Improving Integration and Coordination of Funding, Technical Assistance, and Reporting/Data Collection: Recommendations from CDC and USAPI Stakeholders

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The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Abstract:

Background *Current US Federal funding mechanisms may foster program silos that disable sharing of resources and information across programs within a larger system of public health services. Such silos present challenges to USAPI communities where human resources, health infrastructure, and health financing are limited. Integrative and coordinated approaches have been recommended. The CDC Pacific Islands Integration and Coordination project was initiated by the CDC Division of Cancer Prevention and Control (DCPC). The project aim was to identify ways for the CDC to collaborate with the USAPI in improving CDC activities and processes related to chronic disease. This article focuses on recommendations for improving coordination and integration in three core areas of health services programming: funding, program reporting/data collection and analysis, and technical assistance.*

Method *Preliminary information on challenges and issues relevant to the core areas was gathered through site visits, focus groups, key informant interviews, and other sources. This information was used by stakeholder groups from the CDC and the USAPI to develop recommendations in the core programming*

areas. Recommendations generated at the CDC and USAPI stakeholder meetings were prepared into a single set of recommendations and stakeholders reviewed the document for accuracy prior to its dissemination to CDC's National Center for Chronic Disease Prevention and Health Promotion programs management and staff.

Results: *Key recommendations, include: (1) consideration of resources and other challenges unique to the USAPI when reviewing funding applications, (2) consideration of ways to increase flexibility in USAPI use of program funds, (3) dedication of funding and human resources for technical assistance, (4) provision of opportunities for capacity-building across programs and jurisdictions, (5) consideration of ways to more directly link program reporting with technical assistance.*

Conclusions: *This project provided a unique opportunity for CDC and USAPI stakeholders to share diverse perspectives on challenges to public health programs in the USAPI. Despite diverse experiences, the final set of recommendations reflected a high level of concordance between USAPI and CDC stakeholders. Recommendations have informed or reinforced actions initiated by the DCPC, including the dedication of funds for leadership institutes aimed at enhancing USAPI capacity for sustainable, integrated regional and jurisdictional cancer control infrastructure. Such efforts are an important beginning, but more remains to be done. Indicated is the need for continuous dialogue and collaboration. While this project focused on the USAPI, our results may be relevant to those interested in inter-organizational collaborations, medically underserved areas, public health services programs, and community-based participatory approaches.*

Background Significance

Disparate health resources and continuing differences in health outcomes related to cancer and other chronic diseases are widening between those who live in the United States (US) and those who live in the nations and territories known collectively as the US Affiliated Pacific Islands (USAPI) [1-3]. Located in the western Pacific Basin, the USAPI includes the sovereign nations or freely associated states of the Federated States of Micronesia (FSM); the Republics of the Marshall Islands and Palau (Belau) [4]; and the US territories of American Samoa, the Commonwealth of the Northern Mariana Islands (CNMI), and Guam. The nations and territories of the USAPI are diverse, yet share an enduring alliance with the US as forged through historic ties. Notably, these ties are formalized in treaty and covenant agreements [5]. These agreements are intended to have reciprocal benefits for the USAPI and the US. In exchange for exclusive military and other access rights, the United States agrees to provide funding and technical assistance to improve the health status of those living in the USAPI [6]. By agreement, the nations and territories of the USAPI are eligible to receive US federal health services monies. Thus, USAPI jurisdictions may respond to funding opportunity announcements (FOAs) offered by the Centers for Disease Control and Prevention (CDC) and other U.S. federal health and human services agencies. Eligibility to apply for US funding offers the prospect of improving public health in the USAPI, but to date, this promise is not fully realized [1-3]. While eligible for CDC funding, the USAPI frequently, have been disadvantaged in competitions for funding support due to resource limitations and other factors. When awarded funding, these same factors have hindered delivery of program services, as well as the collection and analysis of program data and the receipt of technical assistance.

Multiple Challenges and Needs

Although there is variation of experience among and within the nations and territories of the USAPI, the jurisdictions face common challenges that hinder their capacity to compete successfully for health funding and to implement effective chronic disease programs once funding is awarded[1, 3-4, 7-14].

Endogenous challenges. Challenges specific to this region of the Pacific include (a) limitations in health resources and information technology infrastructure [4, 7-14]; (b) shortage of adequately trained health services personnel and limited or no access to personnel with training in epidemiology, data management, or other specializations[4, 7-14]; (c) geographic dispersion of communities across islands and atolls, which necessitates costly travel to provide services in remote areas[7-9, 11-12]; (d) cultural-linguistic diversity among its residents[6-8, 12-14]; and (e) lack of economic diversity and concomitant reliance on US funding to support health and public health services, the latter of which is particularly problematic when the US economy is unpredictable[1].

Exogenous challenges. Challenges originating from outside the USAPI, are frequently related to the funding requirements of CDC and other U.S. health services. Specific concerns include (a) the varied ways U.S. federal programs structure their procedures (e.g., operational aspects of program management such as those required for submission and review of program applications), (b) diverse processes such as current systems used for management information and communications, and (c) the many different ways U.S. federal agencies and programs provide activities such as technical assistance. With its limited resources, the USAPI is challenged in responding to different requirements and processes that depend on the source of federal funding. When funded, programs in the USAPI may receive varying levels and types of technical assistance to accomplish program goals and objectives. The need for integrative and coordinated approaches to health/public health services delivery is emphasized in the seminal Institute of Medicine report, *Pacific Partnerships for Health*[1]. Collaboration in the use of such approaches is indicated and provides the rationale for the CDC Pacific Islands Integration and Coordination Project, hereafter referred to as the Project.

Project Overview and Purpose

Discussion on the strengths and challenges of the relationship between CDC and the USAPI were initiated in 2003 by the Pacific Island Health Officers Association (PIHOA) board members[15]. The ongoing challenges of addressing chronic disease needs in the USAPI were stressed in meetings with the CDC Office of the Director, CDC National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) Division leaders, and program consultants. Emphasized was the need to improve the integration and coordination of three core areas: funding support, program reporting/data collection and analysis, and technical assistance. These initial discussions provided the impetus for the proposal funding this project initiated by the Division of Cancer Prevention and Control (DCPC) within the CDC NCCDPHP.

Funded in 2004, the Project sought to generate recommendations on how CDC might collaborate with the USAPI to improve the integration and coordination of activities, procedures, and processes of CDC cancer control and related chronic disease programs in the core areas of funding, reporting/data collection and analysis, and technical assistance. Project work proceeded through the collaboration of several entities. DCPC provided leadership and oversight of project activities. RTI International, a U.S.-based research institute, through a contract with DCPC, assumed primary responsibility for collection and analyses of

information from NCCDPHP with activities occurring in 2004-2005. University of Hawai'i subcontractors collected and analyzed information from the USAPI with activities occurring primarily in 2005-2007. Across the project trajectory, advice and guidance were provided by PIHOA board members, the Pacific Islands Work Group, and the CDC Work Group. Project work was guided by the question: *What can CDC do to make its working relationship with the USAPI more effective in the core areas of funding, program reporting/data collection and analysis, and technical assistance?*

Method for Developing Recommendations

Preliminary information gathered from CDC [15] and USAPI [16] public health services personnel guided the development of recommendations in the core areas. Chart 1 displays a summary of information provided to stakeholders.

Chart 1: Findings Guiding Development of Recommendations

Core Areas	CDC Perspectives by theme	USAPI Perspectives by theme
Funding	**USAPI applications disadvantaged by** (1) being competed against more resource-rich entities such as U.S. states; (2) communication delays, geographic distance, and time differences; (3) reviewers' lack of familiarity with USAPI resource limitations.	**Categorical funding streams foster program silos**, making inter-programmatic sharing difficult. **Funding Opportunity Announcements** (FOAs) need to better reflect USAPI realities. **Funding is often inadequate** due to costs not readily apparent to those reviewing FOAs. **Limitations in technology and staffing** complicate response to FOAs. **Staff constraints** hinder preparation of funding applications.
Reporting, Data Collection/ Analysis	**Reporting requirements** across CDC programs may not be standardized. Types of forms, frequency of reporting, information systems used, and ways of delivering feedback on reports can vary.	**Tension is experienced in data collection** for CDC reports; data may not be useful for local planning. **The collection of data by programs frequently creates data silos**; information collected by one program may be difficult to access by other programs. **Lack of standardized reporting forms** create staff burden and duplication of effort. **Data collection/analysis is challenging** due to lack of training and access to technologies. **TA is needed** in epidemiology, data management, and ways to meet CDC and USAPI needs.

Technical Assistance	**Types, foci, and frequency of technical assistance vary** considerably across CDC programs. Consultants may provide written guidelines or training on program management, budget issues, creating program objectives, and reporting procedures and protocols. Frequency of face-to-face contact with USAPI personnel varies by program consultant.	**Provide TA across programs** and as possible, include all staff in TA on data collection/ analysis and information systems. **Provide more frequent** site visits and in-service training. **Increase frequency** of other types of TA. **Improve coordination** across CDC and other U.S. agencies. **Use adult learning strategies**, integrate cultural learning styles, and emphasize application of learning.

Procedures: CDC Stakeholder Meeting

The CDC stakeholders meeting was convened in Atlanta during the fall of 2005[15]. Stakeholders included administrative leaders (e.g., NCCDPHP branch chiefs, division directors), program personnel (e.g., team leaders, public health advisers), fiscal agents (e.g., procurement and grants management specialists), and others (e.g., personnel with direct experience in the USAPI, representatives from the CDC Offices of Global Health and of Minority Health). Presentations were given on project findings from an analysis of NCCDPHP funding opportunity announcements, interviews with CDC program managers and consultants, and project site visits to the USAPI. A brainstorming session followed with stakeholders generating suggestions for principles that might guide CDC in sustaining effective relationships with the USAPI. Small groups were convened around each of the core areas of health services programming. Groups were encouraged to identify processes, procedures, and activities that were working well and those that might be improved. Small groups developed recommendations which subsequently, were shared and discussed in a large group session.

Procedures: USAPI Stakeholder Meeting

The USAPI stakeholders meeting was convened in Honolulu, Hawai'i during the spring of 2007[17]. Participation was by invitation and followed a plan of inclusion developed by the Pacific Islands Work Group (PIWG). Specific attention was given to representation from diverse occupational perspectives (i.e., public health leaders, policy makers, program services personnel, fiscal agents) and to representation from all USAPI territories and nations.

Participants in the stakeholder meeting included directors and secretaries of health ministries and public health departments, coordinators of CDC-funded chronic disease programs, fiscal/procurements officers, and all PIWG members. All jurisdictions, including the Federated States of Micronesia (FSM) national government and three of the four FSM states were represented.

The USAPI stakeholders meeting followed a process similar to that of the CDC stakeholders meeting[15] and included: (1) an overview of the project and its purpose, (2) information on the organizational structure of CDC, (3) large group discussion to generate principles for sustaining effective relationships with CDC, (4) presentation of information gathered by the project, including information gathered after the 2005 CDC stakeholders meeting[16], (3) convening of small groups, each charged with developing recommendations for improving activities, processes, and procedures in one of the three core areas, and (4) large group

discussion to share recommendations generated by the small groups and develop a plan for reviewing and possibly, revising recommendations prior to their dissemination at CDC.

As agreed, project staff prepared a written draft of all recommendations and disseminated the document to all participants. Based on participant feedback, the recommendations were edited for clarity. USAPI recommendations were compared with those generated by the CDC stakeholders. Initial comparisons suggested a high degree of similarity and agreement on issues related to the core areas. Subsequently, we aligned all recommendations by core area and issues of concern or theme (e.g., in the core area of funding there were common themes on improvement of funding review processes and for procedures that increase flexibility in use of program funds). The final set of recommendations from USAPI and CDC stakeholders were prepared as the focal point for the project summary report[18]. This report was disseminated to management of the National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), as well as to other centers within the CDC and CDC partner organizations.

Results

Recommendations

Core areas, themes of concern, and recommendations of USAPI stakeholders, with related recommendations from CDC stakeholders are displayed in Charts 2-4. Recommendations of both stakeholder groups indicate a high level of agreement on 'what' and 'how' to address the challenges of public health service programs in the USAPI. This concordance is notable because each stakeholder group made their recommendations without prior knowledge of what the other group had suggested. Also included in CDC stakeholder recommendations were specific strategies that the agency might take to improve coordination and integration in procedures, processes, and activities specific to funding support, technical assistance, and program reports/data collection and analysis.

Actions: Division of Cancer Prevention and Control (DCPC)

Generally, project recommendations have informed the use of DCPC strategies aimed at increasing coordination and integration of activities, procedures, and processes across categorically-funded programs in the USAPI. Such strategies offer the prospect of increased efficacy and efficiency in CDC-USAPI collaborations.

Funding: In consideration of the unique challenges of the jurisdictions (although not a direct consequence of this project), DCPC continues to consolidate into a single announcement funding support for three cancer programs (i.e., the National Breast and Cervical Cancer Early Detection

Chart 2: Recommendations on Funding

Theme	USAPI Stakeholders Recommendations	CDC Stakeholders Recommendations
Increase flexibility in funding	**Consider allowing funds to be used in ways that are conventionally designated as "non-allowable" costs.**	Examine roles of various agencies providing support. Determine types of items covered. Explore ways that CDC can provide flexibility to cover needs of the USAPI.
Streamline communications	**Develop improved and streamlined communication processes to the USAPI.** Improved processes will ensure that the Directors/Ministers of Health are made aware of upcoming funding opportunities in a timely fashion and thus offer Jurisdictions sufficient time to prepare applications.	Build in a pre-application workshop that accommodates the USAPI availability. Standardize criteria and processes for how USAPI compete for funding.
Enhance grants management capacity	**Fund and implement a training workshop on grants management.** Such a workshop should be made available to key personnel from the Ministries of Finance, Directors/ Secretaries of Health, program managers, and CDC's Procurement and Grants Office (PGO)	Have PGO provide training around fiscal issues, including basic budget issues, program costs, program consultants, unobligated funds, and restrictions.
Develop consistent drawdown procedures	**Develop drawdown procedures that are consistent across all CDC grants and cooperative agreements.** Drawdowns involve PGO's release of a percentage of a funding award and are intended for use in initial program operations. Drawdowns are of concern to the USAPI because if they are not completed in a timely fashion, USAPI governments need to provide funding to maintain work.	No similar recommendation.
Improve funding review processes to increase likelihood of support	**Consider unique challenges of the Jurisdictions when reviewing applications in response to a Funding Opportunity Announcement (FOA).** Challenges may include limitations in health infrastructure and human resources that are qualitatively greater than those experienced by other applicants.	Increase funding opportunities by (1) consolidating announcements for USAPI; (2) offering opportunities for regional applications; (3) reviewing USAPI applications as a pool separate from states and tribes, and (4) realigning project officer assignments to work across programs in a specific jurisdiction.

Chart 3: Recommendations on Reporting, Data Collection and Analysis

Theme	USAPI Stakeholders Recommendations	CDC Stakeholders Recommendations
Uniformity in data sets and requirements	**Standardize data sets and data requirements across agencies and programs funding the USAPI.** Aim to create a uniform data set. Seek collaboration across federal and international agencies and programs.	Increase uniformity in reporting systems by developing common and standardized forms, action plans, funding applications, expectations, and the like. Leverage resources by linking diseases in existing registries.
Data systems and data-gathering processes	**Collaborate with the USAPI in development of entire data system process.** Efforts might include conducting a data systems review/ inventory to assist the USAPI in developing an appropriate data management system with support for capacity-building to enhance human resources, informational systems, and other health infrastructure, extending to the local level.	Enhance existing information systems by: (1) Conducting (in partnership with PIHOA and other agencies) a feasibility assessment of information systems and needs in the USAPI. (2) Developing an integrated surveillance system with evaluation tools that may be used across chronic disease programs.
Data safety monitoring mechanisms	**Collaborate with USAPI to develop mechanisms for evaluating specific data requests using criteria from the USAPI.** Mechanisms might include a USAPI data review board.	Ensure consistency in application of ethical standards and principles to data gathering and research conducted in the USAPI.
Data reporting & TA	**Data reporting and CDC feedback to USAPI programs need to be linked to technical assistance.** Technical assistance might include training on effective use of data for purposes of advocacy, social marketing, health education, health promotion, and health research.	Conduct collaborative training (either in-person or computer-based) on evaluation of data systems and methods of data collection. Provide clear and timely feedback and recommendations to USAPI. Work to bridge gap between data collectors and data managers.
Seek to understand larger context	**Data reporting, funding, & TA need to be understood in the larger context of USAPI health needs, plans, and strategies.**	Develop culturally appropriate surveillance systems. Tailor HP 2010 objectives for USAPI. Provide cultural competency training for CDC staff, including training on cultural and historical barriers experienced by the USAPI. Develop an advocacy/ educational approach to raise awareness of USAPI chronic disease issues and needs.

Chart 4: Recommendations on Technical Assistance

Theme	USAPI Stakeholders Recommendations	CDC Stakeholders Recommendations
Increase access to TA by those familiar with the region	**Establish a CDC "west" office** in the Pacific Basin to increase USAPI access to technical assistance.	Increase access to CDC experts (e.g. senior management official) already assigned to the region to provide or obtain technical assistance.
Dedicate funding and human resources to enhance system of public health services	**Dedicate funding and human resources to build in-country (i.e., Jurisdiction) public health capacity.** Technical assistance (TA) might include: (1) Pre-service training, in-service or continuing education training, distance learning, and (2) Use of curriculum materials tailored to cultural preferences of those living in the USAPI.	Develop funding opportunities specific to the USAPI that allow tailoring of TA. Distinguish types of TA needed (e.g., TA on process/procedures, and capacity building or focus on health-related knowledge). Pool resources to address common needs across the Jurisdictions (e.g., training). Provide funding specific to enhancing computer systems and other infrastructure.
Consider alternative strategies and venues	**Consider alternative technical assistance strategies to enhance capacity building in the USAPI. Tailor FOAs to better reflect USAPI needs.** To increase USAPI ability to compete for funding, consider alternative learning strategies using existing structures. Consider how to provide "interim TA" to those interested in submitting applications in response to a funding opportunity announcement.	Adapt language in funding announcements and other technical documents using simpler language and terms familiar to Pacific Islanders. Develop funding announcements that are specific to the USAPI and better conform to USAPI public health needs. Develop performance indicators commensurate with USAPI capacity and resources.
Provide training for CDC staff assigned to work with programs in the region	**Consider ways to decrease CDC (project officer) staff turnover**. Turnover can be burdensome to USAPI personnel who are frequently placed in the situation of providing TA to CDC staff unfamiliar with USAPI realities.	Train program consultants in cultural effectiveness before they get assigned to the [Pacific] Islands, or as soon as possible; consider inclusion of USAPI partners in development and delivery of training.

Employ opportunities for capacity-building	**Use meetings and conventions attended by CDC and USAPI personnel as opportunities for capacity building.** Provide technical assistance either before or after such meetings.	Employ technical assistance using the "expertise" of the Pacific Islanders. Empower Pacific Islanders to share success stories and showcase their accomplishments.
Maximize site visits	**Maximize site visits by having the visiting Project Officer meet with other CDC-funded programs.**	Incorporate opportunities for coming together in multiple ways (e.g., carrying messages for other divisions/branches [to the Jurisdictions]). Create more central sources for sharing information across Divisions.

Program, National Program of Cancer Registries, National Comprehensive Cancer Control Program) and encourages both regional and jurisdictional efforts in cancer control.

Technical Assistance To address the need for technical assistance that emphasizes capacity-building across categorically-funded programs, DCPC has collaborated with the American Cancer Society, National Association of Chronic Disease Directors, and other organizational partners to provide leadership institutes and other training tailored on the needs and learning preferences of the USAPI.

Program Reporting/Data Collection and Analysis To address USAPI needs for improved data systems and data gathering processes, support was provided to the Pacific Regional Central Cancer Registry in efforts to identify user-defined variables for chronic disease risk factors, screening and prevention, and ethnicity. On-site training also was supported.

Discussion

Strengths and Limitations of Recommendations

Recommendations from the CDC and USAPI stakeholders reflect several crucial strengths. First, recommendations are based at least in part, on information systematically collected by the project and specific to funding support, technical assistance, and program reporting/data collection and analysis. Guidance from work groups at the CDC and in the USAPI ensured that both perspectives were represented in information gathering efforts. Second, development of recommendations followed several procedures that minimized social desirability bias (i.e., replying in a manner that will be viewed favorably by others) and that maximized the likelihood of responses reflecting diverse perspectives. To minimize social desirability bias, CDC and USAPI stakeholder groups generated recommendations independent of the other group. To advantage diversity of perspectives, stakeholder groups purposefully included participants with diverse occupational backgrounds and experiences. Furthermore, USAPI stakeholders purposefully included representatives from all USAPI territories, nations, and FSM states. We believe that the high degree of project involvement by USAPI public health services personnel from all organizational levels (i.e., policy makers,

department administrators, fiscal agents, program personnel) assured the relevance of recommendations for programs within a system of public health services and across the region. Attention to representation by individuals with diverse national affiliations and public health backgrounds potentiates acceptability to those living in the USAPI. However, it is important to remember that recommendations were produced to specifically guide CDC chronic disease programs in the USAPI. Therefore, recommendations cannot be generalized or directly applied to programs supported by centers of the CDC other than NCCDPHP, other US federal agencies, or other health organizations.

Recommendations and Implications

This project provided a unique opportunity for CDC and USAPI stakeholders to share diverse perspectives on challenges to public health services programs in the USAPI. Despite diversity of perspectives and experiences, the final set of recommendations reflect a high level of concordance on 'what' and 'how' coordination and integration of CDC activities might be improved. Recommendations have informed actions already initiated by the DCPC, including the dedication of funds for leadership institutes aimed at enhancing USAPI capacity for sustainable, integrated regional and jurisdictional cancer control infrastructure. Such efforts are an important beginning but more remains to be done. Some recommendations may be more challenging to implement and it is possible that some recommendations may not be feasible to implement. Indicated is the need for continuous dialogue and collaborative action. Future CDC-USAPI collaborations might assess the feasibility of specific recommendations and/or might work towards the development of an implementation plan.

Both CDC and USAPI stakeholders indicated that it may be important to extend efforts of integration and coordination to include other US Federal and international agencies providing the USAPI with funding support, requiring reports of program statistics and other data, and offering technical assistance. For example, stakeholders stated that data requirements for some CDC programs are similar to those of other (non-NCCDPHP) CDC centers and the World Health Organization. Suggested was the need for more standardization on reporting forms and uniformity in data software used. Efforts of this nature were recognized as lengthy and complex processes, but may hold the promise of decreased burden in program reporting and increased time for program services delivery.

Conclusion

This project suggests the importance of global cooperation and inter-organizational reflexivity, or the willingness of interfacing organizational systems to meaningfully dialogue on how processes, procedures, and activities might be improved through integrative and coordinated approaches. The process of reflexivity described in this article may be relevant to those interested in inter-organizational collaborations, medically underserved communities, public health services programs, and approaches that promote health with and for stakeholders in underserved communities. Protracted efforts and steady dedication to advancing and sustaining productive inter-organizational relations offers the prospect of health equity for all.

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References

1. Feasley JC, Lawrence RS; eds. *Pacific Partnerships for Health. Charting a Course for the 21st Century.* Institute of Medicine, National Academy, WA DC, 1998
2. Palafox NA, Tsark JU. Cancer in the US Associated Pacific Islands (USAPI): history and participatory development. *Pacific Health Dialog 2004; 11* (2): 8-13.
3. Gunawardane K, Demei Y, Cancer Council of the Pacific Islands: speaking with one voice. P*acific Health Dialog 2004; 11* (2): 14-6.
4. Wong V, Taoka S, Kuartei S, Demei Y, & Soaladaob F. Cancer in the Republic of Palau (Belau). *Pacific Health Dialog 2004; 11* (2): 64-9.
5. US Department of the Interior, Office of Insular Affairs. Available at: http://www.doi.gov/oia/Islandpages/cnmipage.htm Accessed on 7/16/09.
6. US Department of the Interior, Office of Insular Affairs. Available at: http://www.interior.gov/oia/Firstpginfo/description.html. Accessed on 9/25/2009.
7. Ichiho HM, Gladu R, Keybond K, Ruben K. Cancer in Chuuk State, Federated States of Micronesia. *Pacific Health Dialog 2004; 11* (2): 30-6.
8. Ichiho HM, Wong V, Hedson J, David WJ. Cancer in Pohnpei State, Federated States of Micronesia. *Pacific Health Dialog 2004; 11* (2): 44-9.
9. Kroon E, Reddy R, Gunawardane K, Briand K, Riklon S, Soe T, Balaoing GAD. Cancer in the Republic of the Marshall Islands. *Pacific Health Dialog 2004; 11* (2): 70-7.
10. Ruidas L, Adaoag A, Tofaeono Williams V, Sesepasara ML. Cancer in American Samoa. *Pacific Health Dialog 2004; 11* (2): 17-22.
11. Shehata C, Kroon E, Skilling VA, Taulung L. Cancer in Kosrae State, Federated States of Micronesia. *Pacific Health Dialog 2004; 11* (2): 37-43.
12. Taoka S, Hancock T, Ngaden V, Yow AR, Durand M. Cancer in Yap State, Federated States of Micronesia. *Pacific Health Dialog 2004; 11* (2): 50-6.
13. Tseng CW, Omphroy G, Songsong JM, Shearer R. Cancer in the Commonwealth of the Northern Mariana Islands (CNMI). *Pacific Health Dialog 2004; 11* (2): 23-9.
14. Tseng CW, Omphroy G, Cruz L, Naval CL, Haddock RL. Cancer in the Territory of Guam. *Pacific Health Dialog 2004; 11* (2):57-63.
15. RTI International. Centers for Disease Control and Prevention, Division of Cancer Prevention. CDC Pacific Islands Integration and Coordination Project. *CDC Stakeholders Meeting. Chamblee, GA, 2005.*
16. Ka'opua LS. Centers for Disease Control and Prevention, Division of Cancer Prevention and Control. *CDC Pacific Islands Integration and Coordination Project. Summary of Information Gathered from the USAPI. Chamblee, GA, 2007.*

17. Centers for Disease Control and Prevention, Division of Cancer Prevention and Control. *CDC Pacific Islands Integration and Coordination Project. USAPI Stakeholders Meeting.* Chamblee, GA, 2007.
18. Ka'opua LS. Centers for Disease Control and Prevention, Division of Cancer Prevention and Control. C*DC Pacific Islands Integration and Coordination Project. Summary Report.* Chamblee, GA, 2008.
19. CancerPlan.org. Available at www.cancerplan.org. Accessed 9/25/2009.

"Wisdom is not a product of schooling but of the lifelong attempt to acquire it."

Albert Einstein

HEALTH LITERACY: THE MAJOR PLIGHT OF PACIFIC HEALTH

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INTRODUCTION

The development of research on health literacy has elicited numerous definitions.

In New Zealand health literacy has been defined as:

"The degree to which individuals have the capacity to obtain, process and understand basic health information and services in order to make informed and appropriate health decisions" (Kickbusch et al., 2005; Kōrero Mārama, 2010.

The Australian Bureau of Statistic says that heath literacy is:

"The knowledge and skills needed to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies and staying health".

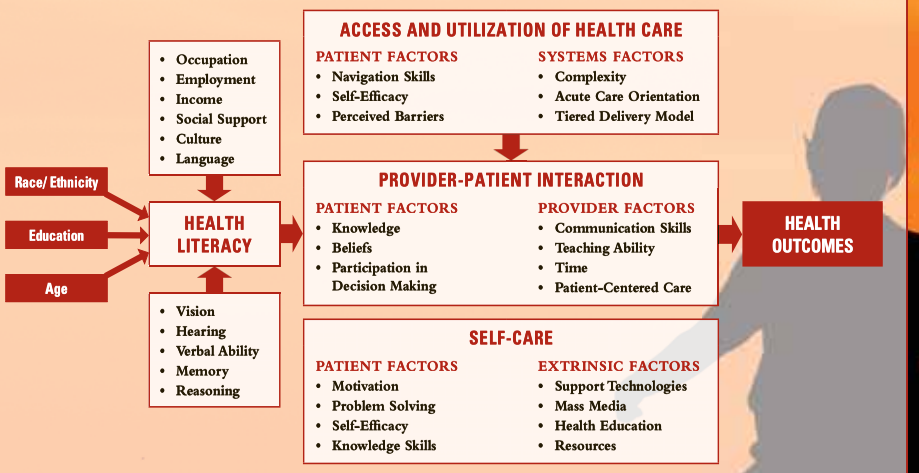
CONSEQUENCES OF LOW HEALTH LITERACY

USA and New Zealand studies have identified that those with low literacy levels:

1. Have poorer physical and psychosocial health than those with higher literacy levels. Those with low health literacy are:
   - More likely to report having had poor health;
   - More frequent users of expensive health services, such as hospitalization and Emergency Department; More likely to suffer worse health outcomes with more complications; More likely to have advanced cases of disease, and are likely to incur higher medical costs Less likely to receive preventive services and follow health care instructions.
2. The poorer health status of those with lower literacy levels may also reflect socioeconomic inequalities such as poorer (and less desirable or safe) employment opportunities, poorer income levels, poorer housing, and poorer nutrition. Thus socio-economic issues implicated in health literacy include the financing of health care and its role in ensuring access to and utilization of health care.
3. International research has also demonstrated that cultural relevance and language are important in how patients understand or respond to health care materials and instructions. Research also showed the problems caused by expecting health literacy to transcend diverse cultural beliefs, social practices and translation from one language to another. Examples are problems of miscommunication and tensions between a system that requires individual responsibility and social customs that view health as a collective responsibility.

CAUSAL PATHWAYS BETWEEN LIMITED HEALTH LITERACY AND HEALTH OUTCOMES

Source: Paasche-Orlow and Wolf, 2007.



CONCLUSION

Across the OECD, more than 50% of the population has low health literacy).

The factors cited above need to be evaluated when assessing health literacy and its implications in New Zealand, especially among Maoris and Pacificans. This paper points to how health literacy contributes to Pacific Health outcomes and its centrality to a healthy future.

This paper also demonstrates how there cannot be better Pacific health without health literacy. It will provide pathways and research framework to improve and define health literacy for Pacificans/Pasifikans in New Zealand.

There cannot be a Healthy FUTURE for Pasifikans without health literacy, in:

- Communicable Diseases
- Non-communicable Diseases
- Maternal Child Health
- Cancers
- Obstetrics and Gynaecology
- Mental Health, etc.

HEALTH LITERACY STATISTICS

1. NEW ZEALAND'S HEALTH LITERACY STATISTICS

New Zealand's health literacy statistics come from the Adult Literacy and Life Skills Survey (ALLS) conducted in New Zealand in 2006, which tested the literacy, numeracy, and problem-solving skills of a large sample of New Zealanders aged 16-65 years. The Ministry of Health's report, Kōrero Mārama (published in February 2010), presented findings on health literacy by gender, location, age, level of education, labour force status, and household income.

Kōrero Mārama (2010) reported that:

- 56.2% of adult New Zealanders have poor health literacy skills, scoring below the minimum required to meet the demands of everyday life and work;
- Four out of five Māori males and three out of four Māori females have poor health literacy skills;
- Māori who live in a rural location have on average the poorest health literacy skills, closely followed by Māori who live in an urban location;
- Māori in the 50-65, 16-18, and 19-24 years of age groups have the poorest health literacy compared to the rest of the population. This is particularly concerning because over half of the Māori population (53%) was less than 25 years of age at the 2006 census. Also, older age groups have high levels of health need and are generally high users of health services;
- Māori and non-Māori with a tertiary education are more likely to have good health literacy skills compared to those with lower levels of education. This is consistent with international evidence; and
- Māori across all labour force status types have poorer health literacy skills compared to non-Māori, but Māori who are unemployed or looking for work have the poorest health literacy skills of all groups;
- Māori have poorer health literacy statistics across gender, age and location than non-Māori. New Zealand's health literacy statistics are very similar to Australia and better than Canada and the USA.

2. AUSTRALIAN HEALTH LITERACY STATISTICS

The Australian health literacy statistics relate to a large sample of Australians aged 15-74 years (in New Zealand we assessed 16 – 65-year olds).

Key findings from Health Literacy, Australia, 2006 (2008) include:

- 59% of adults were assessed as having Level 1 or 2 health literacy skills (poor health literacy skills);
- There are distinct lower health literacy rates among older people compared to those below 49 years of age in Australia;
- When Australian results are restricted to the same age group as New Zealand's survey (16-65), 57% of the Australian population were shown to have low health literacy, very similar to New Zealand's 56.2%.

3. CANADIAN HEALTH LITERACY STATISTICS

Canada undertook the ALL Survey in 2003, assessing a large sample of Canadians aged 16-65 years of age. Key results from Canada, include:

- While Canadians have higher levels of health literacy than Americans, 60% of adults in Canada have low health literacy (compared to 56.2% in New Zealand);
- Average health literacy varies a lot by province and territory and between different population sub-groups within Canada, especially among older people. Like New Zealand, Canadian adults with less than a high school education perform well below adults with higher levels of education and this gap widens with age;
- Differences in literacy and numeracy skills make a big difference to range of social, educational and economic outcomes. Differences in average health literacy skills seem to be associated with large differences in perceived general health status;
- Those that speak French as their first language in Canada were more likely to have lower health literacy.

4. AMERICAN HEALTH LITERACY STATISTICS

The United States of America undertook the National Assessment of Adult Literacy (NAAL) (an earlier version of ALLS Survey) in 2003. American health literacy statistics use 'Below Basic, Basic, Intermediate and Proficient' as health literacy skill levels (which do not align exactly with 'Levels 1-5' used in other OECD countries).

Key findings from the report Literacy and Health in America (2004) are:

- Only 12% of US. adults had proficient health literacy. Over a third of US. adults – 77 million people – would have difficulty with common health tasks, such as following directions on a prescription drug label or adhering to a childhood immunization schedule using a standard chart;
- Adults in the oldest age group – 65 and older (not measured in NZ and Canada, and only partially in Australia) – had lower average health literacy than adults in younger age groups;
- Limited health literacy affects adults in all racial and ethnic groups. The proportion of adults with basic or below basic health literacy ranges from 26% of white adults, to 57% in black adults, and 65% of Hispanic adults;
- Although half of adults without a high school education had below basic health literacy skills, even high school and college graduates have limited health literacy;
- Compared to privately insured adults, both publicly insured, and at that time, uninsured adults had lower health literacy skills;
- All adults, regardless of their health literacy skills, were more likely to get health information from radio/television, friend/family, and health professionals than from print media.

5. UNITED KINGDOM HEALTH LITERACY STATISTICS

The United Kingdom has yet to compile health literacy statistics. However, the Skills for Life Survey did indicate low levels of literacy and numeracy skills for UK citizens. The Department of Health in England has recognised, that the results suggest that there is a high prevalence of low health literacy.

Public Health Wales put a scoping document forward to the National Health Service (NHS) in August 2011. This scoped health literacy in Wales and provides numerous recommendations to improve health literacy for the Welsh.

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