Nomination for the 2015 AES Awards for Excellence in Evaluation: Indigenous Evaluation Award: The Sentinel Sites Evaluation of the Indigenous Chronic Disease Package 2010-2014

Introduction

In this nomination, we present key features of a three-year place-based evaluation of a national multi-program initiative aimed at prevention and management of chronic disease in Aboriginal and Torres Strait Islander communities, and outline how this evaluation is exemplary for the practice of Indigenous Evaluation. We illustrate below how our evaluation has:

• supported positive outcomes for Indigenous communities;

• promoted sound, respectful and appropriate practice of evaluation;

• engaged Indigenous people in evaluation practice; and

• strengthened the evaluation capacity of Indigenous peoples, with a focus on building a culture of evaluation, and an awareness and interest in evaluation and evaluation policy development.

Using examples from our evaluation, we illustrate ways in which these outcomes were achieved, and the potential of this evaluation to contribute to improved quality and use of evaluation for Indigenous peoples in Australasia and beyond. We demonstrate professionalism in the evaluation through identifying the challenges experienced in the evaluation, and what was needed to address these challenges. We also consider the unique ethical considerations that were encountered and addressed in this work. Taken together, we argue that the evidence presented in this nomination provides a firm basis for this evaluation to be considered, and promoted as an exemplar of excellent practice in this category. As a team, we have learned a great deal about what is required to achieve effective evaluation practice on a large scale in Indigenous communities through this work, and would like to share this learning more broadly through the AES.

What was the sentinel sites evaluation?

Our evaluation was commissioned by the Australian Government through competitive tender. The scope of services asked for the evaluation team to conduct a Formative Evaluation of early implementation of a multi-component program - the Indigenous Chronic Disease Package (ICDP). The ICDP was managed through seven different divisions of the Australian Government Department of Health, and implemented through several different service delivery channels (including private and community controlled primary health care services, community organisations, local and regional organisations such as Aboriginal Community Controlled Peak bodies and Medicare Locals), and supported by incentives and workforce initiatives. The evaluation was to be guided by previously developed linear matrix program logics, which used a log frame approach setting out inputs, early results and longer-term results for each of the 11 program areas, as well as a high level set of intended results and activities for the package as a whole.

The evaluation included 24 sentinel sites across Australia with varying degrees of intensity of data collection and analysis. Administrative and program data were collected and analysed for all 24 sites and 16 of the sites also involved the collection of clinical indicator data and key informant interviews. Eight of the sites (called 'case study sites') included community focus groups.

The SSE took a cyclical and place-based approach, involving local stakeholders, and national level stakeholders in cycles of reflection and feedback (Figure 1). This focus on 'place' is critically important for Indigenous programming, a sector often driven by 'top down' spending, with little attention paid to how funding works to improve outcomes for people on the ground, across varied geographical settings and in services with different governance arrangements.
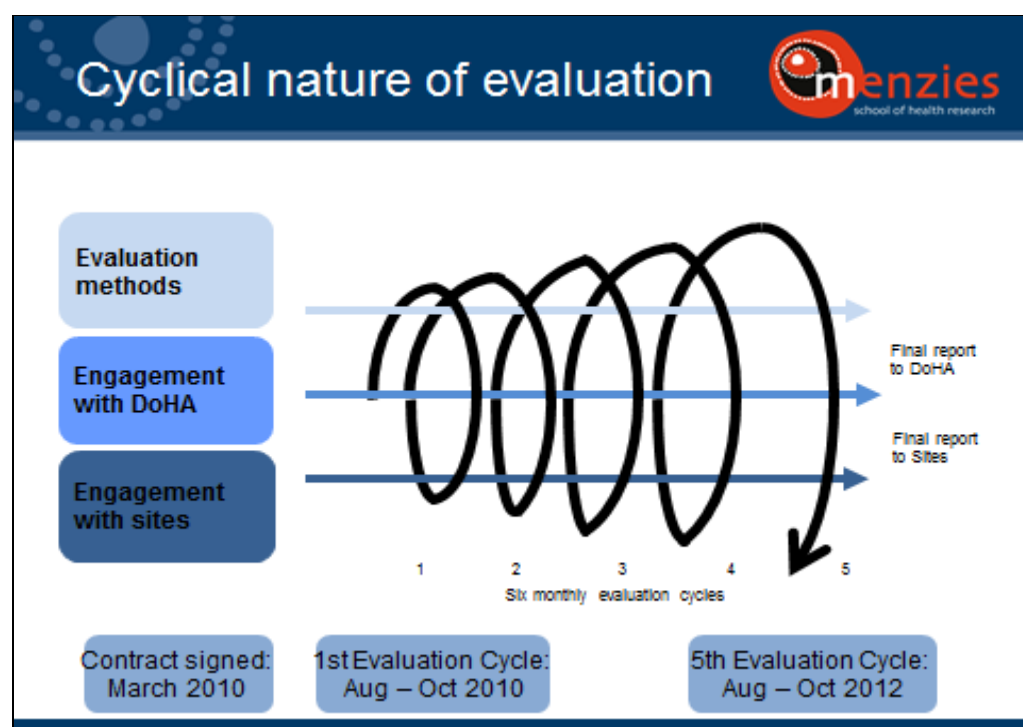

Figure 1: Cyclical nature of the sentinel sites evaluation

Attributes of excellence specific to the AES Award Criteria for Excellence in Indigenous Evaluation are outlined below. Evidence and examples of where generic attributes of evaluation excellence have been addressed through the evaluation are in bold text below.

Supported positive outcomes for Indigenous Communities

Obtaining direct evidence of support to achieve positive outcomes by evaluations of large scale programs is difficult, as there are many different factors influencing outcomes at scale. However there are several areas of indirect evidence for our evaluation's role in supporting positive outcomes for Indigenous communities.

At a general level, improving access to high quality primary health care for Indigenous peoples is critical to closing the gap in health outcomes. Through its focus on informing improvements to a large scale national investment in prevention and management of chronic disease, the evaluation may have had a role in policy and program change to better address needs of Indigenous communities. The approach of the evaluation, focusing on how the ICDP was working at local level, and how different components of the package worked (or failed to work) together and with other potentially complementary initiatives, highlighted areas in which program adjustments and flexibility in policy interpretation were required to better meet the needs of local communities and enable service providers to provide coordinated services.

Our evaluation was identified and reported as one of a series of case studies in the '*Australian National Preventive Health Agency (ANPHA); State of Preventive Health 2013; Report to the Australian Government Minister for Health. Canberra; ANPHA, 2013'.* The case studies included in this volume were selected to illustrate the breadth of good practice and promising work underway across Australia.

The authors of this report to the Minster highlighted the variation in implementation between different sites as a key finding of our evaluation– recognising at a policy level that addressing this variation is critical to improving outcomes for the most vulnerable. (Annex 1, Extract from the State of Preventive Health Report).

As is often the case with assessing influence on policy, it is not clear to what extent the SSE was directly responsible for refinements of the ICDP and the on-going implementation processes. However, it is clear that various elements of the package have been refined in a way that is consistent with findings presented in interim and final evaluation reports, including in:

- program modification of the ICDP at various levels. At the policy level the Department used the findings to adjust implementation.

- supporting ongoing advocacy work of lobbying groups for improved primary health care services for Indigenous people, for example, the Royal Australian College of Physicians lobbied for ongoing access to reduced medications for Indigenous people based on the findings of the SSE.

- furthering the knowledge base regarding the delivery of primary health care for Indigenous people, for example various government reports reference work of the SSE, and peer review publications have referenced the report. There are 18 such references to date.

There has also been strong interest in the SSE methodology. We have presented at over 7 conferences both nationally and internationally to inform the broader evaluation community, and we were contracted by the Department of Health to develop a paper on the use of the sentinel sites methodology and its broader applicability.

Annex 2 contains a listing of selected SSE reports, peer-reviewed publications, conference presentations and posters used for further dissemination of the findings and on methodology. The Annex also includes a listing of where the SSE has been referenced in other reports and documents, reflecting the success of our knowledge exchange strategies.

Engaged Indigenous people in evaluation practice

Indigenous people were engaged in the evaluation practice at each stage of the evaluation, from design through to dissemination. At the outset, Aboriginal Health Forums in each jurisdiction (which by their nature tend to have strong representation of Indigenous people) selected the sites for inclusion in the evaluation. Recognising that engagement of Indigenous people in the selected sites was critical to data validity and quality, the presence of a strong Aboriginal Health Service in the site - that could help to elicit and sustain community engagement with the evaluation – was one of the criteria used in selecting the sentinel sites. Each of the 8 'in depth' case study communities were visited each 6 months (5 times over a period of 2 years). The time spent in the communities over this period enabled trust to be built up over time – noting also that several members of our evaluation team were already known and trusted in communities through other work that pre-dated this evaluation and worked with the same sites over the evaluation cycles. Repeated data collection and reporting cycles were found to be fundamental to sustaining community engagement. After each cycle, we held whole of evaluation-team workshops to debrief and make sense of the data from the different sites. This enabled the team to identify community and institutional dynamics that needed to be taken into account in interpreting the data. Three of the fieldwork team (comprising a coordinator and six site facilitators) identified as Aboriginal, and the remainder had worked with Indigenous communities for a number of years.

Beyond the fieldwork team, Indigenous people were involved in the evaluation as: a) key informants about program implementation, for example, where they held positions as outreach workers, ICDP officers or staff of Aboriginal Health Services and supporting organisations; b) community focus group

members (often participating more than once; 670 attendees) c) participatory data interpretation/discussions, in roles in various support organisations.

Promoted sound, respectful and appropriate practice of evaluation

High quality and effective practice in consultation, design, planning, data collection and analysis played out in the conduct of the evaluation in ways outlined below.

High quality and effective practice in evaluation in Indigenous community settings includes elements of flexibility, community control and ownership, and inclusiveness, along with the more generally applicable standards of rigour that apply to all evaluations. What this meant for our evaluation is that data collection visits were scheduled to fit around what worked for the local workers and community events. Often planned visits had to be re-scheduled due to unforeseen circumstances, such as a death in the community – the continued engagement of sites attests to the professionalism of the evaluation team. Local Aboriginal Health Services and Medicare Locals helped to arrange community focus group discussions and interviews following local protocols. People in local ICDP funded positions confirmed dates and organised the focus groups – how they were publicised, who was invited to attend, venue and transport. These were often held in Aboriginal Health Service and community venues. There was a consistent organising approach across the case study sites with organisingion of the focus groups in local community hands. We developed 'illustrated agendas' to guide community focus group discussions – these enabled people with varying levels of literacy to be informed about what the group was going to be talking about, and helped to keep the conversations on track (Annex 3, Illustrated agenda example). We listened carefully to people's stories. Each time we returned, we explained what had happened with the information people had shared, so it was clear that community voices and stories were respected and valued, that people had something important to say and were heard, and their stories contributed to some changes in the way the ICDP was being rolled out. The following quotation illustrates a participant's positive regard for this evaluation approach.

> 'We know about government services that come and talk to us to tick their boxes, but you have not done that. You have come to hear from us how the program is working for us, and taking that story back to the powers that be to improve the program and services we are getting through that funding.' (Community focus group participant, case study site).

We would recognise people from previous community visits and remember their names – and we could build on their stories, and asked what had changed since the last visit. This giving back was important – it showed we were there to help and answer questions as well as take away stories. We could explain what services were available through the ICDP, who was eligible and how to access the benefits. We sought to ensure that the meaning of data collected during the site visits was not lost when it was fed up the line – we did this by holding full team analysis workshops at the end of each data collection cycle in which fieldworkers came together with the co-ordinators and evaluation lead, and explained the context of the data, clarified stories and discussed their meaning. Together we identified emerging themes and patterns in the data and compared our qualitative data with the quantitative data from sites. The workshops supported interpretation, and compared and contrasted findings in the different sites. From the 3rd cycle onwards, evaluation leaders met with program managers within the relevant Divisions of the Commonwealth (DoHA) to provide early feedback on findings and discuss implications for refining the design of the ICDP as the evaluation progressed. We also identified, through collaboration, the key issues of focus for the following cycle of evaluation.

Appropriate use of evaluation theory –We drew on several different evaluation theories and approaches to inform our choice of methods in the evaluation. The evaluation was conducted at a relatively early stage of implementation of the ICDP, and its intention was to track progress with implementation and inform refinements. This formative purpose to the evaluation, partly, but not solely, guided the design of the evaluation. Considering Michael Patton's "Utilization-Focused Evaluation", we considered what the intended users – the Commonwealth Department of Health

program managers and the local stakeholders in the sites - would find useful, and the purpose to which the findings would/might be used. This focus on utilization helped determine the overall framework within which we worked. According to the terms of our contract, the evaluation needed to report on results specified in the program logic. Whilst this was a useful guide, it did not provide the information most useful to improving the ICDP. As the evaluation progressed, there was increasing interest from the commissioners to understand how the different components forming part of an overall services package, were working together for patients and service providers on the ground. Neither the overall package design nor the overall program logics articulated how the different components of the ICDP were meant to interact with and complement each other. There was also increasing interest in understanding the wide variation in implementation that was observed between different sites. It is widely appreciated that context can have greater influence on uptake of an intervention than any pre-specified implementation strategy. We drew on principles of realist evaluation, and on systems thinking to help draw out how the different components of the ICDP linked together, and played out in different contexts on the ground. Consistent with realist evaluation principles, the sites were purposively selected to include a wide range of different contexts, and in each subsequent evaluation cycle, we refined the focus of enquiry of data collection to test emerging hypotheses about 'what was working for whom and in what circumstances.' Illustrated by our AES conference presentation in 2013, through applying theory from the field of work (systems needed for management of chronic conditions) we sought to understand elements of system capacity influencing implementation (Annex 4, AES presentation on systems).

In its focus on the usefulness of the evaluation to stakeholders, and for program improvement, our place-based evaluation bears some resemblance to the 'developmental evaluation' approach[1] which reflects a 'meta' approach that brings evaluative thinking into 'real time' design of programs, and recognising that even large-scale programs seldom arrive 'fully formed' ready for roll out, but tend to be adapted along the way in response to local contextual factors, political realities, and so forth. Whilst drawing on some elements of this approach, as outlined in various points in this nomination, our evaluation approach also drew on theory relevant to health systems improvement (consistent with health care improvement literature); systems thinking (consistent with health systems strengthening approaches, and large scale transformation in health care), and realist evaluation.

Realist evaluation methodology combined with a systems thinking orientation in the analysis was valued by the Department and site stakeholders. *'… 'realist' evaluation thinking was used to answer the questions 'what works, for whom, and under what circumstance?... More than this, the evaluation helped to foster a 'systems' thinking approach to how the package of measures might be better supported and implemented to achieve its outcomes.' (ANPHA,2013)*

The Department indicated that they often just consider how is this program working on its own, rather than how do we make these things work most effectively with what is already happening on the ground.

Strengthened the evaluation capacity of Indigenous peoples - building a culture of evaluation, and an awareness and interest in evaluation and evaluation policy development

The successful conduct of this large scale, long-term evaluation, and the sustained engagement built over time with Indigenous organisations is likely to have helped to build capacity for evaluation, and an interest in its potential to improve outcomes for Indigenous people. Since completing the evaluation, we have been approached to consider conducting a further evaluation for an Aboriginal community organisation, reflecting on how to further improve and develop their strategy. Illustrated by the

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[1] Patton 2011, *Developmental Evaluation: Applying Complexity Concepts to Enhance Innovation and Use.* The Guilford Press, New York,

quotations from participants below, we believe that our evaluation, through its participatory and 'ground-up' nature, has promoted a positive view of evaluation amongst the communities with whom we worked.

Service providers implementing or accessing different aspects of the funding in Aboriginal community controlled primary health care services also reported a greater appreciation for evaluation and its capacity to make a difference.

> It made me feel important and what I was doing important. I knew it was being taken seriously and fed up the line.' (Interviewee, Case study site)

> 'We have lost the ability to tell the story that supplements the data … and this allows us to with this style of evaluation … it was more useful for us.' (Interviewee, Case study site)

As evidenced by the quotations above, **stakeholders at local level were satisfied with the evaluation – and so were those at other levels of the system**. Following the completion of the evaluation, the evaluation commissioners commissioned our team to write a discussion paper drawing out the lessons learned from the evaluation, in order to consider using the approach more widely.

Members of our evaluation team, including Indigenous team members, have built capacity and confidence in evaluation through participating in the evaluation. Two Indigenous evaluation team members presented aspects of the evaluation at the AES conference in Darwin in 2014 (Annex 5, Community engagement presentation at AES). Our non-Indigenous team members also built greater evaluation capacity in general, and specifically in working in Indigenous communities, through participation. Where ever possible we sought to pair an Indigenous with a non-Indigenous team member in field visits.

The SSE approach has been referenced as an example of a desirable approach for evaluation of reforms and current innovation. For example, a consultation paper for Health workforce Australia suggests: *"An early priority of NMTAN would be to utilise a sentinel site (see the Menzies School of Health review of sentinel sites for the Indigenous Chronic Disease Package) approach for evaluation of reforms and current innovation. Building this in to the training plans allows for ongoing qualitative research rather than retrospective analysis. This builds a richer picture of why certain outcomes occurred and what innovation was required to achieve better outcomes."*

Ethical conduct

Ethical conduct in Indigenous evaluation was central to our approach. We were guided by the *National Aboriginal and Torres Strait Islander Health Data Principles*, endorsed by the Australian Health Ministers' Advisory Council meeting of October 2006, *The Cultural Respect Framework for Aboriginal and Torres Strait Islander Health* (2004 – 2009), prepared by AHMAC's Standing Committee on Aboriginal and Torres Strait Islander Health Working Party, and the *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Researc*h, endorsed at the 148th Session of the National Health and Medical Research Council in June 2003 (Annex 6, Ethics principles applied to the evaluation).

Early consultation and negotiation at each site was a key component of the ethical conduct of the evaluation. The team developed a plain language brochure informing the community about the evaluation. The brochure ensured people received consistent information about the SSE across the sites, and could see that the evaluation was being done in an ethical way. It presented information that could be discussed before people were asked to sign informed consent forms, was a take-home resource for people to share information with others, and made it easy for participants to contact the evaluators if they had questions. Visual agendas for focus group discussions (Annex 3, Illustrated agenda example) helped to ensure inclusivity.

The collection of data was directly relevant to supporting improved health and planning of service delivery. We sought to include Indigenous people at all stages of analysis, interpretation and reporting – this included Indigenous people on the fieldwork team, and Indigenous people and organisations involved in data analysis workshops; feedback workshops were conducted in collaboration with the Aboriginal health services (principle 2). The privacy and confidentiality of Indigenous people were respected - we had a data management strategy in place to guide the team in respecting the privacy and confidentiality of Aboriginal and Torres Strait Islander people (principle 3). Informed consent was obtained from all participants from the outset (Annex 6, Ethics principles applied to the evaluation).

Ethics approvals were sought and granted through the Department of Health Ethics Committee, project 10/2012.

Professionalism

This evaluation, conducted over a two-year period with demanding 6-monthly reporting cycles, required high levels of skill, judgement and polite behaviour in the face of difficulties. Challenges were encountered at different stages, drawing on the different resources of our team. There were practical challenges at the outset in defining sites - sites could not be defined in abstract terms, but needed to be built up iteratively, drawing on local knowledge of patterns of primary health care service use, location of key service providers for the Indigenous population, against Statistical Local areas (SLAs) (used for extraction of some administrative data and population data) and post code boundaries (used for extraction of other benefits data and service location), and finding the best possible match. Sites then comprised groups of contiguous SLAs that had the 'best' fit with residence areas of Indigenous communities, service location, patterns of service use, and areas of responsibility of the main programs included in the evaluation. In the two year period of our evaluation, there were some changes in administrative boundaries over time, requiring repeat requests for data extraction to ensure the best possible fit. Program monitoring data were weaker than expected, and data for the different programs were not always able to be obtained in a way that corresponded to consistent geographic or administrative boundaries. In early evaluation cycles, there was very little program activity to report (since the program was in an early stage of implementation). This caused some frustration to program managers within the commissioning department, who wanted to see evidence of program roll out, and had not appreciated the time needed between resource allocation and evidence of program implementation on the ground. As mentioned earlier, fieldwork trips often had to be re-scheduled owing to unexpected community events or natural events (e.g. flooding making roads impassable in remote locations). The evaluation team (and the Commissioner) had to go through many often tedious revisions to the evaluation reports, in order to ensure that the range of stakeholders were comfortable with the messages of the evaluation, and the way in which they were presented.

Despite these and other challenges, the evaluation team were able to complete this large scale evaluation to a high quality and within the required timeframes. Over the course of the evaluation, the team conducted and analysed over 700 in-depth interviews with service providers and 72 focus groups with 670 Indigenous community members. Forty-one health services contributed clinical indicator data and the commissioner provided administrative data from program roll out, the Australian Medicare and Pharmaceutical Benefits Schemes, and the Practice Incentives Program – Indigenous Health Incentives scheme.

The findings of the evaluation were publically released by the Department, available on
http://www.health.gov.au/internet/main/publishing.nsf/Content/icdp-sentinel-sites-project

Contents

Annex 1: Extract from the State of Preventive Health report

Australian National Preventive Health Agency (ANPHA). *State of Preventive Health 2013*. Report to the Australian Government Minister for Health. Canberra; ANPHA, 2013.

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Closing the Gap – Sentinel Sites Evaluation

The Commonwealth Government's Indigenous Chronic Disease Package (ICDP) commenced in 2009 and is an ongoing commitment of around $260m per annum across three priority areas: tackling chronic disease risk factors; earlier detection, improved management and follow-up of chronic disease in primary health care; and expansion of the Aboriginal and Torres Strait Islander workforce and increased capacity of the health workforce to deliver effective care.

The Sentinel Sites Evaluation (SSE) was a place-based monitoring and formative evaluation designed to provide feedback to government and stakeholders on progress, barriers and enablers to successful implementation. The evaluation was undertaken by the Menzies School of Health Research and involved 24 sentinel sites across Australia with varying degrees of intensity of data collection and analysis. Administrative and program data was collected and analysed for all 24 sites and 16 of the sites also involved the collection of clinical indicator data and key informant interviews. Eight of the sites (called 'case study sites') included community focus groups.

The SSE brought several critical features to the monitoring and formative evaluation of this major national program. The 'site' based approach allowed local service delivery system capacity issues to come into focus in a way that is not often found in the evaluation of national programs. It highlighted the way that, though the ICDP had been designed for its various measures to work as a 'package', the complementary nature of its elements were not always well understood at the local level. The sentinel sites approach is quite different to the use of vignettes or case studies of local practice that are commonly found in national evaluations. The difference arises because the unit of analysis for the whole evaluation was a series of sites which could be compared and contrasted along various dimensions of system capacity and development and were also tracked over time. It enabled a level of analysis of local context that provided rich explanation of the observed differences across sites.

From this platform, 'realist' evaluation thinking was used to answer the questions 'what works, for whom, and under what circumstance?' Factors such as local organisations' history of involvement in and commitment to Aboriginal and Torres Strait Islander health, the quality of leadership, and the availability of enabling physical infrastructure and workforce supports were identified as key. More than this, the evaluation helped to foster a 'systems' thinking approach to how the package of measures might be better supported and implemented to achieve its outcomes.

Annex 2: Presentations, Posters, Where SSE has been referenced

Peer reviewed publications from SSE

1. Bailie J, Schierhout G, Kelaher M, Laycock A, Percival N, O'Donoghue L, McNeair T, Chakraborty A, Beacham B, Bailie R. *Follow-up of Indigenous specific health assessments – a social ecological analysis*. Medical Journal of Australia. MJA 2014; 200: 653-657 doi: 10.5694/mja13.00256. https://www.mja.com.au/system/files/issues/200_11/bai00256.pdf

2. Bailie R, Bailie J, Chakraborty A, Swift K. *Consistency of denominator data in electronic health records in Australian primary health care services – enhancing data quality*. Australian Journal of Primary Health Care. http://www.publish.csiro.au/?act=view_file&file_id=PY14071.pdf

3. Bailie J, Schierhout G, Kelaher M, Laycock A, Percival N, O'Donoghue L, McNeair, Bailie R. *Access to chronic illness care – how has a multifaceted chronic disease package for Indigenous Australians addressed determinants of access?* BMJ Open, Under Review.

4. Schierhout G, Bailie J, Kelaher M, Percival N, Laycock A, Bailie R. *Systems thinking applied to large scale evaluations: lessons learned from a place-based evaluation of a multi-component national program*. In preparation.

Selected published reports

1. Bailie R, Griffin J, Kelaher M, McNeair T, Laycock A, Percival N. *Sentinel Sites Evaluation: Interim Report, December 2011*. Menzies School of Health Research for the Australian Government Department of Health and Ageing, 2011. http://www.menzies.edu.au/icms_docs/189992_Sentinel_Sites_Evaluation_Interim_Report_December_2011.pdf

2. Bailie R, Griffin J, Kelaher M, McNeair T, Percival N, Laycock A, Schierhout G. *Sentinel Sites Evaluation: Interim Report, June 2012.* Menzies School of Health Research for the Australian Government Department of Health and Ageing, 2012. http://www.menzies.edu.au/icms_docs/218392_Sentinel_Sites_Evaluation_Interim_Report_June_2012.pdf

3. Bailie R, Griffin J, Kelaher M, McNeair T, Percival N, Laycock A, Schierhout G. *Sentinel Sites Evaluation: Final Report 2013.* Menzies School of Health Research for the Australian Government Department of Health and Ageing, 2013. http://www.menzies.edu.au/icms_docs/189996_Sentinel_Sites_Evaluation_Final_Report.pdf

4. Bailie R, Griffin J, Laycock A, Kelaher M, McNeair T, Percival N, , Schierhout G. *Sentinel Sites Evaluation: Summary Report 2013.* Report prepared by Menzies School of Health Research for the Australian Government Department of Health and Ageing, Canberra, 2013. http://www.menzies.edu.au/icms_docs/189995_Sentinel_Sites_Evaluation_Summary_Report.pdf

Selected unpublished reports

1. Schierhout G, Griffin J, Bailie R. *Considerations for the applicability and adaptability of a Sentinel Sites type approach to future evaluations of Indigenous-specific primary health care funding.* Report prepared by Menzies School of Health Research for the Department of Health, April 2014.

Blog – methods of the SSE

1. Bailie R and Griffin J. *Dynamic evaluation informs refinement of chronic diseases program*. Croakey: the Crikey health blog online, November 2013. http://blogs.crikey.com.au/croakey/2013/11/07/some-lessons-from-a-major-evaluation-of-efforts-to-improve-care-for-indigenous-people-with-chronic-diseases/

Posters and presentations – methods of the SSE

1. Bailie R, Goddard M, Griffin J, Moore K, McNeair T and Kelaher M. *Applying a Continuous Quality Improvement approach to implementation of a national program to enhance the quality of care for Indigenous Australians.* Poster, International Forum on Quality and Safety, Amsterdam, April 2011.

2. Bailie R, Goddard M, Griffin J, Moore, K, McNeair T, Kelaher M. *Applying a continuous quality improvement approach to implementation of a national program to enhance the quality of primary health care for Indigenous people.* Poster presented at Primary Health Care Research Conference, Brisbane, 13-15 July, 2011.

3. Griffin J, Chakraborty A, McNeair T, Moore K, Bailie R. *Sentinel Sites Program: An evaluation of the Indigenous Chronic Disease Package.* Oral presentation at the Australian General Practice Network Forum, Melbourne, 18 November 2011.

4. Griffin J, Schierhout G, McNeair T, Percival N, O'Donoghue L, Kelaher M, Chakraborty A, Beacham B, Laycock A, Bailie R. *A national place-based formative evaluation of the Indigenous Chronic Disease Package – reflections on an innovative evaluation approach*. Long oral presentation at the AES International Evaluation Conference, Brisbane, Australia, 5 September 2013.

5. Schierhout G, Griffin J, Laycock A, O'Donoghue L, Beacham B, Kelaher M, Bailie R. *Identifying elements of system capacity that influence effective program implementation: findings from a place-based evaluation of the Indigenous Chronic Disease Package*. Long oral presentation at the AES International Evaluation Conference, Brisbane, Australia, 5 September 2013.

6. O'Donoghue L, Laycock A, Chakraborty A, Hicky P, Beacham B, Kite E, Hodgson J, Howard M, Bailie J, Bailie R. *You have come to hear us, taking that story back…to improve the services we are getting*. Oral presentation at the AES International Evaluation Conference, Darwin, Australia, 10 – 12 September 2014.

7. Bailie J, Schierhout G, Laycock A, Kelaher M, Percival N, O'Donoghue L, Bailie R. *Enhancing implementation through evaluation: Reflections on an innovative evaluation of a national chronic disease program.* Oral presentation at the 3rd Global Symposium on Health Systems Research, Cape Town, South Africa, October 2014.

Posters and conference presentations – SSE findings

1. Griffin J, Schierhout G, O'Donoghue L, McNeair T, Kelaher M, Chakraborty A, Laycock A, Percival N, Beacham B, Bailie R. *Barriers and enablers to follow-up of adult health checks for Aboriginal and Torres Strait Islander people: findings from the Sentinel Sites Evaluation*. Oral presentation at the Primary Health Care Research Conference, Sydney, Australia, 11 July 2013.

2. Griffin J, Schierhout G, McNeair T, Laycock A, O'Donoghue L, Percival N, Bailie R. *Addressing social determinants of access to chronic illness care.* Oral presentation at the PHAA 42nd Annual Conference, Melbourne, Australia, 17 September 2013.

3. McNeair T, Schierhout G, Griffin J, Beacham B, Kelaher M, Chakraborty A, Bailie R. *Implementing Care Coordination – key findings from the Australian Indigenous Chronic Disease Package.* Oral presentation at the 8th Health Services and Policy Research Conference, Wellington, New Zealand, 3 December 2013.

4. Bailie R, Bailie J, Chakraborty A, Swift K. *What are we counting? Quality of indicator data – Improving consistency of denominators in electronic health records*. Poster, International Forum on Quality and Safety, London, April 2015.

Where the Sentinel Sites Evaluation has been referenced

1. Australian Institute of Health and Welfare. *Taking the next steps: identification of Aboriginal and Torres Strait Islander status in general practice*. Cat. no. IHW 100. Canberra; AIHW, 2013. http://www.aihw.gov.au/publication-detail/?id=60129543899

2. Australian National Preventive Health Agency (ANPHA). *State of Preventive Health 2013*. Report to the Australian Government Minister for Health. Canberra; ANPHA, 2013. http://www.anpha.gov.au/internet/anpha/publishing.nsf/Content/state-of-prev-health-2013/$FILE/ANPHA%2041087%20State%20of%20Preventative%20Health_acc_pdf.pdf

3. Ware V-A. *Improving the accessibility of health services in urban and regional settings for Indigenous people*. Resource sheet no. 27. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of Health and Welfare & Melbourne: Australian Institute of Family Studies, 2013. http://www.aihw.gov.au/uploadedFiles/ClosingTheGap/Content/Publications/2013/ctgc-rs27.pdf

4. Russel L. *Closing the Gap Indigenous Disadvantage: An analysis of provisions in the 2013-14 Budget and implementation of the Indigenous Chronic Disease Package*. Menzies Centre for Health Policy University of Sydney, 2013. http://www.naccho.org.au/download/aboriginal-health/2013-14IndigenousBudgetandICDP.pdf

5. KPMG. *National Monitoring and Evaluation of the Indigenous Chronic Disease Package First Monitoring Report 2010-11*, Australian Government Department of Health, Canberra, 2013. http://www.health.gov.au/internet/main/publishing.nsf/Content/FD5466A9AF925775CA257D8E00000AD0/$File/National%20Monitoring%20and%20Evaluation%20of%20the%20ICDP%20First%20Monitoring%20Report%202010-11.pdf

6. Mason J. *Review of Australian Government Health Workforce Programs*. Commonwealth of Australia, May 2013. http://www.health.gov.au/internet/main/publishing.nsf/Content/D26858F4B68834EACA257BF0001A8DDC/$File/Review%20of%20Health%20Workforce%20programs.pdf

7. Kehoe H. *So close, yet so far: how a lack of accountability undermined COAG's Aboriginal and Torres Strait Islander health goals*. Masters Thesis. 2013. http://espace.cdu.edu.au/eserv/cdu:38914/Thesis_CDU_38914_Kehoe_H.pdf

8. Biddle N. *Data about and for Aboriginal and Torres Strait Islander Australians*. Issues paper no. 10. Produced for the Closing the Gap Clearinghouse. Canberra: Australian Institute of

Health and Welfare & Melbourne; Australian Institute of Family Studies, 2014.
http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548209

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Submissions using the SSE as evidence

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2. National Heart Foundation of Australia Submission. Senate Select Committee on Health inquiry into health policy, administration and expenditure, with particular focus on Indigenous health, January 2015.

3. VACCHO. Senate Select Committee on Health Submission to Terms of Reference, January 2015.
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Annex 3: Illustrated agenda example

Annex 4: AES presentation 2013 on Systems

Schierhout G, Griffin J, Laycock A, O'Donoghue L, Beacham B, Kelaher M, Bailie R. *Identifying elements of system capacity that influence effective program implementation: findings from a place-based evaluation of the Indigenous Chronic Disease Package.* Long oral presentation at the AES International Evaluation Conference, Brisbane, Australia, 5 September 2013.
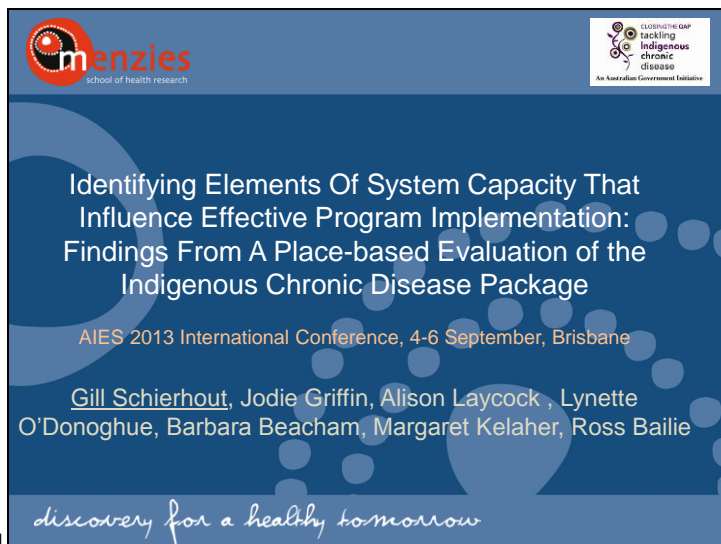
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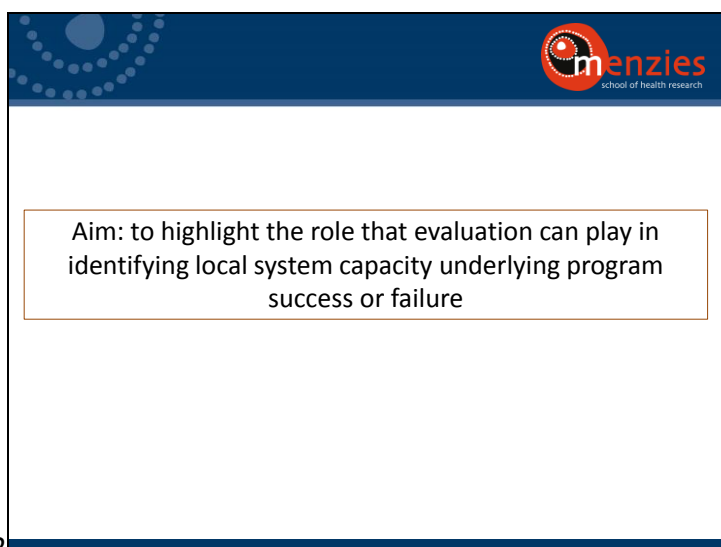
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Why is attention to the capacity of local systems important?

- To the extent that access and effective use of program resources depends on pre-existing capacity, there is potential for the "inverse care law" ~ equity
- Functioning appropriate local health systems necessary for "success" of the ICDP
  - Proactive population health orientation
  - Multi-disciplinary team-based care
  - Equity orientation

What did the ICDP require of local health systems?
What did local health systems "look like" at baseline?
How did the ICDP influence local health systems?

Slide 4

Data sources and methods

- Formative evaluation
- Non-representative "Sentinel Sites" (n=24)
- Qualitative, administrative and program data
  - +700 face-to-face interviews; +70 focus groups
  - Medicare trend data at baseline & during implementation
  - Program data from +- 14 different 'measure areas'
  - Clinical indicator data from health services
- "Chronic Care Model" applied as an analytical framework

Slide 5

Outcomes specified in the ICDP program logics related to management of chronic illness

- Increased access to Primary Health Care services, including medication
- Increased access to specialist and allied health services
- Improved care co-ordination
- Improved chronic disease management and follow up care

To contribute to these program outcomes health services had to take up the resources, and use them to improve care
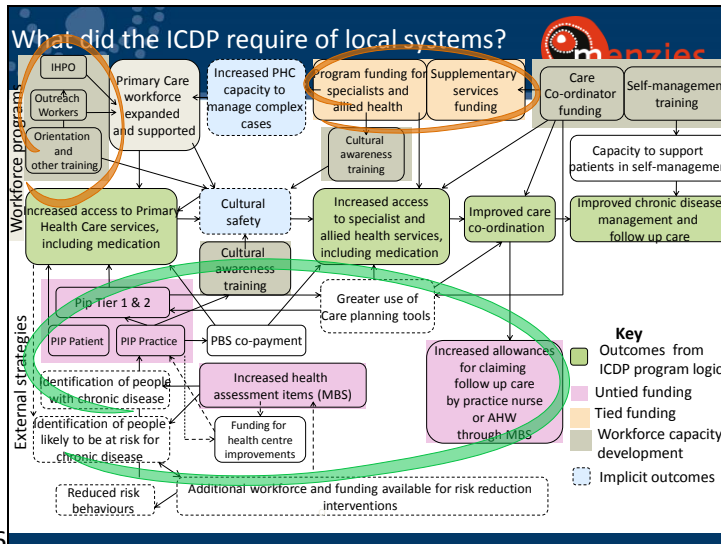
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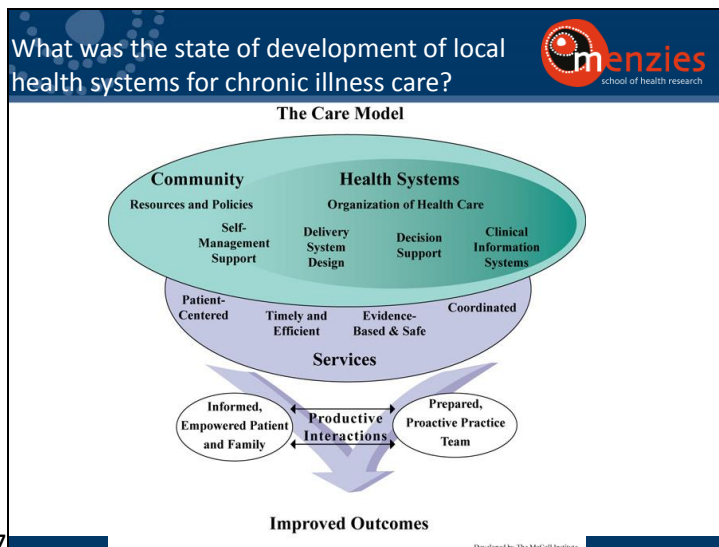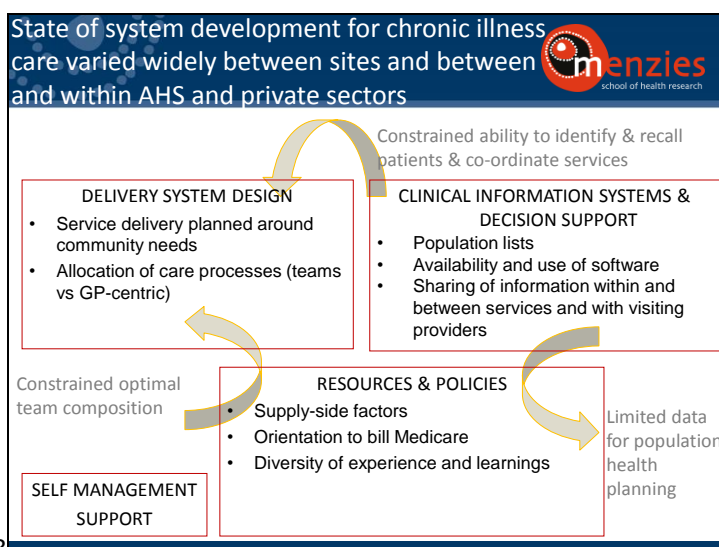
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How and in what circumstances did the ICDP strengthen local health systems?

1. Incentives available through the ICDP were used to improve design of delivery systems, in services motivated for and capable of making these changes
2. Constructive changes to clinical information systems in response to requirements of the ICDP required leadership, and practical and technical support
3. 'Soft' capacities were developed in some services and may have contributed to productive engagement between patients and health care teams
4. Clinicians and patients needed to see the benefit to patient care of the various ICDP incentives and programs

Incentives were used to improve design of delivery systems, in services motivated for and capable of making these changes (1)

• Incentives on their own did not lead to change in practice

"the money [from the PIP-IH] has been very helpful and was much needed but in itself it does not change the way that clinicians practice" **(AHS, GP)**

• Incentives were a significant potential income stream for some services ~ regional support

"It's all about developing a business model of care that maximises the Medicare opportunities....this may involve bringing in a team to upskill the staff and develop systems. It's about looking at what he right mix of staff is for a particular service (AHS, GP)

Delivery system design

Incentives were used to improve design of delivery systems, in services capable of making these changes (2)

• Positive prior experience in Aboriginal and Torres Strait Islander health and/or in chronic care orientation helped services to use resources to change delivery systems to improve care

"...[we started] Diabetes Clinics targeting the Indigenous patients...the process took a fair bit of nurses time, where the PIP-IH money has been used (General Practice, GP – in a practice that was already using GPMP care plans)

Delivery system design

Slide 12

Changes to clinical information systems to support good chronic illness care required leadership, and practical and technical support

- Development of 'siloed' information systems to support ICDP implementation evident in some sites ~ staff capability to use functionality of existing systems
- Integration of relevant reminders, ICDP uptake, and decision support prompts into existing systems less common, but did occur
- Strength of business imperative was a key driver for some health services

Clinical information systems

Slide 13

Development of 'soft' capacities in some settings contributed to productive engagement

"we became aware [through the cultural competence training organised by the ML] that not all Aboriginal population access the AHS "(General Practice, practice manager)

"We get Aboriginal magazines in the waiting room...on Australia day fly an Aboriginal flag too...I was expecting flack when asking 'do you identify...' but didn't get it" (General Practice, nurse)

"It made everyone more aware and accepting that clients might not turn up" (General Practice, GP)

Productive interactions..

Slide 14

Clinicians and patients needed to see the benefit to patient care of the various ICDP incentives and programs

- PBS co-payment which provided a tangible benefit to patients widely considered the key success of ICDP
- Where there were perceptions of inequity in e.g. Resource allocation, this undermined 'valuing'
- Patients and providers needed shared understanding about the value of different services
- Vision, leadership commitment and local champions were critical underlying factors

Productive interactions..

- General lack of valuing of self-management as core
- Top-down approaches did not always fit well with, or draw on community resources

Self management support

Reflecting on findings

- Early stage implementation of a complex intervention

- Different approaches to implementation, with support at regional level key to effective participation for many services
  - "letting it happen" -"helping it happen" –"making it happen"

- Demonstrated potential of use of resources to strengthen local systems for chronic illness care – but how to apply more widely?

Slide 15

Conclusions – 'doing more with less'

- Purposive selection and program adjustment to ensure best fit with system needs, diversity of local context and evidence

- Continue to make use of improvement cycles to resolve systems issues – extend and enhance these for applicability at different levels and between levels

- Ongoing need to understand, organise, manage, and evaluate the ICDP as part of a broader system

Slide 16

THANK YOU

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Annex 5: Community Engagement Oral Presentation at AES Forum

O'Donoghue L, Laycock A, Chakraborty A, Hicky P, Beacham B, Kite E, Hodgson J, Howard M, Bailie J, Bailie R. *You have come to hear us, taking that story back...to improve the services we are getting*. Oral presentation at the AES International Evaluation Conference, Darwin, Australia, 10 – 12 September 2014.

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Indigenous Chronic Disease Package (ICDP) - $A805 million 2009 - 2013

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Tackle chronic disease risk factors	• Tackling smoking & healthy lifestyle teams • Local community health promotion • Healthy community days
Improve chronic disease management & care	• Free or subsidised medications • Health assessments and follow-up • Care coordination – patient registration & workforce • Self management training • Specialists & allied health outreach
Workforce expansion & support	• Workforce support, education & training • Outreach Workers, Practice Managers, Project Officers • Decision support guidelines

Slide 4

Evaluation aims and sites

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- Monitor local implementation in 24 sites

- Understand where and why the ICDP was effective

- Identify barriers and enablers to help refine ongoing implementation and design

Urban, regional and remote sites

Slide 5

Data collection

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Administrative data (DoHA)	• Medicare, PIP and PBS • Program data
Interviews	• Over 700 in-depth interviews: General Practice, Aboriginal Health Services, support orgs e.g. Medicare Locals
Clinical indicators	• 41 Health Services
Community focus groups	• 72 groups - 670 participants • Average of 9 per group

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Reflection: team structure and relationships

Slide 10

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Slide 12

Using the Community Focus Group Tool - example

Improve chronic disease management & care	• **Free or subsidised medications** • Health assessments and follow-up • Care coordination – patient registration & workforce • Self management training • Specialists & allied health outreach

- Has there been a change to the way you get your medications in the last six months?
- Has there been a change in the cost of your medication?
- Do you think that the changes have made a difference in the way you take your medicines?
- Does your doctor talk about how to take your medicines?
- Has this helped you take your medications regularly?
- Has this made a difference to your health?

Slide 13

Reflection : sustaining community engagement

Video covered:

- *Trust*
- *Contacts on ground who advocated for the evaluation, talked about it being worthwhile to participate - community 'champions'.*
- *And the six monthly evaluation cycles developed relationships with people at the local level.*
- *We listened carefully to people's stories. Each time we returned, we explained what had happened with the information people had shared, so it was clear that community voices and stories were respected and valued, that people had something important to say and were heard, and their stories contributed to some changes in the way the ICDP was being rolled out.*
- *We would recognise people from previous FGs and remember their names – and we could build on their stories, asked what had changed since the last visit.*
- *This giving back was really important – it showed we were there to help and answer questions as well as take away stories.*
- *Could explain what services were available through the ICDP, who could be eligible, how to access.*
- *Gave 'big picture' information, helped people to link together related services rolled out under the ICDP.*
- *People informed each other, (and this gave us insight into the breadth or depth of the ICDP rollout).*

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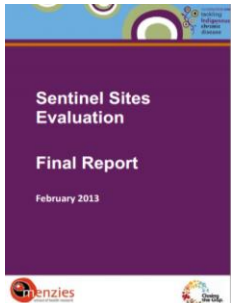## Reflection : maintaining integrity of community stories

How did we retain meanings of stories when they left communities?

Workshops with whole evaluation team

- Share insights, analyse data
- Interpretation

Workshops with evaluation leaders and Commonwealth managers

- Early feedback
- Interpretation
- Informed refinements to ICDP

Sentinel Sites Evaluation

Final Report

February 2013

What the literature says ...

Engagement with Indigenous communities
Resource sheet no. 23. Closing the Gap Clearinghouse (Hunt J, 2013)

What we know

Without genuine engagement of Indigenous people it will be difficult to meet the Council of Australian Government targets for overcoming Indigenous disadvantage.

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Engagement with Indigenous communities
Resource sheet no. 23. Closing the Gap Clearinghouse (Hunt J, 2013)
What we know
- Community engagement requires a relationship built on trust and integrity: it is a sustained relationship between groups of people working towards shared goals.

What works
- Engagement occurring through partnerships with Indigenous organisations within a framework of self-determination and Indigenous control.
- Staff working with Indigenous people who understand the social and cultural context in each place and contemporary social fluidity.

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Engagement in health programs
Resource sheet no. 23 Closing the Gap Clearinghouse (Hunt J, 2013)
Where engagement worked
- Building trust through tangible benefits and implementing an empowering process … (Voyle & Simmons 1999).
- Intellectual property vested in community-controlled bodies and using researchers with good cross-cultural skills (Couzos et al. 2005).
- Participatory processes with Aboriginal research assistants, focus groups, consultation and feedback processes with Aboriginal communities and health services (Massey et al. 2011).
- Extensive community consultation using existing community organisations/ structures, Aboriginal Elders and health workers,… (Adams & Spratling 2001).
- Review and evaluation, both qualitative and quantitative … (Bailey & Hunt 2012).

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Annex 6: Ethics principles applied to the Sentinel Sites Evaluation

1   National Aboriginal and Torres Strait Islander Health Data Principles

The Australian Health Ministers' Advisory Council meeting of October 2006 endorsed a set of national data principles which aim to guide and improve the use of information relating to the health of Indigenous Australians.

Principle	Sentinel Sites
The management of health-related information about Aboriginal and Torres Strait Islander persons must be ethical, meaningful, and support improved health and better planning and delivery of services.	The Sentinel Sites provides place-based monitoring and formative evaluation on progress of the measures identified in the early implementation of the ICDP (also see information below)
The analysis, interpretation and reporting of Aboriginal and Torres Strait Islander health and health-related information should, where feasible, occur collaboratively with Aboriginal and Torres Strait Islander peoples.	ICDP Sentinel Sites were identified through recommendations by the Indigenous Health Partnership Forums. By definition, the ICDP Sentinel Sites include Aboriginal Health Services as key participant organisations. Refinement of data collection and feedback processes is being conducted in consultation with ACCHOs at the local site level. Local Aboriginal community members will be involved in the data collection processes at the site level.
The privacy and confidentiality of Aboriginal and Torres Strait Islander people will be protected in accordance with any relevant legislation and privacy codes.	• See pages 5-7 of the Integrated Data Management Strategy. • To be discussed at agenda item 4.
Aboriginal and Torres Strait Islander peoples should be informed at the point of service that attendance/participation may contribute to administrative or mandatory data collections and that such data will be used to improve the quality, coverage and scope of health services and protect the public health. Data collection agencies and data custodians should have a policy that provides this information to people at the point of data collection and appropriate governance arrangements to review its implementation.	• Service use data (MBS, PBS, PIP) will not require additional burdens of reporting for participants. Collection of this data will remain routine, in line with mandatory reporting requirements for funding. • Clinical indicators data will be extracted from a variety of pre-existing clinical information or quality improvement systems or reports being prepared for other purposes.
In general, free and informed consent should be obtained from Aboriginal and Torres Strait Islander peoples prior to any information management activities, except where	Appendix 3 of the Sentinel Sites Establishment Plan shows the consent forms and information sheets for participants.

mandatory reporting or legislative provisions apply. Otherwise, where there is a proposal to initiate an information management activity without the consent of Aboriginal and Torres Strait Islander peoples, it must be clearly demonstrated both that the activity will advance the interests of Aboriginal and Torres Strait Islander peoples and that it is impractical and infeasible to obtain further specific consent.	
The value of the resources required to collect and use information should be assessed in the light of the potential benefit to Aboriginal and Torres Strait Islander peoples' health.	The participation of organisations and individuals within the Sentinel Sites program is specifically intended to inform and improve implementation of the ICDP.
The collection, collation and utilisation of information should be conducted in the most efficient and effective manner possible and minimise the burden on Aboriginal and Torres Strait Islander people.	In collecting evaluation information, the Sentinel Site team are also guided by the principle of not overburdening the participant organisations. Refinement of data collection and feedback processes is being conducted in consultation with ACCHOs at the local site level.
Systematic and ethical processes for sharing information should be encouraged to assist in policy, planning, management and delivery of health services to Aboriginal and Torres Strait Islander people.	Information sharing will be employed to inform policy and planning for the delivery of the ICDP.
Aboriginal and Torres Strait Islander communities should be provided with feedback about the results and possible implications arising from data analysis.	Relevant data and information will be regularly fed back to participating organisations
Information collections require regular review and refinement in order to ensure ongoing relevance to service delivery and the potential for improved health outcomes.	Indicators to be used in the Sentinel Sites program are intended to reflect the early implementation of the ICDP. It is expected that there may be refinement of these indicators during an initial process of review during development of the evaluation tools and after the first evaluation cycle.
Cultural respect and security of data practices must be promoted across all collections. Aboriginal and Torres Strait Islander individuals and communities should be afforded the same ethical and legal standards of protection as are enjoyed by other Australians. This may require the development	The evaluation is being undertaken in accordance with the Cultural Respect Framework for Aboriginal and Torres Strait Islander Health.

and application of methods that are different to or in addition to those in mainstream data collections.	

2   The Cultural Respect Framework for Aboriginal and Torres Strait Islander Health

The *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health* (2004 – 2009), prepared by AHMAC's Standing Committee on Aboriginal and Torres Strait Islander Health Working Party (comprising the Northern Territory, Queensland and South Australia) aims to influence the corporate health governance, organisational management and delivery of the Australian health care system to adjust policies and practices to be culturally respectful and thereby contribute to improved health outcomes for Aboriginal and Torres Strait Islander peoples.

Principles	Sentinel Sites
A holistic approach to health	OATSIH supports the view that improving Aboriginal and Torres Strait Islander health is not just about improving the physical wellbeing of an individual. It is about working towards the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being.
All of the health sector is responsible to the needs of Aboriginal and Torres Strait Islander peoples	The Sentinel Sites include non-Indigenous health service providers such as General Practices and the Divisions of General Practice.
Supporting the Aboriginal community controlled health sector in recognition of its role in providing comprehensive primary health care	The Sentinel Sites include Aboriginal Community Controlled Health Organisations as key stakeholders.
Combining the efforts of government, non-government and private organisations within and outside the health sector	The Sentinel Sites incorporate efforts led by Government to combine the efforts of non-government and private organisations in delivering effective primary health care services to address the burden of chronic disease for Aboriginal and Torres Strait Islander people.
Localised decision-making	Participation in the Sentinel Sites program is voluntarily agreed to by the stakeholder organisations at the local level. Refinement of data collection and feedback processes is being conducted in consultation with ACCHOs at the local site level.
Promoting good health	Implementation of the ICDP, including the B6 measure for Monitoring and Evaluation, is

	specifically intended to support the prevention of chronic disease and the deliver of effective primary health care services.
Building the capacity of health services and communities	To acknowledge the input, and in respect of the value contributed by the participating organisations, the Sentinel Sites team will provide sites with regular reports to assist the organisations with any local quality improvement issues for ICDP measure implementation.
Accountability for health outcomes	Monitoring and evaluation of the ICDP ensures accountability for health outcomes by providing timely feedback on barriers and enablers impacting implementation. It is expected that this feedback will guide the refinement of the package for the purposes of ensuring effective implementation to improve health outcomes.

3   Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research

Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research was endorsed at the 148th Session of the National Health and Medical Research Council in June 2003. The *National Statement on Ethical Conduct in Research Involving Humans* provides the main guidelines that must be followed for research involving Aboriginal and Torres Strait Islander people, but *Values and Ethics* introduces additional requirements for developing and conducting research in a manner that is respectful and inclusive of Aboriginal and Torres Strait Islander values and cultures. There are six values which form the basis of the guidelines.

Values	Sentinel Sites
Spirit and Integrity – *eg negotiations with Aboriginal and Torres Strait Islander communities need to exhibit credibility in intent and process.*	Participation in the Sentinel Sites has involved respectful negotiations with community controlled organisations about the intent and process of the monitoring and evaluation activities. ICDP Sentinel Sites were identified through recommendations by the Indigenous Health Partnership Forums. By definition, the ICDP Sentinel Sites include Aboriginal Health Services as key participant organisations. Refinement of data collection and feedback processes is being conducted in consultation with ACCHOs at the local site level.
Reciprocity – *eg intent to contribute to the advancement of the health and*	The rationale for this monitoring and evaluation is to enhance the delivery of primary health care

wellbeing of participants and communities.	services delivered through the ICDP.
Respect – *eg that in reaching agreement with participating communities all relevant issues including management of data, publications arrangements and the protection of individual and community identity have been adequately addressed.*	The initial site contact process and establishment process is detailed in the Sentinel Sites Establishment Plan. See page 20 for details of this process for reaching agreement with participating stakeholders.
Equality – *eg whether the ways that participating communities are included in the research process demonstrate equality.*	The Indigenous Health Partnership Forums provided OATSIH with recommendations for potential Sentinel Sites. ICDP Sentinel Sites were identified through recommendations by the Indigenous Health Partnership Forums. By definition, the ICDP Sentinel Sites include Aboriginal Health Services as key participant organisations. Refinement of data collection and feedback processes is being conducted in consultation with ACCHOs at the local site level.
Survival and Protection – *eg respect for social cohesion and cultural distinctiveness of Aboriginal and Torres Strait Islander communities.*	Implementation of the ICDP, including the B6 measure for Monitoring and Evaluation, involves comprehensive stakeholder engagement consistent with the Government's commitment to work in partnership with Indigenous Australians. As indicated above, refinement of data collection and feedback process is conducted in consultation with key Indigenous and other organisations in each site. The data collection processes specifically include data from local Aboriginal community groups in a way that respects social cohesion and cultural distinctiveness of communities.
Responsibility – *eg how provision is made for appropriate ongoing feedback to be received from participating communities.*	The Sentinel Sites Program is specifically designed to obtain feedback from local organisations regarding the effective and appropriate implementation of the ICDP, with the purpose of refining the implementation process.