

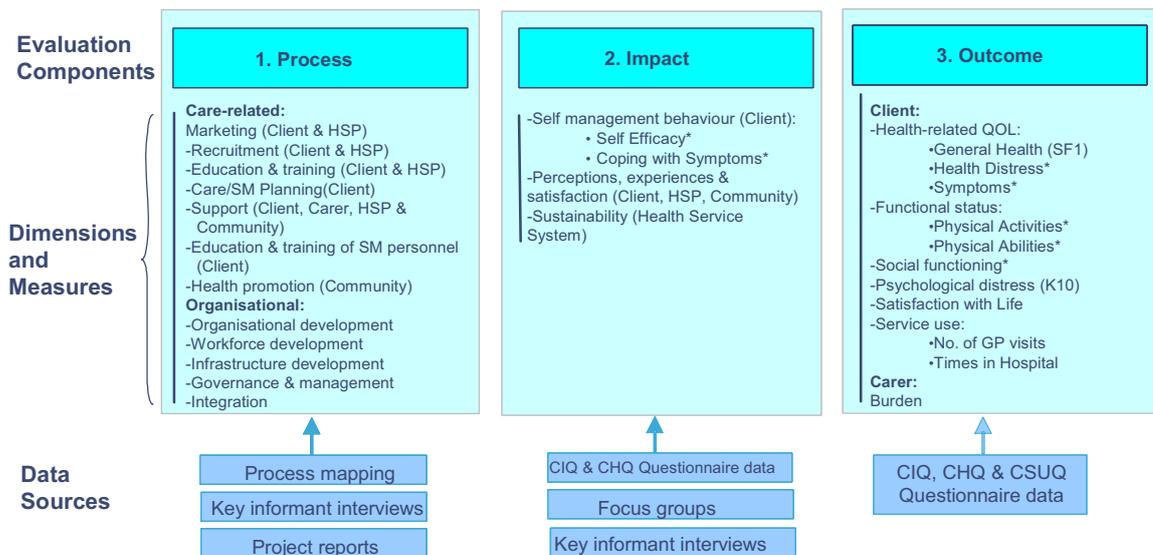
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## **3 Methods**

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In this Section, the methods for the data collection and analysis for each of the data sources for the National Evaluation are set out and explained. The following diagram (See Figure 2) illustrates how the data collection methods described in this Section link in with the overall evaluation framework (i.e. the process, impact and outcome evaluation components) and their relevant indicators, which were set out in Section 2 of the report, ‘The National Evaluation Framework’.

**Figure 2 Evaluation components and associated data sources**



\* Modified Stanford 2000 Questionnaire

The methods for the Indigenous DPs and Non-Indigenous DPs were similar, except where noted. However, in accordance with the discussion at the August 2004 Indigenous National Evaluation workshop, the results from the Indigenous DPs (Katherine West Health Board [NT] and Pika Wiya Aboriginal Health Service [SA]), have been described separately to the non-Indigenous DPs. The results of the non-Indigenous DPs are set out in Section 4 and those of the Indigenous DPs are set out in Section 5.

## 3.1 Demographics – Client Information Questionnaire

The demographics component of the evaluation was included to understand the socio-economic profile of the DPs participants.

The Client Information Questionnaire (CIQ) was developed for the purpose of collecting the demographic information. The approach taken for the collection and analysis of the questionnaire is set out in detail in Section 3.4.1.

## 3.2 Process evaluation

The process evaluation component underpinned the whole of the National Evaluation since it monitored SHCI implementation and provided context to the impact and outcome evaluations. The process evaluation also contributed to an understanding of what was successful and why, and thereby helps to inform the roll-out of future self-management programs.

Another important benefit of conducting a process evaluation was that it enabled the national evaluator to provide almost immediate feedback about the progress of the DPs in accordance with the action research approach of the National Evaluation.

### 3.2.1 *Process mapping*

#### 3.2.1.1 *Purpose*

Process mapping was the main source of data for the process evaluation of the National Evaluation. The process mapping visits undertaken by the national evaluator captured information on the following:

- A description of the processes in place at the time of the visit; and
- Identification of processes that had changed since the previous visit and reasons for these changes.

The purpose of the process maps was to obtain a ‘snapshot’ of how the DPs were progressing at important epochs over the life of the SHCI.

#### 3.2.1.2 *Data collection*

##### **Instrument**

The process mapping visits were based on the process mapping framework (Appendix 1) developed from the process evaluation component of the NEF. Table 13 is a schematic of the process mapping framework.

**Table 13 Process mapping framework schematic**

INPUTS	PROCESS	DOMAIN
People • Who? Technology • What? Infrastructure • What?	How? Why?	Client Carer/Family/Significant Other HSP Community Health Service System

For each process within each domain, the inputs (for example, strategies and program operations; resources and activities to the process) were firstly identified and described. Then the process itself was documented by applying a standardised flow chart methodology with supporting narrative in relation to:

- The relationships between the DP and different organisations, agencies and practitioners;
- The organisational processes in place; and
- The care-related processes in place.

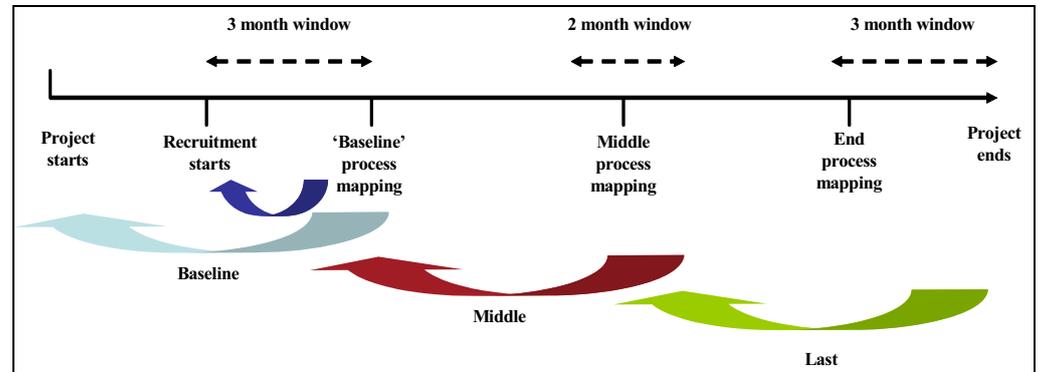
The main source of data was obtained through discussions held with the DP Managers. Evidence was sought (through observation and written documentation) to support the processes described by the DP Managers.

For the remainder of the report, ‘carer/family/significant other’ domain has been incorporated into the client domain for the process evaluation. This is because at each data measurement point, the processes relating to the carer/family/significant other domain were not significantly different from those of the client domain, since on the whole the carer/family/significant other domain was not a primary focus for the DPs.

**Timing**

All process mapping visits took place in accordance with the timing set out in the NEF, as illustrated in Figure 3.

**Figure 3 Data collection timing for process mapping**



There were three measurement points for process mapping – Baseline, Middle and Last. Each visit was DP specific, taking the beginning of recruitment as the starting point for each DP. To capture the process data for these points in an efficient way, (since many of the DPs started client recruitment at different times) the periods of data collection for each DP occurred around a two to three month window, which was specific to DP activity. As a consequence, this diagram does not relate to real time, rather, it is representative of DP-based time only.

### 3.2.1.3 Data analysis

#### Care related processes

The analysis of the process mapping data presented involved the development of an overview process map at each data measurement point, for all of the care-related processes identified for each of the National Evaluation domains (client, HSP and community) in the process evaluation framework. Within this, DPs were grouped into **‘Process Models’** and the following identified:

- Processes that were common to *all* DPs;
- Points of differentiation;
- Change from baseline to the middle data measurement point; and
- Change from middle to the last data measurement point.

From this, common themes were identified within each of the processes to capture *variability* across DPs and *changes* within DPs through a thematic analysis. The themes that were identified fell within one of three levels:

1. **Level One:** an over-arching principle of the process for example, whether care planning is a fundamental process to the DP or not.
2. **Level Two:** the core characteristics of the process for example, the timing of when the care planning takes place which is indicative of the role of the care plan in the DP.

3. **Level Three:** the ‘mechanics’ of the process, which make the process work for example, the frameworks in place/used which determine the formality or otherwise of the care plans.

Depending on the complexity and the importance of the process to the DPs, there were not always three levels of theme for every process.

For each of the themes identified, a four-way classification (going from the narrowest focus to the broadest for example) was then developed, from which it was possible to plot the DPs along a continuum of variation. It is important to note the DPs could operate at several points along this continuum, and in some cases adopt both end points of the spectrum. Overall, it was the range along the spectrum which described the difference between the DPs. See Appendix 2 for all of the classifications across each domain in the thematic analysis.

### **Organisational processes**

The organisational process mapping data had two purposes. Firstly, they provided information on the overall context within which the DPs operated (for example organisational structure, project management and governance). Secondly, they informed the key informant interview data collection and analysis discussed in Section 3.3.3 with respect to capacity building and sustainability. The organisational processes explored as part of the process mapping were based upon the NSW Health’s ‘A Framework for Building Capacity to Improve Health’ (27), and were as follows:

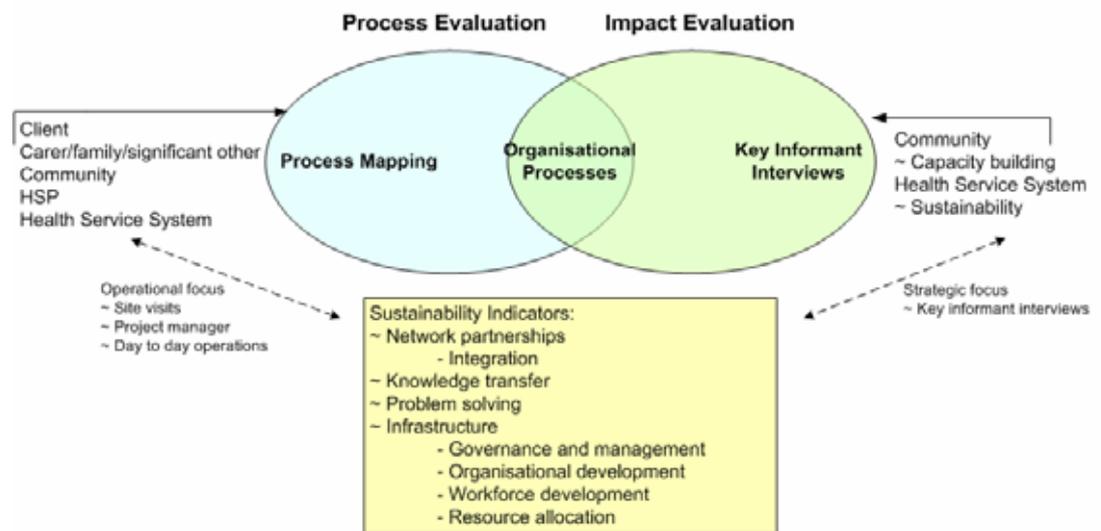
- Integration/network partnerships;
- Governance and management;
- Infrastructure development; and
- Capacity building/sustainability:
  - Organisational development;
  - Workforce development; and
  - Resource allocation.

A thematic analysis of these organisational processes was undertaken for each data measurement point to identify the common experiences of the DPs in rolling-out and establishing their self-management programs, as well as documenting the problems and improvements made in response.

The inter-relationship between the process mapping and key informant interview in terms of organisational process is illustrated in Figure 4. Specifically, for the purposes of summarising the barriers and facilitators experienced in achieving sustainability, the findings from the process

mapping were mapped into the key informant interview sustainability indicators of: 1) Network Partnerships; 2) Knowledge Transfer; 3) Problem Solving; and 4) Infrastructure (as indicated in Figure 4).

**Figure 4 Inter-relationship between process mapping and key informant interviews**



The interaction between the organisational processes observed and the key informant interviews is discussed in Section 4.6.1.

### 3.2.2 Project reports

The purpose of the project reports was to provide additional contextual explanation or support to the evidence collected as part of the process mapping visits.

#### 3.2.2.1 Data collection

##### Instrument

The project report template (see Appendix 3 for project report template) was developed from the process evaluation component of the NEF. Despite the presence of this prescribed format, not all of the DPs used this format nor included elsewhere the required qualitative and quantitative indicators required as part of the NEF in their six monthly progress reports to DoHA. As a result, there is a degree of missing data in the analysis presented. However, this has not been critical to the evaluation given the purpose of the project reports i.e. to provide additional contextual explanation or support to the evidence collected as part of the process mapping visits.

Instructions for the completion of project reports were set out in the NEFs Data Collection Management Guide, see Appendix 4.

##### Timing

The project report templates were completed by the DP Managers and submitted to the national evaluator as part of their six monthly reporting cycles to DoHA.

#### *3.2.2.2 Data analysis*

Content analysis of the qualitative indicators was undertaken for each data measurement point to identify the common themes arising across the DPs. These were presented in terms of barriers and facilitators they experienced in rolling out their self-management program and improvements they made to their processes in response to the SHCIs needs.

A review of the quantitative indicators provided by the DPs was also undertaken. However, this exercise was hampered by a high level of missing data. In addition, much of the information received was not in a comparable format.

## 3.3 Impact evaluation

The impact evaluation measured medium term changes in perceptions and experiences of the SHCI, behaviour and attitudes regarding self-management. The organisational structure of the DPs is also considered, to examine their ability to build capacity and ensure ongoing sustainability of the DP self-management programs.

### 3.3.1 Focus groups

#### 3.3.1.1 Purpose

The purpose of the focus groups was to gain an understanding from clients, carers, HSP and the community of their perceptions and experiences of the self-management program being implemented by the DPs. For the client and carer, this related to:

- Overall satisfaction with the DP self-management program; and
- Perceptions and experiences of:
  - Self-management education and training including relationship with self-management personnel (including follow-up); and
  - Care and relationships (including follow-up) with HSPs.

The same dimensions were also explored in the community focus groups where a whole-of-population approach was being undertaken by the DP, in which the community experience was equivalent to that of the individual. This primarily affected the Indigenous DPs. For the other DPs, where a broader concept of community was of more relevance, the following dimension was explored:

- Perceptions and experiences of the DP self-management programs in the context of the wider community (for example, key groups or stakeholders which represent the views of a defined community).

For HSPs, perceptions/experiences of satisfaction with the DP self-management program were explored.

#### 3.3.1.2 Data collection

##### **Instrument**

In order to capture the dimensions of the NEF in a consistent way across the DPs, a focus group thematic guide was developed for each domain as part of the NEF see Appendix 5, Appendix 6, Appendix 7 and Appendix 8. As part of the MOU between the national evaluator, the DP and the local evaluators,

each focus group had to be conducted in accordance with the instructions as set out in the NEFs Data Collection Management Guide (see Appendix 4).

Whilst focus group participants could vary from one data measurement point to the next, their time exposure variable to the DP self-management program had to be the same, that is, participants had to have been exposed to the DP for the same amount of time i.e. from DP commencement (baseline). Given the practical difficulties that this would pose for the Community domain, this requirement did not apply to the community focus groups.

To obtain an understanding about who participated in the focus groups, de-identified demographic information was collected from each focus group participant prior to the commencement of each focus group.

The focus groups were undertaken by a combination of local evaluators and DP staff. This varied from DP to DP. The information presented in this report has been drawn from the baseline, middle and last Focus Group Reports, that were compiled by the local evaluators and DP staff.

### **Timing**

With the exception of the NT DP, the focus groups were undertaken at three points in time – baseline, middle and last – and the data collection periods spanned the same timeframes as for the process mapping. Due to the late commencement of the NT DP and the concern expressed by the DP that three measurement points would place undue burden on the communities, which included some very remote sites, only two data measurement points (baseline and last) were used.

#### *3.3.1.3 Data analysis*

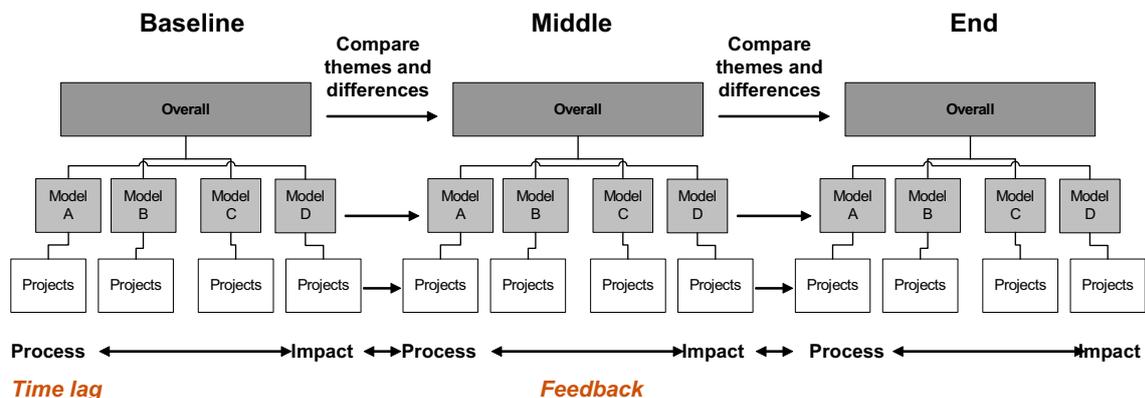
The focus group data were aggregated, analysed and compared as follows:

- At an overall level at one time period and over time;
- Between Process Model at one time period and over time; and
- Within DPs at one measurement point and over time.

An important consideration in the analysis was the time lag between process and impact. Given the medium term nature of impacts and the potential inter-relationship between process and impact, many of the observed impacts at the middle data measurement point, say, may be as a result of processes observed at baseline and in this sense the process/impact timeline is mutually propelling. So, the *impact* of the processes in place at the end of the DP self-management program will not be observed as part of the last focus group data collection. Nevertheless, the views expressed by participants at the middle data measurement point would have had an influence in shaping any change in process observed at this last data measurement point.

This approach taken to aggregating and analysing focus group data can be seen in Figure 5.

**Figure 5 Methods of aggregating and analysing focus group data**



The main focus of this report is the comparison and analysis of themes and difference across data collection measurement points at the *overall* level, since clearly distinguishable trends could not be identified at the Process Model level.

A DP by DP analysis has not been conducted because this is not the purpose or aim of this report.

### 3.3.2 Questionnaires

Two questionnaires were used to capture the impact dimensions of health behaviour and self-management attitudes, specifically:

- **CIQ:** smoking and drinking habits; and
- **CHQ:** coping with symptoms and self efficacy.

The approach taken for the development, collection and analysis of the questionnaires is set out in detail in Section 3.4.1 under Outcome Evaluation.

### 3.3.3 Key informant interviews

#### 3.3.3.1 Purpose

The aim of the key informant interviews was to consider organisational processes at a more *strategic* level with specific regards to the DPs' ability to build capacity within the network and sustain the DP self-management program beyond the life of the SHCI. To fulfil this role of providing strategic information, the interviewees were identified on the following basis:

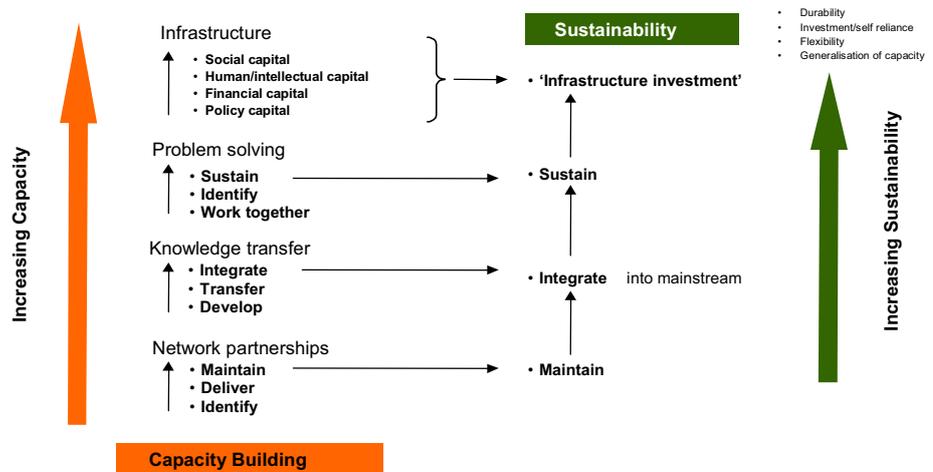
- That they played an active but high level role in the DP (for example, DP sponsor, member of the executive steering committee); and
- That they could also provide views on these core dimensions through their involvement in the wider health system/community.

### 3.3.3.2 Data collection

#### Instrument

The form and content of the key informant interviews were developed from the Community Capacity Index (CCI) (27), and the NSW Health Framework for Building Capacity to Improve Health (27). Figure 6 below outlines the main components of the key informant interview framework from which the interview tool was developed.

**Figure 6 Key components of the key informant interview framework**



The key informant interview framework looks at the two concepts of capacity building and sustainability for which organisational processes (examined during the process mapping visits, see Section 3.2.1) are the building blocks.

Capacity building is a component of the community domain. There are a number of definitions for capacity building but, for the key informant interviews the definition (28) outlined in the CCI was used: *‘development work that strengthens the ability of a network to build their structures, systems, people and skills so that they are better able to define and achieve their objectives and engage in consultation and planning, manage DPs and take part in partnerships and community enterprises’*.

In this conceptualisation, capacity building and sustainability are integrally linked and the four domains to capacity building and ultimate sustainability are:

- **Network Partnerships:** are relationships between groups and organisations within a community or Network. This includes both the comprehensiveness and the quality of the relationships.
- **Knowledge Transfer:** is the development, exchange and use of information within and between the groups and organisations within a Network or community.
- **Problem Solving:** is the ability of the groups and organisations within the DP or community itself to use well recognised methods to identify and solve problems that arise in the development and implementation of an activity or DP self-management program.
- **Infrastructure:** refers to the level of investment in the Network by the groups and organisations involved that make up the Network for the DP.

There is a *progressive* relationship within and between each of these capacities in achieving capacity building and sustainability. So, a strong infrastructure (as indicated, for example, by the network having a capacity to develop social capital) is likely to be the last piece in the capacity building jigsaw and the most important component for enabling sustainability.

### **The interviews**

In order to achieve an objective and consistent approach across all of the interviews, a consultant (independent to the national evaluation team) was nominated to carry out all of the interviews across the DPs for each data measurement point. Approximately three to four interviews were held for each DP, with each interview taking about one hour.

Appendix 9 sets out who was interviewed at each data measurement point.

The purpose of the key informant interviews was to obtain the individual perspectives of those in a position to provide a strategic view on the DPs progress both internally and in the context of the wider health system/community. Therefore, whilst it was not always possible to interview the same personnel at baseline, middle and last, the position of the key informants to the DPs was comparable. This maintained the level of focus and perspective of the key informant interviews over time.

### **Timing**

The key informant interviews were undertaken for each DP by the national evaluator within three months from the process mapping visit to match the three data measurement points - baseline, the middle and last.

### **Scoring**

Following each interview, the interviewee's responses were rated in accordance with a four point scale (1. Not all/very limited; 2. Somewhat; 3. Substantial; 4. Almost entirely/entirely), for each level of capacity. The definitions within each domain were developed from the generic ratings and levels of capacity outlined in the CCI (28). Appendix 10 outlines the capacity components, capacity indicators and rating system for each indicator.

To operationalise and provide a context to the above ratings, the definitions for each level were specified in terms which were of relevance to the DPs, whilst retaining the meaning and purpose of the original so that its continued robustness was ensured.

Finally, the completed ratings were calibrated through an inter-rater review process to ensure reliability of interpretation both within and across data measurement points. The results of the calibration indicated that the key informant interviews had been scored on a consistent basis.

#### *3.3.3.3 Data analysis*

The analysis began with the aggregation of the data by each DP for each capacity indicator of the key informant interview framework. The median was then taken to minimise the impact of outliers. The median rating indicated the relative achievement against each indicator, ranging from weaker (rating = 1) to stronger (rating = 4) with the expectation that as the DPs developed (as measured at each data collection), the ratings would increase, indicating increased capacity.

## 3.4 Outcome evaluation

The outcome evaluation measured how the DPs achieved their longer-term aims with regards to health and wellbeing outcomes as a result of DP self-management program implementation (15). The outcome evaluation was undertaken via a self report questionnaire method.

Given the substantial differences in the questionnaires developed for the Non-Indigenous and Indigenous DPs to measure the change in health outcomes, the approach taken for the Non-Indigenous (ACT, NSW, QLD, SA (excluding Pika Wiya), TAS, VIC, WA) and Indigenous (NT and Pika Wiya ) questionnaires is described separately below.

### 3.4.1 Questionnaires – Non-Indigenous Demonstration Projects

#### 3.4.1.1 Purpose

The purpose of the questionnaires was to capture, through self report, the change in the health and wellbeing status of clients participating in the DP self-management program. Three questionnaires were developed for this purpose:

- **CIQ:** which recorded the demographic nature of the cohort including their self reported disease status.
- **CHQ:** which recorded health behaviour and status measures based on the Stanford 2000 questionnaire.
- **CSUQ:** which recorded service use of HSPs by the cohort in the past six months.

#### 3.4.1.2 Data Collection

##### **Instrument**

##### ***Client Information Questionnaire***

The CIQ was developed for the purpose of understanding the demographic profile of the DPs participants, for example, social economic background and chronic condition status (both in terms of co-morbidities and severity). In particular, it sought to understand what if any, influence these factors may have had on health behaviours or outcomes at baseline and going forward.

The CIQ was primarily developed from established valid and reliable (see Box 3) items for which Australian normative data are available, as indicated in Table 14. The only aspect which was specifically customised for the

questionnaire was the questions around chronic condition co-morbidity and severity.

### Box 3 Definitions for Reliability and Validity<sup>i</sup>

**Reliability:** expresses the degree to which the same score is produced on repeated measures with a given instrument, in the absence of any real change.

**Validity:** expresses the degree to which the tool measures what it purports to measure.

**Table 14 CIQ indicators**

Demographic Indicator		Source
<p><b>Background:</b></p> <ul style="list-style-type: none"> <li>• Sex</li> <li>• Date of birth</li> <li>• Country of birth</li> <li>• Main Language spoken at home</li> <li>• Indigenous status</li> <li>• Marital status</li> <li>• Number of children</li> <li>• Education</li> <li>• Qualification</li> <li>• Current employment status</li> <li>• Occupation</li> </ul>	<ul style="list-style-type: none"> <li>• Prior occupation</li> <li>• Source of Income</li> <li>• Pensions, allowances, benefits</li> <li>• Living arrangements</li> <li>• Living setting</li> <li>• Carer involvement</li> <li>• Carer residence</li> <li>• Smoking</li> <li>• Alcohol consumption</li> <li>• Recruitment date</li> <li>• Postcode of residence</li> </ul>	<p>Relevant components from the:</p> <ul style="list-style-type: none"> <li>• National Health Survey 2001</li> <li>• 2001 Household Census</li> <li>NSW Health Survey 1997/1998</li> <li>• HACC Minimum Data Set 1998</li> <li>• National Health Data Dictionary</li> </ul> <p>(see Appendix 11 for more details on the development of these data sources)</p>
<p><b>Co-morbidity:</b> Chronic condition(s) and the number of years with condition.</p> <ul style="list-style-type: none"> <li>• Diabetes</li> <li>• Arthritis, osteoarthritis, or other joint/bone condition</li> <li>• Chronic respiratory/lung condition</li> </ul>	<ul style="list-style-type: none"> <li>• Cardiovascular disease</li> <li>• Renal disease</li> <li>• Depression</li> <li>• Osteoporosis</li> <li>• Other chronic condition</li> </ul>	<p>Customised design</p>
<p><b>Severity:</b> Condition which impacts most heavily on day-to-day activities</p>		

See Appendix 12 for the CIQ in full.

### *Client Health Questionnaire*

The CHQ was developed for the purpose of understanding the health behaviours and health status of participants, captured first at baseline and then again at specific points across the life of the DP self-management program. The instrument aimed to identify how participants' self reported health may have changed.

The CHQ was developed from the health impact and outcome dimensions identified in the NEF and the scales used to measure these dimensions were taken from established valid and reliable instruments as indicated in Table 15.

**Table 15 Client Health Questionnaire**

Impact/Outcome assessed	Indicator Scale	Data source
<ul style="list-style-type: none"> <li>Health behaviour:                             <ul style="list-style-type: none"> <li>Symptom control</li> <li>Self efficacy</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>Coping with Symptoms (7 items) – 1 item added (“other”)</li> <li>Confidence About Doing Things (6 items)</li> </ul>	<ul style="list-style-type: none"> <li>Modified components from Stanford 2000</li> <li>See Appendix 13 for a 1 page summary</li> </ul>
<ul style="list-style-type: none"> <li>Health status/Health - related Quality of life</li> </ul>	<ul style="list-style-type: none"> <li>General Health SF-1 (1 item)</li> <li>Health distress (4 items)</li> <li>Symptoms (3 items)</li> </ul>	
<ul style="list-style-type: none"> <li>Functional status</li> </ul>	<ul style="list-style-type: none"> <li>Physical Activities (6 items)</li> <li>Physical Abilities (8 items)</li> </ul>	
<ul style="list-style-type: none"> <li>Social functioning</li> </ul>	<ul style="list-style-type: none"> <li>How your illness affects your life (13 items)</li> </ul>	
<ul style="list-style-type: none"> <li>Psychological distress</li> </ul>	<ul style="list-style-type: none"> <li>Kessler 10 (10 items)</li> </ul>	<ul style="list-style-type: none"> <li>Kessler 10</li> <li>See Appendix 14 for a 1 page summary</li> </ul>
<ul style="list-style-type: none"> <li>Overall wellbeing</li> </ul>	<ul style="list-style-type: none"> <li>Satisfaction with Life scale (5 items)</li> </ul>	<ul style="list-style-type: none"> <li>Satisfaction with Life</li> <li>See Appendix 15 for a 1 page summary</li> </ul>

See Appendix 16 for the CHQ in full.

The extent of the modification made to the relevant components of the Stanford 2000 included in the CHQ was very minor. Except for the addition of an ‘other’ option to the ‘Coping with Symptoms’ scale (in response to feedback from the DPs), no other changes to scale construct were made. The only other changes made related to the amendment of words or phrases so that they would be more appropriate to the Australian context. In addition, the proposed modifications were discussed and agreed with Kate Lorig, prior to the finalisation of the questionnaire.

***Client Service Use Questionnaire***

The CSUQ was developed for the purpose of understanding to what extent service use amongst participants changed over the DP self-management program’s duration, the indicators of which are shown in Table 16.

**Table 16 Client Service Use Questionnaire**

Outcome assessed	Indicator	Instrument
<ul style="list-style-type: none"> <li>Use of services</li> </ul>	<ul style="list-style-type: none"> <li>In the past 6 months:                             <ul style="list-style-type: none"> <li>Visits to GP, specialist, practice or Community nurse and other HSPs</li> <li>Admissions to hospital</li> <li>Accident and Emergency attendance</li> </ul> </li> <li>Use of community services</li> <li>Member of Self help groups</li> </ul>	<ul style="list-style-type: none"> <li>Customised design developed from in part the Stanford 2000</li> </ul>

See Appendix 17 for the CSUQ in full.

The questionnaires were collected in accordance with the NEFs Data Collection Management Guide, see Appendix 4. Two DPs (NSW, TAS) scanned their questionnaire data and one DP (VIC) entered their data directly into a statistical package called Statistical Package for the Social Sciences (SPSS, Norisus, 1986), whilst the remaining four DPs used the Access database developed by the national evaluator.

### Timing

The reporting timeframe for the questionnaires is given in the following table.

**Table 17 Questionnaire data collection timetable**

Baseline	Six months	12 months	Last
<ul style="list-style-type: none"> <li>• CIQ</li> <li>• CHQ</li> <li>• CSUQ</li> </ul>	<ul style="list-style-type: none"> <li>• CHQ</li> <li>• CSUQ</li> </ul>	<ul style="list-style-type: none"> <li>• CSUQ</li> </ul>	<ul style="list-style-type: none"> <li>• CIQ</li> <li>• CHQ</li> <li>• CSUQ (excluded if end of DP was less than 18 months)</li> </ul>

The reporting timeframe for the questionnaires is detailed below:

- **CIQ:** captured at two points in time (baseline and last) given that on the whole, much of the information reported at baseline was unlikely to change significantly on a client by client basis.
- **CHQ:** three data measurement points (baseline, six months and Last). The six month data collection was expected to be the point at which most change would be observed, given that it was collected soon after the intervention, however, by measuring health status and behaviour at the last measurement point, it would be possible to see to what extent change had been sustained.
- **CSUQ:** collected at six monthly intervals since it was observed by Lorig that based on the Stanford experience, it was difficult for participants to remember their health service system use much beyond six months.

During the course of the evaluation, completion of the follow-up questionnaires did not always occur at the recommended measurement points. To manage this slippage, the ‘actual’ time difference (in days) between successive data measurement points was calculated and the data were then allocated into the most appropriate time window (baseline, middle and last). This process increased in complexity as the DP drew to a close since, depending on the time available to them, some DPs had completed three (baseline, six and twelve months) data collections, whilst others completed had four (baseline, six, twelve and eighteen months) data collections.

For the DPs that managed to submit both 12 and 18 month data for some clients, the dataset which fitted best to the 12 month time line was used in the analysis. Therefore, data referred to as the ‘last’ data measurement point was an aggregated dataset from both the 12 and 18 month data measurement

points. Table 18 outlines the timing of the data collections including mean follow-up and the associated range due to slippage.

**Table 18 Timing of follow-up**

Measurement point	Timing
Baseline	As soon as possible after date of recruitment
Middle	Mean: 195 days (range 93 to 279 days)
Last	Mean: 399 days (range 280 to 560 days)

### 3.4.1.3 Data analysis

Client data at each measurement point were converted to a format compatible with a standard statistical package (SPSS) and prepared for analysis.

The demographic, health outcome and service utilisation details were examined at three measurement points; baseline, middle (with mean point of six months) and last (with a mean point of 12 months). The numbers and characteristics of clients who were unable to be followed up were compared with those followed up to examine for a potential source of bias (Section 4.1.5).

Group differences for categorical variables were analysed using chi-square tests (group sizes permitting, Cochran's relaxed rule). The distributions of all quantitative outcome measures were tested for goodness of fit; skewness<sup>1</sup> and kurtosis<sup>2</sup> statistics were inspected. Skewness between 1 and 2 was deemed acceptable for parametric methods to be used in the analysis. Between group differences were analysed using Analysis of Covariance. A significance level of 0.001 was adopted to reflect the number of multiple comparisons and the large sample size.

Differences over time were analysed using a repeated measures Analysis of Covariance.

Medians and 95% confidence intervals were plotted using error bar graphs, to visually represent between group comparisons. Bar charts and pie diagrams have also been used to display frequency data between groups.

The final analysis of the quantitative data from the evaluation comprised a comparison of the selected outcome variables over three measurement points in time. More detail about the analysis undertaken for each subcomponent of the outcome evaluation for the non-Indigenous DPs is provided in Section 5.

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<sup>1</sup> A distribution that is symmetric around its mean has skewness zero, and is 'not skewed'. Skewness is calculated as  $E[(x-\mu)^3]/s^3$  where  $\mu$  is the mean and  $s$  is the standard deviation.

<sup>2</sup> Kurtosis describes 'peakedness'. Kurtosis is calculated as  $E[(x-\mu)^4]/s^4$  where  $\mu$  is the mean and  $s$  is the standard deviation.

### **3.4.2 Questionnaires – Indigenous Demonstration Projects**

#### *3.4.2.1 Purpose*

As for the non-Indigenous DPs, the purpose of the questionnaires for the Indigenous DPs was to capture, through self report, the change in the health and wellbeing status of clients participating in the DP self-management program.

#### *3.4.2.2 Data Collection*

##### **Instrument**

The Indigenous questionnaires were tailored to be culturally appropriate. Furthermore, this was the first time that self-management questionnaire data had been collected from Indigenous communities in Australia.

Pika Wiya amended the questionnaires in consultation with the national evaluator so that they reflected both local community needs whilst still being comparable to the non-Indigenous questionnaires in terms of the scales used and questions asked. The NT DP developed its questionnaires independently of the national evaluator, but which did reflect local community needs. As a consequence the NT data is not entirely comparable to the questionnaires used by Pika Wiya.

Given the minimal testing time available for the Indigenous survey instruments it is not known whether the results from these data are valid and/or reliable. Moreover, there are no available comparison data.

##### ***Client Information Questionnaire***

The dimensions for the CIQ which were agreed with Pika Wiya are set out in the following table.

**Table 19 Indigenous Client Information Questionnaire**

Indicator		Instrument
<b>Background:</b> <ul style="list-style-type: none"> <li>• Sex</li> <li>• Date of birth</li> <li>• Main Language spoken at home</li> <li>• Indigenous status</li> <li>• Marital status</li> <li>• Number of children</li> <li>• Education</li> <li>• Occupation</li> </ul>	<ul style="list-style-type: none"> <li>• Qualification</li> <li>• Prior occupation</li> <li>• Source of income (optional)</li> <li>• Living arrangements</li> <li>• Carer status</li> <li>• Smoking</li> <li>• Alcohol consumption</li> <li>• Recruitment date</li> <li>• Postcode of residence</li> </ul>	<ul style="list-style-type: none"> <li>• Modified CIQ</li> </ul>
<b>Co-morbidity:</b> Chronic condition(s) and the number of years with condition: <ul style="list-style-type: none"> <li>• Diabetes</li> <li>• Arthritis or other joint/bone condition</li> <li>• Chronic respiratory/lung condition</li> </ul>	<ul style="list-style-type: none"> <li>• Cardiovascular disease</li> <li>• Renal disease</li> <li>• Depression</li> <li>• Osteoporosis</li> <li>• Other chronic condition</li> </ul>	
<b>Severity:</b> Condition which impacts most heavily on day-to-day activities		

The NT DP made the following changes to their CIQ:

- Change to the wording for a number of questions to be more culturally appropriate;
- Fewer response options for a number of questions;
- A ‘chewing tobacco’ question was added; and
- One alcohol question was dropped from the NT CIQ.

For details on the Indigenous CIQ, see Appendix 18 for Pika Wiya and Appendix 19 for the NT questionnaires.

***Client Health Questionnaire***

The dimensions for the CHQ which were agreed with Pika Wiya are set out in Table 20.

**Table 20 Indigenous Client Health Questionnaire**

Outcome indicator assessed	Scale	Instrument
• Behaviour: self-efficacy	• Confidence about doing things (6 items)	• Modified CHQ
• Health status/Health related Quality of life	• General health (3 items) • Symptoms (7 items)	
• Functional status	• Physical activities (6 items) • Physical abilities (8 items)	
• Social functioning	• How your illness affects your life (10 items)	

The NT DP made the following subsequent changes to their CHQ:

- Different wording of all questions to be more culturally appropriate;
- Fewer response options and/or scale numbering for all questions, including changing the number of levels for the visual analogue scales;
- Removal of the disability scale; and
- Removal of some questions within scales.

For details on the Indigenous CHQ see Appendix 20 for Pika Wiya and Appendix 21 for NT.

***Client Service Use Questionnaire***

The dimensions for the CSUQ which were agreed with Pika Wiya are set out in Table 21.

**Table 21 Indigenous Client Service Use Questionnaire**

Outcome indicator assessed	Indicator	Instrument
• Use of services	<ul style="list-style-type: none"> <li>• In the past 1 month:               <ul style="list-style-type: none"> <li>- Visits to GP, specialist, practice or Community nurse and other HSPs</li> </ul> </li> <li>• In the past 6 months:               <ul style="list-style-type: none"> <li>- Admissions to hospital</li> <li>- Accident and Emergency attendance</li> </ul> </li> <li>• Use of community services</li> <li>• Member of self help groups</li> </ul>	• Modified CSUQ

The NT DP made the following subsequent changes to their CSUQ:

- Different wording for some questions to be more culturally appropriate;
- Removal of some questions; and
- Fewer response options for some questions.

For details on the Indigenous CSUQ, see Appendix 22 for Pika Wiya and Appendix 23 for the NT questionnaires.

These variations in the questionnaires have impacted upon the analysis of the impact and outcome evaluations (see Section 5.5). It is also unknown about how these variations could have impacted upon the way the questionnaires were interpreted by the participants of the Indigenous DPs.

The questionnaires were collected in accordance with the NEFs Data Collection Management Guide, see Appendix 4. The Pika Wiya and NT DPs used tailored databases developed by the national evaluator for data entry.

### Timing

The planned reporting timeframe for the questionnaires is given in the following table.

**Table 22 Questionnaire data collection timetable**

Baseline	Six months	12 months	Last
<ul style="list-style-type: none"> <li>• CIQ</li> <li>• CHQ</li> <li>• CSUQ</li> </ul>	<ul style="list-style-type: none"> <li>• CHQ</li> <li>• CSUQ</li> </ul>	<ul style="list-style-type: none"> <li>• CSUQ</li> </ul>	<ul style="list-style-type: none"> <li>• CIQ</li> <li>• CHQ</li> <li>• CSUQ (excluded if end of DP was less than 18 months)</li> </ul>

The issue of slippage in follow-up data collection also arose for the Indigenous DPs, so the measurement points for completion were calculated to match the non-Indigenous data with the analysis focusing on three measurement points – baseline, middle and last. Baseline data was collected as soon as possible after date of recruitment. Middle data was collected approximately six months (actual mean: 195 days, range 93 to 279 days) after baseline. Data referred to as the ‘last’ measurement point was collected at an actual mean time between baseline and last follow-up of 399 days (range: 280 to 560 days).

#### 3.4.2.3 Analysis

It is important to recognise that this is the first time that self-management questionnaire data have been collected from Indigenous communities in Australia, therefore with minimal testing of the survey instrument; it is not known whether the results from these data will be valid and/or reliable.

Also, the substantial variation between the two sets of Indigenous questionnaires has had a considerable impact on the extent of analysis that can be undertaken at an aggregated national level. In particular, only a limited number of questions can now be directly compared either nationally or against international findings.

To at least in part address the comparability of the two sets of Indigenous questionnaires, the CHQ individual scale items were put into broader

groupings or merged (for example, 'Low', 'Medium', 'High'), to produce common categories. The impact of this strategy on scale validity is unknown, but it does offer the opportunity of at least broadly descriptive summary and comparison with the wider non-Indigenous cohort.

The results presented in this report relate to demographic characteristics, and some indicative health status and behaviour information. Data are summarised in either table form or as a series of cross-tabulations with chi-squared tests, where appropriate. The use of statistical tests was limited due to the small sample sizes. Categorical data at each measurement point are displayed visually using either bar charts or pie diagrams.

Spearman's correlation co-efficient was used to examine relationships between the health status and behaviour variables at baseline. Comparisons were made between baseline and middle measurement points and baseline and last measurement points. Analysis across three measurement points was not possible due to the small sample size (n=36). Significant differences were reported using a non-parametric Wilcoxon's Matched Pairs Signed ranks test.

### **3.4.3 Intervention Schedule**

#### *3.4.3.1 Purpose*

Due to the variation which was observed across and within the care-related Process Models described in the overall process maps, it became necessary to identify which interventions clients had actually received as recognised at the National Evaluation Workshop (22 April 2004). To a lesser extent, but responding to DP interest, the Intervention Schedule also enabled DPs to record the reason for drop-out from the evaluation (and DP self-management program).

#### *3.4.3.2 Data collection*

##### **Instrument**

In order for the DPs to identify the range of interventions their clients received, the national evaluator developed an Excel spreadsheet based on the processes identified from the process mapping visits. To increase the accuracy of the information received, the spreadsheet was tailored for each DP. The list of possible intervention components was as follows:

- Self-management/action plan;
- EPC Care Plan;
- EPC Care Plan follow-up;
- Stanford<sup>3</sup> training;
- Stanford group or Stanford one-on-one;
- Other education and training;

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<sup>3</sup> Chronic Disease Self-management (CDSM) course developed by Stanford University ('Stanford Model')

- Non EPC Care Plan;
- Support from DP provided; and
- Non EPC Care Plan follow-up.

The list of clients for which information was requested, was taken from the client identification numbers received for baseline by the national evaluator. A positive by-product of this process therefore was that it also provided a completeness check for the National Evaluation data with the DPs baseline data. See Appendix 24 for the Intervention Schedule proforma.

The Intervention Schedule was sent to the DPs in May 2004, together with comprehensive instructions for completion which included a list of definitions (obtained from the process mapping data collection) for each of the interventions to ensure clients were categorised in a standard way across all of the DPs.

Intervention Schedules were completed and returned to the national evaluator for seven out of the eight DPs. The NT DP did not return the Intervention Schedule to the national evaluator; therefore it has not been possible to use the intervention information as part of the analysis for the Indigenous DPs.

### **Timing**

As indicated above, the information for the Intervention Schedule was collected at the end of the SHCI when the DPs had complete knowledge about which interventions all their clients had received.

#### *3.4.3.3 Analysis*

From the information contained in the Intervention Schedule, it was possible to group the interventions into three main activities: Planning, Training and Support. From this, four new '*Intervention Models*' (Intervention Models 1, 2, 3 and 4) emerged. These were based on the level of participation in each of these key interventions as detailed in Table 23.

**Table 23 Intervention Model Groupings**

<b>Intervention Model</b>	<b>Characteristics<sup>4</sup></b>
<b>1</b> 'Predominantly Stanford'	<ul style="list-style-type: none"> <li>• No planning</li> <li>• 94% training (69% Stanford Model)</li> <li>• No support</li> </ul>
<b>2</b> 'Complete suite of interventions'	<ul style="list-style-type: none"> <li>• 98% planning</li> <li>• 94% training (60% Stanford Model)</li> <li>• 95% support</li> </ul>
<b>3</b> 'Generic'	<ul style="list-style-type: none"> <li>• 50% planning</li> <li>• 55% training (20% Stanford Model)</li> <li>• 83% support</li> </ul>
<b>4</b> 'Telephone coaching'	<ul style="list-style-type: none"> <li>• 99% planning</li> <li>• 92% training (0% Stanford Model)</li> <li>• 97% support</li> </ul>

These groupings were then used to progress the analysis (see Section 4.5.2). In particular, these groupings offered the opportunity to examine changes in health behaviour and service use over time taking the type of intervention or Intervention model into consideration.

### **Attrition**

Whilst the information on interventions received was completed to a satisfactory standard by all of the DPs who returned the Intervention Schedule, the information on attrition was less complete. Therefore, its primary purpose has been to provide additional qualitative support to the observations made as part of the process mapping and project report analysis.

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<sup>4</sup> The percentages refer to the proportion of participants in an Intervention Model who received a particular intervention