HIS-related issues
  - vi. Enhance HIS leadership and sustainable governance).
- p. HIS regional meeting in 2011 with PHIN, UQHISHib, and WHO
- q. Pacific Health Dialogue journal has a special issue on HIS Vol 18, No 1 April 2012.
- r. PHIN receives technical support from UQHISHub, SPC, Health Metrics Network, and WHO. Support from AusAID.

# 14.UQ - HISHub - presented by Nicola Hodge

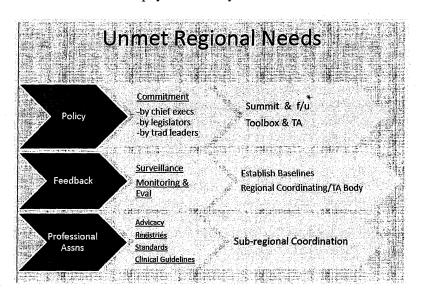
- a. HISs in the Pacific currently do not give Pacific decision makers enough information to address the information needs for NCD prevention and control
- b. Pacific NCD decision makers need information on:
- a. The magnitude of the public health problem posed by NCDs
- b. Levels and trends in the prevalence of risk factors and in NCD conditions
- c. The impact of current policies and programs on these trends
- c. HIS issues and challenges: Completeness of data (Hospital registries, CRVS systems, surveys; Data integration and sharing); Accuracy of data (Certification and coding of underlying cause-of-death; Analytical skills among data producers); Timeliness and dissemination of data; HIS legislation or regulation (Data standards); and Recruitment and retention of workforce.
- d. Use the Health Metrics Network HIS tool.
- e. Involvement with PHIN (Secretariat) events, membership, website, coordination, facebook, etc.
- f. PHIN 2012-17 Regional HIS Plan.
- g. Resource mobilisation e.g., PHIN has just commenced undertaking ICD coding training.
- h. Capacity building annual short-course on HIS; Civil Registration/Vital Statistics course; etc; regional workshop in 2011 another one planned for June in preparation for the July Health Ministers Meeting.
- i. No funding beyond June 30.
- j. Need for data analysis much data available but never gets analysed this needs to be addressed.
- k. HISHub have developed a number of tools with SPC Civil registration and vital statistics assessment tool; Handbook on cause-of-death certification
- 1. Member of Brisbane Accord Group.
- m. In 2 weeks, hosting a meeting what are the HIS implications for NCDs the focus is academic to develop the research agenda and then pass this onto organisations like SPC to undertake.
- n. Need to avoid vertical programs.
- o. Questions/comments:
  - i. Question about how data analysis can be improved many institutions/individuals with interest, and expertise to undertake this but need a harmonised approach. Suggestion to use institutions that are already available FNU; POHLN network; Etc.
  - ii. Comment on SPC PHD increasing involvement in data analysis in health.

#### 15. C-POND presented by Wendy Snowdon

- a. C-POND is three years old and stands for the Pacific Research Centre for the Prevention of Obesity and Non-communicable Diseases.
- b. The aim of C-POND is to provide a Pacific Centre of excellence in <u>research</u>, <u>research</u> training <u>program and</u> <u>policy evaluation</u>, knowledge translation, and other research-related activities for the prevention of obesity and NCDs.
- c. The objectives are:
- a. To conduct solution-oriented research on obesity and NCDs: focus on finding solutions
- b. To disseminate the research findings and translate them into policies and practice
- c. To build research capacity in obesity and NCD prevention: incl. student supervision and training.
- d. Collaboration between Deakin University (Melbourne) WHO Collaborating Centre for Obesity Prevention *and* Fiji School of Medicine (now CMNHS, FNU). Based at CMNHS Tamavua campus.
- e. Research in line with country priorities and requests (although country priorities not always clearly stated)
- f. Collaborations: Organizations e.g. WHO, SPC; MoH around the region; academic institutions; Within FNU (staff and students).
- g. Have a reference group; Support and research staff; 2 local PhD students enrolled at Deakin University.
- h. Want to work within country priorities first question how will you use this research in practice.
- i. Big focus on capacity building in evidence-informed policy development.
- j. TROPIC & TROPIC II ADRA funded; done in collaboration with Deakin 2009-2012: Fiji component focused on knowledge exchange; Workshops and mentoring for participants to develop evidence-informed policy briefs; Funded by FHSSP, extension of TROPIC capacity building arm only.
- k. Led Pacific Islands Health Research Symposium 2011 and 2012 growing interest event next is planned for 2014. Also ran a writing workshop as part of this.
- 1. Ran Obesity Prevention short course in collaboration with Deakin and CMNHS in 2012.
- m. Next week sub-regional workshop on trade and NCDs in collaboration with SPC, UNDP and WHO.
- n. Undertook a regional and country consultation on research priorities in 2011, regionally these were:
  - i. Secondary analysis of STEPS data
  - ii. Waist circumference action points for Pacific (this could be done within secondary analysis of STEPS data)
  - iii. Economic impact of NCDs, and cost-effectiveness of interventions
  - iv. BMI (and other relevant information) of children
  - v. Pacific risk scores
  - vi. Diabetes Prevention in Pacific (DPiP)
  - vii. Socio-cultural issues (determinants and solutions)
  - viii. Policies assessment of current actions, OPIC recommendations
    - ix. Sodium levels in foods, intake.
- o. Nutrient database research project (from labels) 5 countries to create regional database, part of international collaboration, WHO funding.
- p. Cost-effectiveness salt reduction strategies in Fiji and Samoa: NHMRC grant with George Institute, Deakin. Just commenced. Three years. Will work closely with MoH and NFNC in Fiji for Fiji arm, and through MoH in Samoa
- q. Salt intake assessment: Fiji (Masters student), WHO funded.
- r. Junk food advertising: Student project in Fiji 2011 (TV, street, child questionnaire). WHO funded work in 4 PICs (TV) 2012. Student project: Fiji 2012 (radio)
- s. Infant diet study Fiji: exploratory qualitative study conducted with mothers of young children to identify influencers on feeding of children
- t. Tonga young child activity study: exploratory qualitative study conducted with mothers and fathers of young children to identify influencers on physical activity
- u. Preliminary study of NCD-related disability in 5 PICs and rehab service availability (underway)
- v. Case study Fiji health system responsiveness to NCDs: Nossal Institute
- w. TA for Cooks survey of alcohol use in youth
- x. Solomon Islands survey of NCD-related behaviours in vocational school students planned with MoH Sols
- y. Further analysis of OPIC dataset
- z. Upcoming work:
  - i. Food policy impacts and processes: under NHMRC 'Centre of Research Excellence for Obesity Research'
  - ii. Tobacco and trade research (led by Uni Auckland and Uni Sydney)
  - iii. Assist Fiji with STEPS report.

#### 16.PIHOA NCD surveillance framework presented by Mark Durand

- a. Criteria for Selection of Core Indicators: Not dependent on a single instrument (e.g. both NCD Steps and BRFSS "friendly"); Consistent with WHO and SPC Recommendations; Addition of youth risk indicators because: 1) focus on youth useful for promoting painful policy changes; 2) leading indicators to define end to declaration
- b. Fifteen Essential Policies for Reversing the Epidemic of Non-Communicable Diseases in PIHOA jurisdictions:
  - i. Risk Factor: Tobacco
    - Commitment 1: Increase taxes on tobacco products (to extent needed to offset costs)
    - Commitment 2: Pass and enforce model comprehensive smoke-free air acts
    - Commitment 3: Ban all forms of tobacco product advertising
    - Commitment 4: Establish and sustain tobacco cessation programs.
  - ii. Risk factor: Alcohol
    - Commitment 5: Ban all forms of alcohol advertising
    - Commitment 6: Restrict access to alcohol
    - Commitment 7: Increase taxes on alcohol (to extent needed to offset costs)
  - iii. Risk Factor: Poor Nutrition
    - Commitment 8: Implement policies that reduce salt consumption
    - Commitment 9: Implement policies that reduce sugar consumption
    - Commitment 10: Implement policies that reduce fat consumption
    - Commitment 11: Implement policies that promote breastfeeding
    - Commitment 12: Implement policies that promote local foods
  - iv. Risk Factor: Lack of Physical Activity
    - Commitment 13: Develop the built environment to promote physical activity
    - Commitment 14: Promote physical activity in the work place
    - Commitment 15: Promote physical activity in the schools.



- c. Surveillance Challenges:
  - i. Forging consensus on core indicators, and organization of regional surveillance system.
  - ii. "Penetration" of consensus to program and jurisdiction level.
  - iii. Alignment of donors for regional surveillance system.
  - iv. "Actualizing" sense of urgency.
  - v. Painting and disseminating a clear regional picture.
- d. Surveillance Opportunities:
  - i. Using Existing Structures & Partnerships, e.g., PPHSN.
  - ii. Building workforce development into regional surveillance system (e.g. FETP).
  - iii. Using surveillance as a tool for Pacific to assume position of global leadership in NCD response.

#### 17. Pacific Public Health Surveillance Network presented by Christelle Lepers

- a. PPHSN is a voluntary network of countries/territories and institutions/ organisations
- b. Created in 1996 under the auspices of SPC & WHO
- c. Dedicated to the promotion of public health surveillance & response
- d. Current focus on CDs: epidemic ones first, but should expand to all public health emergencies
- e. PPHSN Goal is to improve public health surveillance and response in the Pacific Islands, in a sustainable way
- f. Previous calls from health minsters meetings to link NCD surveillance to/under PPHSN.
- g. Four main services: PacNet (alert and communication); LabNet (verification and identification); EpiNet (investigation and response); PICNet (infection control).
- h. Plans for a regional EpiNet team with country and regional experts to respond to outbreaks.
- i. Pacific Syndromic Surveillance System data sent to WHO; shared on PacNet; translated by SPC; stored on PPHSN website.
- j. Information and communication tools Inform'ACTION (deliberately not a scientific journal)
- k. PPHSN website www.spc.int/phs/PPHSN
- 1. One discussion paper published in Inform'ACTION 16 has done an analysis of possible inclusion of certain elements of NCD surveillance within PPHSN.
- m. New PPHSN website will have greater links with NMDI to avoid duplication.
- n. Questions/comments:
  - i. Why did it take so long to implement the 2003/05 recommendations response: lack of resources/other priorities (e.g., SARS, avian influenza).
  - ii. Need to ensure that PPHSN is appropriate structure for NCDs given the different nature of NCDs to CDs this needs further discussion.
  - iii. PPHSN won't be a perfect fit but it's the closest thing available at the moment.
  - iv. Can be great fragmentation need to coordinate the outcomes of all meetings to ensure a harmonised approach.

#### 18.NCD Observatory presented by Boyd Swinburn

- a. Priority need for basic NCD monitoring data in the Pacific for a long time: 2/3 of respondents in C-POND survey on Pacific research needs identified basic NCD data as top priority
- b. PICTs and many organisations are doing some NCD monitoring, but incomplete, not well coordinated, low capacity, multiple players, and the available data is not fully utilized.
- c. NZ-USA Joint Committee Meeting (Sept 2012) on research collaborations included Pacific health research as a theme. Major priority was the potential for the development of a Pacific NCD Observatory.
- d. NZAid activity: Report commissioned, Dec 2012. Activity Concept Note (ie proposal) developed. Need for further consultation, political support in Pacific, potential input from other funders, submission for approval. Health Research Council has 3y funds to facilitate its development.
- e. Other activities: SPC and PIHOA meetings this week; UQ meeting on Health Information Systems in Brisbane in Feb; SPC work in strengthening mortality/morbidity data; WHO STEPS training and survey activities; C-POND undertaking some regional research on monitoring food environments; Pacific Health Ministers' Meeting in Samoa in July (on agenda for political endorsement).
- f. Potential content:
  - i. NCD mortality/morbidity (WHO, SPC, UQHISHub)
  - ii. Risk factors (STEPs/BRFSS and exploring harmonisation of these tools)
  - iii. Environments (esp. Food)
  - iv. Other health information
  - v. ?Cost data.
- g. Likelihood that various players would take responsibilities for funding, undertaking, curating various parts of the Observatory i.e., it would be a coordinated, multi-player initiative
- h. Potential players: SPC, WHO, C-POND, various networks and professional organisations.
- i. Potential funders: NZAID, AusAID, US funders, PI countries.
- j. Potential universities: Queensland, Deakin, Auckland, Hawaii,?others.
- k. Needs feedback and commitment to the concept from: Experts in the Pacific, potential donors, regional organisations, universities, PIC health officials and ministers.
- 1. Then, development of full proposal for ongoing funding with framework and scope, content areas, costs, responsibilities, governance, coordination, etc.
- m. Questions/comments:

- i. Many players/locations for housing NCD data for this Observatory, is one of the visions to find a data home, or will it be multi-location? Response: Because a number of regional players involved, it makes sense to divide it into various responsibilities (e.g., gathering, cleaning, etc) as long as it's a one coordinated approach with good availability. Repositories will be in several places.
- ii. Comment on the need to discuss things further as the Observatory further develops and that we need to build on current activities/frameworks.
- iii. Point made that while it may take three years to develop, further work needs to be done in the meantime.
- iv. Dr Ake stated that the ministers have already said NCDs should be under PPHSN so that is what we should be doing.

# 19. Group exercise: What are the NCD surveillance needs in the Pacific? What are the NCD operational research needs in the Pacific?

Participants listed current themes in NCD surveillance based on the presentations made so far. These were grouped into the following:

- a. Indicators: WHO Global Monitoring Framework; PIHOA framework; etc.
- b. Health information systems: PHIN regional plan; PPHSN; HISHub; WHO; PIHOA; CDC; etc; Fragmented Health Information systems a challenge/issue
- c. Data collection: Mortality / morbidity/ STEPs / determinants; DHS surveys; others sources (Police/ cancer councils/ etc)
- d. Data quality tools: UQ HISHub.
- e. Database/data collation/data dissemination: existing systems SPC NMDI, WHO HIIPs, WHO-STEPs database, SPC Survey metadata tool (Paris 21); planned observatory.
- f. Coordination: BAG-Pacific Vital Statistic Action Plan.
- g. Capacity building: PHIN; SPC: UQ HISHub; C-POND; WHO; etc.
- h. Operational research: C-POND; SPC Surveillance and Operational Research Team.

Two groups were then formed and spent one hour discussing what they felt were the main NCD surveillance and operational research needs in the Pacific. They wrote surveillance needs on green cards and operational needs on blue cards. The two groups then formed one group and presented their cards on a table. The green surveillance cards were grouped according to common themes and then sequenced through a process of group discussion. The sequence was determined by the sequential order (on a time scale) in which things would need to be implemented. The blue operational research cards were grouped according to common themes and the put into two broad groups: those broader structural issues around operational research; and specific operational research issues. The results are shown in the left hand column of Table 1.

#### 20. Group Exercise: How can the identified needs for NCD surveillance and operational research be addressed?

Two tables were formed. The first table was for discussing how the surveillance needs could be addressed, and the second table was for discussing how the operational research needs could be addressed. The group was divided in two and allocated to the two tables. After 45 minutes, participants swapped tables and spent another 45 minutes discussing how the needs could be addressed. The main points were written on post-it notes, and were then grouped and built upon by the subsequent group. The results are shown in the right hand column of Table 1.

# Table 1: NCD surveillance and operational research needs and how to operationalise those needs Operationalising those needs

- 1a. Improved harmonisation, coordination, collaboration between regional agencies (incl. Improving clarity of functions; and harmonisation of HIS at regional and national levels).
- 1b. Comparable indicator <u>definitions</u> and surveillance strategies (global, regional, national) Need widespread agreement from agencies; need to include surveillance of youth and children; need to include exposures (risk factors and other determinants of health), environmental determinants, demographics, morbidity and the health/other sector response (e.g., policy, legislation, etc); need to include realistic timeframes for data collection/analysis. Inclusion of core indicators, and optional ones if deemed appropriate by the countries.
- 2. Formal stock take/mapping of NCD activities (key programs) and key stakeholders, including surveillance and operational research.
- 3. One harmonized regional open online access point and hub for NCD data sharing to inform health programs. The database should be flexible (include routine surveillance, surveys and studies), owned by the countries, accessible also in offline settings and that is able to convert data from one software to another.
- 4. Situational report on the state of NCDs in the Pacific, including targets (multi-sectoral data, morbidity, mortality etc.) for NCDs.
- Sharing of knowledge and experiences between countries.
- 6. Capacity building for surveillance. Increase country involvement in the analysis of data (e.g., STEPs).
- 7. Capacity building for communication and advocacy at a policy level, engaging all government sectors.
- 8. NCD surveillance be part of the broad HIS i.e., should be integrated and not create an NCD surveillance silo

- High-level internal discussions at SPC on the concept below.
- Draft a plan based on the outcomes from this Noumea meeting and then further consult with countries, people from Brisbane meeting and Honolulu meeting to endeavour to have a harmonised approach to strengthening NCD surveillance and operational research in the region.
- Table concept note at the July Health Ministers meeting.
- Also lobby PIFS Pacific Plan (currently in development) for better support/inclusion of NCD surveillance and operational research.
- Plan to Health Minsters meeting to include:
  - Advocating for a contact person (and back-up person) for NCD surveillance in each PICT – good to have a CD/NCD surveillance person and someone who is a general NCD person.
  - Tailor/build on/shape the WHO NCD framework of indicators to the Pacific:
    - Develop discussion paper on this for countries that lists the pros and cons (utilise Pacsel as part of this process). This needs resourcing - ?hire consultant external to SPC for this??
    - Hold regional or sub-regional meeting (s) to undertake this.
       This needs resourcing (NZAID, US, AusAID).
  - Sketch out the potential structure, processes and visualisations for a regional access point for health (e.g., show existing options) -> may not be possible to have consensus before the Health Minsters meeting?? SPC, WHO, Boyd Swinburn to chat further about this and reach consensus.
  - Mapping exercise of what people are currently doing re NCD surveillance and operational research -> then come up with a joint concept/vision of where we want to go - this should be the focus (not the organisations). After this, then discuss who does what.
  - National-level HIS assessment (inclusive of NCD surveillance assessment) where required -> identify national gaps/needs -> advocate to national politicians of the importance of NCD surveillance.
  - o NCD surveillance and operational

9. Further discussion required on potential inclusion of: disability; mental health; suicide; injuries; accidents.

research needs vary from country to country. At the PHIN meeting in June, Sione will conduct an exercise to map out the various country needs (with support from SPC).

Support PHIN

- Support Pacific Vital Statistics Action Plan (i.e., work around improving vital statistics and cause of death data should continue to be coordinated through this process – don't create separate processes for improving NCD death reporting separately to other causes).
- Further country-level consultation on this plan.

#### Operational research needs

#### Frameworks and mechanisms:

- 1. Sharing of information
  - a. Mechanism for bilingual information sharing (like Inform'ACTION)
  - b. Pacific Health Dialogue issue on NCD
  - c. Formalised communication strategy to share information
  - d. Share research in the region (e.g., Pacific Island Health Research Symposium in 2014)
  - e. Linked to the regional access point
- 2. Ethics
  - a. Support and streamline national and regional processes for Ethics approval (Country Ministries, WHO, Universities ???)
- 3. Support translating research into policy and practice (identifying barriers/enablers, e.g., why is policy/legislation change sometimes slow, etc.)
- 4. Capacity building
  - In operational research at country and regional levels, including through courses, programs, mentoring/supervision (through the continuum of research planning to publication).
- 5. Taking stock of activities
  - Identification/mapping of country and regional NCD operational research needs and activities (building on C-POND research needs work; Noumea meeting needs; UQ HISHub needs; and wider consultation with countries).

#### Operationalising those needs

- 1. Report output of meeting
  - a. Share with countries and major stakeholders (WHO) in the area
- 2. Concept note (on this and other meetings) to present to the Pacific Islands Minister's of Health Meeting July 2013, to endorse:
  - a. Mapping of key NCD activities and OR needs in countries, ensuring coverage of key topics
    - i. Consultation process to generate research questions and regional OR agenda
  - b. Regional network for NCD research capacity building, sharing, increasing links with students and universities, and having a more strategic vision/focus, including information on contacts, procedures, guiding principles, etc. As part of this, the OR research network platform (visible site) should be linked to the surveillance platform.
- 3. Information sharing:
  - a. Another Pacific Health Dialogue issue on NCDs
  - Training and mentoring on NCD OR at Pacific Island research symposium 2014
  - c. NCD bulletin for the Pacific. Part of Inform'Action or other bulletin dedicated to NCD (interim solution)
- 4. Capacity building research into action/policy
  - a. Spread TROPIC concept mentoring/supporting Ministry officials in policy making

#### Operational research areas and topics:

- 1. Usability and accessibility of existing data
  - More extensive analysis of routine collected data, pre-existing and future datasets (e.g., aggregating school health records to look at obesity).
- 2. Quality of care/life with NCD
  - a. Disability related to NCD
  - b. Survivorship (after diagnosis) research
  - c. Quality and impact of care for NCD patients
  - d. why people don't access healthcare centres, why don't people access care early
  - e. Opportunity lost for care givers (especially women)
- 3. Effectiveness of NCD interventions
  - a. Cost-effectiveness of interventions (clinical and public heath)
  - b. Impact assessment of what has been done (clinical and public health)
  - c. Economic burden of NCDs
- 4. Other approaches
  - a. Intervention research project
  - b. ?Intensive monitoring/longitudinal studies of defined populations
  - c. Qualitative research (e.g. perception of disease).

#### Next Steps

The information from this report will be used in SPC's Public Health Division Strategic Planning. Further consultation of Pacific Island countries and territories will take place at the PHIN meeting and other key regional meetings. SPC will work with countries and other key regional institutions to develop an agreed set of recommendations and plan for strengthening NCD surveillance and operational research in the Pacific.

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