A national minimum data set for Home and Community Care

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AGED CARE SERIES

A national minimum data set for Home and Community Care

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Canberra

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Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
AIHW	Australian Institute of Health and Welfare
CIARR	Client Information and Referral Record
CNMDSA	*Community Nursing Minimum Data Set Australia*
CSDA	Commonwealth/State Disability Agreement
HACC	Home and Community Care
HACCSERV	HACC Service Provision data collection
HACCUSER	HACC User Characteristics data collection
IPPs	Information Privacy Principles
MDS	Minimum Data Set
NCCS	*National Classifications of Community Services*
NCSDC	National Community Services Data Committee
NCSIMG	National Community Services Information Management Group
NMDS	National Minimum Data Set

1 Introduction

1.1 Background

In February 1997, Commonwealth and State/Territory government officials responsible for the Home and Community Care Program (HACC Officials) commissioned the Australian Institute of Health and Welfare (the Institute) to undertake developmental work on a national HACC Minimum Data Set. The Home and Community Care (HACC) Program assists frail older people, younger people with disabilities, and their carers by providing support and assistance to those living at home or in the community. It aims to prevent premature or inappropriate institutionalisation, by providing appropriate home- and community-based services. The HACC program is jointly funded by the Commonwealth and State and Territory Governments.

The need for a review of HACC data requirements arose in response to several developments. The program had grown rapidly since its inception in 1985, with expenditure in 1995–96 two and a half times greater than it was in 1985–86 in real terms (AIHW 1995, 1997). There were a number of changes in the administration of the HACC program over recent years, and in the broader policy environment in which the program operates. In addition, various reviews and reports had pointed to the need for better data in the HACC program.[*] HACC Officials agreed that improvements in the quality and reliability of HACC data were necessary to ensure program accountability and to assist with planning and monitoring of the program.

The existing data collections (the HACC Service Provision collection, the HACC User Characteristics collection and the Community Options Project collections) had provided much needed data on home-based care over the last decade. They suffered, however, from some major limitations which increasingly impinged on the policy appraisal and planning processes as home-based care became a larger and more central part of the national aged care service system. Most importantly, these data do not provide comprehensive answers to questions such as:

- How many people receive HACC services?
- How much HACC service is provided in a particular region?
- What ‘package’ of care does an ‘average’ HACC client receive?
- What is the dependency profile of the HACC client population?
- What does it cost to support a ‘high dependency’ HACC client?

The proposed new national database for HACC was intended to make it possible to answer such questions, and to this end HACC Officials emphasised that the new MDS should be client-centred and have an outputs/outcomes focus rather than a focus on processes or inputs. The development of such a database was made difficult, however, by the nature of

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[*] *The Efficiency and Effectiveness Review of the Home and Community Care Program: Final Report* (DHSH 1995), *Home But Not Alone* (House of Representatives Standing Committee on Community Affairs 1994), and *Everyone's Future* (H&CS 1993).

the HACC program itself. While jointly funded by the Commonwealth and State/Territory Governments, the program is managed at the State/Territory level. There are approximately 4,000 service delivery outlets across Australia, some of which are part of a large organisation such as Home Care in New South Wales or Silver Chain in Western Australia, while others are small stand-alone agencies staffed by only one or two persons. The agencies provide a wide range of services, including home help, community nursing, allied health care, delivered meals, transport, personal care, respite care, centre day care, home maintenance, home modification, social support, information, advocacy, formal linen services, training and development. Clients can, and often do, access services from more than one agency in the same episode of care. Usage of computers and computer-based data systems varied from the sophisticated to the non-existent. Taken together, these factors constituted some serious difficulties to be overcome in developing a new MDS capable of providing the required information for policy appraisal, accountability and planning purposes.

1.2 The HACC MDS Project

The first major step toward developing a new national database for the HACC program was a consultancy to review data requirements undertaken by Brian Elton & Associates in 1995–96. That project generated a draft set of HACC Minimum Data Set (MDS) items. Further information on that process is available in the *National Review of HACC Data Requirements Final Report: Future Directions* (Brian Elton & Associates 1996). The draft items identified in that report provided the starting point for the work described in the present report.

The Institute commenced further developmental work on the HACC MDS in 1997. The HACC MDS Project was overseen and assisted by a National Steering Committee comprised of HACC Officials (or their representatives) and HACC service provider representatives (a list of Steering Committee members is provided at Appendix A). The project involved:

- reviewing and developing data elements for inclusion within the HACC MDS;
- undertaking comparisons with other relevant collections;
- field testing the proposed data elements;
- the production of a HACC data dictionary;
- recommendations for a linkage key for statistical purposes; and
- recommendations for implementing the HACC MDS collection.

Over the course of the HACC MDS consultancy, the Project Team prepared a range of detailed reports and documents for the consideration of the Steering Committee and the purposes of field testing.

Interim documents and reports included:

- Preliminary Project Report (March 1997)
- Progress Report I (May 1997)
- Progress Report II (August 1997)
- Service Activity Types Discussion Paper (October 1997)
- Carers Discussion Paper (November 1997)
- Field Test II Consultation Document (January 1998)
- Linkage Key Report (February 1998)

- Draft *HACC Data Dictionary* Version 0.5 (February 1998)
- Draft *HACC Data Dictionary* Version 1.0 (March 1998).

The final products of the consultancy were the *HACC Data Dictionary* Version 1.0 (May 1998) and the *Final Report: HACC Minimum Data Set Project* (June 1998).

The *HACC Data Dictionary* Version 1.0 was completed and approved by HACC Officials in May 1998. The *HACC Data Dictionary* is intended to provide the basis for the new national HACC data collection. This data collection would replace the existing HACC Service Provision, HACC User Characteristics and Community Options Project collections.

The final report of the project documented and summarised key components of work undertaken for the project but not contained within the *Data Dictionary*. These included the process of developing and field testing the minimum data set elements, the drafting of the *Data Dictionary*, comparisons of the MDS items with other relevant data collections, testing a linkage key for statistical purposes in the new HACC data collection and recommendations for its implementation, and recommendations for implementing the HACC MDS and for future development.

The present report, published in the Aged Care Series by the Australian Institute of Health and Welfare, is a modified version of the final project report. Essentially, the main body of the report is retained, while the more technical and detailed material included in appendices has been removed. This report was produced in order to provide an accessible summary account of the project for dissemination to a wider audience.

1.3 Context

This work on the HACC MDS was undertaken in the context of a number of other relevant developments in both the community services field more generally, and the HACC program more specifically. Wherever possible, these related activities were taken into account, in order to promote uniformity and consistency of data elements, and to reduce duplication of effort by different players in the community services information field. The HACC MDS Project Team benefited from the work and expertise of others involved in these related areas, and we are grateful for their contributions (both direct and indirect). Concurrent work on other projects also led to some changes in the HACC MDS Project work program at the direction of the Steering Committee. Of particular importance here (and discussed later in this report) was the decision to stop MDS work in the area of dependency pending the results of the Community Care Classification Project (Hindle 1998) and work on the *National Framework for Comprehensive Assessment in the HACC program* (Lincoln Gerontology Centre 1998).

Developments in national community services information

Over the past year, there have been significant developments in the field of community services information development. National community services information refers to community services data that is collected on, or aggregated to, a national level, and that has either national coverage, or national relevance for planning, policy making and policy analysis. The HACC MDS falls within this definition.

Throughout the HACC MDS Project, careful attention has been paid to concurrent national developments in community services information. Consistency with national standards for data definitions (wherever possible) was recognised, from the outset, as an important goal of the HACC

MDS Project. The HACC MDS Project has proceeded within the context of these developments and has both contributed to, and reflected the outcomes of, these processes.

The key elements of these recent national developments were the signing of the National Community Services Information Agreement, the establishment of the National Community Services Data Committee, the development of the *National Community Services Data Dictionary*, and the development of the National Community Services Information Model.

National Community Services Information Agreement

The National Community Services Information Agreement was developed during 1995–96 and came into effect as of March 1997. The purpose of the Agreement, and its associated committee structure, is to promote the development of nationally consistent high quality data concerning Australia's community services. It does this through seeking to develop consistent data definitions and data elements for use in national, State/Territory and non-government collections on community services.

National Community Services Data Committee

In February 1997, the National Community Services Data Committee (NCSDC) was established under the auspices of the National Community Services Information Management Group (NCSIMG). Membership of the NCSIMG includes representatives of all signatories of the National Community Services Information Agreement, including Commonwealth and State/Territory Government departments responsible for community services, the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. Representatives of several peak community services organisations were also invited to participate as members of the Committee.

National Community Services Data Dictionary

The National Community Services Data Committee was established primarily to develop and maintain the *National Community Services Data Dictionary* and relevant minimum data sets in all areas of community services. The NCSDC has a coordinating role to ensure national consistency in data definitions and standards in quality control. Every effort has been made to ensure compatibility between the data elements included in the *HACC Data Dictionary* Version 1.0 (Commonwealth and State/Territory HACC Officials 1998) and those of the *National Community Services Data Dictionary* Version 1.0 (AIHW 1998b). HACC Officials have proposed that data items in the HACC MDS be assessed for inclusion in the *National Community Services Data Dictionary*.

National Community Services Information Model

During 1997, the Australian Institute of Health and Welfare (including members of the HACC MDS Project Team), in consultation with a working group of the NCSDC, developed the National Community Services Information Model Version 1.0. This information model has been used as the organisational framework for the *National Community Services Data Dictionary* Version 1.0 (AIHW 1998b) and for the *HACC Data Dictionary* Version 1.0 (Commonwealth and State/Territory HACC Officials 1998). The *National Health Data Dictionary* Version 7.0 (AIHW 1998c) follows the lead of the community services work in this respect, having been reorganised to use the National Health Information Model as the organising principle for data definitions.

Related data developments in HACC

The HACC MDS Project has been undertaken in the context of other significant developmental activities in the HACC program which have influenced, and are likely to continue to influence, the HACC MDS in various ways.

The HACC Officials Assessment Working Group

Throughout 1997 and 1998 the HACC Officials Assessment Working Group has been developing new processes and structures for the assessment of clients in the HACC program. One key element in this work was the completion of a consultancy by staff of the Lincoln Gerontology Centre on the development of a national framework for comprehensive assessment in the HACC program (Lincoln Gerontology Centre 1998). The significance of this work was such that the National Steering Committee of the HACC MDS Project decided to suspend developmental work being undertaken by the Project Team on data elements specifically related to a client's need for assistance or level of dependency for the course of the HACC MDS Project. This delay does not in any way deny the importance of these data elements in the HACC MDS. Indeed, further work to develop dependency measures for inclusion in the HACC MDS is presently under consideration by HACC Officials.

The outcome of this and other work being undertaken by the HACC Officials Assessment Working Group (including the redevelopment of the Client Information and Referral Record) is likely to have a significant impact on information to be included in subsequent versions of the HACC MDS. However, the timeframe for the introduction of the new assessment processes and structures did not allow for the development of relevant data elements for inclusion in the *HACC Data Dictionary* Version 1.0. The development of these data elements is identified as a priority area of work for Version 2.0 of the HACC MDS.

Community care classification

In the latter half of 1997, HACC Officials commissioned a consultant to develop and make recommendations on the implementation of a community care classification scheme for the HACC program (Hindle 1998). The introduction of such a scheme would be likely to have major implications for the HACC MDS collection. The development of dependency and assessment data elements (as discussed above) is also of great significance to future work on a client classification scheme in the HACC program. Although no decision has been made on the implementation of a community care classification scheme, future versions of the HACC MDS will need to take into account any requirements associated with the introduction of a community care classification.

Community Nursing Minimum Data Set Australia

During 1996 and 1997, Version 2.0 of the *Community Nursing Minimum Data Set Australia* (CNMDSA) was completed with the assistance of funding by the Commonwealth Department of Health and Family Services (ACCNS 1997). Members of the HACC MDS Project Team have worked closely with those responsible for the development of the CNMDSA Version 2.0 to ensure consistency between these two closely related data sets. (Chapter 5 of this report includes information on mapping between the HACC MDS and the CNMDSA.)

HACC MDS Technology Project

In 1998, HACC Officials plan to let a consultancy to investigate and make recommendations on the technology aspects of the implementation of the HACC MDS.* The collection, reporting and transfer of the information contained in the HACC MDS will be greatly assisted by the use of computerised information systems. Although many HACC agencies do not have computerised information systems, or do not make extensive use of the computer technology that they do have, the HACC MDS anticipates the growing use of such technology across the HACC field. The results of the forthcoming HACC technology project are likely to have a major influence over the implementation of the new HACC data collection.

1.4 Objectives and scope of the HACC MDS

Objectives of the HACC MDS

The objectives of the HACC MDS as set forth by HACC Officials are to:

- provide HACC program managers with a tool to access data required for policy development, strategic planning and performance monitoring against agreed output/outcome criteria;
- assist HACC service providers to provide high quality services to their clients by facilitating improvements in the internal management of HACC-funded service delivery; and
- facilitate consistency and comparability between HACC data and other aged, community care and health data collections.

Scope of the HACC MDS (Version 1.0)

Version 1.0 of the HACC MDS is a client-centred data set that focuses on information about the clients of HACC-funded agencies and the assistance they receive from the HACC program. Version 1.0 encompasses what is considered by HACC program managers to be the minimum management information requirements relating to the:

- characteristics of clients (e.g. sex, age);
- circumstances of clients (e.g. carer availability, residential location); and
- assistance received by clients from the HACC program (e.g. the amount and type of assistance received).

The scope of the HACC MDS was, to a considerable extent, determined by the requirement that the future HACC MDS national data collection replace the existing HACC Service Provision, HACC User Characteristics and Community Options data collections. Thus, the MDS needed to encompass information about the characteristics and circumstances of individual clients (previously collected through HACC USER) and information about service provision (previously collected by the HACC Service Provision collection). It was

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* Previous consultancies have canvassed some of these issues (see Brian Elton & Associates 1996; Hindle 1998).

also to accommodate information about clients and services in Community Options Projects (also known as Linkages or Options Co-ordination).

Given the scope of the HACC MDS, there are two factors that exerted significant influence over the content and structure of the MDS. Firstly, the HACC MDS was to be based on individual client unit record files. Secondly, the HACC MDS data collection was to be based on 100% coverage of HACC clients (rather than a sample of clients or agencies) and on data which is to be collected by agencies on an ongoing basis (that is, a rolling collection period rather than on a sample time period).

These two factors were considered by HACC program managers as essential to achieving improvements in the quality, reliability and usefulness of HACC data. To some extent, they also reflected the concern of HACC service providers that previous HACC data collections did not adequately represent the full extent of their activities or their client base (see Brian Elton & Associates 1996). Project staff have been mindful of these two aspects of the future HACC MDS collection when developing and testing data elements. The acceptability or otherwise of the HACC MDS to service providers involved in field testing was often related to these aspects of the collection rather than the data elements themselves. These and other related issues are discussed in further detail in Chapters 3 and 4.

Finally, it should be noted that while the HACC MDS is an important component contributing to program planning, monitoring and evaluation, it is nonetheless only one of several mechanisms intended to provide information for these purposes. Thus, the HACC MDS is not designed to capture all possible information about the HACC program. Other mechanisms which contribute to program planning and accountability include financial accountability measures (such as audited financial statements), quality assurance measures (such as the application of the HACC Service Standards Instrument), and the Service Provision Planning Framework.

2 The HACC Minimum Data Set

After a three-year process of consultation and data development, the HACC Minimum Data Set was endorsed by HACC Officials in May 1998 for implementation across the HACC program. The data elements which form the HACC MDS are listed in Table 2.1.

The HACC MDS comprises a set of data elements which are to be collected by HACC agencies on an ongoing basis and which are to be reported nationally as part of the overall data collection strategy being pursued within the HACC program. The HACC MDS collection is a client-centred data collection, designed to support program management and planning by supplying basic information about HACC clients and the services they receive. The HACC MDS is also intended to assist service providers in monitoring service provision and in meeting program reporting requirements.

The original specifications for the HACC MDS emerged from the *National Review of HACC Data Requirements* undertaken by Brian Elton & Associates in 1995–96. This review entailed wide-ranging consultations with service providers, peak organisations, government officials, and other key stakeholders in all States and Territories. It recommended a draft set of 23 data items for inclusion within the proposed HACC MDS, broadly relating to client details, client need and dependency, and client service receipt and outcomes (Brian Elton & Associates 1996). At the completion of this first phase of the HACC MDS development, broad agreement had been reached by the relevant stakeholders about which data items were to be included in the MDS; there remained, however, substantial work to be undertaken in testing and refining the proposed data items into a comprehensive and viable basis for a national data collection.

The Australian Institute of Health and Welfare commenced this further developmental work on the HACC MDS in 1997. The work was overseen and assisted by a National Steering Committee comprising HACC Officials (or their representatives) and HACC service providers. Members of the Steering Committee performed an invaluable role in reviewing the data development process, providing feedback, engaging in information gathering and consultation in their relevant jurisdictions, and setting directions for the project as a whole.

Refining the HACC MDS involved a range of data development strategies. The Project Team assessed the viability, clarity and comprehensiveness of proposed data elements, and identified areas requiring particular attention. Data modelling techniques were used to assess the internal logic of the minimum data set and to clarify some of the vexing issues associated with the proposed collection. In drafting the data elements, extensive use was made of international standards for the specification of data elements. Data elements were mapped across different data sets and data collection standards with a view to maximising consistency across collections wherever practicable. Detailed attention was also given to 'problem areas' such as service utilisation, the position of carers within the HACC MDS, and the capacity of the collection to accommodate service episodes.

Two rounds of field testing were undertaken during the course of the project, in July 1997 and January 1998. The first round of field tests involved in-depth consultations with a range of HACC agencies in the Australian Capital Territory and northern New South Wales, while the second round included HACC agencies in most States and Territories.

Table 2.1: The HACC MDS

Data element	Definition
Accommodation setting	The setting in which the person lives.
Accommodation setting after cessation of services	The setting in which the person resides immediately after they cease to receive services from the agency.
Amount of assistance received (cost)	The amount of assistance received by the person on a HACC service event (measured by cost).
Amount of assistance received (quantity)	The amount of assistance received by the person on a HACC service event (measured by quantity).
Amount of assistance received (time)	The amount of assistance received by the person on a HACC service event (measured by time).
Assistance with goods and equipment received	The goods or equipment provided to the person (by purchase or loan) on a HACC service event.
Area of residence	The geographic location of the person's residence.
Carer availability	Whether someone, such as a family member, friend or neighbour, has been identified as providing regular and sustained care and assistance to the person without payment other than a pension or benefit.
Carer residency status	Whether or not the carer lives with the person for whom they care.
Country of birth	The country in which the person was born.
Date of birth	The date of birth of the person.
Date of entry into HACC service episode	The date on which a period of delivery of HACC-funded assistance to the person begins.
Date of exit from HACC service episode	The date on which a period of delivery of HACC-funded assistance to the person ends.
Date of last assessment	The last date on which the agency undertook an assessment of the person.
Date of receipt of assistance	The date on which the person receives assistance from the agency.
Family name/surname	The name a person has in common with other members of her/his family, as distinguished from her/his first name.
First given name	The person's first name that precedes the family name/surname.
Funding source category	The source of funding for the delivery of assistance to the person.
Government pension/benefit status	Whether or not the person is in receipt of an income support payment from the Commonwealth Government in the form of a government pension or benefit.
Indigenous status	Whether or not the person identifies themselves as being of Aboriginal and/or Torres Strait Islander origin.
Letters of name	A specific combination of letters selected from the person's family name/surname and their first given name to assist with record linkage.
Living arrangements	Whether the person lives with other related or unrelated persons.
Main language spoken at home	The language reported by the person as the main language spoken by the person in his or her home (or most recent private residential setting) on a regular basis, to communicate with other residents of his or her home and regular visitors.
Main reason for cessation of services	The main reason that the person ceased to receive services from the agency.
Postcode	The postal code for the geographic location of the person's residence.
Primary type of assistance received	The primary type of assistance that the person receives from the agency during a service delivery event.
Reason for HACC client status	The reason why the person receives HACC-funded assistance from the agency.
Relationship of carer to care recipient	The relationship of the carer to the person for whom they care.
Service delivery setting	The setting in which the person receives assistance from the agency on a service delivery event.
Sex	The biological sex of the person.
Source of referral	The individual or organisation that referred the person to the agency.
Suburb/town/locality name	The name of the geographic area in which the person lives.
Total amount of type of assistance received (cost)	The total amount of each type of assistance received by the person from the agency during the reporting period (measured by cost).
Total amount of type of assistance received (quantity)	The total amount of each type of assistance received by the person from the agency during the reporting period (measured by quantity).
Total amount of type of assistance received (time)	The total amount of each type of assistance received by the person from the agency during the reporting period (measured by time).
Total assistance with goods and equipment received	The goods and equipment provided (by purchase or loan) to the person by a HACC agency during a reporting period.

Field testing the minimum data set served two key functions: firstly, to consult with agencies about successive changes to the HACC MDS and to assess the clarity, utility and collectability of the proposed data elements; secondly, to canvass focused sets of issues with agencies, such as those pertaining to data linkage, the general structure of the HACC MDS, and the development of appropriate guidelines and counting rules for the collection.

As part of the project brief, the Institute also investigated options for the use of a statistical linkage key within the HACC program. This involved testing a range of candidate linkage keys, and making recommendations for the specification of a unique linkage key that would not identify individuals but would enable statistical linkage across the HACC program.

Drawing on the insights of each of these phases of data development, the Project Team finalised the HACC MDS and drafted the *HACC Data Dictionary* Version 1.0, both of which were approved by HACC Officials in May 1998. Data elements in the *HACC Data Dictionary* are specified in a format based on international standards, using the template devised by the Institute for use in the *National Health Data Dictionary* and the *National Community Services Data Dictionary*. An example of one of the data elements specified in this format is provided in Box 2.1.

Full details of the data elements which comprise the HACC MDS can be found in the *HACC Data Dictionary* Version 1.0. This can be obtained by contacting the government department(s) responsible for the administration of the HACC program in each State and Territory. Alternatively, the full text of the *HACC Data Dictionary* Version 1.0 is also accessible via the 'Publications' button on the Australian Institute of Health and Welfare's Internet web site (http://www.aihw.gov.au).

The remainder of this report documents the process of developing and refining the HACC MDS to its final stage. This report also documents the testing of the statistical linkage key, and the recommendations made by the Project Team regarding the implementation of a statistical linkage key within the HACC program.

Box 2.1: Fully specified data element from the *HACC Data Dictionary* Version 1.0

Sex [3.1.1–2]

Admin. status: TRIAL ***Date***: 01/07/1998

Reporting status: SUPPORTING AND REPORTING DATA REQUIREMENT

Identifying and definitional attributes

Data element type: DATA ELEMENT

Definition: The biological sex of the person.

Context: The sex of the person is required for demographic analyses of clients' patterns of service utilisation in the HACC program. The sex of the person is also used in conjunction with the person's Letters of Name and Date of Birth for record linkage purposes.

Relational and representational attributes

Datatype: Numeric ***Representational form:*** Code

Field size: ***Min.*** 1 ***Max.*** 1 ***Representational layout:*** N

Data domain:

1 Male

2 Female

9 Not stated/inadequately described

Guide for use: Coding for this data element is based on the biological distinction between male and female. Where uncertainty exists about the sex of the person (e.g. for transvestites or transsexuals) the sex to be recorded is to be based on the sex nominated by the person themselves or on the observations/judgement of the interviewer. Although this may lead to some error, it is considered preferable to any offence that may be caused by a question that suggests that there is some doubt about the person's sex or sexuality.

Coding option 9 should only be used when the person has not provided this information upon request and/or the service provider is unable to make an informed judgement about the person's sex.

Verification rules:

Collection methods: This data element should be recorded for all HACC clients.

Reporting requirements: This data element is required for reporting in the HACC MDS collection. Agencies are required to report Sex for all HACC clients for whom the agency submits a HACC MDS record.

If the agency's system or records do not provide sufficient information to accurately report on this data element, the agency should use code *9 Not stated/inadequately described.*

Related data: Is used in conjunction with the data elements Letters of Name and Date of Birth

Is related to the data element concept Record Linkage.

Box 2.1 (continued): Fully specified data element from the *HACC Data Dictionary* Version 1.0

Administrative attributes

Source document:	Australian Bureau of Statistics: A directory of concepts and standards for social, labour and demographic statistics, 1995. National Community Services Data Dictionary Version 1.0, 1998.
Source organisation:	Australian Bureau of Statistics. National Community Services Data Committee.

Comments:

The Australian Bureau of Statistics advises that the correct term for this data element is 'sex'. The term 'sex' refers to the biological distinction between males and females. The term 'gender' refers to the socially expected/perceived dimensions of behaviour associated with males and females—masculinity and femininity. Although the ABS makes a clear distinction between sex and gender, the ABS considers sex to be a reliable indicator of gender for those who wish to analyse data in terms of social and economic behaviour. ABS surveys only collect data on sex and the meaning, description and use of the concept is generally standard across all ABS data collections.

The *National Health Data Dictionary* includes an 'indeterminate' category in the classification of this data element to accommodate the classification of some perinatal clients. At this stage, neither the *National Community Services Data Dictionary* Version 1.0 nor the *HACC Data Dictionary* Version 1.0 has included this coding option. This code will be considered for inclusion in future versions of the *National Community Services Data Dictionary*.

3 Process

3.1 Introduction

The draft MDS items developed by Brian Elton & Associates formed the starting point for the HACC MDS Project. These items had emerged from a process of extensive consultation with service providers and HACC program managers, undertaken on a national basis in the course of that consultancy. The task of the HACC MDS Project Team was to develop and refine those items into a set of data elements suitable for implementation as a national minimum data set.

Building on the consultation phase already completed, the Project Team adopted a two-pronged approach to meet these objectives.

Firstly, the Project Team employed internationally recognised techniques for the development of metadata, most specifically information modelling (Section 3.2) and the use of international metadata standards for the definition of data elements (Section 3.3), to ensure the internal consistency, logic, accuracy and comprehensiveness of the proposed MDS.

Secondly, the Project Team undertook extensive field testing of the data elements, with a range of agencies (by both size and type) across urban and rural areas of Australia. The field tests were undertaken in two stages. The preliminary field test (Section 3.4) was undertaken to assess the utility, clarity, appropriateness, practicality and feasibility of the proposed data elements. In essence, this field test served as a ‘reality check’ in the early stages of the project to ensure that data development was not proceeding in a way that was incompatible with service provider practice and expectations. The final field test addressed similar issues but in greater depth and detail, employing a significantly revised draft version of the MDS (Section 3.8). Reports on both field tests were provided to the Steering Committee during the course of the project. For reasons of brevity they are not included in full here; rather, key issues which influenced the subsequent evolution of the HACC MDS are highlighted.

Between the preliminary and final field tests, a great deal of developmental work took place. The knowledge gained in the preliminary field tests and from the data mapping exercises of the HACC MDS elements against other relevant data sets (outlined in Chapter 5), together with guidance and advice from steering committee members, and the analytic leverage provided by information modelling techniques, led to substantial revisions in the proposed MDS.

In particular, significant issues emerged with regard to categorising service activity types and defining the information on carers that needed to be included in the MDS. These issues were viewed as both complex and important by the Steering Committee, leading the Project Team to undertake detailed discussion papers on both topics. A summary account of this developmental work and decisions taken on that basis are included in Sections 3.5 and 3.6.

In addition, a brief account of the developmental work undertaken on dependency prior to the decision by the Steering Committee to suspend work on this area, pending the results of the projects on Community Care Classification and the National Framework for Comprehensive Assessment in HACC, is included in this chapter (Section 3.7).

3.2 Information modelling

Throughout the duration of the project, the HACC MDS Project Team used information or data modelling techniques to assist in the refinement and further development of data elements for the HACC MDS.

Information modelling applies formal techniques, using standardised processes and terminology, to the task of mapping the information resources of a specific field or sector. Over the past two decades a consistent set of techniques have emerged and are now internationally accepted and applied (Simsion 1994). An information model provides a framework for the organisation of information and the development of data, as well as the design of new information systems. In Australia, these techniques have been used to develop a range of information models from different fields in different jurisdictions, including the National Health Information Model developed by the Australian Institute of Health and Welfare (AIHW 1995).

In the case of the HACC MDS Project, the use of information modelling provided a standard nationally and internationally accepted methodology for refining and clarifying the meaning of data elements proposed for inclusion in the HACC MDS and for clarifying the relationships between them. Data modelling also supported an iterative approach to data development, reconciling top-down and bottom-up data needs and requirements throughout the process of developing the HACC MDS.

The work undertaken in the initial consultancy on HACC data requirements (Brian Elton & Associates 1996) had focused largely on a 'bottom-up' consultative approach and involved extensive consultations with HACC service providers. This was entirely appropriate given that the agreed principles guiding data reform in the HACC program emphasised the need to build upon existing data collections and data collection practices while being mindful of the demands on service providers collecting the data. These guiding principles also emphasised the importance of increasing the relevance and utility of data collection (and its subsequent analysis) to service providers (Brian Elton & Associates 1996).

Given this previous work, further refinement and development of the HACC MDS required the inclusion of a 'top-down' approach, reflecting the information needs of program managers and policy directions, alongside continuing sensitivity to existing data collection processes and practices and the concerns of service providers. To this end, the Australian Institute of Health and Welfare used data modelling as a mechanism for integrating top-down and bottom-up perspectives in developing and refining the HACC MDS. This iterative approach to data development helped to ensure that conceptual models were cross-checked against the 'reality' and requirements of the HACC service network whilst also servicing the information needs of program managers and planners.

In June 1997, the Project Team conducted an Information Modelling workshop for members of the Steering Committee (including Commonwealth, State, Territory and service provider representatives).[*] While it was not intended to develop a fully-fledged and conceptually tidy information model for the HACC program, Steering Committee members were encouraged to identify information needs and issues of relevance within their respective jurisdictions. Not only did this workshop clarify the information required for the HACC MDS to fulfil its role for program accountability and planning purposes, but it also provided an opportunity

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[*] The Project Team also conducted a data modelling workshop with a small group of staff from the Community Care Branch of the Department of Health and Family Services to help clarify HACC-related information needs at the Commonwealth level.

to clarify some of the vexing issues which surrounded many of the draft HACC MDS data elements.

Another significant benefit of the application of information modelling to the HACC MDS Project was the clear identification of the information that was not covered by the HACC MDS. In particular, the process identified the inability of the proposed HACC MDS collection to produce information about service providers or to encompass types of clients other than individual persons—such as groups or organisations—and the assistance they receive from the HACC program. While it was acknowledged that the HACC program requires information about all types of clients, it was also apparent that encompassing these other types of HACC clients requires the development of a far wider range of data elements and possibly a different type of data collection than that currently proposed. Future enhancements to the HACC MDS should consider the program's information needs in these areas. The use of information modelling techniques to identify and clarify those information requirements is highly recommended by the Project Team.

By clarifying the information requirements of different stakeholders, the Project Team was also better equipped to evaluate draft HACC MDS elements, thereby ensuring that key information needs and areas were not overlooked, and that the data elements included in the final HACC MDS were comprehensive and adequate to the task of meeting a broad range of information requirements.

The use of information modelling techniques in developing the HACC MDS also facilitated compatibility with the work of the National Community Services Data Committee which was responsible for overseeing the development of the National Community Services Information Model and the *National Community Services Data Dictionary* during 1997. While that work proceeded in tandem with the development of the HACC MDS, the fact that the National Community Services Information Model and the *National Community Services Data Dictionary* were being developed within the Australian Institute of Health and Welfare encouraged close ties between these projects and the HACC MDS.

The National Community Services Information Model (incorporating the draft Disability and Aged Care Information Model previously developed under the aegis of the Institute) was developed as a first step in the process of improving the quality and consistency of national community services information. This was accompanied by the completion of Version 1.0 of the *National Community Services Data Dictionary* early in 1998 (published in June 1998), which was designed to establish national standards for the collection of community services data.

These processes and developments with regard to community services information mirror the earlier establishment of the National Health Data Committee, the National Health Information Model and the *National Health Data Dictionary*. Over time, it is envisaged that the separate health and community services information models and data dictionaries will be incorporated into a National Health and Community Services Information Model and a National Health and Community Services Data Dictionary.

In keeping with the format used in the *National Community Services Data Dictionary*, the National Community Services Information Model has been incorporated into the *HACC Data Dictionary* as the organising principle, with data elements and data element concepts grouped according to the relevant sections of the model. Although a HACC information model may in some ways have provided a more specific and relevant reference tool for the HACC MDS, the use of the National Community Services Information Model promoted compatibility between the development of the HACC MDS and current and future developments in the National Community Services Information Model. This is consistent with one of the declared objectives of the HACC MDS to facilitate consistency and comparability between HACC data, existing national standards and other aged, community care and health data collections.

The Project Team attempted to maintain consistency between the *HACC Data Dictionary* and the *National Community Services Data Dictionary* wherever possible, using either comparable or mappable data elements and data definitions/data domains. As the *National Community Services Data Dictionary* was released prior to the completion of the *HACC Data Dictionary*, it was not possible to resolve all inconsistencies between the two documents. Any remaining anomalies have, however, been brought to the attention of those responsible for the further development of the *National Community Services Data Dictionary*. While the *National Community Services Data Dictionary* and the *HACC Data Dictionary* have somewhat distinct purposes, it is worth noting that several of the draft HACC MDS data elements have already been included in Version 1.0 of the National Community Services Data Dictionary.

The Project Team recommends the submission of the *HACC Data Dictionary* Version 1.0 to the National Community Services Data Committee for approval. As one way of facilitating on-going consistency and quality in data development activity in the aged and community care field, the Project Team also suggests that HACC Officials ask the National Health Data Committee to consider establishing an aged and community care data working group under the auspices of the National Health Data Committee to oversee data development activity across the aged and community care field.

A final benefit associated with the use of information modelling techniques is its usefulness to the process of designing information systems. Data modelling is commonly used for designing information systems, including the development of appropriate software. While the planned HACC Technology Project (see Section 1.3) did not run concurrently with this project as originally envisaged by HACC Officials, the clarity afforded by the use of data modelling techniques should facilitate the integration of the *HACC Data Dictionary* and the work of the forthcoming HACC Technology Project.

3.3 Application of ISO/IEC standard

In addition to data modelling techniques, the Project Team employed international standards in formulating and presenting the data elements that comprise the HACC MDS.

The presentation of data element definitions in the *HACC Data Dictionary* is primarily based on the international standards for defining data elements issued by the International Organisation for Standardisation and the International Electrotechnical Commission, ISO/IEC Standard 11179 Specification and Standardisation of Data Elements. The *National Community Services Data Dictionary* Version 1.0 (AIHW 1998b), *National Health Data Dictionary* Version 6.0 (AIHW 1996), and the *Community Nursing Minimum Data Set Australia* Version 2.0 (ACCNS 1997) are also based on the ISO/IEC Standard 11179. The application of this international standard across data dictionaries and data collections in the health and community services fields adds to the completeness, integrity and consistency of data definitions and consequently to the quality and utility of national data definitions.

Collectively, the format used (see Box 3.1) describes a set of attributes for data definitions that comprise a set of 'metadata' standards applicable to each data definition. Metadata may be defined as data describing the identifying, definitional, relational and representational attributes of data definitions (AIHW 1998b, p. A-3).

The ISO/IEC 11179 is a six-part standard consisting of:

- Part 1 Framework for the specification and standardisation of data elements

- Part 2 Classification of concepts for the identification of domains
- Part 3 Basic attributes of data elements
- Part 4 Rules and guidelines for the formulation of data definitions
- Part 5 Naming and identification principles for data elements
- Part 6 Registration of data elements.

The format used in the *HACC Data Dictionary* Version 1.0 (and in the other data dictionaries mentioned above) is based largely on Part 3 of the standard. Definitions for each of the data element attributes used in Version 1.0 are provided at Appendix D of the *HACC Data Dictionary* Version 1.0.

Specific mention should be made of some enhancements to the standard set of data element attributes which were developed specifically for the *HACC Data Dictionary* Version 1.0. Two additional data element attributes were included. These are:

- *Reporting status*

  This field indicates whether the data element needs to be recorded by the agency as part of its ongoing day-to-day information gathering practices (i.e. supporting data requirement); and whether the data element needs to be reported by the agency as part of the HACC MDS collection (i.e. data transfer) at the end of each reporting period (i.e. reporting data requirement). Possible values are supporting data requirement, supporting and reporting data requirement, and reporting data requirement. (This distinction is discussed in further detail in Section 4.2.)

- *Reporting requirements*

  This field indicates to HACC agencies how the data element should be reported within the HACC MDS collection (as opposed to the actual capture of the data which is addressed under Collection Methods). This includes, for example, instructions on which record for the data element should be reported when more than one record may exist in a database and not all records are required (e.g. the client's most recent Date of Entry into Service Episode or the most recent record of their Living Arrangements). Where a particular data element does not need to be reported as part of the HACC MDS collection (that is, where the data element is a supporting data requirement only) this is reiterated within the Reporting Requirements field.

Box 3.1: Template used for specification of data elements

Name

Admin. status:

Reporting status:

Identifying and definitional attributes

Data element type:

Definition:

Context:

Relational and representational attributes

Datatype:			*Representational form:*
Field size:	*Min.*	*Max.*	*Representational layout:*

Data domain:

Guide for use:

Verification rules:

Collection methods:

Reporting requirements:

Related data:

Administrative attributes

Source document:

Source organisation:

Comments:

3.4 Field test I

During July 1997 the Project Team conducted its first foray into the field, with visits to nine HACC-funded agencies within the Australian Capital Territory and the New England area of New South Wales. Agencies included in this preliminary field test are listed in Table 3.1.[*] Services provided by agencies visited during the first round of field testing included home help, centre day care, community respite, transport, delivered meals, and community options. In essence, the preliminary round of field testing was to be a 'reality check' on the

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[*] The Project Team did not visit all service types during the first field test, the aim of which was to provide project staff with a preliminary sense of the range of agencies and agency responses likely to be encountered in the course of the project.

content and the assumptions underpinning the HACC MDS Project. It was also designed to assist in planning the scope and processes for the final round of field testing which occurred during January 1998.

The aims of this initial round of field testing were:

- to explore the possibility of extracting the proposed data elements from existing service provider data systems;
- to identify the likely quality of the data provided;
- to test the clarity and comprehensiveness of proposed data definitions and data domains; and
- to examine the consistency of proposed data elements with data collection forms used at the service delivery level.

Table 3.1: Participating agencies, Field Test I

State	Agency
NSW	Tablelands Community Options, Uralla
	Garden Court Centre, Glen Innes
	Tablelands Community Transport, Armidale
	North East New England Community Options Project, Glen Innes
	Home Care Service of NSW, Armidale
	Eenarwan, Aboriginal Home Care, Armidale
ACT	Red Cross Meals on Wheels and Heavy Linen Service, Canberra
	Respite Care ACT Inc., Canberra
	Home Help Service ACT Inc., Canberra

Procedures

Each agency was asked to put aside a half-day for a visit from the Project Team. The agency was sent a brief outline of the draft HACC MDS elements to be discussed at the meeting and the purpose and proposed structure of the visit was discussed by telephone with the agency's coordinator or manager. Agencies were asked to make available a staff member with knowledge and expertise in their client record systems wherever possible. A draft HACC MDS collection form was developed for use during the agency visits, which the Project Team was to attempt to complete for a number of clients from each agency.

Data elements included within the documentation sent to agencies related to:

- client characteristics and circumstances;
- client dependency, need for assistance and informal assistance received;[*]
- dates of entry and exit from care and referral patterns; and
- patterns and amounts of service utilisation by particular types of activities/services.

The draft HACC MDS used in this field test was substantially different from the original HACC MDS proposed by Brian Elton & Associates in 1996 in *the National Review of HACC Data Requirements Final Report: Future Directions.* The July draft also differed substantially

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[*] The decision to exclude data elements related to client need and dependency from Version 1.0 of the HACC MDS was taken by the Steering Committee in August; at this stage it was still within the purview of the project brief.

from the final version of the HACC MDS presented to the Steering Committee in May 1998. Nonetheless, it contained within it many of the basic ideas and concerns that were to become more clearly elucidated further along in the process. These included:

- the need to break into their component parts data elements which had been servicing multiple functions or which had contained within them multiple pieces of information;
- the need to more clearly identify carers within HACC data collections;
- the recognition that the date of receipt of assistance was a central precursor to much of the information required about service utilisation;
- the move toward disentangling the assistance provided to a person from a rigid model of funded service types;
- the need to measure amounts of service provision in a unit of measurement appropriate to the relevant service type; and
- the recognition that the receipt of any given type of service activity has a beginning and end not necessarily synchronous with the broader concept of an episode of care.[*]

Results

Perhaps the most striking result of the initial field test was the extent to which agency data collections did not easily support the draft MDS; and the difficulty agencies experienced in locating much of the information required to support the MDS. The expectation of completing the draft HACC MDS form for several clients during each agency visit proved unrealistic. This was largely as a consequence of the aforementioned difficulties in locating the necessary information, but also reflected the time spent by the Project Team in briefing agency staff on the project and discussing the agency's data needs and information systems.

Clarification of the meaning and purpose of the draft MDS elements and the meaning of the data recorded by agencies was also a time-consuming process. Not only was it clear that the same information was recorded under a variety of different fields, but it was also apparent that similar data fields were often used to record quite disparate kinds of information by different agencies. Information about the language spoken by clients, for example, was recorded by some agencies under fields labelled NESB (non-English-speaking background), NESC (non-English-speaking culture), Ethnicity or LOTE (language other than English); while other agencies with fields labelled 'main language spoken at home' used these as rough indicator of language or ethnicity (e.g. 'Asian') or to record a language appropriate to service delivery (e.g. 'French' as the language of mutual competence between a Vietnamese client and an English-speaking worker).

The full results of the preliminary field test, presented in an interim project report to the Steering Committee, are not included here. The more salient findings, in particular those that influenced subsequent developments in the HACC MDS, are summarised below:

- Most agencies had to draw from two or more sources to supply the information required by the draft HACC MDS. These sources included computer records, paper

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[*] This idea was not fully developed within Version 1.0 of the HACC MDS. As discussed in Section 3.4, to develop this idea further within the HACC MDS would require a level of data collection and reporting far in excess of the capacity of most service providers (and beyond the information requirements of most program managers). As such it was not considered feasible to pursue service episodes by activity type, at least within the first version of the HACC MDS collection.

files, case notes and timesheets for workers. This process was very time consuming, especially for agencies servicing large numbers of clients.

- Certain information held by agencies (e.g. about dependency profiles or client circumstances) was often out of date, having been collected at the time of the person's entry into the agency. Larger agencies had reassessment policies in place but workers indicated that reassessments were often late. Updated information of relevance was generally buried in file notes.
- The Client Information and Referral Record (CIARR) was found to have considerable potential as a basic source document for the HACC MDS. Certain fields on the CIARR would, however, require modification to provide consistency with the final HACC MDS, particularly in relation to carers. Consistency between CIARR fields and HACC MDS elements would be likely to assist with the consistency and quality of data provided in the MDS collection.[*] Although the implementation of the CIARR varies across States and Territories it remains one of the few common tools available to all HACC agencies (see Chapter 5 for further discussion).
- It became clear in the preliminary field test that the introduction of the HACC MDS would require a lengthy lead time. If the agencies visited in this field test were asked to provide returns for a HACC MDS in the near future, the impression gained from the field test was that many would provide information based on local knowledge and 'guesstimates'. Even so, the process would be time consuming for the agencies and would do little to improve the quality of the data already available on the HACC program.
- The need for extensive training in the purpose and meaning of the HACC MDS if implementation is to be successfully achieved emerged quite strongly in discussions with service providers. Service providers reported that they would put more effort into improving their data collection practices if they could see the relevance of the collection and the uses to which the data would be put. Targeted training for community-based management committees of HACC agencies may be worthwhile.
- The relevance of some of the HACC MDS data elements to Indigenous people, agencies and their communities emerged as a significant issue, especially in relation to the effectiveness of the proposed statistical linkage key.
- Agencies expressed a great deal of uncertainty as to the links between the HACC MDS, the unit costs framework[†] and funding agreements.
- For most agencies, the source records for service utilisation were held on a different system or area of the computer to information about client characteristics and circumstances. Given that the HACC MDS includes data on both aspects, and in particular on service use as it relates to individual clients, this aspect of agency practice may require modification and development in order to efficiently support the HACC MDS.
- Detailed guidelines and clear definitions and descriptions would be required by agencies in order to know how to record particular activities (e.g. shopping, banking, helping with medication).

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[*] Work is currently under way under the auspices of HACC Officials to make the modifications to the CIARR required to produce consistency between the CIARR and the HACC MDS.

[†] See Alt Statis and Associates (1993).

- One Community Options agency reported difficulty in providing details on the amounts of different service types provided to clients because these details were only available from accounts submitted by contracted private agencies. The accounts themselves only differentiated between services according to pay rates, that is, if home help and personal care were charged at the same rate, the hours of service provided would be collapsed into a single amount.
- Some agencies suggested that the proposed system had the potential to allow double counting. For example, an agency (Community Options) which pays for a worker to attend/supervise an elderly person with dementia at a local HACC day centre would record this as hours of Respite to the client, while the HACC day centre would also record the same hours as Centre-based Day Care for the client.
- Heavy linen/laundry assistance was missing from the list of service types/activities.
- Difficulty was experienced in representing agency contributions to the purchase of goods and equipment and there was a lack of clarity on the level of detail required.
- Actual service utilisation figures were not available centrally for the Meals on Wheels service. Centralised computer records contained only the planned rather than actual number of meals provided (i.e. the agreed pattern of service delivery), and while the actual service delivery was known at distribution points by volunteers, these were not computerised.
- Different meals agencies were found to count meals in different ways (e.g. one agency would count a dessert as a meal while another would consider a meal to equal six desserts).
- Given the difficulty that many agencies would face in implementing the proposed HACC MDS, the possibility of a staged approach (i.e. by sets of data elements) to implementation should be considered.

Overall, results from the first field test underscored the sheer size of the gulf between the real and the ideal—the difference between what agencies actually do collect (and how they collect it) and what the program might wish to collect in the future. These issues were discussed with the Steering Committee in August 1997. It was agreed that the development of the HACC MDS should proceed with a view toward the ideal in full recognition that it would take most HACC agencies a considerable amount of lead time and assistance in order to implement the significant departures from current practice required by the proposed HACC MDS.

3.5 Key developmental area: service activity types

Data elements relating to service utilisation in the HACC MDS were intended to become the primary vehicle for replacing the HACC Service Provision (HACCSERV) data collection and for providing a more fine-grained understanding of patterns of individual service use than had been previously available from existing aggregate data. This requirement is in keeping with the emphasis given by HACC Officials to the need for more client-focused, outcome-oriented data for future program planning and monitoring. The results of the preliminary field test had underlined the importance of a comprehensive set of service activity types, with clear definitions and guidelines to allow accurate data recording by service providers. Service activity type was thus identified as a key developmental area for the HACC MDS Project.

During the August meeting of the Steering Committee, the Project Team agreed to develop a list of service types that would form the basis of the HACC MDS coverage of service utilisation. The Project Team prepared a discussion paper on this issue for distribution to Steering Committee members in October 1997, and discussion at the November Steering Committee meeting.

From funded services to service activity types

During the August meeting, the Steering Committee agreed that data development work in this area need not be bound by existing funded service types, such as those used in the HACC Service Provision collection or the Unit Costs Framework. It was, however, acknowledged that the HACC MDS would play a role in supporting program funding accountability.

The move away from existing funded service types was supported for a range of different reasons. In particular it was considered that HACC funding categories had lost some of their descriptive power over time as the HACC program and individual agencies have diversified and enhanced their service delivery to clients. This diversification has been largely consistent with the program emphasis on responding flexibly and innovatively to client's individual needs. This flexibility and responsiveness are considered aspects of good practice within the HACC field. Moreover, HACC service providers have consistently highlighted the often varied nature of what they actually do for clients and their frustration at being unable to adequately describe the assistance they provide to clients within the confines of the traditional listing of funded service types.

Although the possibility of disjunctions between the categories under which agencies are funded and the categories against which they report their outputs raise some issues for the HACC program, the principle of recording the actual types of service activities received by the client was supported by the Steering Committee. It was also considered that future directions for the HACC program (including a move toward a community care classification) indicate the likelihood of moves toward a funding process that emphasises the package of care to an individual and minimises administrative and program barriers to responding flexibly to client needs.

Both of these reasons indicated the need for a data collection that could more adequately and accurately reflect actual practice across the HACC field. Indeed, although funding accountability is an important part of the HACC MDS role, aligning what happens with what should happen is largely an administrative process that firstly requires information about what actually does happen. If agencies were asked to report against funding categories, it was considered likely that they would continue to 'squeeze' service provision into the categories or 'boxes' which they thought program managers wanted or expected.

Rather than institutionalise the limitations of existing funded service types in the HACC MDS, it was agreed that a categorisation of service activities which more accurately reflected practice would be better placed to support both future data requirements and future funding arrangements. Nonetheless, the use of a greater number of service activity types with enhanced descriptive power was not seen to necessitate a concomitant shift in funding practices. That is, the Steering Committee did not see a need to begin funding agencies against this more detailed range of categories.

Table 3.2: Recommended service activity types (October 1997)

Service activity type	Unit of measurement	Original service type (*Future Directions*)
Domestic assistance	Hours	Home help (excluding social support)
Social support	Hours	Neighbour aid and other social support
Nursing care at home	Hours: Occasions	Community nursing
Nursing care at centre	Hours: Occasions	Community nursing
Paramedical care at home	Hours	Allied health services (paramedical)
Paramedical care at centre	Hours	Allied health services (paramedical)
Personal care	Hours	Personal care
Centre day care	Hours	Centre-based day care services
Home meals	Meals: Deliveries.	Meal services
Centre meals	Meals	Meal services
Other food services	Hours	Meal services
In-home respite care	Hours	Respite care (overnight care included in Personal care)
Case management	Hours	Case management
Assessment	No. of assessments	Assessment and referral
Advocacy	Hours	Other services
Home maintenance	Hours	Home maintenance
Home modification	Cost	Home modification
Purchase of goods and equipment	Cost	Purchase of goods and equipment
Linen service	No. of weeks	Home help
Transport	Trips (one-way)	Transport services
Education, training and information	Hours	Education, training and information activities for service providers and consumers
Other (interim only)	Hours	Other services

In determining the list of service activity types, consideration was given to the original listing of service types developed by Brian Elton & Associates (1996), to current collections and to the *National Classifications of Community Services*. Table 3.2 provides a summary listing of the 22 service activity types recommended by the Project Team in October 1997, the unit of measurement, and the original service types proposed by Brian Elton & Associates (1996).

In moving from the original list proposed by Brian Elton & Associates to the revised list, the Project Team:

- made some changes to the names of elements;
- included additional elements based on setting/location distinctions;
- separated out certain elements from their original composite categories; and
- made recommendations as to appropriate units of measurement which had not been specified in the original list proposed by Brian Elton & Associates.

In order to underscore the distinction between funded service types and the categorisation of services recommended for the HACC MDS, the Project Team renamed this set of elements ‘service activities’ or ‘service activity types’.

Table 3.3: Final service activity types (*HACC Data Dictionary* Version 1.0: May 1998)

Service activity type	Unit of measurement
Domestic assistance	Time (hours: minutes)
Social support	Time (hours: minutes)
Nursing care	Time (hours: minutes)
Allied health care	Time (hours: minutes)
Personal care	Time (hours: minutes)
Centre-based day care	Time (hours: minutes)
Meals	Quantity (number of meals)
Other food services	Time (hours: minutes)
Respite care	Time (hours: minutes)
Assessment	Time (hours: minutes)
Case management	Time (hours: minutes)
Case planning/review and coordination	Time (hours: minutes)
Home maintenance	Time (hours: minutes)
Home modification	Cost (dollars)
Provision of goods and equipment	Type[(a)]
Formal linen services	Quantity (number of deliveries/collections)
Transport	Quantity (number of one-way trips)
Counselling/support, information and advocacy	Time (hours: minutes)

(a) Provision of goods and equipment is not measured as an amount, as are the other types of service activities. Rather, the agency records the type of good or equipment received to the client using the code list provided at Appendix B of the *HACC Data Dictionary*.

The use of the term 'service activities' is consistent with the *National Classifications of Community Services* (NCCS) which was used in developing the recommended listing of service activity types.* Each of the proposed service activities was cross-referenced to the activities classification within the NCCS. In some instances the name of the activity was changed to reflect the classification where this was considered to add clarity to the HACC listing (e.g. Domestic Assistance).

The move towards service activities was designed to support a framework for recording and reporting outputs which was more indicative of what HACC agencies actually provide to their clients. It was also considered to be more consistent with the intentions of a client-focused collection. Given the client-focused nature of the HACC MDS, it was seen as legitimate that the recording and reporting of assistance received by clients may not necessarily match an agency's funded service type/s. It was agreed that the service activities should be named and defined from a client's perspective, thereby encouraging agencies to record what they do for clients in a way that better reflects the client's perception of what is being done for them.

Some further changes were made to the list of service activities prior to the release of the *HACC Data Dictionary* Version 1.0 in May 1998, as a result of additional feedback and other considerations relating to the internal structuring of the MDS collection. The October 1997

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* The NCCS contains three sub-classifications—Activities, Target Groups and Settings—of which the Activities and the Settings classifications were central to the development of Version 1.0 of the HACC MDS. Identification of Target Group is facilitated by the combination of socio-demographic items included in the MDS, and would be further assisted by the inclusion of items related to the dependency or identified areas of need for assistance for each client as intended for Version 2.0 of the HACC MDS Data Dictionary.

list is included here as an indication of the position of the Project Team at that time. The final listing of service activity types is included in Table 3.3.

Additions and alterations

Setting

The service activity list incorporated some distinctions in the setting of the receipt of service where this was considered of significance to program management information needs, and where such reporting was not considered to place an undue burden on service providers. Nursing Care, Paramedical Care and Meal Services were divided and identified by setting ('at home' and 'at centre'). Meal Services were split even further to allow for the reporting of Other Food Services. This was one example where the proposed service activity list was designed to enable more accurate reporting of the assistance agencies actually provide to their clients.

Personal Care remained as a single category because setting information about Personal Care was not considered of the same significance to program managers and because (unlike Nursing or Paramedical Care) it was considered more likely to be an incidental or secondary activity when provided in centre-based settings.* Subsequent developments in the HACC MDS retained the distinction on the basis of setting for these types of assistance but separated setting out from the service activity list for reasons of conceptual clarity (see the data elements 'Primary Type of Assistance Received' and 'Service Delivery Setting' in Version 1.0 of the *HACC Data Dictionary*).

Linen services

Another variation in the list included the addition of a separate category for Linen Services. This activity was included as a separate category because it is conducted away from the client's home; requires a different unit of measurement; and tends to be associated with carer support. It was subsequently renamed Formal Linen Services to underscore the distinction between this service activity and general washing and ironing etc. which may be done within a person's home (i.e. domestic assistance).

Advocacy

Advocacy was included as a separate category in order to accommodate the work of agencies specifically aimed at providing formal advocacy services to individuals within the HACC program. As only some States and Territories specifically fund advocacy services within the HACC program, assistance with formal advocacy was subsequently removed as a separate category and included within the category Counselling/Support, Information and Advocacy in the final listing of service activities.

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* The Project Team also suggested that the category Centre Based Day Care indicated more about the setting than the kinds of activities undertaken and that assistance received by individuals in centre-based settings might be more appropriately encompassed under other categories (e.g. social support at centre) or accommodated within future developments of the HACC MDS designed to incorporate different kinds of clients (e.g. group clients, organisational clients, etc.). While agreeing in principle that Centre Based Day Care was an anomaly in the listing, the Steering Committee did not agree to the suggestion to eliminate it as a category on the grounds that Centre Based Day Care is a commonly understood category of service provision within the HACC program.

Domestic assistance and social support

The separation of Domestic Assistance (formerly Home Help) and Social Support was in accordance with the recommendations of Brian Elton & Associates (1996) but represented a shift away from the HACC Service Provision collection that includes social support within Home Help.

Respite and respite care

In an attempt to distinguish between respite and respite care, the Project Team also developed more prescriptive guidelines for the use of respite care as a service activity type. This was in line with the distinction made by the Respite Review between respite as the desired outcome or effect of an intervention, and respite care as a description of those alternative care arrangements that are funded and provided to produce the desired respite effect for carers.

In accordance with this distinction, the Project Team defined Respite Care as a service activity type which should only be used where:

(a) there is a carer, and

(b) a substitute carer takes the place of the usual carer, and

(c) where any other activities undertaken as part of substituting for the usual carer are incidental or secondary to the primary purpose of the activity.[*] The Project Team also stipulated that the recipient of Respite Care should always be the carer (that is, Respite Care should always be reported on a HACC MDS record for the carer rather than their care recipient).[†]

Counting issues

In developing the service activity types, a range of issues emerged regarding procedures for counting clients and services appropriately, consistently and reliably. In response to these problems, the Project Team made a series of recommendations for the counting of services and assistance. These included:

- that the amount of service received by a client be recorded against the primary activity on an occasion of service;
- that the MDS record the amount of each type of service activity received directly by a client excluding time spent on behalf of a client and time spent travelling to and from a client;

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[*] Although some services are funded as 'respite services', their services are not restricted to 'clients with carers who are in need of respite'. Indeed, it is not uncommon for clients without carers to be recorded as receiving 'Respite' with the Respite Review showing that some 30% of HACC Day Care Centre clients had no carer, and 20% of HACC In-Home Respite clients had no carer. For the purposes of the HACC MDS, this kind of assistance is to be recorded as one of the other service activity types, such as Centre Based Day Care or Social Support.

[†] The original Respite Care category was changed to In-home Respite Care in the October version to underscore the narrow definition of respite care proposed by the Project Team. This was later changed back to Respite Care to accommodate kinds of respite care services which meet the above criteria but which are not provided in-home.

- that the guide for use should specify a five-minute level of accuracy in the recording of time involved in each occasion of service in order that aggregations for the reporting period accurately reflect the amount of service received.

The second and third of these recommendations were subsequently altered in response to feedback received from agencies during the second field test. In the final draft of Version 1.0 agencies are directed to record and report time spent on behalf of individual clients in case management/coordination type activities. Also, the level of accuracy when recording time spent was revised upwards from 5 to 15 minutes for each occasion of service. These specifications have been incorporated into the relevant data elements within Version 1.0 of the *HACC Data Dictionary.*

The Project Team also made a series of recommendations which have not been specifically incorporated into the *HACC Data Dictionary*, but which would need to be addressed within collection guidelines, the production of which is a required precursor to the successful implementation of the HACC MDS. These recommendations related to the process of determining which agency should be responsible for recording and reporting the provision of assistance to clients in certain circumstances; the validity of concurrent counting in certain circumstances; and the process for attributing amounts of assistance to multiple clients within the same household in certain circumstances.

The recommendations were:

- that where a HACC-funded agency purchases a service for a client from a non-HACC-funded agency, the HACC-funded agency should record the service activity details for MDS reporting;
- that where a HACC agency purchases a service for a client from another HACC agency, the purchasing HACC agency should record the service activity details for MDS reporting;
- that where a HACC-funded agency provides a bulk service to another HACC agency (e.g. multiple meals), the agency actually distributing or delivering the services to individual clients (e.g. day centre) record this service activity for MDS reporting on their clients;
- that concurrent counting be seen as an acceptable and accurate measure of services received by the client, despite the disjunction between the reported amount of service and the ‘real time’, where the separate services are delivered by separate agencies or separate staff members, and where it would be considered reasonable for that service to be received as a ‘stand alone’ service;
- that where two or more HACC clients are present in a household which receives Domestic Assistance, Home Maintenance or Home Modification, and where each would be considered eligible to receive that service in their own right, then the amount of service provided to the household on each occasion of service should be divided between the eligible recipients.

3.6 Key developmental area: data on carers

In the course of refining and developing the HACC MDS it became increasingly apparent that one of the more vexed areas within both the project and the HACC program more generally concerned the position and treatment of carers.

In large part, the ambiguity surrounding carers stems from the fact that their legitimacy within the HACC program is predicated upon and mediated by their relationship to another person—either a frail or disabled older person or a younger person with a disability. As such, carers have not had the same prima facie or self-evident claim on HACC client status as have frail or disabled older people and younger people with disabilities.

While in legislative terms it is clear that carers can be clients of HACC agencies in their own right, in operational terms the distinction between carer as client and care recipient as client is not quite so straightforward. While a respite service may feel quite comfortable in identifying the carer as their direct client, the situation is not quite so self-evident with regard to a linen service (is the help directed to the person who is incontinent or to the person who must wash the sheets), and perhaps even less clear in the case of home help. The situation becomes even more complex when the carers in question are themselves frail or disabled older people or younger people with disabilities. Thus, the same person may require assistance from the HACC program in two distinct capacities—in relation to their own frailty, disability or condition, and to support them in their caring role. Different agencies have resolved the question as to who constitutes the client in these cases in a variety of ways, resulting in a lack of consistency in defining when a carer is a client in their own right.

These inconsistencies render the concept of 'client' far from transparent in relation to carers. They also hamper attempts to answer basic questions about the extent to which the HACC program assists carers—and in what capacities—and make it difficult to even define the kinds of information that the HACC program may require to enable such an understanding.

To date, many of the data collections or data collection instruments used within the HACC field have embodied rather than clarified these confusions about carers and their position vis-a-vis the HACC program. The CIARR, for example, is predicated around a seeming dichotomy between carers and clients as two separate and distinct identities—a distinction which suggests that carers are never themselves clients of HACC, but are only ever a secondary resource which may be available to a HACC client (i.e. a frail or disabled older person or a younger person with a disability). Yet this contrasts with other initiatives which are specifically targeted at carers within the HACC program (such as respite services, carer information and support services etc.) which assume that carers can and do have HACC client status in their own right.

Some attempt was made to clarify the HACC program information needs about carers in June 1997 during the data modelling workshop (see Section 3.2). At that time it was generally agreed that the HACC program was interested in carers in three different roles or capacities. These included:

- where a HACC client *has* a carer;
- where a HACC client *is* a carer; and
- where a HACC client *is both* a frail or disabled older person or a younger person with a disability *and* a carer.

In August, the Project Team agreed to develop some options for the coverage of information about carers within the HACC MDS. This resulted in the preparation of a discussion paper, presented to members of the Steering Committee in November.

In drafting the discussion paper on carers, it became clear that many of the more difficult issues actually required resolution at the program level, rather than at the level of the HACC MDS. Indeed, while the HACC MDS may lead agency practice in some respects, in other ways it will simply reflect agency practice and the decisions that agency workers take in relation to everyday events (such as the process of deciding who constitutes a client). Yet these decisions by agency staff do have implications for the data submitted by agencies and the conclusions which can be drawn from it. Questions of appropriate data usage and appropriate data analysis also received substantial attention within the discussion paper on carers. While these issues were pertinent in terms of understanding the context and potential of the HACC MDS, their impact on Version 1.0 of the HACC MDS in terms of data elements and data element concepts proved to be relatively minimal.

After November, the proposed data elements on carers continued to evolve and change, with input from Steering Committee members and the final field test. Only those aspects of the carers discussion paper which continued to influence the development of the HACC MDS or which are considered to have ongoing significance are summarised in the discussion below.

Given the lack of precision about information requirements concerning carers, the Project Team drafted the carers discussion paper around a series of four questions which were considered to have some relevance to program management, accountability and planning. These were:

- How many carers are in the HACC target population?
- How many carers are receiving assistance from the HACC program?
- How much and what sort of assistance is provided to carers by the HACC program?
- What are the characteristics and circumstances of carers who are receiving assistance from the HACC program?

To aid clarity, the word ‘client’ is used in the following discussion (and more generally within this document) to refer to a person who is receiving HACC-funded assistance from an agency. A client for HACC MDS purposes may be a carer, a frail older person, a younger person with a disability, or a combination of these. The words ‘carer’ and ‘care recipient’ are used to describe distinct roles within a care dyad, irrespective of HACC client status.

How many carers are in the HACC target population?

In relation to this first question, the discussion paper went into some detail concerning the conceptual and methodological problems in defining ‘carers’. In particular, it identified the difficulties in comparing carers loosely identified within the HACC program with the more rigorously constructed definitions of carers (primary carers, main carers, all carers) in data derived from the ABS Survey of Disability, Ageing and Carers. Given that the ABS survey data are used as the basis for estimating the size of the HACC target group and for various other population estimates, these definitional and conceptual divergences make it difficult to locate or compare HACC carers against the broader context of ABS national population estimates of carers and their characteristics.

The complexities of this issue are beyond the scope of the present report. Nor can they be resolved at the level of the HACC MDS as they relate to the basic processes used in determining the size and composition of the HACC target group. The information required to establish a valid basis for comparison between the ABS and HACC carer data hinges on the interplay between the care recipient’s need for assistance in particular aspects of daily living, and the nature of the assistance provided to the person by their carer. This level of information is unlikely to be collected about all HACC clients. Moreover, the proportion of HACC clients for whom these data are collected will depend on as-yet-to-be-made decisions by HACC Officials concerning the implementation of the national framework for comprehensive assessment in HACC, and the community care classification.

If it is agreed that valid comparisons between ABS survey estimates and HACC data should be enabled, the Project Team recommends:

- that comprehensive assessments include information about the assistance provided by carers as well as the need for assistance of their care recipients;
- that comprehensive assessments include information related to the areas of self-care, mobility and verbal communication;[*]
- that carers be considered within the scope of HACC comprehensive assessment authorities; and
- that the need to develop an appropriate assessment instrument for carers in the HACC program be referred to HACC Officials.

Defining carers in Version 1.0 of the HACC MDS

Pending any such developments within the HACC program, the definition of carers within Version 1.0 of the *HACC Data Dictionary* resonates with more general community understandings. A carer is defined as 'a person such as a family member, friend or neighbour, who provides regular and sustained care and assistance to another person without payment other than a pension or benefit'. This equates with common usage of the term 'carer' which is generally understood as referring to a person who helps or looks after someone who needs assistance with some ordinary tasks. A carer is a person who 'cares for' as opposed to 'cares about' another person. A certain amount of imprecision is to be expected, with situations that are objectively similar being described in different ways by the participants in a carer/care recipient relationship. Nonetheless, the capacity of the HACC MDS to identify carers in this more general sense represents a significant improvement in the quality and availability of HACC data about carers.

How many carers receive assistance from the HACC program?

In relation to this question, there is an important distinction to be recognised between carers who are direct recipients of HACC-funded assistance (that is, carers who are clients themselves); and carers who are indirect recipients of HACC-funded assistance (that is, carers of HACC clients).

The types of assistance which best support a carer in their caring role will depend on the needs, circumstances and preferences of the carer and their care recipient(s). For one carer, the provision of direct assistance may be of most assistance (such as carer support or a period of respite care) while for another, the provision of assistance to their care recipient (e.g. help with bathing, feeding, dressing; the provision of a walking aid, or the installation of grab rails or ramps) will be of more benefit. Indeed, in many cases it is assistance provided to meet the needs of the care recipient that provides the greatest support to carers. That is, indirect assistance to carers should not be assumed to be of lesser importance to carers in their caring role.

In counting carers, then, the Project Team argued that it is legitimate to include both groups of carers in the number of carers who are assisted through the HACC program. It is suggested that this more accurately reflects the wide range of forms of assistance that do, in fact, relieve or support carers in their caring role.

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[*] These are the three areas which are used to determine levels of handicap within the ABS data and which, in turn, form the basis for the identification of carers within the ABS Survey of Disability, Ageing and Carers.

To be able to count carers, however, implies the need to identify persons receiving assistance from HACC on the basis of their membership of different sub-sets of the HACC target group. To facilitate this in the HACC MDS, the Project Team included a new data element, Reason for HACC Client Status.[*] This data element was designed to identify those HACC clients who receive assistance in their role as a carer. The data domain for Reason for HACC Client Status comprises the following options:

1. Person receives assistance from the agency due to their own frailty, disability or condition;
2. Person is a carer and receives assistance from the agency to support them in their caring role; and
3. Person receives assistance from the agency due to their own frailty, disability or condition *and* to support them in a caring role (i.e. both of the above).

The sum of clients in categories 2 and 3 above gives a count of the total number of carers who have received direct assistance from the HACC program within a given reporting period.

A count of carers who have received indirect assistance from the HACC program within a reporting period can be established using the Carer Availability data element. For any HACC client whose MDS record indicates that he or she has a carer, that carer should be counted as receiving indirect assistance from the HACC program.

There remains, however, a problem of double counting carers if one simply adds these two groups together in order to establish the total number of carers receiving assistance (either direct or indirect) from the HACC program. Given that the same carer may have their own HACC MDS record as a direct recipient of HACC assistance, and be identified as a carer (i.e. indirect recipient) on the HACC MDS record of their care recipient, persons in this situation will be counted twice if the two totals are summed.

How much and what sort of assistance is provided?

The capacity of the HACC MDS to supply data relating to the third question outlined above (how much and what sort of assistance is provided to carers?) again depends on the different roles played by carers with regard to the HACC program.

For HACC clients who are carers (i.e. direct recipients) and who receive assistance to support them in their caring role only[†], all of the assistance they receive can be attributed to their role as carers. Similarly, for carers of HACC clients (i.e. indirect recipients), all of the assistance provided to their care recipient can be considered as indirect assistance provided to carers by the HACC program.

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[*] This was formerly called Client Group Type with a data domain comprising frail aged person, younger person with a disability and carer (with a multiple response option). The element was amended in response to feedback obtained in the final field test, in which agency workers found the categories insufficient, unclear and in some cases offensively blunt or inappropriate. For more information on the rationale for developing this data element see Section 3.3.

[†] That is, clients who are recorded under coding option 2 for the data element Reason for HACC Client Status.

For clients who have received assistance both in respect of their own frailty, disability or condition *and* to support them in a caring role[*], the process of allocating assistance to one or the other category becomes more complex.

This process is partly assisted by reference to the primary types of assistance received. The Project Team considers it reasonable to assume that some types of assistance are only ever provided to a person on the basis of their own frailty, disability or condition. These might include:

- Nursing care
- Allied health care
- Personal care
- Centre-based day care
- Home maintenance
- Home modification and
- Provision of goods and equipment.

It would be reasonable to assume that other types of assistance would be provided to a person to support them in their caring role. These might include:

- Respite care[†] and
- Formal linen services.

Other service activities are not so amenable to such assumptions. The following service activity types are more difficult to attribute to any specific client group:

- Domestic assistance
- Social support
- Meals
- Other food services
- Assessment and case management/coordination
- Transport and
- Counselling/support, information and advocacy.

Unless some kind of protocols are established across the program for determining the appropriate recipient of these services (for instance, that Domestic Assistance always be recorded against the care recipient), then the amounts of these types of assistance may need to be attributed half to the person as a carer and half to them in relation to their frailty, disability or condition.

Packages of care: linking care dyads

The primary incentive for introducing a statistical linkage key within the HACC program is to enable a reliable count of HACC clients and to overcome some of the difficulties

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[*] That is, clients who are recorded under coding option 3 for the data element Reason for HACC Client Status.

[†] Respite Care should always be recorded as being provided to the carer. That is, any carer who receives Respite Care within the reporting period should have their own HACC MDS record which details this. Respite Care is the only service activity type that the *HACC Data Dictionary* is prescriptive about in this respect.

associated with evaluating client service utilisation. In attempting to assess the support and assistance provided to carers, however, the Project Team also canvassed the possibility of using linkage key data elements to link records across care dyads. This would enable a much greater understanding of the package of services and assistance which go toward supporting a given care situation, rather than only focusing on service utilisation by individual clients. Such a linkage process could take two forms.

Firstly, for any disabled HACC client with a carer (i.e. as indicated by the Carer Availability data element), one could embed the necessary linkage key information about their carer within the HACC MDS record of the client. This would require agencies to collect and supply personal information about the carers of their clients—namely, certain (not all) letters of name, date of birth and sex. This information would then be cross-matched against all of the client records received from HACC agencies to establish whether that carer was a HACC client in their own right (i.e. they may be receiving HACC services such as respite care or carer support and will therefore have their own HACC MDS client record). In this way, the support and assistance received separately by the care recipient and by the carer (from either the same or different agencies) can be seen as a package of care going toward supporting them both.

This approach has several difficulties. Firstly, most agencies do not routinely collect detailed information about the carers of their HACC clients, unless that carer also happens to be a client of the agency. As such, any requirement to collect such information would increase the data collection burden in a way that may have very little resonance with the operational needs of the agency. Secondly, the collection of personal information about people who may not receive any direct services or assistance from HACC is likely to be a sensitive issue and may result in high proportions of missing data. Thirdly, the possible collection of such information via care recipients also raises significant privacy and consent considerations, and in some cases may have an impact on the reliability of the data provided (for example, where a client has dementia).

The second alternative is to approach the problem from the other side. That is, for any carer–client (i.e. as indicated by the Reason for HACC Client Status) one could embed the necessary linkage key information about their care recipient within the HACC MDS record of the client (in this case the carer). This would require agencies to collect and supply personal information about the care recipients of their carer–clients—again, specified letters of name, date of birth and sex. This information would then be cross-matched against all of the client records received from HACC agencies to establish whether that care recipient was a HACC client in their own right. This would enable the same analysis of 'packages of care' described above.

The latter approach has several strengths. Firstly, the volume of carer–clients is likely to be substantially smaller than the volume of frail or disabled clients who have carers. This minimises both the extent of the collection burden and the volume of cross-matching to be done. Secondly, agencies that provide direct assistance to carers (i.e. where the carer is the client) are more likely to have recorded information about their care recipients in the course of service delivery. For instance, if an agency provides a carer with respite care then it follows that the agency will need to have recorded at least some basic information about their care recipient (including their name, age and sex). As such, the necessary linkage information is likely to be more available to the agency and to equate more readily with agency needs and practice. Lastly, the potential sensitivity of the task is likely to be less, given that many of the care recipients in this case are likely to be receiving some form of HACC services also. Obtaining appropriate consent for the release of information would still remain an issue that would need to be addressed.

The Project Team considers the linking of client records across care dyads to be a worthwhile goal to pursue within the HACC MDS Collection. Without the capacity to link care dyads, the capacity of HACC program managers and planners to effectively assess the adequacy and appropriateness of the packages of care provided through the HACC program will be substantially diminished. The possibility of embedding linkage key data within HACC MDS records in such a way as to allow the identification of care dyads was discussed with agencies in the second field test.

What are the characteristics and circumstances of carers who are receiving assistance?

In relation to the fourth question outlined above (what are the characteristics and circumstances of carers who are receiving assistance from the HACC program?) the amount of relevant information generated by the HACC MDS again varies according to the role of the carer. Carers who are HACC clients should have their own HACC MDS record complete with the same information about their characteristics and circumstances as for any other HACC client, with the exception of the data element Carer Availability.

The HACC MDS will supply only a more limited profile of carers of HACC clients (i.e. those receiving indirect assistance from the HACC program), namely, their residency status and their relationship to the care recipient. The data domain for the relationship data element has been structured in such a way as to indicate the sex of the carer.

3.7 Key developmental area: dependency and need for assistance

When the Australian Institute of Health and Welfare was contracted to undertake further development of the draft HACC MDS, included within its purview was the development of appropriate data elements for the collection of information about client dependency and need. As has been previously noted, the Steering Committee decided to suspend further work in this area in August 1997 pending the results of several other developments in the field. Of particular relevance to the Steering Committee in this respect were the Community Care Classification Project (Hindle 1998) and the National Framework for Comprehensive Assessment (Lincoln Gerontology Centre 1998).

Prior to this decision, however, the Project Team had undertaken considerable work in this area. In particular, the Project Team undertook extensive comparisons with other data collections, data collection instruments and standard assessment instruments, to enable the development of appropriate dependency and need for assistance measures for inclusion within the HACC MDS. These comparisons have been included at Appendix B.

Tables B1 and B2 (Appendix B) compare the draft dependency items from the report by Brian Elton & Associates 1996) with data elements relating to physical and mental function from a series of 11 different data collections and data collection instruments, including:

- Aged Care Assessment Program Minimum Data Set
- Aged Care Application and Approval (then draft)
- Single Classification Instrument
- Domiciliary Nursing Care Benefit application form
- Commonwealth/State Disability Agreement Minimum Data Set

- Client Information and Referral Record
- Community Options Projects Client Characteristics survey
- Home and Community Care User Characteristics survey
- *Community Nursing Minimum Data Set Australia* Version 2.0
- Australian Bureau of Statistics, Survey of Disability, Ageing and Carers
- International Classification of Impairments, Disabilities and Handicaps

Tables B3, B4 and B5 (Appendix B) compare data elements relating to physical, mental and social function across a series of seven standard assessment instruments, including:

- Barthel Index (Mahoney & Barthel 1965)
- Bryan Domiciliary Dependency Instrument (as developed by the Royal District Nursing Service, Melbourne)
- Katz Scale (Katz et al. 1963; Katz et al. 1970; Katz & Amechi 1976)
- Resource Utilisation Groups (Fries et al. 1994)
- Older American Resources and Services (Center for the Study of Ageing and Human Development, 1978)
- Lawton and Brody Philadelphia Geriatric Center (PGC) Scale (Lawton & Brody 1969; Lawton 1978)
- Functional Independence Measure (Granger et al. 1986).

3.8 The final field test

During January 1998, the Project Team conducted its second and final field test, with visits to a total of 16 agencies. They were located in Queensland, New South Wales, Victoria, South Australia, Tasmania, and the Northern Territory. The consultation document prepared for field testing was also sent to a total of four agencies in Western Australia and the Australian Capital Territory and to all members of the HACC MDS Steering Committee for written comment. Agencies included in the final field test are listed in Table 3.4.

The agencies visited during this second round of field testing provided a wide range of service types, including home help, respite care, centre-based day care, allied health care, home maintenance and modification, nursing care, personal care, transport, community options, meals and social support. Agencies were chosen in such a way as to ensure not only a coverage of service types, but also to include those delivering multiple service types, Aboriginal agencies in both metropolitan and remote locations, agencies funded from multiple sources, agencies with State-wide or regional coverage, and agencies operating out of hospitals and area/community health centres. In general, agencies selected for inclusion in the second field test were deliberately chosen to be representative of agencies which provided assistance to relatively large numbers of clients and which had well developed information systems compared to the general pool of HACC-funded agencies.

The aims of the second round of field testing were:

- to expose the revised draft of the HACC MDS to a range of HACC agencies;
- to gain feedback on the proposed guidelines for the collection;
- to evaluate the clarity and comprehensiveness of proposed data definitions and data domains;

- to evaluate the relevance and adequacy of the draft HACC MDS to particular client groups and types of agencies; and
- to ascertain the difficulty experienced by agencies with relatively sophisticated information systems in supporting the MDS collection.

Table 3.4: Participating agencies, Field Test II

State	Agency
NSW	Wyong Aged and Disability Support Services, Wyong
	Home Care Service, NSW, Sydney
	Northern Sydney Area Health Service, Mona Vale Hospital, Sydney
	Northern Sydney Area Health Service, Royal North Shore Hospital, Sydney
Vic	Aged and Disability Services, City of Greater Geelong, Geelong
	Brotherhood of St Laurence Mornington Peninsula Linkages Project, Melbourne
Qld	Blue Nurses (Uniting Church in Australia, Division of Aged Care and Domiciliary Services—DACADS), Brisbane Centre
	Mt Gravatt Community Health Centre, Brisbane
WA	Silver Chain Nursing Association Inc., Perth
SA	Mid North Domiciliary Care, Port Pirie
	Aboriginal Elders and Community Care Service, Adelaide
	Red Cross, Adelaide
Tas	Family Based Care (North) Inc., Launceston
	Aged Care, Community and Rural Health, Department of Health and Community Services, Launceston
ACT	Respite Care ACT Inc., Canberra
	Home Help Service ACT Inc., Canberra
	Red Cross Meals on Wheels and Heavy Linen Service, Canberra
NT	Council of the Aged, Darwin
	Red Cross, Darwin
	Tangentyerre Council, Alice Springs

Procedures

As was the case in the first field test, agencies were asked to make available a half-day for a visit from the Project Team and were encouraged to involve staff with knowledge of their information systems and data collection practices. Each visit lasted between 2 and 4.5 hours, with an average of around 3.5 hours.

The consultation document prepared for the field test included an introduction to the project; information about the proposed statistical linkage key; a review of five of the key guidelines underpinning the collection; and drafts of the data elements proposed for inclusion in the HACC MDS. This document was sent out prior to visits, with most agencies receiving the documentation in ample time to peruse the material in some depth. The guidelines included in the consultation document are listed in Box 3.2 and the data elements are included in Table 3.5.

Perhaps the most salient feature of the list in Table 3.5 is the list of 20 data elements relating to the total amounts of assistance received by the person with different services activities.

While the presentation (rather than the intention) of this information was substantially modified for the final draft of the *HACC Data Dictionary*, the use of this format for field testing did serve to underscore to agencies the kinds of information that they would be required to report within a HACC MDS collection (see Section 4.2 for further discussion of the distinction between supporting and reporting data elements).

Box 3.2: Guidelines included in the consultation document

Guideline 1*: That the amount of service received by a client be recorded against the type of activity that was the primary or main focus of each instance of service delivery.*

Guideline 2*: That separate recording of Centre Based Day Care and other assistance received by a client at the same time in HACC-funded Day Care Centres is acceptable when the other type of assistance received is one or more of the following types:*

Nursing care at centre/other
Allied health care at centre/other
Centre meals

Guideline 3*: That, for MDS purposes, HACC agencies record the amount of each type of assistance received directly by the client, excluding time spent on behalf of a client and time spent travelling to and from a client.*

Guideline 4*: That for those data items recording the total amount of assistance received in hours, HACC agencies should ensure that the amount of time recorded for each occasion of service or visit is rounded to the nearest 5 minutes (or a higher level of accuracy).*

Guideline 5*: That where two or more clients of a HACC agency are living in a household that receives Domestic Assistance, Home Maintenance or Home Modification, the amount of these types of assistance received by the household should be divided equally between those clients whose needs the service is designed to meet.*

Results

Overall, the draft HACC MDS was well received by agencies, with surprisingly little concern about most of the proposed data elements, data definitions and data domains. Once agencies recognised the full implications of reporting by client—and for all clients for all time—there was more resistance to the collection as a whole but not to the actual data elements themselves.

Almost all agencies indicated concern about the costs required to support the level of reporting associated with a future HACC MDS collection, both in terms of staffing and the costs of system redevelopment. Agencies who had done substantial work on analysing and organising their own information flows and record keeping were less concerned with the scope and structure of the MDS, but still recognised the systems' implications and had some concerns with definitional issues. Some agencies with less well developed information management practices required access to more general information management training above and beyond the requirements of the HACC MDS. These agencies tended to be more concerned about the scope of the HACC MDS and their ability (or inclination) to support it.

Table 3.5: Data elements included in the consultation document

Agency identifier
Date of birth
Date of birth status
Sex
Linkage key
Client group type
Country of birth
Main language spoken at home
Indigenous status
Area of residence
Living arrangements
Carer availability
Carer type
Relationship of carer to care recipient
Type of accommodation
Type of tenure
Pension/benefit status
Compensable status
Date of entry into care
Source of referral
Date of first receipt of assistance
Date of last receipt of assistance
Client status
Main reason for cessation of service
Care setting at cessation of service
Total domestic assistance received
Total social support received
Total nursing care received at home
Total nursing care received at centre/other
Total allied health care received at home
Total allied health care received at centre/other
Total personal care received
Total centre-based day care received
Total home-delivered meals received
Total meals received at centre/other
Total other food services received
Total in-home respite care received
Total case management received
Total assessments received
Total home maintenance received
Total home modification received
Total goods and equipment received
Total transport received
Total education, information and training received

While the HACC MDS has major implications for computerised systems, it also has implications for primary source documents such as referral forms (including the CIARR), workers' timesheets, contracts and invoices from sub-contracted agencies. On some occasions Project Team members observed that relatively minimal changes to source documents would enable or facilitate agency compliance with HACC MDS reporting requirements, although this was not always immediately apparent to service providers themselves.

In general, agencies did not record each occasion of service and service provision was usually recorded via staff timesheets, invoices or billing procedures, or by individual contracts between clients and agencies. Information on staff timesheets was often not easily attributable to individual clients, while information contained in contracts usually provided planned rather than actual service provision. Agencies did not generally collect service provision information under categories that enabled mapping to the service activities included in the HACC MDS.

Agencies expressed concern about connections to funding, indicating a need for the program to clearly articulate the role of the HACC MDS in funding accountability. For example, many agencies were concerned that despite their own and the program's commitment to flexible and responsive service provision, they would be penalised for reporting honestly on activities not directly matching their funded service type(s). The level of concern about the connection to funding suggested that general assurances would not be sufficient to ensure accurate recording of what clients receive from agencies. One organisation also questioned the intention to require the reporting of HACC data at the agency/outlet level in the context of regional funding agreements.

Although only one agency raised this issue during field testing, comments from Steering Committee members highlighted the potentially difficult issues surrounding the level at which a HACC-funded organisation will be required to report for the HACC MDS. The Project Team's recommendation is that HACC MDS reporting should be at the service delivery level of any HACC-funded organisation, that is, as close as possible to the source of the data. The MDS does not include a data element identifying the individual agencies. Such an identifier is obviously required, but will have to be allocated by a central authority rather than collected from clients or allocated by each individual agency. Determining the components of the agency identifier will also require decisions by program managers on linkages to be made through the identifier with other relevant HACC administrative databases.

Most agencies indicated difficulties in identifying HACC-funded occasions of service, with some admitting to a general shuffling of funds (often at the end of the financial year). Many agencies were similarly open about the guesswork involved in their HACC Service Provision reporting, with one agency joking about their routine formula for calculating HACCSERV data.

Aboriginal agencies in remote areas

Overall, Aboriginal agencies in remote areas are likely to be very poorly equipped to report on the HACC MDS, with the extent of the problems being large enough to warrant consideration of a different type of collection and/or different data elements (e.g. place of birth). A different collection form that accommodates pictures rather than words (e.g. the Bubbles Segal Model) may help, but this will need to be supported by day-to-day documentation of activities and clients. The recent *Aboriginal and Torres Strait Islander HACC Financial and Management Training Manual* may be a useful resource in this regard (HACC program undated).

The linkage key

The Project Team discussed at some length the purpose and scope of the proposed statistical linkage key with the agencies. Agencies were informed that the Project Team would be recommending that record linkage be undertaken by an independent third party body rather than a government department, and that the linkage information be encrypted within the database, thereby ensuring that any potentially identifying information was removed from the record. In addition, where data were to be released to a government department or agency for analysis, various steps would be taken to further ensure client anonymity. This could include the removal of the encrypted linkage key, replacement of date of birth by year of birth, and the conversion of residential area information to a statistical local area or larger geographic region. Such measures would further reduce any potential identifiability of clients records.

Overall, the proposal to link client records for statistical purposes met with widespread agreement. Most agencies indicated that they would be able and willing to supply the information required for the statistical linkage key given adequate protocols for the protection of client confidentiality and privacy. A few agencies agreed with the principle of record linkage but remained sceptical about the capacity of the program to adequately guarantee client confidentiality and the appropriate use of the information. Several agencies indicated that they would need to revisit their process of obtaining client consent.

The Project Team also discussed the possibility of using linkage key data elements to link records across care dyads. It was found that the process of explaining why a so-called ‘linkage key for carers’ could be useful or necessary was difficult without conducting a somewhat lengthy and technical discussion with agency staff. As a result, some agencies may not have fully understood the purpose of the proposal.[*]

The difficulties involved in explaining the linkage process in relation to care dyads suggests that the idea of such a key may still be somewhat premature for the HACC program, given that a basic linkage key for HACC clients has not yet been established within the field. Nonetheless, the Project Team maintains that the HACC MDS should move toward linking client records across care dyads, and that the feasibility of this should be considered more fully within the context of pilot-testing.

Guidelines for the HACC MDS collection

Agency feedback on each of the five guidelines (see Box 3.2) proposed in the consultation document for implementation in the HACC MDS Collection is summarised below.

Guideline 1 (recording of type of assistance by primary focus) was supported by the majority of agencies. Many agencies strongly agreed, while only one strongly objected; some agencies reluctantly supported the primary focus rule once they recognised the implications of reporting on all activities by occasion of service by client. One agency suggested including a secondary activity as well (without amount); this is not currently recommended due to the added complexity for data collection and uncertain utility of such an option for data analysis.

Overall, the primary focus rule raised the most issues of any of the five guidelines, with disagreement and confusion chiefly related to concerns about the role of the MDS in funding accountability. Again, it must be reiterated that general assurances are unlikely to be sufficient to quell the anxiety of service providers. State/Territory HACC workers will also need training prior to implementation of the HACC MDS if agencies are to receive the kinds of clear and consistent messages which would encourage accurate reporting and reduce ‘gaming’.

Guideline 2 (separate reporting of concurrent provision of one-to-one assistance and centre-based day care by HACC-funded day care centres) attracted little comment, with most agencies deeming it irrelevant to the scope of their service provision. Agencies providing centre-based day care agreed, while others wanted more clarification about how and when it should apply.

This guideline has not been incorporated into the final *HACC Data Dictionary*, as it would be better incorporated into the ‘Guidelines for Collection’ document which will be required prior to implementation. The Project Team continues to hold the view that Centre Based Day Care is an incongruous category within a data element concerned with type of assistance—as it is more about setting than activity—and that Centre Based Day Care would be better incorporated into future MDS development of other types of clients (i.e.

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[*] At the time of the second field test, the Project Team was considering the possibility of embedding linkage key data in both of the directions mentioned in the discussion of linking care dyads in Section 2.6, that is, embedding information about carers in the HACC MDS records of care–recipient clients, and information about care recipients in the HACC MDS records of carer–clients. This would have enabled a more accurate count of the number of carers assisted through the HACC program by minimising problems with double counting. This aspect of the proposal discussed with agencies in the second field test served to further complicate the issue. Since that time, the Project Team has revised its position and now considers the use of such a key would be most feasible if it were restricted to embedding linkage key information about care–recipient clients in the HACC MDS records of carer–clients.

organisations and groups). Centre Based Day Care has, however, been retained in response to the Steering Committee's decision to include reporting on this type of activity by individual client within Version 1.0 of the MDS.

Guideline 3 (recording of direct assistance excluding activities on behalf of client and travel time) elicited considerable disagreement from many agencies. Although most understood the distinction between direct and indirect assistance, agencies argued that outputs should not be considered on their own and that HACC needs to recognise both the activities undertaken on behalf of a client and the total resources needed to account for a given level of output.

The definition of case management met with a surprisingly high (though not universal) degree of acceptance. Concerns about case management largely related to the difficulty of separating this type of activity from case coordination/case review and assessment activities. Agencies also expressed a strong desire to report on activity done on behalf of individual clients despite the implications for data recording. Some agencies misconceived the case management type of assistance as only applying to Community Options/Linkages/
Options Coordination agencies.

Agency feedback contributed to a significant reworking of this guideline within the final version of the *HACC Data Dictionary* (see Section 4.2).

Guideline 4 (the five-minute accuracy rule) was considered unrealistic by most agencies, with the majority of agencies recording time spent by workers in either 15- or 30-minute blocks (only one of the agencies was currently recording to a 5-minute level of accuracy). Even when recording in 15- or 30-minute blocks, most agencies did not record by individual client. Several agencies specified the amount of time or assistance that would be provided to the client (i.e. planned assistance) in a service contract/agreement, and relied on clients to inform them if workers did not abide by the contract. Client fees were generally based on 15-, 30- or 60-minute blocks, and this inconsistency would be likely to cause some problems (although recording assistance received at a 5-minute level of accuracy would not necessarily have to affect fees schedules).

In view of agency feedback, the Project Team revised its recommendation to specify a 15-minute level of accuracy in reporting, or a higher level of accuracy where agencies can support it.

Guideline 5 (splitting the amount of service between clients in the household for certain activity types) was supported by most agencies, although requiring a change in practice for many. Representatives from the Department of Health and Community Services in Tasmania indicated that such a shift would be problematic in the context of their new flat fee policy with some households being charged twice as much for the same amount of service. This guideline has not been incorporated into the final *HACC Data Dictionary*, as it would be more appropriately placed within the proposed 'Guidelines for Collection' document.

Recommendations

Implementation resource issues

1. It is recommended that two documents, 'Guidelines to the HACC MDS Collection' and a user-friendly 'Summary of the *HACC Data Dictionary*' be prepared to aid implementation. The *HACC Data Dictionary* will remain of relevance, but as a reference

text to be used by agencies in conjunction with other more easily digestible information about the HACC MDS collection.

2. It is recommended that a telephone helpline be established for the duration of the first collection/reporting period. This could be conducted at either the national or State/Territory level.
3. It is recommended that paper-based proformas for collection of the HACC MDS (for example the modified CIARR for client characteristics data) be designed and made available for service providers to aid in the streamlining/modification of their existing paper-based collections.
4. It is recommended that the construction of equivalent technical specifications for implementation in computer-based systems be referred for consideration by the proposed HACC Technology Consultancy.

Training issues

5. It is recommended that all HACC agencies as well as HACC Project Officers in State/Territory departments receive training about the purpose and scope of the HACC MDS; the record linkage process; and the role the HACC MDS collection plays in the overall HACC program accountability framework.
6. It is recommended that training resources be developed and implemented before the beginning of the first data collection/reporting period and be synchronised both within and across States and Territories.
7. It is recommended that general training in information management be provided or facilitated for HACC agencies to assist them to efficiently manage the overall information collection and flows within their agency, as well as with implementing the HACC MDS. To this end, consideration could be given to developing a training module for use in the HACC program on identifying management information needs at the agency level and developing and managing information systems (computerised and paper-based). Such training could be made available to agencies on a voluntary basis or to those agencies identified by Project Officers as requiring this training.
8. It is recommended that a module of basic information management training be included in the HACC MDS specific training program.
9. It is recommended that training to support the implementation of the HACC MDS pay particular attention to those data elements which are likely to be poorly collected by agencies, such as ‘Indigenous Status’.

Program issues

10. It is recommended that State/Territory and Commonwealth Governments clarify the relationship between the HACC MDS requirements (especially relating to service use) and administrative issues related to funding categories. Clear communication of the relationship between the HACC MDS collection and financial accountability mechanisms is considered essential to effective implementation of the HACC MDS.
11. It is recommended that the HACC MDS should be reported at the service delivery outlet level of a HACC-funded organisation—in line with the definition of the data element concept HACC Agency included in the *Data Dictionary*.

12. It is recommended that HACC program managers develop specifications for an agency identifier that makes appropriate links to administrative databases and which should be allocated to HACC agencies before a HACC MDS collection.

Aboriginal and Torres Strait Islander agencies

13. It is recommended that the usefulness and appropriateness of the HACC MDS should be reviewed in the context of the particular difficulties and circumstances faced by Indigenous communities, particularly those in rural and remote areas.
14. It is recommended that the HACC MDS be modified to take account of such considerations, with the involvement or oversight of the recently constituted Aboriginal and Torres Strait Islander Reference Group.
15. It is recommended that attention be directed to certain data elements associated with cultural issues (e.g. country of birth, carer data, locality names, person naming conventions) and to the general appropriateness of the *HACC Data Dictionary*, in terms of its level of complexity, literacy issues, etc.
16. It is recommended that the impact of different operational contexts found in many Indigenous agencies on the feasibility of the HACC MDS collection be considered.

Data development/data integrity issues

17. It is recommended that future developments of the HACC MDS encompass types of HACC clients other than individual persons, and the services they receive.
18. It is recommended that future developments of the HACC MDS encompass information about service providers and the organisations responsible for HACC service delivery.
19. It is recommended that the HACC program use information modelling techniques to assist with identifying and clarifying the program's information requirements.
20. It is recommended that future developments in the HACC MDS consider strategies which facilitate the collection of historical data, i.e. that agencies move toward developing the capacity to store updated information against particular data elements whilst retaining earlier versions.
21. It is recommended that the *HACC Data Dictionary* Version 1.0 be submitted to the National Community Services Information Management Group for endorsement and for the consideration of data elements for inclusion in the *National Community Services Data Dictionary*.
22. It is recommended that consideration be given by the National Community Services Data Committee to the establishment of an aged and community care data working group to oversee data development activity in the aged and community care field.

Assessment and dependency issues

23. It is recommended that the development of data elements related to dependency and assessment be treated as a priority in future HACC MDS development.
24. It is recommended that attempts be made to include information about both a client's need for assistance and assistance received, as an indicator of 'unmet need'. Such measures should, if possible, be aligned to the ABS Survey of Disability, Ageing and Carers.

25. It is recommended that the need to develop a comprehensive assessment tool for carers should be referred to HACC Officials.
26. It is recommended that any comprehensive assessment of carers should incorporate information about the assistance provided by carers as well as information about the care recipient's need for assistance. Such measures should be aligned, if possible, with the ABS Survey of Disability, Ageing and Carers, to facilitate valid comparisons between HACC and ABS data and to facilitate the identification of principal carers.
27. It is recommended that consideration be given to the development of protocols to encourage consistency across service providers in attributing client status and assistance to carers and care recipients.

Carer linkage

28. It is recommended that further consideration be given to the implementation of the linkage key for carers in order to enable the identification of care dyads and to assist in gaining a more reliable count of carers assisted through the HACC program.
29. It is recommended that, where possible, strategies should be developed to minimise error associated with changes in name (e.g. capacity to report a previous linkage key in the MDS where change of name is known to have occurred could be considered).

4 The *HACC Data Dictionary*

4.1 Introduction

The process of drafting the final version of the *HACC Data Dictionary* brought to the fore a number of issues and tensions which had been under consideration throughout the life of the project, but which were not fully clarified and resolved until its final stages. All of these matters had been the subject of lengthy deliberation by the Steering Committee, with successive stages of the project generating additional input and information to the deliberative process. The first issue requiring resolution at the stage of drafting the *Data Dictionary* was to clarify the difference between a minimum data set and a data dictionary. While the two terms are often used interchangeably, the task of producing the *Data Dictionary* forced the Project Team and the Steering Committee to revisit the distinction between the two. Other issues requiring similar resolution and clarification at this stage of the project were the emerging distinction between supporting and reporting data requirements, the need to identify HACC-funded support and assistance, and the resolution of the issue surrounding direct versus indirect assistance to HACC clients. These issues are discussed in Section 4.2.

The analytical framework for the data set is also worthy of some elaboration, as without it the rationale for particular data elements remains unclear (Section 4.3). Service episode remained an intractable problem within the MDS, with considerations of accuracy and comprehensiveness in direct opposition to those of practicality and feasibility. The level of detail required for accurate and comprehensive information on this important data concept remains beyond the data collection capacity of most HACC service providers (Section 4.4). The chapter concludes (Section 4.5) with an overview of the *Data Dictionary* itself, providing an introduction to the material published in the *HACC Data Dictionary* Version 1.0.

4.2 Drafting the *Data Dictionary*

Differentiating between a minimum data set and a data dictionary

A major issue which emerged in the process of drafting the *HACC Data Dictionary* was the difference between a minimum data set and a data dictionary. While the process undertaken by the Australian Institute of Health and Welfare was one of developing and refining the HACC minimum data set, the actual product of the consultancy was to be a HACC data dictionary which could support such a collection. While these terms are often used loosely or interchangeably, there are significant differences in their purpose and scope.

A national minimum data set (NMDS) is a minimum set of data elements and standards for collection across an industry or field at a national level. A NMDS is contingent upon a national agreement to collect uniform data and to supply it as part of the national collection. The agreed common core of data elements is intended to meet the reporting needs, but does not preclude agencies and service providers from collecting additional data to meet their own specific needs. That is, it is not necessary that agencies collect only identical data or have the same data collection systems.

A NMDS can also be seen as a specified subset of data elements from a data dictionary that will be collected nationally in a forthcoming collection period. That is, the data elements which constitute a NMDS may change from one collection period to the next, providing that the subset of data to be collected and reported within a given period is agreed by all relevant parties.

Key words that describe a national minimum data set include:

- minimum
- standards
- agreement
- collection and
- reporting.

The HACC National Minimum Data Set is thus a minimum set of data elements and standards agreed to be collected and reported nationally by all HACC-funded agencies.[*] That is, the HACC NMDS requires an agreement, needs to specify a minimum set of items, requires standardised data elements, must be collected and reported, and is national in scope.

A data dictionary is a vehicle for specifying data collection standards. Insofar as a data dictionary establishes such standards, it is a useful and necessary tool for enabling the collection of a NMDS. Nonetheless, a data dictionary does not normally specify what data elements are to be included in a NMDS for a given collection/reporting period. Nor does a data dictionary normally specify the format in which the information is to be reported, as the required reporting format may vary over time.

The tension for the current project lay in the need to accommodate the purpose and scope of the HACC NMDS (essentially a set of reporting requirements) within the format of a data dictionary (essentially a set of collection standards). That is, the one product needed to:

- specify the minimum data requirements for HACC agencies;
- establish standards for the consistent collection of this information; and
- indicate how this information is to be reported by agencies at the end of each reporting period.

The Project Team achieved this by differentiating between supporting and reporting data requirements and by adding two extra fields to the data specification format that forms the basis of the *HACC Data Dictionary* Version 1.0. These were the Reporting Status field and the Reporting Requirements field (see Section 3.3).

The fifth and arguably most important aspect of a NMDS, that is, the agreement to collect and report a given set of data elements, was not within the purview of the *Data Dictionary*, nor within the scope of the present project. While the Project Team has sought Steering Committee approval throughout the process of developing and refining the HACC MDS, the ultimate political decision to implement the proposed collection remains with Commonwealth, State and Territory Governments.

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[*] For the sake of readability (and as a result of the shorthand convention employed by Commonwealth and State/Territory HACC Officials in referring to this project) the report refers throughout to the HACC MDS rather than the more technically precise HACC NMDS.

Differentiating between supporting and reporting data requirements

As noted above, the Project Team introduced two new fields to the data specification format of the *HACC Data Dictionary*—the Reporting Status field and the Reporting Requirements field.

The Reporting Status field is used to indicate to HACC agencies:

1. whether a particular data element needs to be recorded by the agency as part of its ongoing day-to-day information-gathering practices; and
2. whether the data element needs to be reported by the agency as part of the HACC MDS collection (i.e. data transfer) which will take place at the end of each reporting period.

This distinction between the day-to-day recording of information by agencies and the periodic reporting of information to government authorities forms the basis of the distinction between supporting and reporting data requirements.

The Project Team has used the term 'supporting data requirements' to refer to those data elements that the agency needs to record on a day-to-day basis as part of ongoing service delivery to clients. Supporting data requirements include basic information about a client's characteristics and circumstances, and the services they receive from the agency. This data would be gathered by the agency during standard processes such as intake, assessment and exit, and during the course of providing support and assistance to the client. If an agency routinely collects all of the supporting data requirements specified within the *HACC Data Dictionary* it will be able to meet the reporting requirements of the periodic HACC MDS collection accurately and reliably and without undue burden.

The Project Team has used the term 'reporting data requirements' to refer to those data elements which the agency needs to report as part of the periodic data transfer associated with the HACC MDS collection. This data transfer will occur at specified time intervals (e.g. every 6 or 12 months) and will require information about the characteristics and circumstances of the clients assisted by the agency, as well as summary information about the total amounts and types of assistance they have received during the reporting period.

Many data elements within the *Data Dictionary* are designated as both supporting *and* reporting data requirements, such as Living Arrangements or Source of Referral. This simply means that this information needs to be recorded by the agency during the course of normal service provision *and* reported as part of the HACC MDS collection. For supporting and reporting data elements, the agency uses the same codes and format for reporting the information within the HACC MDS collection as they use for recording it on a day-to-day basis.

Some data elements within the *Data Dictionary* are supporting data requirements only. This means that these data elements are recorded by the agency on a day-to-day basis but are not themselves reported within the HACC MDS collection. Rather, they are included within the *Data Dictionary* to support other data elements that are derived from them. Conversely, other data elements are reporting data requirements only. This means that these data elements are not directly recorded by the agency, but are derived from other data elements for reporting purposes associated with the HACC MDS collection.

For instance, First Given Name and Family Name/Surname (supporting data requirements) are not reported within the HACC MDS collection. However, the agency does need to record this information as part of their routine practice in order to derive the data element Letters of Name (reporting data requirement) which does need to be reported as part of the HACC MDS collection. Similarly, data about individual service events (supporting data requirements) are not directly reported but are used to derive the client's total service utilisation for the reporting period (reporting data requirements).

The Reporting Requirements field is used to indicate to HACC agencies exactly how particular data elements should be reported within the HACC MDS collection (for instance, the client's most recent Date of Entry into Service Episode or the most recent record of their Living Arrangements). Where a particular data element does not need to be reported as part of the HACC MDS collection (that is, where the data element is a supporting data requirement only) this is reiterated within the Reporting Requirements field.

Identifying HACC-funded support and assistance

Differentiating between supporting and reporting data requirements allowed the Project Team to tackle some of the basic issues in agency-level data collection practices which had emerged during field testing. In particular, it had become clear that most agencies were poorly equipped to accurately calculate or report service utilisation data or to separate HACC-funded service provision from that funded by other programs or from other sources. Not only did this suggest that data provided as part of the existing HACCSERV collection had been subject to substantial guesswork, but it also suggested that accurately reporting the HACC MDS would present substantial difficulties for most agencies given current data collection and information management practices.

To accurately report service utilisation data for the HACC MDS, an agency would need to:

- collect data about individual service events;
- be able to attribute individual service events to individual clients; and
- be able to separate HACC-funded service events from those funded from other sources.

While such requirements may seem straight-forward, it was clear from field testing that very few of even the more sophisticated HACC-funded agencies could do this with any degree of ease or precision. The inability to identify HACC-funded service events and attribute these to individual clients results in an inability to accurately determine client service use over time.

For the quality of HACC service utilisation data to improve, then, agencies need to change their basic day-to-day data collection practices. Moreover, simply specifying the *reporting* requirements for service utilisation data is unlikely to be a sufficient incentive to promote a coherent move in this direction.

For example, informing agencies that they will be required to report the total amount of each service activity type that a person has received within a given reporting gives no clear indication as to how the agency should adjust their day-to-day practices to enable this.* The likely result then would be a continuation of current practices and continued poor quality data based on rough calculations made by the agency at the end of each reporting period.

To overcome this the Project Team has specified a cluster of data elements which describe individual service events. These form the bedrock for the collection and reporting of service utilisation data within the HACC MDS. An agency using the *HACC Data Dictionary*

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* Service utilisation data differs from other data elements in this respect insofar as the 'building blocks' required to report total service use are not immediately apparent. By contrast, if an agency is told that it will be required to report client Living Arrangements according to specific categories then it is immediately apparent that the agency needs to collect such information in a comparable format.

Version 1.0 as the basis of their information collection practices would record data about each service event, including:

- the date on which the service event took place;
- the primary type of assistance received by the client;
- the amount of assistance received (in an appropriate unit of measurement);
- the service delivery setting (only for service events involving nursing, allied health care or meals); and
- the funding source.

While this may at first glance appear substantial, it may not be so onerous once incorporated into the day-to-day practices of the agency. Indeed, it is not that agencies do not collect data about what they do. In fact many agencies already collect a comparable amount of information about day-to-day service provision in the form of timesheets, case notes, contracts, invoices, etc. Indeed, for many agencies there would be substantial efficiencies to be gained by clarifying the purpose of collecting information and by rationalising the processes by which that information is recorded and reported. The Project Team hopes that the specification of the basic building blocks required to support the reporting of service utilisation data will assist agencies in this respect.

To some extent, HACC-funded agencies can tailor data elements to their own operational needs and requirements. For example, an agency that never provides nursing care, allied health care or delivered meals would not need to include the Service Delivery Setting data element within their data systems. Similarly, an agency that does not provide assistance with goods or equipment, or undertake home modifications, would not need to include the data elements relating to those service activities in their information systems.

The operationalisation of the data element Funding Source Category will also vary from agency to agency. The *HACC Data Dictionary* Version 1.0 specifies that Funding Source Category be collected at the level of individual service events. This is to underscore the importance of the agency being able to clearly separate HACC-funded support and assistance from that funded from other sources at the most basic level. This is particularly relevant for agencies with multiple sources of funding (e.g. Home and Community Care, Veterans' Affairs, Commonwealth/State Disability Agreement, etc.), but is also relevant to fully HACC-funded agencies under certain circumstances (e.g. where an insurance company covers the cost of services to a client).

Some agencies may be able to record the funding source category at a higher, more administrative level. For example, if certain types of assistance are always funded from the same source within an agency, or if certain clients belong to a specific funded project, then the agency may choose to record this information only when it changes. Where this is the case the agency would still need to date any changes in the funding source category for the person, to enable the separation of HACC from non-HACC support and assistance over time.

The extent to which an agency chooses to use the HACC MDS as the basis for their information collection strategy and practices may also depend on the centrality of HACC funding to the workings of the agency. An agency which is 90% HACC-funded may choose to implement the HACC MDS as the basis of its data collection for all service provision, whereas an agency which is only 10% HACC-funded may have less incentive to adjust its data collection practices to the same extent.

Overall, then, these elements of the *Data Dictionary* are intended to function as a basic template or framework for the collection of service utilisation data within the HACC program. Nonetheless, agencies should exercise caution in modifying data elements for their own purposes where such changes may undermine the integrity or internal consistency of the *Data Dictionary* as a whole, or the agency's capacity to adequately and accurately meet the reporting requirements of the HACC MDS.

Direct versus indirect support and assistance

It was clear from the outset of the project that the proposed HACC MDS collection would not be able to accommodate all types of assistance provided by agencies across the HACC program. In part, this related to the client types which could be feasibly incorporated into the first version of the HACC MDS. While the collection is client centred, the concept of client as developed in Version 1.0 of the *HACC Data Dictionary* was deliberately limited to individual persons receiving HACC-funded assistance from agencies. That is, it was recognised that at this stage the collection would not be able to accommodate other types of HACC clients such as organisational clients, groups of clients or anonymous individual clients (e.g. one-off telephone enquiries), or the assistance provided to such clients by HACC-funded agencies.

The shift from an agency to a client focus also impacts on the kinds of activities that can be reported within the HACC MDS. This is in line with the shift away from measuring agency inputs toward measuring client outcomes (or outputs). In effect, the client focus of the collection means that only service activities which are directly associated with individual clients can be reported within the HACC MDS collection. For example, there is no scope for recording general agency tasks such as internal training and staff development, drawing up rosters, completing timesheets, or ordering supplies. While these are essential to the ongoing viability of the agency, they are not activities which are directly associated with or attributable to individual clients and as such are not within the scope of the HACC MDS.

Less clear cut are those kinds of service activities which are undertaken on behalf of individual clients but which do not involve direct client contact. In particular, an agency may need to spend considerable time in case coordination type activities which enable or support the provision of direct face-to-face assistance to a client. Such assistance might include liaising with other service providers or government agencies about the needs or circumstances of a client, making arrangements necessary to the effective provision of services to an individual (such as organising equipment) or administrative activities associated with providing assistance to the person (such as case planning and review, or writing case notes).

While such activities are essential to service delivery, they were initially excluded by the Project Team on the grounds that they retained an emphasis on agency inputs rather than client outcomes and experiences. It was thought that many HACC clients would be unaware of the organisational activities which support direct face-to-face assistance and that such activities would not be perceived by many clients as part of the assistance they receive from the agency. Project staff also considered the possibility that recording this level of detail on a day-to-day client by client basis may present difficulties for agency staff.

As such, the draft HACC MDS taken to field testing in January 1998 specifically excluded these forms of 'indirect 'assistance from the scope of the collection. The one exception to this was the inclusion of formalised case management which was defined in such a way as to include both direct and indirect assistance, as it was considered unrealistic to restrict 'reportable' case management to only those activities which involved the client directly. Case management was considered a sufficiently discrete and identifiable service activity type to warrant its inclusion within the HACC MDS and was seen as essential for many

Community Options and Linkages projects that were not involved in the direct provision of other types of service activities.

This approach was modified in the face of strong representations by agency staff who participated in field testing of the HACC MDS. Agencies objected to the different status accorded to case management and case coordination activities within the draft document. While agencies agreed with the general concept of formalised case management services and applauded its inclusion as a separate category, they also felt that the time and energy which they expended in case coordination activities internal to their agency should also be included within the scope of the collection. Moreover, they argued convincingly that internal case coordination was attributable to individual clients and that it was a specific and identifiable service activity that contributed to client outputs and to improved client outcomes.

In response to these concerns, the final version of the *HACC Data Dictionary* includes both direct and indirect assistance provided to individual clients. That is, the HACC MDS retains the qualification that assistance be associated with a specific individual, but does not distinguish direct client contact from other service activities. To accommodate this decision, the data element Primary Type of Assistance Received was modified to include the category case planning/review and coordination, which can accommodate both face-to-face assistance provided to an individual as well as planning, review and coordination activities undertaken by the agency on behalf of an individual.

The Project Team and the Steering Committee concluded that the inclusion of both direct and indirect support and assistance would enable the HACC MDS to more adequately reflect the package of care provided to clients by HACC-funded agencies. Recognising case coordination type activities also addressed service provider concerns as to where this activity fitted within the MDS.

A final advantage associated with the decision to include indirect assistance is that such assistance can be recorded as a 'service event'. This alleviates some of the difficulties associated with defining services episodes within the HACC MDS collection, given that the processes by which clients are accepted into and discharged from agency records often involve activities which are not face-to-face client contact.

4.3 The analytical framework

Throughout the process of developing the HACC MDS the Project Team needed to take account of the probable information needs of Commonwealth, State and Territory Governments. This included both the kinds of data which would need to be collected by the HACC MDS and the ways in which such data would or could be used by various jurisdictions for various purposes (planning, monitoring, review, research). Such considerations have influenced the content and structure of the HACC MDS and the *HACC Data Dictionary* throughout. In essence, the design of the HACC MDS and the *HACC Data Dictionary* required a coherent analytical framework which ensured that maximum utility could be gained from the data development exercise. An explicit understanding of that framework is a helpful introduction to understanding the final structure of the *Data Dictionary* itself.

The analytical framework for the HACC MDS can be conceptualised as a four-tiered structure.

- At the most basic level are the fundamental concepts which underpin the entire data collection—data element concepts such as HACC Agency, HACC Client, Carer, HACC Service Event, HACC Service Episode and Record Linkage.
- At the second level is the data that agencies record on a day-to-day basis. This is the level of supporting data requirements and includes data about clients, their characteristics and circumstances, and the services they receive on an ongoing or day-to-day basis.
- At the third level is the data that agencies actually report as part of the HACC MDS collection. This is the level of reporting data requirements and includes a subset of data about client characteristics, circumstances and service episodes, as well as summary data about the total services that a client has received over a given period of time (i.e. the specified reporting period).
- At the fourth level is the way the data generated by the HACC MDS collection is used—the kinds of analyses which the data are required to support and the conclusions which may be drawn from them.*

Although the HACC MDS Project worked within this analytical framework, it largely proceeded without the benefit of defined management reporting requirements—an important component of the fourth level. The Project Team recommends early consideration of the program's management reporting requirements based on the data to be reported in the HACC MDS collection.

For the most part, the rationale for including the data elements in the *HACC Data Dictionary* will be relatively transparent. For example, information about sex or country of birth is recorded by agencies, reported as part of the HACC MDS collection, and used to answer basic questions about the demographic profile of HACC recipients.

However, the *HACC Data Dictionary* Version 1.0 also includes two data elements which relate specifically to what came to be referred to by Steering Committee members as 'the fourth column' (or in this context the 'fourth tier') and associated considerations. These are Date of Last Assessment which relates to establishing data currency for certain data elements in linked records; and Reason for HACC Client Status which relates to ability of the HACC program to identify carers and the assistance they receive. Given that the rationale for these data elements may not be readily apparent, the reasons for their development and inclusion are detailed below.

Determining data currency

One issue requiring resolution in the context of the HACC MDS was the potential for (indeed, the likelihood of) some variation in a client's circumstances over time. While this may be manageable if records were to be analysed at the agency level, it emerges as a significant problem once HACC MDS records are linked across different agencies. Variability in client circumstances means that different HACC agencies may submit conflicting data about the same person within the same reporting period, making it difficult to establish an accurate profile of the individual for data analysis purposes.

To illustrate this difficulty, assume that the record linkage process has accurately linked three records which belong to Client A and that the information in these records has been

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* This level includes client record linkage, as the linkage process is designed to support statistical analyses, and to answer basic questions about the people serviced by the HACC program and the packages of care that they receive.

accurately collected and reported by the three HACC agencies in question. These HACC MDS records may still contain conflicting data about Client A's circumstances. For example, two agencies may record Client A as living alone, while the third records her as living with family; one might record her as having a co-resident carer who is a spouse, one as having a non-resident carer who is a daughter and the other as having no carer at all; two might record her as living in a private residence and the other as living in a retirement village; one might record her as living in Brisbane while the other two record her as living in northern New South Wales, and so on. Each of these records may represent an accurate picture of Client A's circumstances at the time of her involvement with each agency.

For data analysis involving linked records and client circumstances, however, one needs to be able to establish a single profile of a given client. To enable this the HACC MDS includes the data element Date of Last Assessment. Date of Last Assessment is a reporting data requirement that is derived from the data elements Date of Receipt of Assistance and Primary Type of Assistance Received. In effect, the Date of Last Assessment is the date on which the client last received a HACC service event from the agency for which the primary type of assistance received was assessment. This data element assumes that information about a person's circumstances should be at least as current as the person's last assessment or reassessment (in line with the collection requirements for these data elements). As such, the Date of Last Assessment can be used to select the most recent profile of the client's circumstances across multiple agencies for the purposes of data analysis.[*]

At present the problem of determining data currency only affects those data elements that relate to client circumstances. Other data included in the HACC MDS are not affected by this problem either because they can be assumed to remain stable over time (e.g. sex, country of birth), or because they only relate to the interplay between a single client and a single agency (e.g. service utilisation data and data about the person's episode of care within the agency) and therefore do not present the same potential for conflict at the higher level of aggregation required for client-centred data analysis. Nonetheless, the problem of determining data currency will become similarly problematic for dependency and need for assistance data once these are incorporated into the HACC MDS collection.

Identifying carers and the services they receive

Given that carers constitute a specific subsection of the HACC target group, the HACC MDS also needed to enable the separate identification of carers and the assistance they receive. Such information is necessary for program planning and accountability, and for answering basic questions about the interaction between carers and the HACC program.

As outlined in Section 3.6, carers are of interest to the HACC program in three different roles or capacities. Namely, where a HACC client *has* a carer; where a HACC client *is* a carer; and where a HACC client *is both* a frail or disabled older person or a younger person with a disability *and* a carer.

Where a HACC client has a carer, this can be readily identified via the Carer Availability data element. Such carers are considered to be indirect recipients of HACC-funded assistance within the HACC MDS, as the assistance received by the frail aged or younger disabled person for whom they care can be considered to alleviate the burden of care and contribute to the wellbeing of the carer.

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[*] Where no Date of Last Assessment is available (insofar as some types of agencies may be less likely to undertake assessment activities) the date of entry into service episode could be used as a proxy for this purpose.

More difficult is the identification of carers who are clients, that is, carers who are direct recipients of HACC-funded assistance. While the distinction between younger and older HACC clients can be made on the basis of age, a specific flag is required to distinguish a carer–client from a frail or disabled older client or a younger client with disabilities; and to identify where a person receives assistance as both a carer and as a frail or disabled older person or a younger person with disabilities. The capacity to distinguish between such clients is required to support the analysis of total assistance received by particular sub-groups of the HACC client population. The data element Reason for HACC Client Status was developed for this purpose.

Reason for HACC Client Status is both a supporting and reporting data requirement that indicates why the client receives HACC-funded assistance from the agency. As a supporting data requirement, Reason for HACC Client Status is recorded historically and indicates why the person receives HACC-funded assistance at a given point in time. As a reporting data requirement, it summarises the reason(s) why the person has received HACC-funded assistance from the agency during the reporting period.

The need to summarise the reason(s) for HACC client status over the reporting period results from the fact that a person may have multiple service episodes during a reporting period; or may receive assistance from an agency for different reasons over time. A summary indication of why the person has received assistance from the agency is therefore more comparable to the (summary) measures of total assistance received during the reporting period. It also allows assistance provided by the HACC program to be more readily attributed to particular sub-sections of the HACC client group at the stage of data analysis.

The data element Reason for HACC Client Status does not, however, allow for the identification of care–recipient/carer dyads in the HACC MDS. This is of particular interest for data analysis purposes where both care recipient and carer are clients of the HACC program, and where services received by the dyad may be divided between the two in agency records. The possibility of implementing a ‘carer linkage key’ has been discussed in previous sections of this report (see Sections 3.6 and 3.8) and while it may not be feasible to implement such a linkage key immediately, the area is one in which the Project Team recommends further developmental work be undertaken in subsequent versions of the HACC MDS.

4.4 Service episode

Some of the more intractable difficulties faced by the Project Team in developing the HACC MDS and the *HACC Data Dictionary* related to the capacity of the data collection to accommodate data requests based on service episodes, or the equivalent information provided by measures such as length of stay in a nursing home or bed days in an acute care hospital. While of interest in its own right, such a measure is also a necessary element in order to calculate intensity of service provision to HACC clients (i.e. amount of service in relation to a specified period of time).

Given that previous HACC collections have relied on aggregated agency level data, the move toward a client-centred collection will represent a substantial and time-consuming shift in practice for most HACC agencies. Any shift toward implementing a data collection which entails reporting data by client by service episode would constitute a much more far-reaching and intensive shift again. Indeed, defining collection and reporting requirements to support detailed length of stay and intensity data would add considerably to the data collection burden facing HACC-funded agencies.

The difficulties associated with service episodes are basically twofold. Firstly, there are conceptual and logical considerations (and their systems ramifications) about how service episode data could or should be implemented within the HACC MDS. Secondly, there are policy and program level issues which militate against an overly prescriptive operationalisation of service episodes within the proposed HACC data collection.

Conceptual and logical issues

The logical complexities of service episodes relate to the level at which service episode data is implemented. Indeed, there is an inherent tension between defining data elements to their most conceptually tidy level; and maintaining a reasonably feasible set of data collection and reporting requirements for HACC agencies given the current state of systems and data literacy across the HACC field.

To implement a data collection predicated around service episodes, one needs to agree on how far down the logical path toward refining and defining the concept of ‘service episode’ one would wish to go. For instance, would one require agencies to report total services received by service episode (rather than the current requirement of total services received within a reporting period)? This in itself would have substantial implications for data collection, storage and transfer, as it requires the potential to report data about multiple service episodes for each client.

The complexities do not stop there, however. Many clients receive multiple types of assistance from a single agency within the same time period. As such, to give a better indication of intensity and length of stay one would need to pitch the concept of service episode at the level of each service activity type—for example, a person may receive intensive community nursing over several short periods of time but assistance with personal care over an ongoing period of several years, both from the same agency. That is, the person would have several discrete service episodes each of which involve X amount of nursing care, and one more prolonged episode involving Y amount of personal care. To analyse length of stay and intensity at this level implies a requirement to collect and report not only total service receipt by service activity type by service episode, but also dates of entry and exit (and other associated data such as source of referral, reason for cessation, etc.) for each episode of each type of service activity for each client of an agency. Such requirements are likely to be too demanding for even the most sophisticated of HACC agencies.

To analyse length of stay or intensity in relation to basic client characteristics—such as living alone or not having a carer—implies yet another level of complexity in data collection. In fact, client characteristics change over time and relate more logically to a particular service episode than to a superimposed ‘reporting period’. Moreover, the changing circumstances of a client give rise to the need for different types of services at different times. For example, a client who has a carer may receive some social support and domestic assistance. However, if that carer were absent for a time they may also require meals, personal care and transport. Yet to enable such analysis also requires the collection of data about a client’s circumstances (area of residence, living arrangements, carer availability, accommodation setting, etc.) at the beginning of each episode of receipt of each type of service activity type for each client of an agency. This would be in addition to the data about the amount of the service activity actually received, and associated entry and exit information.[*]

In an ideal world, such a system would enable some fascinating data analysis. In the context of the HACC program, however, any such move would be patently implausible given the current state of affairs. Even moving to the first level of complexity—reporting service use and client characteristics by the broadest understanding of service episode—would require considerable investment in agency information systems, and the extensive and sophisticated use of computerised technology, if such a change were to result in consistent quality data across the HACC field.

Policy and program issues

The second area of concern relates to policy and program level issues within the HACC field. Indeed the above discussion has assumed that irrespective of the level at which one defines a service episode, the actual identification of a discrete service episode would be straightforward. Yet there are few if any standardised processes and protocols associated with the beginning and ending of service episodes across the HACC field. Moreover, those protocols that may be said to exist—such as a basic determination of eligibility or need for service—are not rigorously specified by the HACC program.

This lack of specificity is in many respects one of the great strengths of the HACC program. Not only does it reflect the enormous diversity of HACC-funded agencies and their different operational requirements, but it allows agencies to respond innovatively and flexibly to clients with very diverse needs and circumstances. The lack of specificity in HACC procedures for entry and exit from services also allows HACC agencies to establish local service networks which facilitate a more seamless delivery of services to clients. This is particularly evident in terms of assessment and referral protocols, whereby established local networks can minimise duplication in basic entry procedures. For instance, a Meals on Wheels agency may accept referrals from the local GP, or a home modification agency may accept referrals from a local allied health worker or housing trust.

Yet this same flexibility means that entry and exit procedures are idiosyncratic in their application both from agency to agency and across different funded service types. No specific type of service event (such as a referral or assessment event) can be assumed to trigger either the beginning or end of service delivery in all cases. As such the concept of a HACC service episode resists rigorous definitional specificity. Indeed, attempts to rigorously proscribe a set format for 'service episodes' appear bound either to compromise the flexibility of HACC service provision or simply to fail to reflect ongoing practice in this area.

In accordance with this, the Project Team has not specified exact entry and exit procedures in the definition of HACC service episodes. To do so would be to drive policy and practice in the HACC field in a way that would far exceed the brief of the HACC MDS Project. Rather, a HACC service episode has been defined more broadly as 'a period of time during which a person receives HACC-funded assistance from an agency'. As such, a HACC service episode can begin and end with the receipt of any kind of HACC-funded service activity by the client (i.e. a HACC service event) and can involve the receipt of one or more types of HACC-funded support and assistance. While the definition qualifies that assistance

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[*] The same arguments would apply to information about client dependency and need once this is incorporated into the HACC MDS.

must be HACC-funded[*]—itself a substantial jump for many agencies—the loosely specified 'period' of assistance accommodates variations in agency practice.

This approach maintains the flexibility necessary to reflect current agency practice in this area. As a result, it is likely to generate more accurate data that is indicative of actual patterns of entry and exit from HACC services than would be the case had the Project Team been more proscriptive in defining service episodes. The chosen approach also retains an emphasis on the more general conceptual level (rather than moving toward the more 'logical' service episode by service activity type). As such, it is easier to both apply and collect given the current state of the information systems and practices of most HACC agencies, thereby keeping the data collection burden to a more acceptable and realistic level.

The weakness of the approach is that it remains open to inconsistent application, particularly in respect of the ways agencies understand and operationalise the concept of a 'period' of assistance. For instance, nursing or allied health care providers may implement discrete but often recurring 'periods' of assistance. By contrast, other types of agencies may tend toward more lengthy periods of assistance spanning months and years, irrespective of times when the client may not be actively receiving services from the agency (e.g. they may be 'on hold' or 'on suspension' for periods within a single 'service episode'). While these differences have implications for data comparability across agencies—and particularly across service types—they are a facet of current agency practice within the HACC field. Implementing a more coherent and comparable approach to the measurement of entry and exit patterns across agencies would require a more consistent approach to entry and exit criteria in practice—and that would require a concerted policy impetus from HACC program managers.

Service episode data within the HACC MDS

The five data elements which relate to service episodes within the *HACC Data Dictionary* are:

- Date of Entry into HACC Service Episode
- Source of Referral
- Date of Exit from HACC Service Episode
- Main Reason for Cessation of Services
- Accommodation Setting after Cessation of Services.

As will be evident from their names, the first two relate to the beginning of a service episode while the latter three relate to the end. In effect, the date of entry locates source of referral in time, while the date of exit locates the main reason for cessation and the accommodation setting after cessation in time.

All five of these data elements are supporting and reporting data requirements within the HACC MDS. As supporting data requirements, they are collected at the beginning/end of each service episode. As reporting data requirements, they are reported for the most recent

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[*] This does not mean that all assistance within a given period or service episode must be HACC-funded. The fact that the *HACC Data Dictionary* uses the concept of a service event as the basic building block for service utilisation data means that non-HACC-funded service events are simply excluded from the calculation of the total amounts of services received by the person (currently calculated on the basis of a reporting period rather than a service episode). Nonetheless, a non-HACC-funded service event would not begin or end a HACC service episode as the Date of Entry into HACC Service Episode and the Date of Exit from HACC Service Episode both relate to a specific HACC service event.

entry into a HACC service episode and the most recent exit from a HACC service episode that the agency has recorded for the person. It is anticipated that the reported dates of entry and exit will refer to the same service episode for most HACC clients. However, given the potential for multiple service episodes, and for incomplete service episodes at the time of data transfer, it is recognised that the date of entry and source of referral will not always relate to the same service episode as the date of exit, main reason for cessation and accommodation setting after cessation of services.

While this may appear at first glance to be a curious reporting requirement, it simply reflects the difficulties of accommodating service episodes within an arbitrary and superimposed reporting period. Given that service utilisation data are reported for the entire reporting period (e.g. January to June) rather than by service episode, the need to identify a single discrete service episode is also less critical than would otherwise be the case.

In terms of length of stay, the data generated will indicate the length of the most recent service episode for those HACC clients who have completed their most recent service episode. For those clients whose service episode is incomplete, the length of service episode can be calculated on a 'to date' basis. In addition, linking client records across reporting periods will give an indication of a person's general length of stay within the HACC program. For those clients with multiple 'service episodes', however, only the most recent episode will be reported in the HACC MDS collection.

In terms of intensity of service receipt, the HACC MDS will thus give a good indication of intensity for many, but not all, HACC clients. The clients for whom these data will be a poor indicator of intensity are those with multiple service episodes during the reporting period, as the MDS will furnish service episode data for only the most recent entry and exit from service provision. While the data will thus not be sufficient to support a universally accurate calculation of intensity of service, the fact that many HACC clients tend to receive services from agencies over protracted periods of time will reduce the error component in this regard. To enable a more accurate or detailed analysis of intensity would require service provision data to be reported by service episode and the capacity to report multiple service episodes for any given client. While this may be possible in the future, it was not considered feasible for the first stage of the HACC MDS collection.

4.5 *HACC Data Dictionary* Version 1.0: overview

The *HACC Data Dictionary* Version 1.0 was the major 'product' of the HACC MDS Project. It was completed in May 1998, and approved by HACC Officials. Those interested in obtaining a full understanding of the proposed HACC MDS are advised to refer to that document, which contains detailed information on the MDS.

For the purposes of this report, however, the following overview of the *Data Dictionary*, including its structure and contents, has been prepared. While some of the material presented below has been discussed elsewhere in the report, this section is intended to function as a summary and 'ready reference' to the *Data Dictionary*. Key terms are defined, and the main elements described.

The three data types

There are three distinct data types that describe the elements included within the *HACC Data Dictionary*. These are data element concepts, data elements and derived data elements.

The *HACC Data Dictionary* contains a total of six data element concepts, 31 data elements, and six derived data elements (see Table 4.1).

Data element concepts

Data element concepts are included to clarify the concepts underpinning related data elements within the *Data Dictionary*. These are neither supporting nor reporting requirements in themselves, but define the higher level concepts that many of the individual data elements describe. Dictionary entries for data element concepts are presented in a more limited format than other data elements.

Data elements

Data elements specify particular pieces of information which need to be collected by HACC agencies and in some cases need to be reported as part of the HACC MDS Collection. Of the 30 data elements included within the *HACC Data Dictionary* Version 1.0, 20 are supporting and reporting data requirements and 10 are supporting data requirements only. Data elements that are supporting and reporting data requirements need to be both collected by agencies and reported as part of the HACC MDS collection. Data elements which are supporting data requirements only are not reported in the HACC MDS collection but form the basic building blocks for accurately calculating other information which agencies do need to report.

Derived data elements

Derived data elements are data which are not collected directly but which are calculated or derived from other information specified for collection by HACC agencies in order to meet HACC MDS reporting requirements. The six derived data elements included within the *HACC Data Dictionary* are reporting data requirements only. (In effect, 10 data elements which are supporting data requirements only constitute the basic building blocks needed to accurately report on the six derived data elements which are reporting data requirements only.)

Data clusters

A more intuitive way to understand the *HACC Data Dictionary* is on the basis of what the different clusters of data elements do and the kinds of information they provide. In essence, the *Data Dictionary* includes information about client characteristics, client circumstances, service events, service episodes, and reporting periods.

As has been discussed, not all of this information is for reporting within the HACC MDS collection. Table 4.2 shows the different clusters of information included within the *Data Dictionary* and separates these out according to the reporting status of each item. Many of the data elements are listed in both the second and the third columns of Table 4.2. This simply reflects the fact that these data elements are both supporting and reporting data requirements within the *Data Dictionary*.

Table 4.1: Data elements by data type

Data element concepts

Carer
HACC agency
HACC client
HACC service episode
HACC service event
Record linkage

Data elements (supporting and reporting data requirements)

Accommodation setting
Accommodation setting after cessation of services
Area of residence
Carer availability
Carer residency status
Country of birth
Date of birth
Date of entry into HACC service episode
Date of exit from HACC service episode
Government pension/benefit status
Indigenous status
Living arrangements
Main language spoken at home
Main reason for cessation of services
Postcode
Reason for HACC client status
Relationship of carer to care recipient
Sex
Source of referral
Suburb/town/locality name

Data elements (supporting data requirements)

Amount of assistance received (cost)
Amount of assistance received (quantity)
Amount of assistance received (time)
Assistance with goods and equipment received
Date of receipt of assistance
Family name/surname
First given name
Funding source category
Primary type of assistance received
Service delivery setting

Derived data elements (reporting data requirements)

Date of last assessment
Letters of name
Total amount of type of assistance received (cost)
Total amount of type of assistance received (quantity)
Total amount of type of assistance received (time)
Total assistance with goods and equipment received

Client characteristics

Client characteristics are those pieces of information about a person which tend to remain relatively stable over time. While this is not always the case,[*] the propensity for change in this kind of information is assumed to be less than for information about client circumstances. In light of this assumed stability over time, there are no special considerations for reporting this information within the HACC MDS collection.

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[*] Name changes are the most obvious example here. Country of birth and date of birth are inherently stable but may be reported differently over time. Indigenous origin is also inherently stable, but the propensity of a person to self-identify as being of Indigenous origin may vary over time or across agencies.

Table 4.2: Data clusters by reporting status

	Supporting data	Reporting data
Client characteristics	Family name/surname	
	First given name	
		Letters of name
	Date of birth	Date of birth
	Sex	Sex
	Country of birth	Country of birth
	Indigenous status	Indigenous status
Client circumstances	Main language spoken at home	Main language spoken at home
	Living arrangements	Living arrangements
	Carer availability	Carer availability
	Carer residency status	Carer residency status
	Relationship of carer to care recipient	Relationship of carer to care recipient
	Area of residence	Area of residence
	Suburb/town/locality name	Suburb/town/locality name
	Postcode	Postcode
	Accommodation setting	Accommodation setting
	Government pension/benefit status	Government pension/benefit status
	Reason for HACC client status	
Service event	Date of receipt of assistance	
	Primary type of assistance received	
	Amount of assistance received (time)	
	Amount of assistance received (quantity)	
	Amount of assistance received (cost)	
	Assistance with goods and equipment received	
	Service delivery setting	
	Funding source category	
		Date of last assessment
Service episode	Date of entry into HACC service episode	Date of entry into HACC service episode
	Source of referral	Source of referral
	Date of exit from HACC service episode	Date of exit from HACC service episode
	Main reason for cessation of services	Main reason for cessation of services
	Accommodation setting after cessation of services	Accommodation setting after cessation of services
Reporting period		Total amount by type of assistance received (time)
		Total amount by type of assistance received (quantity)
		Total amount by type of assistance received (quantity)
		Total assistance with goods and equipment received
		Reason for HACC client status

Client circumstances

Client circumstances are those pieces of information about a person which tend to change over time on a relatively regular basis. This includes, for example, information about where a person lives, who they live with and the availability and nature of informal support, all of which can have an important bearing on a person's need for services. Given the changeability of this data, agencies are asked to update their records of client circumstances information on a regular basis (at the beginning of each service episode and during any subsequent reassessments as a minimum) and to report the most recent record available for each data element in the HACC MDS collection.* Information provided by the agency about the client's circumstances will be considered to be at least as up-to-date as the date of last assessment provided for the person.

Service events

Information about service events is included to help agencies in meeting the basic HACC MDS reporting requirements about client service use. These data elements were developed after it became clear that even agencies with very sophisticated information systems often had a very limited capacity to accurately report on services and assistance received by their clients within a given period of time. Indeed, one of the most salient findings of field testing was the difficulty experienced by agencies in identifying basic information about individual service provision events, with many agencies unable to specify the date or funding source for a given occasion of service.

These data elements, then, constitute basic information about service events that the agency should be recording on a day-to-day basis to enable the accurate calculation of service utilisation by individual clients over a period of time. That is, each time a client receives support or assistance from the agency, the agency should record the date, the primary type of assistance received and the amount of assistance received (in an appropriate unit of measurement).† For any service event involving the receipt of nursing care, allied health care or meals, the agency should also record the service delivery setting. Agencies also need to be able to differentiate between service events which are HACC-funded (either in whole or in part) and service events which are not HACC-funded. While this is particularly important for agencies with multiple sources of funding, it can also be relevant in certain circumstances to agencies which are only funded through the HACC program.

It is important to note that these data elements can be streamlined to suit the operational context and requirements of different HACC-funded agencies. While open to some degree of modification (see Section 4.2), the agency should ensure that:

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[*] To accommodate differential systems capacity across agencies, there are two options for reporting the area in which a client lives: either Area of Residence (comprising a one-digit State/Territory code and a four-digit SLA code), or Suburb/Town/Locality Name in conjunction with Postcode. In either case, the agency still reports the most recent record of this information held by the agency about the client.

[†] The Project Team had some difficulty resolving the measurement of assistance in the case of service events involving goods and equipment. Earlier drafts of the *HACC Data Dictionary* only included the purchase of goods and equipment for individual clients and measured this in cost terms. This was changed to the current format in recognition of the widespread practice of lending equipment rather than purchasing it outright for clients. As such, the agency should record the type of goods or equipment received by the person on a given occasion using the pre-coded list provided at Appendix C of the *HACC Data Dictionary*. At the end of the reporting period, the agency can specify up to ten different types of goods and/or equipment received by the client during that period.

- service events are attributable to individual clients; and that
- the date, primary type, amount, funding source and (where applicable) service delivery setting can be ascertained for each service event in a format consistent with HACC MDS reporting requirements.

With one exception, data elements which relate to service events are not for reporting within the HACC MDS collection. The one exception is the Date of Last Assessment which is a reporting data requirement derived from the data elements Date of Receipt of Assistance and Primary Type of Assistance Received. The rationale for including the derived data element Date of Last Assessment has been discussed in greater length in Section 4.3 of this report.

Service episode

As previously discussed, service episodes are only covered to a limited extent within the *HACC Data Dictionary*. In effect, the HACC MDS will only collect basic information about the person's entry into a HACC service episode (date of entry and source of referral) and exit from a HACC service episode (date of exit, main reason for cessation of services and accommodation setting after cessation of services). These data elements provide basic information about the patterns of interaction between the HACC program and other related programs and sectors within the health and community care field; and the patterns of client movement into and out of the care and support of HACC-funded agencies. These data elements can also be used to derive some indication of length of stay for most clients, and to estimate the number of current HACC clients at the end of any given reporting period.

Agencies are asked to collect these data elements for each HACC service episode and to report the most recent date of entry and source of referral, and the most recent date of exit, main reason and accommodation setting after cessation of services. For clients who have received multiple episodes of care from the same HACC agency, this reporting requirement may mean that reported dates of entry and exit (and related information) may refer to different service episodes (see Section 4.4).

Reporting period

Most of the data elements relating to a reporting period specify the format for calculating and reporting the total assistance received by a client during the specified reporting period. In effect, the agency is required to report a total for each of the types of assistance received by a client during this time. For example, during the reporting period January 1 to June 30 of a given year, Client A received 42 hours of domestic assistance, 12 hours personal care, home modifications totalling $460 and 73 home-delivered meals.

The one exception is Reason for HACC Client Status which is both a supporting and a reporting data requirement. As a reporting data requirement, Reason for HACC Client Status relates to a reporting period in that agencies are asked to summarise the reason(s) for which the person has received HACC-funded assistance from the agency within the reporting period. As a supporting data requirement (i.e. for collection), Reason for HACC Client Status is collected in the same format as the client circumstance data elements (see Section 4.3).

Recommendations

Data review issues

30. It is recommended that HACC program managers give early consideration to the program's management reporting requirements based on the data to be reported in the HACC MDS collection. This would assist in identifying any further gaps in the HACC MDS and should be done prior to the full implementation of the HACC MDS.
31. It is recommended that HACC Officials consider the need for ongoing review and maintenance of the *HACC Data Dictionary* after implementation in order to retain the currency, comprehensiveness and integrity of the MDS. However, caution is recommended in the development of new data elements for inclusion in the *HACC Data Dictionary* to ensure that the integrity and internal consistency of the *Data Dictionary* and the MDS are maintained.

5 Mapping the HACC MDS

5.1 Introduction

Throughout the course of developing the HACC MDS, the Project Team has taken considerable care to maintain comparability and 'mappability' between the data elements included within the *HACC Data Dictionary* and those of related collections without compromising the logic and integrity of the HACC MDS collection.

In line with the project brief, standards and data collections which have been given particular attention within this process have been:

- Australian Bureau of Statistics (ABS) standards;
- *National Community Services Data Dictionary* (NCSDD);
- *National Health Data Dictionary* (NHDD);
- *Community Nursing Minimum Data Set Australia* (CNMDSA);
- Client Information and Referral Record (CIARR);
- Aged Care Assessment Program Minimum Data Set (ACAP MDS);
- Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS).

Where data elements have aligned with or are mappable to ABS, NCSDD and NHDD standards, this has been indicated within the Source Document and Source Organisation fields of the data element template used within Version 1.0 of the *HACC Data Dictionary.* As such, the following discussion will concentrate on the mappability of the HACC MDS with the CNMDSA, CIARR, ACAP MDS and the CSDA MDS.

5.2 *Community Nursing Minimum Data Set Australia*

Considerable time and effort was devoted by the Project Team and those responsible for the CNMDSA to ensuring that the HACC MDS and the CNMDSA Version 2.0 were mappable. In addition to assisting with aligning these two data sets, the close liaison between the HACC MDS Project Team and those responsible for the CNMDSA has also been of great assistance to the Project Team in developing the HACC MDS.

Although the CNMDSA is not required to be collected by community nursing agencies receiving HACC funding, the CNMDSA is a well established and recognised data set that has been adopted by many community nursing agencies as the basis of their information systems. HACC Officials have also invested considerable resources in the development of this data set. Thus, alignment of the CNMDSA and the HACC MDS was considered to be an important aspect of the HACC MDS development process.

A considerable degree of consistency has been achieved between the two data sets. However, some inconsistencies remain. In particular, the following HACC MDS data elements are not totally mappable with the CNMDSA Version 2.0:

- Source of Referral

- Accommodation Setting
- Main Reason for Cessation of Services
- Accommodation Setting after Cessation of Services
- Carer Availability.

Source of referral

The data domain in the CNMDSA data element Source of Referral does not include a separate code for Comprehensive HACC Assessment Authority (code 5 in the HACC MDS Source of Referral). As these agencies have yet to be introduced in the HACC program, there may be an opportunity to add this coding option to the CNMDSA before they are established. CNMDSA coding option '20 Respite Care—any setting except Palliative Care' has no equivalent in the HACC MDS. If it can be assumed that CNMDSA code 20 applies to referrals from residential aged care facilities (nursing homes or hostels), then CNMDSA code 20 can be mapped to HACC MDS code 13.

Accommodation setting

Considerable inconsistency exists between the data domains of this HACC MDS data element and the CNMDSA data element Type of Dwelling/Accommodation. The CNMDSA data element reflects an earlier draft of the HACC MDS that was subsequently revised to bring it in line with the *National Classifications of Community Services*.

As it stands, the CNMDSA code 1 'House/flat' incorporates differences in tenure arrangements that are separately coded in the HACC MDS and cannot, therefore, be mapped to the HACC data element.

CNMDSA code 5 'Group home/special housing for person with disabilities' incorporates codes 7 and 8 in the HACC MDS data element which distinguish between domestic scale (i.e. smaller) supported living facilities with varying degrees of support available to residents and those larger supported accommodation facilities that usually offer 24-hour support services. However, the Project Team recognises that the distinction made between codes 7 and 8 in the HACC MDS data element may be difficult to implement. It has been included in recognition of the significant policy issues surrounding the provision of HACC services in settings where responsibility for support services may rest with other program areas. Pilot testing of the HACC MDS should give some indication whether this distinction can be supported in practice.

Caravans and mobile homes are included in codes 1, 2 or 3 in the HACC MDS depending on tenure, whereas they are separately coded in the CNMDSA and are also grouped with 'tent' which, in the HACC MDS, would be more appropriately coded under '11 Public place/temporary shelter'.

The CNMDSA does not include a separate code for HACC MDS code 10 'Psychiatric/mental health community care facility'. As it stands, the CNMDSA would probably code these accommodation settings under CNMDSA code 5 'Group home/special housing'.

Main reason for cessation of services

CNMDSA code 5 'For respite care' has no counterpart in the HACC MDS codes for this data element. If it can be assumed that 'for respite care' means that the person has been admitted to a residential aged care facility then CNMDSA code 5 can be mapped to HACC MDS code 2.

HACC MDS code 6 'Client moved out of area' is incorporated into CNMDSA code 12 'Person terminated care'—that is, the CNMDSA cannot separately identify persons who have ceased to receive HACC services because they moved out of the area serviced by the HACC agency.

HACC MDS code 4 'Client's needs have not changed but agency can no longer provide assistance due to budget constraints' and code 5 'Agency terminated service to client for worker (or volunteer) occupational health and safety reasons' have no equivalent in the CNMDSA codes for this data element.

Accommodation setting after cessation of services

As with the HACC MDS data element Accommodation Setting, difficulties in mapping between the CNMDSA data element Destination on Cessation of Services and the HACC MDS Accommodation Setting After Cessation of Services generally relate to the HACC MDS use of the *National Classifications of Community Services*. However, they also relate to the use of the CNMDSA code 1 'Home' which is not mutually exclusive of other CNMDSA codes (e.g. 3 'Supported care facility', 4 'Residential aged care facility', 7 'Mental health facility'). A person's home may be a supported care facility or a residential aged care facility or a mental health facility. These types of accommodation settings are included in the HACC MDS data element Accommodation Setting because they may be where a person lives while receiving services from the HACC agency. The HACC MDS data element Accommodation Setting after Cessation of Services includes a similar range of accommodation settings to those used in the Accommodation Setting data element. However, as different sub-types of accommodation settings are of interest in the two data elements' different contexts, the settings have been broken down differently although both code sets are mappable to the *National Classifications of Community Services*.

The CNMDSA has no equivalent codes for the HACC MDS codes 12 'Public place/temporary shelter', 13 'Not applicable—client died', and 15 'Not known'. This data element is the only one in the HACC MDS that allows for a 'Not known' response.

Carer availability

Although most CNMDSA codes can be superficially mapped to the HACC MDS Carer Availability data element (with the exception of CNMDSA code 1 'Person independent'), there are some fundamental differences between the two data elements—both named Carer Availability. In summary, these differences relate to the following:

- In the CNMDSA, carer availability is dependent upon whether the community nurse assesses the client as needing a carer. CNMDSA code 1 'Person independent' acts as a screen or filter so that the question about the availability or otherwise of a carer only relates to those clients who a nurse assesses as needing one.
- The CNMDSA data element includes an assessment of the carer's capacity to provide care and only considers a carer to be available if the nurse considers the person nominated as carer to be capable of providing the assistance needed by the client. This process acts as a further screen or filter through which Carer Availability passes.
- The CNMDSA data element incorporates information about the residency status of the carer that is provided through a separate data element in the HACC MDS—Carer

Residency Status. The HACC MDS has created two data elements in the interests of data quality. This is because the problem of determining who is the principal carer when more than one carer is present is limited to the Carer Residency Status data element (and the Relationship of Carer to Care Recipient data element), thus leaving the Carer Availability data element as a 'cleaner' source of information about carer availability. As the Project Team considers that the collection of quality data about carers is likely to be a major challenge facing the HACC MDS collection, it is considered preferable to do whatever is possible to encourage 'clean' data.

- The HACC MDS data element is designed to capture descriptive information about the availability of carer. That is, it is designed to record whether someone does provide care to another person, not whether they should be expected to provide that care based on someone else's assessment of whether a carer is needed.

Resolution of these differences between Carer Availability in the HACC MDS and CNMDSA will require a level of agreement between HACC program managers on some fundamental conceptual and policy issues. It was not possible, nor was it considered appropriate, for the HACC MDS Project Team and the CNMDSA team to resolve these issues at the level of data element definitions.

To summarise, given the significance of the CNMDSA to the effective implementation of the HACC MDS, the Project Team recommends that further work be undertaken to align the CNMDSA to the HACC MDS.

5.3 Client Information and Referral Record

During the course of field testing the HACC MDS, the Client Information and Referral Record (CIARR) emerged as a primary data collection instrument which had currency across a relatively diverse range of service providers. To date, the uptake of the CIARR has been variable both across and within States and Territories. Some States and Territories have not encouraged the use of the CIARR, while others (including New South Wales and Victoria) have either endorsed or mandated its use within HACC agencies. More recently, the CIARR has also received attention as a potential vehicle for the collection and dissemination of information within the context of the development of new assessment structures and processes for the HACC program.

Not only does the CIARR have some standing within the HACC field, but it also has the potential to support the collection of data elements in the HACC MDS. In particular, the CIARR has the potential to support the collection of information relating to client characteristics and client circumstances. To a more limited extent, the CIARR may be able to support the collection of information about service episodes, that is, by collecting information about the source of referral.

While the CIARR has the potential to support the collection of this information, it became apparent to the Project Team that for the CIARR to adequately realise this potential it would require some further development and changes to its format and content. Rather than circumscribe the development of the HACC MDS on the basis of the current format of the CIARR, the Project Team decided to recommend modifications to the CIARR to support the HACC MDS wherever this was considered practicable and not in conflict with the nature and the purpose of the CIARR.

The final stages of the HACC MDS Project coincided with a workshop for members of the HACC Officials Assessment Working Group to discuss the redevelopment of the CIARR to support the role of the new Comprehensive HACC Assessment Authorities. The Project

Team was invited to attend the workshop in order to brief participants on the HACC MDS Project, and to demonstrate the potential for comparability between the HACC MDS and the CIARR.

It was demonstrated that the bulk of the HACC MDS collection relating to client characteristics, client circumstances and source of referral either were supported by equivalent fields on the CIARR, could be supported with relatively minor adjustments in formatting or intent, or by the inclusion of pre-coded response categories. HACC MDS data elements that were, or could be, supported by a modified CIARR include:

- Letters of Name
- Date of Birth
- Sex
- Country of Birth
- Main Language Spoken at Home
- Indigenous Status
- Living Arrangements
- Area of Residence
- Accommodation Setting
- Government Pension/Benefit Status
- Source of Referral.

The Project Team made recommendations for the redevelopment of the CIARR in relation to the above data elements that were endorsed by the workshop participants (see Appendix B).

It was indicated that in relation to collecting information about carers, the CIARR would require a more substantial redevelopment for it to support the HACC MDS. In particular, the current version of the CIARR does not adequately identify carers as it conflates them with contact persons and next of kin. Currently, the CIARR reflects the lack of clarity surrounding the definition of carers and clients discussed in Section 3.6, and is therefore inadequate to the task of accommodating carers who are clients. In relation to the issue of carers, the Project Team recommended that in redeveloping the CIARR attention be paid to more clearly identifying the:

- availability of carers
- residency status of carers
- relationship of carers to care recipients.

The Project Team also recommended that the client consent section of the CIARR more clearly identify the person giving the consent; and that the consent be redrafted to include the disclosure of information for research/statistical purposes. This is in line with the recommendation made in this report that standard wording be developed for use across the HACC field for obtaining client consent. These issues were taken up for consideration by the HACC Officials Assessment Working Group.

In light of the current efforts being undertaken to redevelop the CIARR, it is considered likely that future versions of the form will be a useful tool that could be used to support the collection of information included within the HACC MDS.

5.4 Commonwealth/State Disability Agreement Minimum Data Set

Overall there is relatively minimal overlap between the CSDA MDS and the HACC MDS and the potential for the CSDA MDS to support the HACC collection remains small. The only data elements which are included in both the CSDA MDS and the HACC MDS are:

- Date of Birth/Age
- Sex
- Country of Birth
- Main Language Spoken at Home
- Indigenous Status
- Living Arrangements.

Even for these data elements that do overlap, there remain substantial discrepancies between the two in the ways in which the information is conceptualised and collected. These discrepancies are detailed below.

Date of birth

The HACC MDS requires Date of Birth and gives detailed specifications for the recording of the date, and for its estimation in cases where Date of Birth is not known. The CSDA MDS only requires Age to be reported, but does recommend the recording of Date of Birth at the agency level to allow for the easy extraction of age. The HACC MDS could not align with the CSDA MDS in this respect given the centrality of Date of Birth to the proposed statistical linkage key.

Sex

Both collections have comparable recording of Sex, though the HACC MDS provides instruction for the recording of Sex where uncertainty may exist about the sex of the person (e.g. transvestites and transsexuals).

Country of birth

The HACC MDS uses the Australian Bureau of Statistics four-digit country classification and allows agencies to record information using either a predefined list of countries or an open-ended question/text field, as they prefer, given that the country can be identified and mapped to the classification. The CSDA MDS only includes the following options:
1 Australia; 2 Other (English-speaking); 3 Other (non-English-speaking); and 4 Not known. These coding options are insufficient for mapping to the ABS classification.

Main language spoken at home

The HACC MDS uses the ABS two-digit version of the ABS Australian Classification of Languages. Again HACC agencies may use either a predefined list of languages or an open-ended question/text field, as they prefer, given that the language can be identified and mapped to the classification. The CSDA MDS uses a list of eight different languages in addition to an ‘other’ and a ‘not known’ category. While most of these can be mapped to the two-digit classification (with the exception of Chinese and Other) the list is not sufficient to support the requirements of the HACC MDS.

Indigenous status

Indigenous Status is collected in the HACC MDS in a format consistent with the ABS standard, which allows both a detailed separation of Aborigines and Torres Strait Islanders, and a more general separation of Indigenous and non-Indigenous. The CSDA is only mappable to the less detailed level of distinguishing between Indigenous and non-Indigenous.

Living arrangements/accommodation (CSDA)

The CSDA MDS data element Living Arrangement/Accommodation is not readily mappable to either of the relevant HACC MDS data elements (Living Arrangements and Accommodation Setting). If all persons living in group homes, institutions, retirement villages etc. are considered to be living alone , the CSDA version may be considered to map superficially to the HACC MDS data element Living Arrangements. The CSDA MDS does not support the HACC MDS data element Accommodation Setting.

5.5 Aged Care Assessment Program Minimum Data Set

The ACAP MDS and the HACC MDS both collect some information about the following areas:

- sex
- date of birth
- country of birth
- area of residence
- usual residence/accommodation
- housing tenure
- living arrangements.

For several of these there is some degree of overlap or mappability, though in many cases the intentions of the data elements are not precisely aligned. Again the development of the HACC MDS data elements was not restricted by the contents of the ACAP MDS as the level or type of information collected by the ACAP MDS was deemed inadequate to the needs of the HACC collection in several respects.

Sex

This is the only data element for which the coding categories/data domain in both the HACC MDS and ACAP MDS are fully aligned, though the ACAP MDS includes no instructions for the recording of sex in cases where there may be some doubt.

Date of birth

Date of Birth is collected in a six-digit format in the ACAP MDS, rather than the HACC MDS eight-digit format, though both collections use 01/01/year for estimated dates of birth.

Country of birth

For Country of Birth the ACAP MDS uses a two-digit version of the ABS countries classification while the HACC MDS uses a four-digit version, though the HACC data could be collapsed up to the two-digit version to enable comparisons across the two collections.

Area of residence

The ACAP MDS collects a four-digit Local Government Area/Statistical Local Area of Usual Residence. While these are used as one within the ACAP MDS, the HACC MDS Project Team understands that these two codes cannot always be equated. If Statistical Local Areas were required by the ACAP MDS, the ACAP MDS data element would support the HACC data element Area of Residence with the addition of the State/Territory code required by the HACC MDS. There are also discrepancies between the concept of 'usual' in the ACAP MDS and 'while receiving services' in the HACC MDS.

Housing tenure

Most of the categories in the ACAP MDS Usual Residence and Housing Tenure can be mapped to the HACC MDS Accommodation Setting when used in conjunction with one another. The exception to this is the ACAP MDS category 'granny flat/self care unit in a retirement village' which would be coded in different categories within the HACC MDS (this could be resolved by considering both as private residences). Again there are discrepancies between the concept of 'usual' in the ACAP MDS and 'while receiving services' in the HACC MDS, and several of the categories specified within the HACC MDS would be collapsed into 'other' in the ACAP data element (including 6, 7, 8, 10 and 11).

Living arrangements

Living arrangements are not readily mappable across the two collections with the exception of the 'lives alone' category. Again the concept of 'usual' is different, and the 'lives with family' distinction included in the HACC MDS is not supported by the ACAP MDS. If all people in institutions were considered to be living alone, the two could be compared across the broader categories of lives alone, and lives with others.

Overall, then, the ACAP MDS and the HACC MDS may be considered to be somewhat mappable, though differences in some of the underlying concepts suggest that some care should be taken in making any direct comparisons between the two.

Recommendations

Data review issues

32. It is recommended that the *HACC Data Dictionary* and MDS collection continue to be integrated with and reviewed against other data collections and data collection instruments across the aged and community care fields including the CIARR, the CNMDSA, the ACAP MDS, the CSDA MDS as well as residential aged care data collections. This is of particular importance for those agencies which are funded from multiple programs (e.g. CSDA- and HACC-funded agencies).
33. It is recommended that particular attention be paid to resolving outstanding differences between the CNMDSA Version 2.0 and the HACC MDS as soon as possible, with a view to ensuring that the CNMDSA can support the collection of the HACC MDS.
34. It is recommended that the HACC MDS be integrated with and reviewed against other HACC developments and projects that have information and data requirement implications including the assessment project, the community care classification project, output-based funding initiatives, and the development of performance indicators.

Primary collection tool issues

35. It is recommended that the CIARR be revised to support record linkage and to include appropriate client consent wording.
36. It is recommended that the CIARR be revised to support the collection of HACC MDS information about client characteristics, client circumstances, source of referral information and carer information, as recommended by the Project Team (details of these recommendations, made to the Assessment Working Group in April 1998 and supported by them, are included in Appendix B).
37. It is recommended that consideration be given to the wide-ranging implications of the *HACC Data Dictionary* and MDS for other primary data collection tools (i.e. other than CIARR), including agency-based forms such as intake and referral forms, worker timesheets, invoices and contracts, etc.
38. It is recommended that standard wording for client consent be drafted for use across the HACC program, and that such wording include consent for the release of information for statistical and research purposes.

6 Data linkage

6.1 Introduction

Record linkage refers to the bringing together of two or more records that are believed to belong to the same individual. This process does not alter the records in any way but allows a view of the data at a higher level than that of the records on their own. The creation of linked data is of particular value in a program such as HACC where many clients receive services from more than one agency. In order for research, planning or program accountability work to adopt a client-focused view, data linkage is a basic first step to establish how many HACC clients there are and what services they are receiving. Given the nature of the HACC program, the development of a linkage key is an essential prerequisite to obtaining the answers to those questions.

As part of the further development of the HACC MDS, the Australian Institute of Health and Welfare was asked to make recommendations for the specifications of a unique linkage key that would not identify individuals but would enable statistical linkage. It is important to recognise at the outset that while record linkage can be used to facilitate the provision of care or assistance, treatment, case management or for administrative purposes relating to individual clients, this is not the form of record linkage at issue here.

The Final Report of the *National Review of HACC Data Requirements: Future Directions* included a recommendation to proceed with the 'investigation of a unique identifier for the HACC MDS, including the use of the Medicare Number' (Brian Elton & Associates 1996, p. xi). The report also noted that general support among stakeholders for the use of such identifiers was qualified by the need for assurances that privacy, confidentiality and access to information issues would be effectively addressed. As HACC has close links with other programs it was also considered important that any unique identifier for HACC should also be relevant to other programs (Brian Elton & Associates 1996, p. 28 and 31).

In great part, the difficulties associated with implementing a linkage key within the HACC program relate to the process of establishing a clear understanding of the purpose, scope and desired outcomes of statistical record linkage. There is a need to establish processes and protocols for the linking of client records which comply with privacy principles and offer suitable assurances of privacy and confidentiality to both service providers and their clients. These issues of privacy and confidentiality are discussed in Section 6.3.

The technical aspects of record linkage are relatively straightforward, at least by contrast with those of privacy and confidentiality. The process of resolving the technical aspects of recommending an appropriate linkage key are dealt with in Section 6.2.

6.2 Linkage key testing

As noted above, record linkage refers to the bringing together of two or more records that are believed to belong to the same individual, allowing a higher view of data than is possible from the perspective of individual records. Linkage can occur across data systems or within data systems and is done by using a range of identifiers. The most common data elements used for identification purposes are names (or part thereof), address (or a location descriptor), date of birth, sex, or medical record numbers (for health systems).

In technical terms, a perfect linkage key should have two basic aspects:

- one individual has only one key number
- two people do not share one identical key number.

Given that record linkage within the HACC program is intended for statistical purposes only and not for case management, the process of linking client records does not need to be 100% accurate. Rather, statistical record linkage need only be sufficiently accurate to enable the drawing of statistically valid conclusions. Previous experience in the use of a variety of linkage keys shows that linkage for statistical purposes can be achieved to a high degree of reliability through the use of standard personal information data elements, of the kind described above.

Record linkage could also be undertaken with the use of pre-existing personal ID numbers—such as a Medicare Number. The Project Team does not recommend the use of the Medicare Number in (or as) the linkage key in the HACC program and did not test it as part of the development process. The decision not to recommend the Medicare Number for record linkage centred on a range of limitations associated with the Medicare Number which have been documented in greater detail in a recent report to the Australian Health Ministers' Advisory Council by the Australian Institute of Health and Welfare (AIHW 1998a). In short, difficulties associated with using the Complete Medicare Card Number as the basis for record linkage related to its lack of universal applicability (some people do not have a Complete Medicare Card Number and many agencies do not collect them); its lack of singularity (some people may be registered against more than one number); and its lack of stability (over time a person may have more than one Complete Medicare Card Number).[*]

Having recommended against the use of Medicare Numbers as the basis for record linkage, the Project Team proceeded with the investigation of a variety of other potential linkage keys using different combinations of commonly available personal information to link client records. This initial testing was done using the nursing home resident database and was designed to ascertain the frequency with which two individuals could be expected to receive the same linkage key (referred to here as the proportion of duplications). Table 6.1 summarises the results produced by testing a range of linkage keys derived from combinations of date of birth, sex and parts of names; and date of birth, sex and postcode.

A variety of the candidate linkage keys tested during this initial round of testing yielded sufficiently low levels of duplication to be suitable for statistical purposes. However, choosing constituent items for a linkage key also requires consideration of several other issues including:

- the collectability and availability of the constituent items;
- the accuracy with which the constituent items are likely to be captured;
- the capacity of the constituent items to identify the individual; and
- the stability of the constituent items over time.

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[*] The Health Insurance Commission uses an internal unique and stable client identifier, the Medicare Personal Identification Number rather than the Complete Medicare Card Number as the linkage key on its databases. This number is not made available outside the Commission.

Table 6.1: Summary of initial linkage key tests

No.	Combination	Length	Total cases	No. of duplications	% of duplications
1	SCOHM key (formerly used for linking nursing home records): First four characters of surname, first two characters of first given name, initial of second given name, sex, date of birth, tiebreaker one character (a blank space represents a missing character)	15	439,273	0	0
2	All variables except SCOHM key	Vary	439,273	76	0.02
3	SCOHM without the tiebreaker: First four characters of surname, first two characters of first given name, initial of second given name, sex, date of birth	14	439,273	585	0.10
4	Surname, first name, initial of second given name, sex, date of birth	Vary	439,273	505	0.10
5	Sex, date of birth and postcode	11	194,148	2,870	1.50
6	Supported and Assisted Accommodation Program (SAAP) data collection ID: First two and the last characters of surname, second and third characters of first given name, sex, year of birth ('2' substitutes for all missing chars)	10	438,662	57,658	13.10
7	Supported and Assisted Accommodation Program ID: First two and the last characters of surname, second and third characters of first given name, sex, year of birth ('L' substitutes for all missing chars)	10	438,662	57,690	13.20
8	Date of birth replaces year of birth in SAAP ID: First two and the last characters of surname, second and third characters of first given name, sex, date of birth ('L' substitutes for all missing chars)	14	438,662	3,046	0.70
9	Second, third and last characters of surname, second and third first given name, initial of second given name, date of birth, sex ('2' substitutes for all missing characters)	15	438,662	1,363	0.30
10	Second, third and fourth characters of surname, second and third first given name, initial of second given name, date of birth, sex ('2' substitutes for all missing characters)	15	438,662	1,016	0.20
11	Second, third and fifth characters of surname, second and third characters of first given name, initial of second given name, date of birth, sex ('2' substitutes for all missing characters)	15	438,662	1,286	0.30

Note: Data from the nursing home resident database were used in these initial tests. This data collection includes the relevant data items for persons admitted to a nursing home between 1 January 1988 and 1 July 1995. The database contains 439,273 cases, although there are significant proportions of missing data on some items. A total of 611 records contained a comment after the surname or first givemame which may adversely affect the test. After excluding these records, 438,662 records were used for tests 6 to 11. A total of 194,148 records had a postcode.

On the basis of these criteria several of the combinations were excluded from consideration. For example, while the SCOHM key (formerly used to link nursing home records) has an extremely low proportion of duplications it is also the combination most likely to identify an individual and was therefore deemed unsuitable for use within the HACC context. Similarly, the use of the first letters of a name may be more likely to identify an individual, while the use of a final letter of a name may be subject to greater inaccuracies in recording.

Having discussed these issues with members of the Steering Committee it was agreed that the Project Team would proceed with a further round of testing involving the following two linkage keys.

These were:

- the second, third and fifth letters of the surname plus the second and third letters of the person's first name, sex and date of birth;
- the second letter of the surname, sex, date of birth and postcode.

Table 6.2: Summary of test results using the nursing home database

No.	Combination	Length	Total records	No. duplications	% of duplications
1	Second, third and fifth characters of surname, second and third characters of first given name, sex, date of birth	14	438,662	2,768	0.6
2	Second character of surname, sex, date of birth,postcode	14	194,148	1,129	0.6

Table 6.3: Summary of test results using the Silver Chain database

No.	Combination	Length	Total records	No. duplications	% of duplications
1	Second, third and fifth characters of surname, second and third characters of first given name, sex, date of birth	14	64,051	355	0.6
2	Second character of surname, sex, date of birth,postcode	14	64,051	571	0.9

Note: Of the total 69,021 client records on the database, 4,970(or 7%) had no date of birth. Dr Gill Lewin of Silver Chain suggested that the client records without date of birth were most likely to be clients who were referred to, or approached, Silver Chain for service, but withdrew (for any number of reasons) before service delivery and/or full personal details were collected during an assessment.

These two linkage keys were tested on the nursing home database, the Silver Chain database in Western Australia, and the National Death Index (held within the Institute). The results of this round of testing for the nursing home database and the Silver Chain database are presented in Tables 6.2 and 6.3. In effect, both linkage keys generated duplication rates of less than 1%.

Only the first linkage key was tested on the National Death Index. The structure of this database caused some difficulty as it was found to contain many instances of multiple records for the one person. However, once this was taken into account the linkage key generated approximately 1% duplications.

Testing the proportion of duplications for a particular linkage key gives an indication of the frequency with which two or more people are likely to share the same linkage key. The results of this testing suggest that both keys performed more than adequately for statistical purposes against this criterion. The level of error introduced as a result of the same person having more than one linkage key is, however, more difficult to establish. It cannot be undertaken within existing databases, as by definition the same personal details will always yield the same linkage key. For the two proposed linkage keys tested above, this kind of error would be most likely to result from:

- inaccurate or inconsistent recording of information by service providers (e.g. misspelling names or incorrect recording of date of birth);
- name changes over time or unstable reporting of name information by clients (e.g. the same client may give different names or different versions of a name to different agencies during the same period of time, such as a traditional name and an anglicised name, or an abbreviated and a full version of a first name);
- inconsistent estimations where a full date of birth is not known; and
- changes in area of residence resulting in different postcodes over time.

Of these, error associated with changes in postcodes would affect only the second linkage key (comprising the second letter of the surname, sex, date of birth and postcode). On the basis of information derived from census data and analyses of mobility rates, the Project Team made a tentative estimate that some 10% of HACC clients may be expected to change their residential address in any given year. Moreover, postcodes themselves change on an irregular basis in line with the needs of Australia Post. In light of these factors, the inclusion of postcode was considered to introduce an unnecessary element of instability over time and was not recommended for inclusion within the HACC statistical linkage key.

While changes in a person's name would result in similar problems to a change in the person's postcode, it is expected that name changes occur with substantially less frequency than changes in residential address. Given that most name changes are associated with life events such as marriage or divorce, it might also be assumed that such changes may be less frequent within the HACC target group than within the population as a whole. Nonetheless, the Project Team recommends that agencies using automated systems incorporate some form of validation processes to search for existing names within their databases, based on matching the components of the linkage key. The program could also consider other strategies to minimise error associated with changes in name, such as developing the capacity to report a previous linkage key in the HACC MDS where change of name is known to have occurred.

The Project Team has been unable to ascertain the error rates associated with the other factors listed above. Nonetheless, attempts have been made to minimise these kinds of error by providing detailed specifications within the data elements in relation to the recording and reporting of name information, and standard processes for estimating dates of birth where this may be necessary.

On the basis of these considerations, the Project Team recommended a linkage key for the HACC program comprising letters of name (second, third and fifth of surname plus second and third of first given name), date of birth and sex. The acceptability of the proposed linkage key to service providers was explored during the two field tests undertaken during the course of the consultancy, with generally positive results obtained. The Project Team does, however, have some concerns about the appropriateness of the linkage key for use in particular communities where reporting of name and date of birth is likely to create problems of accuracy and consistency for agency staff (see Sections 3.4 and 3.8 for a summary discussion of service providers' views on the linkage key).

6.3 Issues for implementation

Linking client records can serve two purposes:

- to facilitate the provision of care or assistance, treatment and case management, and for administrative purposes relating to individual clients; and
- for statistical purposes, including planning, accountability or research.

Record linkage for the first of these purposes is of interest to the HACC program and to the health and community services field more broadly. There is a growing interest in facilitating 'seamless' patient/client care across the sub-acute, acute and post-acute care sectors through the sharing of client/patient related information.[*]

The proposed use of a statistical linkage key in the HACC program falls, however, into the second category. As a minimum, the use of a statistical linkage key is designed to achieve a more accurate count of HACC clients (by reducing double counting) and the services which they receive. It is important to recognise that the proposed use of record linkage for

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[*] A recent Australian Institute of Health and Welfare report to the HACC Officials provides a more comprehensive discussion of data linkage in this other context (AIHW 1998a).

statistical purposes only is a more modest and achievable proposal than the introduction of record linkage across health and community services sectors, or even within the HACC program, for the purpose of care management or administration. Nonetheless, the linkage of client records for statistical purposes in the HACC program requires consideration and resolution of substantial policy and procedural issues, as distinct from the technical aspects discussed above.

In particular, the administrative and ethical framework surrounding data linkage within the HACC program needs to offer sufficient assurances of privacy and confidentiality to service providers and clients, and protections against the use of personal information for purposes other than those originally intended. Such protections and protocols need to inform not only the actual process of linking of client records, but also related processes such as obtaining client consent, data storage, transfer, encryption and release.

Existing privacy safeguards and standards

The *Commonwealth Privacy Act 1988* identifies privacy safeguards that must be observed in the collection, storage, use and disclosure of personal information and discusses inappropriate practice in personal information exchange. However, the Act has limited application as it only regulates the data collection activities of Commonwealth and Australian Capital Territory Government agencies and does not extend to other State/Territory Governments or the private sector. In March 1997, the Commonwealth Government reported that the Privacy Act would not be extended to the private sector in the foreseeable future, but that ‘voluntary codes’ would be implemented instead.

Standards Australia has released two standards related to this field*: Personal Privacy Protection in Health Care Information Systems* (AS4400) in 1995 and *Information Security Management* (AS/NZS4444) in 1996. The latter standard does not specifically apply to the health or community services sectors but deals with the protection of confidentiality and data integrity within all industries. The former deals with protecting personally identifiable information held in health care information systems but does not deal with the transfer or exchange of this information. Although these standards do not directly apply to the record linkage process, they are useful sources of information for HACC agencies seeking to ensure that their own systems contain appropriate safeguards for personal client information. Encouraging agencies to follow these standards when designing their own systems would assist with fostering an appropriate culture that is respectful of their clients’ rights to privacy and confidentiality.

At present, States and Territories are developing privacy codes or guidelines or legislation. In the absence of privacy legislation that covers all jurisdictions and the private sector, States and Territories are taking some form of action to ensure that health and community service providers are adequately covered. The Australian Capital Territory Government, for example, has decided to enact its own privacy legislation that will cover private and public health service providers and establish a set of privacy principles that are consistent with the Privacy Act.

Steps forward

In the absence of nationally applicable privacy legislation, the Office of the Privacy Commissioner has advised (informally) the Project Team that the Information Privacy Principles contained in the Privacy Act can be taken as a framework for considering the privacy issues related to record linkage in the HACC program. The Office of the Privacy

Commissioner has also advised (informally) that there is no requirement that any record linkage process in the HACC program be screened by the Privacy Commissioner or submitted for the Commissioner's approval. While the Privacy Commissioner has general powers to give advice on privacy matters, there exists no compulsion to seek such advice. Responsibility rests with the government officials responsible for the HACC program to ensure that the introduction of record linkage within the HACC program is undertaken in a manner consistent with existing legislation.

One option that could be considered for the HACC program is the possibility of using contracts between data providers and users to specify the respective roles and responsibilities of contracting parties in relation to HACC record linkage. Ensuring consistent national coverage of all HACC agencies through standardised contracting arrangements would present considerable challenges but may repay further investigation.

If adequate protocols can be established for the protection of privacy and confidentiality, the introduction of a statistical linkage key may not be unwelcomed by HACC service providers. Indeed, the results of field testing the HACC MDS revealed near-universal agreement on the introduction of record linkage in the HACC program for statistical purposes. Those few agencies expressing hesitation or disagreement generally wanted to know more about how their clients' privacy and confidentiality were to be protected before being willing to express support for the proposal. This hesitation, however, does indicate the need to adequately inform agencies about the purpose, scope and process of statistical data linkage within the HACC program.

In addition to the protocols which need to surround the data linkage process, and the encryption of the linkage key, the Project Team also recommends that two straightforward conversions be made to client information prior to its release to relevant jurisdictions for data analysis. These include:

- the conversion of date of birth to year of birth or age; and
- the conversion of suburb/town/locality name and postcode to statistical local area, where the area of residence of the client has not already been reported in this format.

While these conversions are basic to much data analysis, the fact that they would occur prior to the release of data for data analysis may partially allay fears that unit record files could be used to identify individual HACC clients.

At a broad level, it is recommended that the record linkage process be undertaken by an independent, trusted third party (i.e. not a government department) subject to stringent ethical guidelines and privacy safeguards consistent with the Information Privacy Principles contained in the Privacy Act. Should the trusted third party have appropriate legislated privacy protection provisions, the need for encryption of the linkage key may be redundant or substantially reduced.

However, it is anticipated that addressing service provider and client concerns related to privacy issues will require that adequate and specific information be made available about the proposed linkage process. That is, exactly who will do the linkage and how will the privacy of the individual client be protected throughout this process? These issues will require further consideration and clarification by HACC Officials prior to implementation.

Information Privacy Principles

The following discussion focuses on a range of issues related to the HACC record linkage process in the context of the Information Privacy Principles contained in the *Privacy Act 1988*.

Establishing informed consent

The issue of whether clients have the right to maintain control over their personal information is central to any data collection. Under Australian common law, health records are owned by the agency or individual who creates them, with service providers being subject to confidentiality obligations. Under some State Government privacy guidelines, the consent of the individual is required for information to be transferred to anyone other than the original collection agency.

The Office of the Privacy Commissioner has advised (informally) the Project Team that gaining the client's consent to the release of information by a service provider would be the most appropriate way of complying with the provisions of the Privacy Act in this respect. This process would also be more likely to reassure the service provider that the provision of this information to a third party is legitimate. Gaining client consent in this way can take two forms to the extent that clients can be asked to either 'opt in' or 'opt out' of the data collection. 'Opting in' is where a client is asked to give consent to the release of information and any non-response is interpreted as being non-consent. 'Opting out' is where clients are asked if they object to their information being released and any non-response is interpreted as consent. While the appropriateness of different options will need to be considered by the Program, the 'opting out' option has been found to give better results in general in terms of overall response numbers.

The alternative to establishing consent client-by-client would be to issue a formal notice at the point of data collection which informs the client that certain information will be disclosed to certain parties for particular purposes.

In the HACC context, the National Service Standards already establish a basic framework related to privacy and confidentiality of client records. Consistent with these standards, a client consent segment is included on the Client Information and Referral Record (CIARR). However, if information about the client is to be provided to other parties for purposes unrelated to the client's need for care or assistance (i.e. for statistical purposes as well as facilitating care and assistance to the individual) there may be a need to revise the wording of the client consent in the CIARR. Given that many agencies do not use the CIARR, some standard wording for this purpose should be developed and a requirement placed on all HACC agencies to incorporate such wording into any client consent process. The *Federal Privacy Handbook* contains guidelines to the Information Privacy Principles and would assist with deciding on appropriate standard wording for this purpose.

Who should undertake the linkage of client records?

There are two aspects to this issue. Firstly, the nature of the agency or organisation which is chosen to undertake data linkage, and secondly, whether data linkage is done at a national or State/Territory level.

Nature of the agency/organisation

In respect of the first issue (the nature of the agency), there is a higher likelihood of generating resistance from service providers and/or clients if record linkage were to be undertaken by a government department, due to concerns that personal information may be used for purposes other than those for which it was intended. Past experience in Australia with the attempted introduction of the Australia Card demonstrates the general sensitivity of the Australian population to a perceived 'big brother' role of government. Although the introduction of record linkage in the HACC program is a far more modest proposal than the Australia Card, it would be reasonable to assume a degree of resistance to record linkage if it were to be undertaken by a government department.

Alternatives would include the engagement of a 'trusted third party', at least one step removed from the government departments responsible for the HACC program, to undertake the linkage process itself. Linked and de-identified data would then be released to government for aggregation and analysis.

The WA Linkage Project provides one possible model for consideration. Under a collaborative arrangement between the Western Australian Health Department and the University of Western Australia, a discrete unit of staff co-located with the WA Health Department have the responsibility for linking and de-identifying data before its release for analysis. While the unit is comprised of both University of Western Australia and Health Department staff, it acts as a 'trusted third party' insofar as only those directly involved in the data linkage process have access to identifiable records. Any other person wishing to access identifiable data through the WA Linkage Project (including general Health Department staff), is required to secure the approval of both the Health Department ethics committee as well as the ethics committee of their own organisation. In this way the perceived and actual confidentiality of the linkage process are protected by the application of ethical safeguards and procedures, and by separating the linkage process from program responsibility.

The Australian Institute of Health and Welfare also undertakes record linkage (e.g. the National Death Index, the National Cancer Statistics Clearing House, and for the Supported and Assisted Accommodation Program collection) under agreement with State and Territory Government authorities. The *Australian Institute of Health and Welfare Act 1987* and ethical safeguards provide a suitable framework for undertaking this role.

In summary, the important features of any agency or organisation undertaking record linkage include the existence of stringent ethical safeguards and processes that circumscribe the activity and provide for appropriate penalties if contravened. In addition, it is considered advisable that some 'trusted third party' be selected as the agency/organisation to undertake the record linkage function, in order to safeguard the perceived as well as the actual confidentiality of the linkage process.

National versus State/Territory level

Resolving the level at which data linkage should be undertaken is an issue which will need to be decided among the different Commonwealth, State and Territory Governments. The following points may be of relevance to that decision.

If record linkage were to be undertaken by a Commonwealth (or Australian Capital Territory) Government agency the provisions of the Privacy Act would apply. Falling within the jurisdiction of the Privacy Act has both advantages and consequences. One advantage is the extra protection that the Act provides to service providers and clients, including access to the Privacy Commissioner and legal redress. Coverage by the Privacy Act may well engender a higher level of compliance by service providers and thus a more effective linkage process. A consequence of falling within the jurisdiction of the Privacy Act is that the record linkage process is subject to the legal provisions of that Act and thus to any legal action related to it.

There may be sound reasons for undertaking record linkage at the State/Territory level, not least of which relate to the sense of ownership by State and Territory Governments of data relating to their jurisdiction. Moreover, while State and Territory Governments (excepting the Australian Capital Territory) are not subject to the Privacy Act, they all have their own privacy guidelines and procedures to follow. Given that many of these guidelines and procedures are still being refined, however, it would be difficult to ensure a necessary degree of consistency across all States and Territories.

While not specifically related to privacy, it is also important to recognise the difficulties of ensuring coordinated data collection and processing across all States and Territories, if the intention is to establish a national minimum data set for the HACC program. Problems experienced in trying to collate or use national data from the Aged Care Assessment Program MDS are telling in this respect. Although the MDS was agreed in 1987, data began to be available on a State/Territory level only in 1993, and the first national report was released in 1997. One consequence of a decision to undertake record linkage at the State/Territory level worthy of note in its own right is that a national count of HACC clients would not be possible unless a second round of record linkage was undertaken at the national level.

The issue of the resources required to undertake the required linkage task and prepare data for analysis should also be considered. The task will require significant levels of skill and familiarity with the HACC data. From the perspective of smaller States and Territories in particular, the duplication involved in establishing eight separate linkage units may be less attractive than one central linkage unit in resource terms.

Technical and processing issues

While the Project Team did not undertake any exhaustive investigation into technical or processing issues related to record linkage, the following comments are made from our own consideration of the issues as they emerged through the HACC MDS Project. These may be issues that could be usefully taken forward through the planned HACC Technology Project.

Firstly, the data processing task of record linkage is likely to be very large. The Australian Institute of Health and Welfare roughly estimates that there may be as many as 2 million client records submitted by HACC agencies in any one HACC MDS reporting period. If records are to be linked across collections, the number of records would be cumulative and the increase in the number of linkages to be processed would grow accordingly. That is, with every new HACC MDS reporting period an additional 2 million records or so would need to be linked with previously linked records. The data processing capacity of any agency undertaking the record linkage process would have to be substantial.

Secondly, there are also detailed and important considerations related to security measures for the record linkage process. The Privacy Act provides a framework for consideration of appropriate security measures and the *Federal Privacy Handbook* gives more detailed advice on implementing the Information Privacy Principles. The Office of the Privacy Commissioner is also able to provide more detailed and specific advice on these matters. Security measures will need to encompass the transmission of data (electronic, disk and paper), storage, processing and the release of data. Security measures will also need to clearly specify access controls, audit trails and penalties.

6.4 Further testing of the proposed statistical linkage key

Further testing of the acceptability and effectiveness of the linkage key should be conducted as part of the pilot process associated with the MDS. This may be undertaken as part of the general pilot process, or through more specific means including:

- selection of communities or regions likely to have a higher incidence of linkage problems (e.g. remote Indigenous communities; areas with a high concentration of migrants; areas with high mobility rates) for follow-up validation of the accuracy of record linkage (i.e. that linked records actually do belong to the same person) and/or a survey of a sample of clients to see if any linkages were missed;

- examination of the probability of different types of errors occurring across different sub-populations of HACC clients, based on the results of various sample surveys.

Recommendations

Linkage key issues

39. It is recommended that a linkage key comprising letters of name (second, third and fifth of surname plus second and third of first given name), date of birth and sex be adopted for implementation in the HACC MDS.
40. It is recommended that the proposed statistical linkage key (letters of name, sex and date of birth) should be supplemented by a fallback linkage option (sex, date of birth and postcode) during piloting in order to enable comparisons between the two (postcode therefore should be routinely collected in the pilot phase).
41. It is recommended that linkage be undertaken by an independent third party in an 'honest broker' role and be protected by adequate ethical standards and protocols to ensure client privacy, confidentiality and the appropriate use of information.
42. It is recommended that the linkage key be encrypted at the point of linkage.
43. It is recommended that where databases are transferred to agreed authorities (e.g. State or federal departments) for data analysis, unit records should be unidentifiable.
44. It is recommended that further testing be undertaken concerning the accuracy and effectiveness of the proposed linkage key for communities or regions which are likely to have a higher incidence of linkage problems (including Indigenous communities, especially remote Indigenous communities, areas with a high concentration of migrants, or areas with high mobility rates if postcode becomes part of the linkage key). Such testing should focus particularly on the level of error associated with the same person having multiple linkage keys due to name changes, unknown dates of birth, instability in the reporting of name and date of birth information, and changes in client location (if postcode were to be included).
45. It is recommended that for those communities which are found to have excessively high levels of duplication in respects described above, or other problems of accuracy, other options for record linkage should be considered.
46. It is recommended that all automated systems used in HACC agencies incorporate validation processes which include searches for existing names based on matching the components of the linkage key.
47. It is recommended that, where possible, strategies should be developed to minimise error associated with changes in name (e.g. capacity to report a previous linkage key in the MDS where change of name is known to have occurred could be considered).
48. It is recommended that a review of the technical aspects of undertaking the linkage process be referred for consideration by the proposed HACC Technology Project.
49. It is recommended that a review of the technical aspects of undertaking the data transfer process be referred for consideration by the proposed Technology Project.

7 Piloting the HACC MDS

7.1 Introduction

The HACC MDS Project resulted in the production of a detailed data dictionary and the specification of a final HACC MDS, both of which have been accepted and approved by HACC Officials. The implementation of the HACC MDS, however, will require the investment of substantial resources in training materials, training programs, supporting documentation, development and/or modification of paper-based data collection forms, and innovations or modifications to information management systems. While the Project Team has made recommendations to this effect, the time and resources involved in these developments should not be underestimated.

The Project Team also recommends that a pilot of the HACC MDS be undertaken prior to a full-scale national implementation. The ramifications of such a substantial shift in data collection requirements in a program involving some 4,000 agencies are considerable. A pilot test of the HACC MDS and *Data Dictionary* would provide the opportunity to refine the MDS itself, whilst also yielding valuable information to inform the national implementation. Training packages and techniques should be developed and tested, as should the proposed ancillary documentation (the 'Guidelines to the HACC Collection' and the 'Summary of the *HACC Data Dictionary*'), in the process of conducting the pilot test.

Several possible strategies for the design of the pilot can be considered, including manipulation of sample size, the duration of the test, the use of a variable implementation period, or the use of a staged implementation period. At essence, however, the key consideration involved is a technique to reduce the size and/or scope of the enterprise to a level that is more manageable and substantially less resource-intensive than a full-scale implementation.

7.2 Options for the pilot

The agency sample

The most common strategy in implementing a pilot project is to limit the sample size. For the purposes of piloting the HACC MDS, this would involve agreement that a limited number of HACC agencies agree to undertake a pilot test of the MDS, rather than all such agencies. The trade-off between a census versus a sample of agencies for inclusion in the pilot is one of resources and feasibility against the sheer amount of data and implementation experience gained. The Project Team views this as a decision for HACC Officials, but if a census were under serious consideration then the Project Team recommends that the resource implications and the feasibility of such an undertaking should be carefully examined. No recommendation is made here as to sample size, which would ultimately be determined by the resources (time, personnel and money) available.

Consideration should be given as to whether a representative random sample or a purposive sample is most appropriate for the pilot test. A representative random sample would require that agencies providing a range of service activity types were included, as well as an appropriate coverage of multi-purpose versus single-purpose agencies, rural and remote, urban- and metropolitan-based agencies, and this in all States and Territories. In addition, agency size and the structure of the agency (individual as opposed to part of a larger organisation) would need to be taken into account, and perhaps the level of sophistication in the agency's information systems. A decision would have to be taken as to whether participation would be voluntary or mandatory for selected agencies.

The representative random sample is likely to be the more expensive option in resource terms. Such an approach would clearly involve a substantial number of agencies in order to cover the range of possible combinations outlined above, even assuming that a stratified sampling design is adopted. The geographic spread would be wide, making both training and support a more expensive option. Documentation and training packages would need to be developed to cover the entire spectrum of HACC agencies (a resource-intensive process). The advantage of the approach is that experience would be gained in implementing the MDS in a range of agencies operating in a variety of circumstances.

A purposive sample could be constructed in a variety of ways. The recommendation of the Project Team is that a relatively small sample should be chosen amongst agencies who already have information systems in place which could, with modest modifications, support the HACC MDS. Participation would be on a voluntary basis, with agencies that opt to assist in the trial being offered the incentive of assistance with any required modifications to their information systems. A limited range of service types could be included, to allow the more rapid development of training materials, documentation etc. On the basis of pilot testing, these materials could then be refined and expanded to cater to the full range of HACC service delivery agencies.

This option does not preclude the identification and implementation of testing using other purposive samples, constructed for other reasons. One example would be the construction of a sample of agencies serving remote Aboriginal communities, with the aim of the pilot being the development and testing of a modified version of the HACC MDS.

The client sample

The HACC MDS is proposed as an all-client, all-time data collection. For the purposes of the pilot test, however, it would be possible to obtain a substantial amount of useful information, whilst reducing the data collection burden on agencies, by including only a sample of clients seen by the agency. The sample could, for example, be selected randomly from the agency files, or from new clients entering the agency during the survey period. The decision on sampling strategy would need to take into account such considerations as the number of clients likely to be generated in the pilot survey period (if only new clients were to be included), and the burden on agencies in having to 're-visit' established clients in order to collect additional information.

If the decision is taken to include all rather than a sample of clients from participating agencies, consideration would still need to be given as to whether the pilot should involve all new clients, or all clients on the agency's books, or all new clients plus a proportion of existing clients.

Duration

The HACC MDS is constructed as an all-time collection, with regular (e.g. six-monthly) downloads of service data to a central data collation agency. Given the difficulties likely to be encountered in implementing the system, it is recommended that a reasonable amount of time is allocated to maximise the value gained from the pilot test. The Project Team considers that a six-month pilot period may be necessary to allow sufficient 'bedding in' time and to generate data of the required quantity and quality.

A variable implementation period

Regardless of decisions made on the components discussed above, the use of a variable implementation period may have advantages to offer in terms of practicality and feasibility. Variable implementation simply means that participating agencies be given the option of starting data collection anywhere within a set period of time, and that implementation may initially involve some data elements and not others. Such a strategy would allow some agencies which might otherwise not be in a position to participate in the pilot to come 'on stream' thereby contributing a wider range of information on implementation issues. Against these advantages must be set administrative complexity, and the likelihood that compliance may be quite low in participating agencies as the individually negotiated implementation periods are altered owing to particular agency circumstances. The quality and quantity of the data provided may be compromised by this strategy.

A staged implementation

In a staged implementation, HACC officials would set implementation deadlines for particular blocks or clusters of variables in the HACC MDS. Such a model could apply to any of the sampling methods discussed above, or indeed to a census (or to the national implementation). Data elements which are relatively simple to implement on an information systems basis (e.g. client characteristics and client circumstances) would be proposed for stage 1 implementation, with other data elements with more complex system requirements (e.g. the totals of assistance received) being slated for later implementation periods.

This strategy has the advantage of allowing some data to be obtained quite quickly, possibly from quite a wide range of agencies, whilst allowing additional lead time for the implementation of more complex aspects of the HACC MDS. Associated benefits include the possibility of staging the development of training and resource materials. Again, the disadvantage may be that agencies will become stalled with a partial implementation of the MDS, and the actual implementation will extend over a more lengthy period. If this were to be the case, the quality of data generated in the intervening period would not be adequate or sufficient for program planning, monitoring or accountability purposes.

Recommendations

Pilot test issues

50. It is recommended that the implementation of the HACC MDS be preceded by a pilot test, the exact nature of which should be determined under the aegis of HACC Officials.
51. It is recommended that the pilot test be used as an opportunity to develop and test a training package for the implementation of the MDS, and to develop and test the proposed ancillary documentation required for the collection of the MDS (the 'Guidelines to the HACC Collection' and the 'Summary of the *HACC Data Dictionary*').
52. It is recommended that consideration be given to establishing a telephone helpline for use in the pilot test. The helpline could function at either a national or State/Territory level.

8 Summary of recommendations

Implementation resource issues

1. It is recommended that two documents, 'Guidelines to the HACC MDS Collection' and a user-friendly 'Summary of the *HACC Data Dictionary*' be prepared to aid implementation. The *HACC Data Dictionary* will remain of relevance, but as a reference text to be used by agencies in conjunction with other more easily digestible information about the HACC MDS collection.
2. It is recommended that a telephone helpline be established for the duration of the first collection/reporting period. This could be conducted at either the national or State/Territory level.
3. It is recommended that paper-based proformas for collection of the HACC MDS (for example the modified CIARR for client characteristics data) be designed and made available for service providers to aid in the streamlining/modification of their existing paper-based collections.
4. It is recommended that the construction of equivalent technical specifications for implementation in computer-based systems be referred for consideration by the proposed HACC Technology Consultancy.

Training issues

5. It is recommended that all HACC agencies as well as HACC Project Officers in State/Territory departments receive training about the purpose and scope of the HACC MDS; the record linkage process; and the role the HACC MDS collection plays in the overall HACC program accountability framework.
6. It is recommended that training resources be developed and implemented before the beginning of the first data collection/reporting period and be synchronised both within and across States and Territories.
7. It is recommended that general training in information management be provided or facilitated for HACC agencies to assist them to efficiently manage the overall information collection and flows within their agency, as well as with implementing the HACC MDS. To this end, consideration could be given to developing a training module for use in the HACC program on identifying management information needs at the agency level and developing and managing information systems (computerised and paper-based). Such training could be made available to agencies on a voluntary basis or to those agencies identified by Project Officers as requiring this training.
8. It is recommended that a module of basic information management training be included in the HACC MDS specific training program.

9. It is recommended that training to support the implementation of the HACC MDS pay particular attention to those data elements which are likely to be poorly collected by agencies, such as 'Indigenous Status'.

Program issues

10. It is recommended that State/Territory and Commonwealth Governments clarify the relationship between the HACC MDS requirements (especially relating to service use) and administrative issues related to funding categories. Clear communication of the relationship between the HACC MDS collection and financial accountability mechanisms is considered essential to effective implementation of the HACC MDS.
11. It is recommended that the HACC MDS should be reported at the service delivery outlet level of a HACC-funded organisation—in line with the definition of the data element concept HACC Agency included in the *Data Dictionary*.
12. It is recommended that HACC program managers develop specifications for an agency identifier that makes appropriate links to administrative databases and which should be allocated to HACC agencies before a HACC MDS collection.

Aboriginal and Torres Strait Islander agencies

13. It is recommended that the usefulness and appropriateness of the HACC MDS should be reviewed in the context of the particular difficulties and circumstances faced by Indigenous communities, particularly those in rural and remote areas.
14. It is recommended that the HACC MDS be modified to take account of such considerations, with the involvement or oversight of the recently constituted Aboriginal and Torres Strait Islander Reference Group.
15. It is recommended that attention be directed to certain data elements associated with cultural issues (e.g. country of birth, carer data, locality names, person naming conventions) and to the general appropriateness of the *HACC Data Dictionary*, in terms of its level of complexity, literacy issues, etc.
16. It is recommended that the impact of different operational contexts found in many Indigenous agencies on the feasibility of the HACC MDS collection be considered.

Data development/data integrity issues

17. It is recommended that future developments of the HACC MDS encompass types of HACC clients other than individual persons, and the services they receive.
18. It is recommended that future developments of the HACC MDS encompass information about service providers and the organisations responsible for HACC service delivery.
19. It is recommended that the HACC program use information modelling techniques to assist with identifying and clarifying the program's information requirements.
20. It is recommended that future developments in the HACC MDS consider strategies which facilitate the collection of historical data, i.e. that agencies move toward developing the capacity to store updated information against particular data elements whilst retaining earlier versions.
21. It is recommended that the *HACC Data Dictionary* Version 1.0 be submitted to the National Community Services Information Management Group for endorsement and

for the consideration of data elements for inclusion in the *National Community Services Data Dictionary*.

22. It is recommended that consideration be given by the National Community Services Data Committee to the establishment of an aged and community care data working group to oversee data development activity in the aged and community care field.

Assessment and dependency issues

23. It is recommended that the development of data elements related to dependency and assessment be treated as a priority in future HACC MDS development.
24. It is recommended that attempts be made to include information about both a client's need for assistance and assistance received, as an indicator of 'unmet need'. Such measures should, if possible, be aligned to the ABS Survey of Disability, Ageing and Carers.
25. It is recommended that the need to develop a comprehensive assessment tool for carers should be referred to HACC Officials.
26. It is recommended that any comprehensive assessment of carers should incorporate information about the assistance provided by carers as well as information about the care recipient's need for assistance. Such measures should be aligned, if possible, with the ABS Survey of Disability, Ageing and Carers, to facilitate valid comparisons between HACC and ABS data and to facilitate the identification of principal carers.
27. It is recommended that consideration be given to the development of protocols to encourage consistency across service providers in attributing client status and assistance to carers and care recipients.

Carer linkage

28. It is recommended that further consideration be given to the implementation of the linkage key for carers in order to enable the identification of care dyads and to assist in gaining a more reliable count of carers assisted through the HACC program.
29. It is recommended that, where possible, strategies should be developed to minimise error associated with changes in name (e.g. capacity to report a previous linkage key in the MDS where change of name is known to have occurred could be considered).

Data review issues

30. It is recommended that HACC program managers give early consideration to the program's management reporting requirements based on the data to be reported in the HACC MDS collection. This would assist in identifying any further gaps in the HACC MDS and should be done prior to the full implementation of the HACC MDS.
31. It is recommended that HACC Officials consider the need for ongoing review and maintenance of the *HACC Data Dictionary* after implementation in order to retain the currency, comprehensiveness and integrity of the MDS. However, caution is recommended in the development of new data elements for inclusion in the *HACC Data Dictionary* to ensure that the integrity and internal consistency of the *Data Dictionary* and the MDS are maintained.

32. It is recommended that the *HACC Data Dictionary* and MDS collection continue to be integrated with and reviewed against other data collections and data collection instruments across the aged and community care fields including the CIARR, the CNMDSA, the ACAP MDS, the CSDA MDS as well as residential aged care data collections. This is of particular importance for those agencies which are funded from multiple programs (e.g. CSDA- and HACC-funded agencies).
33. It is recommended that particular attention be paid to resolving outstanding differences between the CNMDSA Version 2.0 and the HACC MDS as soon as possible, with a view to ensuring that the CNMDSA can support the collection of the HACC MDS.
34. It is recommended that the HACC MDS be integrated with and reviewed against other HACC developments and projects that have information and data requirement implications including the assessment project, the community care classification project, output-based funding initiatives, and the development of performance indicators.

Primary collection tool issues

35. It is recommended that the CIARR be revised to support record linkage and to include appropriate client consent wording.
36. It is recommended that the CIARR be revised to support the collection of HACC MDS information about client characteristics, client circumstances, source of referral information and carer information, as recommended by the Project Team (details of these recommendations, made to the Assessment Working Group in April 1998 and supported by them, are included in Appendix B).
37. It is recommended that consideration be given to the wide-ranging implications of the *HACC Data Dictionary* and MDS for other primary data collection tools (i.e. other than CIARR), including agency-based forms such as intake and referral forms, worker timesheets, invoices and contracts, etc.
38. It is recommended that standard wording for client consent be drafted for use across the HACC program, and that such wording include consent for the release of information for statistical and research purposes.

Linkage key issues

39. It is recommended that a linkage key comprising letters of name (second, third and fifth of surname plus second and third of first given name), date of birth and sex be adopted for implementation in the HACC MDS.
40. It is recommended that the proposed statistical linkage key (letters of name, sex and date of birth) should be supplemented by a fallback linkage option (sex, date of birth and postcode) during piloting in order to enable comparisons between the two (postcode therefore should be routinely collected in the pilot phase).
41. It is recommended that linkage be undertaken by an independent third party in an 'honest broker' role and be protected by adequate ethical standards and protocols to ensure client privacy, confidentiality and the appropriate use of information.
42. It is recommended that the linkage key be encrypted at the point of linkage.
43. It is recommended that where databases are transferred to agreed authorities (e.g. State or federal departments) for data analysis, unit records should be unidentifiable.

44. It is recommended that further testing be undertaken concerning the accuracy and effectiveness of the proposed linkage key for communities or regions which are likely to have a higher incidence of linkage problems (including Indigenous communities, especially remote Indigenous communities, areas with a high concentration of migrants, or areas with high mobility rates if postcode becomes part of the linkage key). Such testing should focus particularly on the level of error associated with the same person having multiple linkage keys due to name changes, unknown dates of birth, instability in the reporting of name and date of birth information, and changes in client location (if postcode were to be included).
45. It is recommended that for those communities which are found to have excessively high levels of duplication in respects described above, or other problems of accuracy, other options for record linkage should be considered.
46. It is recommended that all automated systems used in HACC agencies incorporate validation processes which include searches for existing names based on matching the components of the linkage key.
47. It is recommended that, where possible, strategies should be developed to minimise error associated with changes in name (e.g. capacity to report a previous linkage key in the MDS where change of name is known to have occurred could be considered).
48. It is recommended that a review of the technical aspects of undertaking the linkage process be referred for consideration by the proposed HACC Technology Project.
49. It is recommended that a review of the technical aspects of undertaking the data transfer process be referred for consideration by the proposed Technology Project.

Pilot test issues

50. It is recommended that the implementation of the HACC MDS be preceded by a pilot test, the exact nature of which should be determined under the aegis of HACC Officials.
51. It is recommended that the pilot test be used as an opportunity to develop and test a training package for the implementation of the MDS, and to develop and test the proposed ancillary documentation required for the collection of the MDS (the 'Guidelines to the HACC Collection' and the 'Summary of the *HACC Data Dictionary*').
52. It is recommended that consideration be given to establishing a telephone helpline for use in the pilot test. The helpline could function at either a national or State/Territory level.

Appendix A

National Steering Committee: HACC MDS Project

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Meals on Wheels Association
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Queensland Department of Health
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Appendix B

Dependency and need for assistance: comparison of standard collection tools and assessment instruments

Tables B1 and B2: Comparison of standard collection tools

Comparing the draft dependency items from the *Future Directions* report (Brian Elton & Associates 1996) with data elements relating to physical and mental function from a series of 11 different data collections and data collection instruments:

- Aged Care Assessment Program Minimum Data Set (ACAP MDS)
- Aged Care Application and Approval (then draft) (ACAA)
- Single Classification Instrument (SCI)
- Domiciliary Nursing Care Benefit (DNCB) application form
- Commonwealth/State Disability Agreement Minimum Data Set (CSDA MDS)
- Client Information and Referral Record (CIARR)
- Community Options Projects Client Characteristics survey (COPs)
- Home and Community Care User Characteristics survey (HACC USER)
- *Community Nursing Minimum Data Set Australia* (CNMDSA) Version 2.0
- Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (ABS)
- International Classification of Impairments, Disabilities and Handicaps (ICIDH).

Tables B3, B4 and B5: Comparison of standard assessment instruments

Tables B3, B4 and B5 (Appendix B) compare data elements relating to physical, mental and social function across a series of seven standard assessment instruments:

- Barthel Index (Mahoney & Barthel 1965)
- Bryan Domiciliary Dependency Instrument (as developed by the Royal District Nursing Service, Melbourne)
- Katz Scale (Katz et al. 1963; Katz et al. 1970; Katz & Amechi 1976)
- Resource Utilisation Groups (RUGs) (Fries et al. 1994)
- Older American Resources and Services (OARS) (Center for the Study of Ageing and Human Development, Duke University 1978)
- Lawton and Brody Philadelphia Geriatric Center (PGC) Scale (Lawton & Brody 1969; Lawton 1978)
- Functional Independence Measure (FIM) (Granger et al. 1986).

Table B1: Comparison of standard collection instruments (physical function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Continence		17 Completely continent Not completely continent Unable to determine	21 *Incontinent* Day only Night only Always Unable to determine					12 *need for assistance* Yes No	9 *need for assistance* Yes No Not known		47 *difficulty controlling* Bladder? Bowel? None of the above. 48 *ever need help managing difficulty?* Yes/No	
Continent of urine			21 *Incontinent* Never Some support Major support Extensive support Unable to determine	5 Not applicable Some support Major support Extensive support	27 *significantly incontinent?* Never Sometimes in the day Night only Always					N7 1 Continent of urine 2 Incontinent <daily 3 Incontinent once per 24 hours 4 Incontinent 2–6 times/ 24 hrs 5 Incontinent >6 times/24 hrs 6 Incontinent >once at night only	47 *difficulty controlling* Bladder? Bowel? None of the above 48 also *need help* but not specific to bladder	I70400 Urinary Stress Urge Reflex Continual Mixed

(continued)

Table B1 (continued): Comparison of standard collection instruments (physical function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Continent of faeces			21 *Incontinent* Never Some support Major support Extensive support Unable to determine		27 *significantly incontinent?* Never Sometimes in the day Night only Always					N7 1 Continent of faeces 2 Incontinent <daily 3 Incontinent once/24 hours 4 Incontinent regularly, > once/24 hrs 5 Incontinent >once at night only	47 *difficulty controlling* Bladder? Bowel? None of the above 48 also *need help* but not specific to bowel	I50340 Faecal incontinence I50310 Consistency of faeces I50320 Frequency of defecation I50330 Defecation
Use of toilet	N2 Without assistance With some assistance Completely unable		24 *assistance required* No Some Moderate Extensive	5 (*not including transfers) assistance required* No Some Major Extensive	26 *toiletting* Independent Needs assistance Dependent		Page 3 *assistance required* Yes/No			N7 *toiletting* 1 Independent 2 Requires observation or rare physical assistance 3 Cannot perform without some assistance 4 Full assistance (totally dependent)	46 *ever need help /supervision* Yes No Do not use toilet	A50310 Regulating toilet needs A50320 Carrying out activities A50330 related to urination and defecation
Location change, mobility and transfers			24 *assistance required* No Some Moderate Extensive	2 *assistance required* No Some Major Extensive								

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Mobility	N2 *get around the house independently* Without assistance With some assistance Completely unable	16 Walks independently Does not walk independently Unable to determine			24 Walks unaided Walks with stick or frame Walks with assistance of one person Walks with assistance of two people Wheels self Wheeled by others Is bedfast 25 *does he/she fall?* Rarely Occasionally Frequently	10 *around the house or away from home* (frequency of support or assistance required) Without support Occasional Frequent Continual (or cannot do at all) NA (due to age) Not known	Page 3 *walking* (assistance required) Yes/No	14 *get around the house independently* Without assistance With some assistance Completely unable	9 *e.g. walking, getting in/out of bed* (need for assistance) Yes No Not known	N7 *applies to walking, walking aid or wheelchair (excludes bed mobility)* 1 Independent 2 Requires observation or rare physical assistance 3 Cannot perform without some assistance 4 Full assistance (totally dependent) N7 *Bed mobility (same scale)*	61 *(going to, or getting around places away from home) ever need help/supervision?* Yes/No 62 *ever find it difficult without help/supervision?* Yes/No 63 *(moving about the house) ever need help/supervision?* Yes/No 64 *ever find difficult without help/supervision?* Yes/No 78 *easily walk 200 metres?* Yes/No/Does not leave home 79 *take longer than most people same age?* Yes/No 80 *walk up/down stairs without handrail?* Yes/No/Does not move about house	A30410 Walking A30420 Running A30430 Jumping/Hopping/Skipping A30440 Crawling A40100–40400 Mobility, excluding transport.

(continued)

Table B1 (continued): Comparison of standard collection instruments (physical function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Mobility (continued)											81 *without difficulty?* Yes/No 82 *pick up object from floor without assistance?* Yes/No	
Transfers	N2 *get in and out of bed* Without assistance With some assistance Completely unable				26 *transferring to/from bed/ chair/ walking aid* Independent Needs assistance Dependent Requires lifting device		Page 3 *get in/out of bed* (assistance required) Yes/No	14 *get in/out of bed* Without assistance With some assistance Completely unable		N7 1 Independent 2 Requires observation or rare physical assistance 3 Cannot perform without some assistance 4 Full assistance (totally dependent) 5 Bedfast	63 *ever need help/ supervision (bed or chair)?* Yes/No 64 *ever find it difficult without help/ supervision?* Yes/No	A30300 Changing body position A30500 Transferring oneself while sitting or lying
Personal care			24 *Personal hygiene including all grooming, showering, dressing/ undressing etc.* (assistance required) No Some Moderate Extensive	4 *Personal hygiene* (assistance required) No Some Major Extensive		10 *self care* (frequency of support or assistance required) Without support Occasional Frequent Continual (or cannot do) NA (i.e. due to age) Not known			9 *e.g. bathing, feeding* (need for assistance) Yes No Not known			

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Grooming	N2 Without assistance With some assistance Completely unable						Page 3 *assistance required* Yes/No	14 *take care of appearance* Without assistance With some assistance Completely unable				A50200 Care of body parts, teeth, nails and hair
Bathe/ shower	N2 Without assistance With some assistance Completely unable				26 Independent Needs assistance Dependent		Page 3 *assistance required* Yes/No	14 Without assistance With some assistance Completely unable		N7 *bathing* 1 Independent 2 Requires observation or rare physical assistance 3 Cannot perform without some assistance 4 Full assistance (totally dependent)	40 *ever need help/ supervision?* Yes/No 41 *ever find it difficult without help/ supervision?* Yes/No	A50100 Washing oneself
Dress/ undress	N2 Without assistance With some assistance Completely unable				26 Independent Needs assistance Dependent		Page 3 *assistance required* Yes/No	14 Without assistance With some assistance Completely unable		N7 *dressing* 1 Independent 2 Requires observation or rare physical assistance 3 Cannot perform without some assistance 4 Full assistance (totally dependent)	42 *ever need help/ supervision?* Yes/No 43 *ever find it difficult without help/ supervision?* Yes/No	A50400 Dressing

(continued)

Table B1 (continued): Comparison of standard collection instruments (physical function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Eating	N2 Without assistance With some assistance Completely unable		24 *meals and drinks* (assistance required) No Some Moderate Extensive	3 *meals and drinks* (assistance required) No Some Major Extensive	26 Independent Needs assistance Dependent Tube-fed		Page 3 *assistance required* Yes/No	14 Without assistance With some assistance Completely unable		N7 1 Independent 2 Requires observation or rare physical assistance 3 Cannot perform without some assistance 4 Full assistance (totally dependent) 5 Tube-fed only	44 *ever need help/ supervision?* Yes/No 45 *ever find it difficult without help/ supervision?* Yes/No	A50500 Eating and drinking
Foot-care							Page 3 *assistance required* Yes/No				147 *need help with caring for feet?* Yes/No 149 *always?* Yes/No	
Take medicine	N2 Without assistance With some assistance Completely unable		24 *assistance required* No Some Moderate Extensive	19 *assistance required* No Some Major Extensive				14 Without assistance With some assistance Completely unable		N8 1 Responsible for taking medication in correct doses at correct time 2 Takes responsibility if prepared in advance in separate doses 3 Is not capable of dispensing own medication	146 *ongoing help/ supervision with taking medicine or dressing wounds?* Yes/No 149 *always need help?* Yes/No	A50640 Taking care of one's health, includes taking medicine

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Shopping	N2 Without assistance With some assistance Completely unable		24 *assistance required* No Some Moderate Extensive				Page 3 *including banking* Independent With assistance Dependent NA	14 Without assistance With some assistance Completely unable		N8 1 Takes care of all shopping needs independently 2 Shops independently for small purchases 3 Needs to be accompanied on all shopping trips 4 Completely unable to shop	221 *(transport related) need help/ supervision with transport to shop?* Yes/No	A60120 Procuring and/or selecting items
Money and finance	N2 Without assistance With some assistance Completely unable		24 *assistance required* No Some Moderate Extensive					14 Without assistance With some assistance Completely unable		N8 1 Manages financial matters independently, collects and keeps track of income 2 Manages day-to-day purchases, but needs help with banking, major purchases etc 3 Incapable of handling money	196-206 *Financial management/letter writing* 196 *need help?* Yes/No 199 *always need help?* Yes/No	A80700 Economic skills A60120 Paying

(continued)

Table B1 (continued): Comparison of standard collection instruments (physical function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Clean house	N2 Without assistance With some assistance Completely unable		24 *housework including laundry* (assistance required) No Some Moderate Extensive				Page 3 *housework* Independent With assistance Dependent NA	14 *housework* Without assistance With some assistance Completely unable	9 *housekeeping e.g. cleaning, meal preparation* (need for assistance) Yes No Not known	N8 housekeeping 1 Maintains house alone or with occasional assistance 2 Performs light daily tasks such as dishwashing or bed-making 3 Performs light daily tasks but cannot maintain acceptable level of cleanliness 4 Needs help with all home maintenance tasks 5 Does not participate in any housekeeping tasks N8 *laundry* 1 Does personal laundry completely 2 Launders small items 3 All laundry must be done by others	158-69 *(home help including laundry)* 159 *find difficult?* Yes/No 160 *could do without assistance?* Yes/No 161 *why difficult?*	A60400 Laundry A60500 Taking care of dwelling

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Prepare meals	N2 Without assistance With some assistance Completely unable		24 *assistance required* No Some Moderate Extensive *Also assistance required to follow special diet if needed*				Page 3 Independent With assistance Dependent NA	14 Without assistance With some assistance Completely unable		N8 1 Plans, prepares and serves adequate meals 2 Prepares adequate meals if supplied with ingredients 3 Heats, serves and prepares meals but does not maintain adequate diet 4 Needs to have meals prepared and served	184–95 *Meal preparation* 185 *find difficult?* Yes/No 186 *could do without assistance?* Yes/No 187 *why difficult?*	A60300 Taking care of meals (A50640 Taking care of one's health also includes special diet)
Minor home maintenance	N2 Without assistance With some assistance Completely unable		24 *assistance required* No Some Moderate Extensive				Page 3 Independent With assistance Dependent NA	14 Without assistance With some assistance Completely unable			170–83 *(Homemaintenance/ gardening)* 170 *difficult to do?* Yes/No 171 *could do without help?* Yes/No 172 *why difficult?*	A60550
Telephone	N2 Without assistance With some assistance Completely unable		24 *assistance required* No Some Moderate Extensive				Page 3 Independent With assistance Dependent NA	14 Without assistance With some assistance Completely unable		N8 1 Operates telephone on own initiative 2 Dials few well-known numbers	252 *can use?* Yes/No	

(continued)

Table B1 (continued): Comparison of standard collection instruments (physical function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Telephone (continued)										3 Answers but does not dial 4 Does not use at all		
Transport	N2 *get to places out of walking distance* Without assistance With some assistance Completely unable		24 *Public transport* (assistance required) No Some Moderate Extensive 24 *Private transport* (assistance required) No Some Moderate Extensive				Page 3 Independent With assistance Dependent NA	14 *get to places out of walking distance* Without assistance With some assistance Completely unable		N6 *mode of transportation* 1 Travels independently on public transport or drives own car 2 Arranges own travel via taxi but does not use other public transport 3 Travels on public transport accompanied 4 Travel limited to taxi or auto with assist-ance of another 5 Does not travel at all	208–33 *Public transport (also shopping, driving)* 208–9 *can use?* Yes/No 212 *need help/ supervision?* Yes/No 213 *difficult to use?* Yes/No 214 *why difficult?*	A40500, A40600 *Using transportation (includes public, private and driving)*
Read			24 *assistance required* No Some Moderate Extensive								106–10 *Print handicap* 106 *difficulty holding book/ magazine or turning pages?* Yes/No 108 *glasses or contacts for reading?* Yes/No	A10910

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Read (continued)											109 *(when wearing) difficulty reading normal print?* Yes/No 110 *main reason?*	
Write			24 *assistance required* No Some Moderate Extensive								197 (letter writing, not writing per se)	A10920 A20700
Vision			22 No impairment Minor Major								9–13 Household form) *Loss of sight?* Yes/No *If yes, total loss?* Yes/No *(excludes contacts etc)*	I20100–20500 Vision A00100 Seeing (far/middle/near distance; poor light)
Hearing			22 No impairment Minor Major								14–17 (Household form) *Loss of hearing?* Yes/No *If yes, total loss?* Yes/No	I10700 Hearing (mild/moderate/severe/profound decrease) A00200 (loud noises/when background noise/sounds from different directions/moderately loud sounds/soft sounds)

(continued)

Table B1 (continued): Comparison of standard collection instruments (physical function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPs	HACC USER	CNMDSA	ABS	ICIDH*
Primary diagnosis		15	23			7 *primary disability group* 8 & 9 *other significant disability groups*	Page 2a *perceived health problems*				21 *Main disabling condition*	Relates to Impairment Classification of the ICD
Allied health/ therapy requirements			Yes No Physiotherapy Occupational therapy Speech therapy Podiatry Other	21 Therapy —physiotherapy 22 Therapy —other No support Some support Major support Extensive support								
Specialised treatments			24 *includes catheter, colostomy, tube-feeding, intravenous treatments* (assistance required) No Some Moderate Extensive	20 *Technical and nursing procedures* None or minimal Some technical procedures Nursing procedures Specialised nursing procedures	26 *Catheter/colostomy* Independent Needs assistance Dependent NA					N5 *Technical care* 1 Not required Or *time in minutes* • daytime technical • evening technical • night technical • infrequent technical		A90300 Catheter/ Colostomy

*ICIDH Activity (A) Dimension has two qualifiers.

The first qualifier relates to difficulty and is rated:
0 No difficulty
1 Slight difficulty
2 Moderate difficulty
3 Severe difficulty
4 Unable to carry out activity
9 Level of difficulty unknown

The second qualifier (optional) relates to assistance and is rated:
0 No assistance required
1 Non-personal assistance (e.g. aids)
2 Personal assistance
3 Both non-personal and personal assistance required
9 Level of assistance unknown

Table B2: Comparison of standard collection instruments (mental function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPS	HACC USER	CNMDSA	ABS	ICIDH*
Orientation		18 Aware of time and place Not aware of time and place Unable to determine	19 Generally aware of place and time Sometimes disoriented/ confused Generally disoriented/ confused Unable to determine		28 Always aware of time and place Sometimes disoriented/ confused Always disoriented/ confused			11 *behaviour e.g. wandering, confusion* (need for assistance) Yes No	9 *behaviour e.g. confusion, disorientation* (need for assist-ance) Yes No Not known			Orientation to I00310 time I00320 place I00330 person
Comprehension/awareness				8 No difficulty Some difficulty Major difficulty Extensive difficulty								I01610 Comprehension (in terms of language)
Speech			22 No impairment Minor Major									I10100 Voice I10200 Articulation I10300 Fluency and rhythm of speech
Communication				1 No difficulty Some difficulty Major difficulty Extensive difficulty/ no communication	5 *method of communication*	10 *frequency of support or assistance required* Without support Occasional Frequent Continual (or cannot do at all) NA (due to age) Not known	Page 3 Independent With assistance Dependent NA	13 *e.g. due to stroke or disability* (need for assistance) Yes No	9 *e.g. due to stroke or disability* (need for assistance) Yes No Not known		85-97 *Verbal communication* 85 *use sign language?* Yes/No 86 *what type* 87 *lip reads?* Yes/No 89 *understand someone doesn't know?* Yes/No	A20100–20200 Understanding messages (non-verbal and verbal) A20400, 20500, 20600 Producing and communicating messages

(continued)

Table B2 (continued): Comparison of standard collection instruments (mental function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPS	HACC USER	CNMDSA	ABS	ICIDH*
Communication continued)											91 *easily understand family/friends?* Yes/No 92 *be understood by someone does not know?* Yes/No 93 *easily understood by family/friends?* Yes/No 94 *always need help communicating with others?* Yes/No 95 *anyone usually help?* Yes/No	
Extra surveillance										N5 1 No additional attention 2 <30 minutes/day 3 30–90 minutes/day 4 at least 2 hours/week episodic 5 >90 but < almost constant 6 almost constant 7 cannot be left alone at all		

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPS	HACC USER	CNMDSA	ABS	ICIDH*
Physical aggression			20 *aggressive behaviour* (frequency) Never Occasionally Intermittently Extensively									A70360 Managing own physical aggression
Verbal disruption				11 *noisy* 13 *aggressive verbally* NA Occasionally Intermittently Extensively								A70350 Managing own verbal aggression
Disruptive behaviour			20 (frequency) Never Occasionally Intermittently Extensively	10 *interfering with others and/or others' belongings* NA Occasionally Intermittently Extensively	29 (frequency) Never Rarely Occasionally (2–3 times/ week) Frequently							A70300 Managing own personal behaviour
Wandering			20 (frequency) Never Occasionally Intermittently Extensively	9 *wandering or absconding* NA Occasionally Intermittently Extensively	29 (frequency) Never Rarely Occasionally (2–3 times/week) Frequently			11 *behaviour e.g. wandering, confusion* (need for assistance) Yes No				

(continued)

Table B2 (continued): Comparison of standard collection instruments (mental function)

Items	Future Directions	ACAP	ACAA	SCI	DNCB	CSDA	CIARR	COPS	HACC USER	CNMDSA	ABS	ICIDH*
Sleep disturbance			20 (frequency) Never Occasionally Intermittently Extensively		29 (frequency) Never Rarely Occasionally (2–3 times/week) Frequently							I00111 Alertness/ wakefulness
Extreme emotional dependence				14 NA Occasionally Intermittently Extensively								
Danger to self and/or others				15 NA Occasionally Intermittently Extensively								A70340 Refraining from self-mutilation
Dementia								10 (needs assistance) Yes/No			57 *Type of condition?* (dementia included on prompt card)	I00420 Intellectual deterioration

*ICIDH Activity (A) Dimension has two qualifiers.
The first qualifier relates to difficulty and is rated:
- 0 No difficulty
- 1 Slight difficulty
- 2 Moderate difficulty
- 3 Severe difficulty
- 4 Unable to carry out activity
- 9 Level of difficulty unknown

The second qualifier (optional) relates to assistance and is rated:
- 0 No assistance required
- 1 Non-personal assistance (e.g. aids)
- 2 Personal assistance
- 3 Both non-personal and personal assistance required
- 9 Level of assistance unknown

Table B3: Comparison of standard assessment instruments (physical function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Continence			1 Controls urination/bowel movement completely by self 2 Occasional accidents 3 Supervision helps keep urine/bowel control; catheter used/or incontinent				
Continent of urine	Bladder continence Independent 1. Intact 2. Limited Dependent 3. Helper 4. Null	Bladder management—Continence: 1 Continent of urine 2 Incontinent <daily (or occasionally at night) 3 Incontinent once per 24 hours 4 Incontinent 2–6 times per day 5 Incontinent >6 times per 24 hours 6 Incontinent >once per 24 hours, only at night Incontinence severity: 1 NA—continent 2 Damp 3 Wet 4 Saturated Urinary drainage: 1 No urinary drainage 2 Urinary drainage in situ					Bladder Management: 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance

(continued)

Table B3 (continued): Comparison of standard assessment instruments (physical function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Continent of urine (continued)		Urinary drainage management: 1 Not applicable 2 Requires observation/ rare physical assistance 3. Cannot manage without some physical assistance 4. Full assistance required					
Continent of faeces	Bowel continence Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null	Bowel management: 1 Continent offaeces 2 Incontinent <daily (or occasionally at night) 3 Incontinent once per 24 hours 4 Incontinent regularly >once per 24 hours 5 Incontinent >once per 24 hours, only at night Stoma: No/Yes Stoma Management 1 Not applicable 2 Requires observation/ rare physical assistance 3. Cannot manage without some physical assistance 4. Full assistance required					Bowel Management: 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Use of toilet	Care of perineum/clothing at toilet: Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null	1. No assistance or has stoma/urinary drainage 2 Requires observation/ rare physical assistance 3 Cannot toilet without some physical assistance 4 Full assistance required 5 Never uses toilet Toilet alternatives: 1 Not applicable 2 Uses commode 3 Uses bedpan/bottle 4 Incontinence pads/ linen changes	Level of mobility/ dexterity re:toiletting: 1 No assistance required/has stoma, urinary drainage device 2 Requires observation/rare physical assistance 3 Cannot toilet without some physical assistance 4 Full assistance required	1 Independent/ supervision 2 Requires assistance from 1 person 3 Uses an aid + assistance from 1 person 4 Requires 2 people to assist	Have trouble getting to the bathroom on time: 1 No 2 Yes 3 Have a catheter/colostomy 4 Not answered If yes, how often wet/soil yourself 1 1–2 times/week 2 >=3 times/week 3 Not answered		1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance
Mobility	Walk on level 50 yards or more: Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null Same scale for: —up and down stairs for one flight or more: —wheelchair/50 yards (only if not walking)	Ambulation: 1 No assistance with walking 2 Independent with aids 3 Independent in wheelchair 4 Requires observation/rare physical assistance with aids/wheelchair 5 Cannot walk with/without aid and some physical assistance 6 Cannot use wheelchair without some physical assistance 7 Full assistance with walking 8 Full assistance with wheelchair 9 Rarely leaves bed Climb stairs: 1 Independently 2 With help from another 3 Unable to negotiate stairs		Bed mobility (ability to move in bed after transfer): 1 Independent/ supervision 2 Needs assistance of 1 other person 3 Assistance of 1 person + using aid 4 Requires 2 people to assist	Get to places outside of walking distance: 1 Without help 2 With some help 3 Unable to travel unless emergency arrangements made (e.g. ambulance) 4 Not answered Can you walk: 1 Without help 2 With some help from persons/walker, crutches 3 Completely unable 4 Not answered		Walking 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance Same scale for: —using wheelchair and —going up and down 12–14 stairs

(continued)

Table B3 (continued): Comparison of standard assessment instruments (physical function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Mobility (continued)		Walk 45 m on level surface 1 independently 2 Walk >=45 m with some help/supervision 3 Unable to walk 45m					
Transfers	Transfer chair: Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null Same scale for: —transfer toilet: —transfer tub/shower	1 No assistance 2 Requires observation/encouragement/rare physical assistance 3 Cannot transfer without assistance from >=1 person 4 Cannot transfer without assistance from >=2 people	1 No assistance required 2 Requires observation/rare physical assistance 3 Cannot transfer without some physical assistance from 1 person 4 Cannot transfer without physical assistance from >=2 people	1 Independent/ supervision 2 Limited assistance (hands-on assistance of 1 person) 3 Assistance of 1 person, or 1 person + device 4 Requires 2 people to assist	Getting in and out of bed: 1 Without any help or aids 2 With some help 3 Totally dependent on someone else 4 Not answered		Bed, chair, wheelchair: 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance Same scale for: —toilet transfer and —tub /shower transfer
Grooming	Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null	1 No assistance 2 Requires observation/encouragement/rare physical assistance 3 Cannot perform without some assistance 4 Full assistance required			Take care of own appearance: 1 Without help 2 With some help 3 Completely unable 4 Not answered		1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependenc (expends <50% of effort) 8 Maximal assistance 9 Total assistance

Items	15-item Modified Barthel	Bryan domiciliary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Bathe/ shower	Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null	1 No assistance 2 Requires observation/encouragement/ rare physical assistance 3 Cannot perform without some physical assistance 4 Full assistance	1 No assistance 2 Assistance bathing 1 part of body 3 Assistance bathing >1 part of body		1 Without help 2 With some help 3 Completely unable 4 Not answered		1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance
Dress/ undress	Dress upper body: Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null Same scale for: —dress lower body —don brace orprothesis	1 No assistance 2 Requires observation/encouragement/ rare physical assistance 3 Cannot perform without some physical assistance 4 Full assistance	Gets clothes and gets dressed: 1 Completely without assistance 2 Without assistance except for tying shoes 3 Receives assistance, or stays partly/completely undressed		1 Without help 2 With some help 3 Completely unable 4 Not answered		Dressing—upper body: 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependenc (expends <50% of effort) 8 Maximal assistance 9 Total assistance Same scale for: —dressing lower body

(continued)

Table B3 (continued): Comparison of standard assessment instruments (physical function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Eating	Drink from cup/feed from dish: Independent 1 Intact 2 Limited Dependent 3 Helper 4 Null	1 No assistance 2 Requires observation/encouragement/ rare physical assistance 3 Cannot perform without some physical assistance 4 Full assistance required 5 Tube-fed only	1 No assistance 2 Requires observation 3 Requires observation/encouragement/ rare physical assistance 4 Cannot eat without some physical assistance 5 Full assistance required 6 Tube-fed only	1 Independent/ supervision 2 Limited assistance (assistance of 1 person) 3 Extensive assistance/total dependence/tube fed	1 Without help 2 With some help 3 Completely unable 4 Not answered		1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance
Take medicine		*Lawton and Brody compatible*			1 Without help 2 With some help 3 Completely unable 4 Not answered	Responsibility for own medication: 1 Correct dosages at correct times 2 If prepared in advance in separate dosages 3 Not capable of dispensing own medication	
Shopping		*Lawton and Brody compatible*			Shopping for groceries/clothes (assuming transportation available): 1 Without help 2 With some help 3 Completely unable 4 Not answered	1 Takes care of needs independently 2 Shops independently for small purchases 3 Needs to be accompanied 4 Completely unable to shop	

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Money and finance		*Lawton and Brody compatible*			Handle own money: 1 Without help 2 With some help 3 Completely unable 4 Not answered	Ability to handle finances: 1 Manages financial matters independently, collects & keeps track of income 2 Manages day-to-day purchases, needs help with banking, major purchases 3 Incapable of handling money	
Housekeeping		*Lawton and Brody compatible*			Housework: 1 Without help 2 With some help 3 Completely unable 4 Not answered	1 Maintain house alone, or with occasional assistance 2 Performs light daily tasks 3 Performs light daily tasks, not acceptable level of cleanliness 4 Needs help with all home maintenance tasks 5 Does not participate in any housekeeping	
Laundry		*Lawton and Brody compatible*				1 Does personal laundry competently 2 Launders small items 3 All laundry done by others	
Prepare meals		*Lawton and Brody compatible*			1 Without help 2 With some help 3 Completely unable 4 Not answered	1 Plans, prepares, serves adequate meals independently 2 Prepares adequate meals if ingredients supplied 3 Heats, serves, prepared meals, or prepares meals not adequate diet 4 Needs to have meals prepared/ served	

(continued)

Table B3 (continued): Comparison of standard assessment instruments (physical function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Telephone		*Lawton and Brody compatible*			Can you use the telephone: 1 Without help 2 With some help 3 Completely unable 4 Not answered	Ability to use telephone: 1 Uses own initiative 2 Dials well-known numbers 3 Answers, does not dial 4 Does not use	
Transportation		*Lawton and Brody compatible*				Mode of transportation: 1 Travels independently (public transport or car) 2 Arranges own travel via taxi, not use public transport 3 Travels on public transport accompanied by another 4 Travel limited to taxi or car with assistance from another 5 Does not travel at all	
Vision		1 No difficulty 2 Difficulty seeing/identifying small objects 3 Difficulty seeing and identifying large objects 4 No useful vision					
Hearing		1 No difficulty 2 Difficulty with normal conversation 3 Hears loud sounds/ voices only 4 No useful hearing					
Prevention of pressure areas		1 Infrequent or no attention 2 1–3 times daily 3 4–6 times daily 4 >6 times daily					

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Maintenance of independence		1 No additional attention 2 <1 hour of individual attention per 24 hours 3 1–2 hours of individual attention per 24 hours 4 >2 hours of individual attention per 24 hours					

Table B4: Comparison of standard assessment instruments (mental function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Confusion/ wandering		Requires attention/intervention? 1 Minimal/none 2 1-3 times daily 3 4-6 times daily 4 > 6 times daily					
Speech/ comprehension		Requires individual attention/planned intervention? 1 No 2 Some activities 3 Majority activities 4 All activities					Comprehension (Auditory and Visual separately identified) 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance Expression (Vocal/Non-vocal separately identified) 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Consciousness		1 Conscious 2 Unconscious most or all of the time					
Surveillance		1 No additional attention 2 <30 minutes daily 3 30–90 minutes daily 4 >2 hours at least once week 5 >90 minutes daily, not almost constant 6 Almost constant attention 7 Cannot be left unattended					
Physical aggression		Requires attention/ intervention? 1 Minimal/none 2 Most days 3 2–3 times daily 4 >3 times daily					
Verbal disruption		Requires attention/ intervention? 1 Minimal/none 2 1–3 times daily 3 4–6 times daily 4 >6 times daily					
Other behaviour		Requires attention/ intervention? 1 Minimal/none 2 1–3 times daily 3 4–6 times daily 4 >6 times daily					

(continued)

Table B4 (continued): Comparison of standard assessment instruments (mental function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Social cognition							Social interaction 1 Complete independence 2 Modified independence 3 Modified dependence (expends >=50% of effort) 4 Supervision or setup 5 Minimal contact assistance 6 Moderate assistance 7 Complete dependence (expends <50% of effort) 8 Maximal assistance 9 Total assistance Same scale for: —problem solving —memory

Table B5: Comparison of standard assessment instruments (social function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Marital status					1 Single 2 Married 3 Widowed 4 Divorce 5 Separated 6 Not answered If married, whether spouse lives here: 1 Yes 2 No 3 Not answered		
Living arrangement					No-one, husband/wife, children, grandchildren, parents, grandparents, brothers/sisters, other relatives, friends, non-related paid help, other Social resource scale		
Carer		Carer stress factors 1 Poor carer health 2 Carer has physical limitations 3 Limited availability/ other commitments 4 Difficulty following care regime 5 Unwilling carer 6 Heavy care burden 7 Constant demand/ disturbed sleep 8 Distressing patient condition 9 Lack support network 10 Social/financial problems 11 Carer's lifestyle compromised 12 Insufficient formal support			Is there someone who helps with shopping, housework, bathing, dressing and getting around? 1 Yes 2 No 3 Not answered If yes 1 Relationship to major helper 2 Relationship to who else helps Homemaker—Household Services scale		

(continued)

Table B5 (continued): Comparison of standard assessment instruments (social function)

Items	15-item Modified Barthel	Bryan domicilary	Katz	RUGs	OARS	Lawton & Brody (PGC Scale)	Functional Independence Measure
Patient risk factors		Patient risk factors: 1 Deteriorating/ unstable health problem 2 Disabling sensory deficits 3 Altered mental state 4 Frailty/risk of falls 5 Potential medication problem 6 Lives alone 7 Self-neglects 8 Unsafe environment 9 Inadequate/no formal support 10 Social/financial problems					
Support services		1 Home help 2 Delivered meals 3 Aged Care Assessment Team (ACAT) 4 Other health professional 5 Palliative care/hospice service 6 Respite/day care 7 Equipment loan 8 Transport 9 Home maintenance 10 Case management 11 Other support services					

Appendix C

Recommended modifications to the Client Information and Referral Record (CIARR)

Table C1: Mapping the CIARR and the HACC MDS — data elements requiring minimal modifications

HACC MDS	CIARR current	CIARR recommended	Reason for recommending change
First given name Family name/surname	Title Full name Prefer to be called	Title First given name Family name/surname Prefer to be called	Agency will be required to clearly differentiate the person's first name and surname in order to report the Letters of Name data element used linking client records. Support retention of the 'preferred name' field to help maintain integrity of other name fields.
Date of birth (8 digit)	Date of birth (6 digits)	Date of birth (8 digits) *Will need to include instructions for estimating dates of birth.*	An 8-digit DOB will be required for record linkage. CIARR specification should align with this.
Sex Male Female Not stated/inadequately described	Female Male	No change	
Country of birth	Country of birth	No change	For MDS reporting country of birth would be coded according to the 4-digit ABS code.
Main language spoken at home	Language spoken at home	Main language spoken at home	Gives clearer indication of which language to record if there is more than one. Maintains consistency with MDS item. For MDS reporting main language spoken at home would be coded according to the 2-digit ABS code.
Indigenous status Aboriginal but not Torres Strait Islander Torres Strait Islander but not Aboriginal Both Aboriginal and Torres Strait Islander Neither Aboriginal nor Torres Strait Islander Not stated/inadequately described *(not for use in primary collections)*	Does the client identify themselves as an Aboriginal or Torres Strait Islander? Yes/No	Are you of Aboriginal or Torres Strait Islander origin? No Yes, Aboriginal Yes, Torres Strait Islander *(With instruction to tick both boxes if person is of both Aboriginal and Torres Strait Islander origin.)*	Conforms with ABS standards for the collection of information on Indigenous status using a one-question format. Enables coding to the MDS. Provides better quality data by differentiating between people of Aboriginal and Torres Strait Islander origin. Guidelines for the CIARR should give further information on how this information should be collected.

HACC MDS	CIARR current	CIARR recommended	Reason for recommending change
Living arrangements Lives alone Lives with family Lives with others Not stated/inadequately described	Client's usual living arrangements With spouse/partner only Other relatives/persons Alone Other (specify)	Living arrangements Lives alone Lives with family Lives with others *Or:* Lives alone Lives with spouse/partner only Lives with other family Lives with non-family	The preferred coding options would depend on the perceived importance of the 'lives with spouse/partner only' category. For the MDS it was decided that the most crucial distinction was whether the person lived alone or not and the second most crucial was whether they lived with family or not. The inclusion of the spouse/partner only option was not seen as sufficiently useful to warrant its collection in the MDS, though this may be very different at the service provider level. Neither of the recommended options are mutually exclusive and guidelines would need to clarify this. The current version of the CIARR would not support MDS reporting. The current version of the CIARR also uses the concept of 'usual' whereas MDS uses the concept of 'while receiving services'. These may lead to different responses at times.
Area of residence *can use either a:* *1-digit a State/Territory code in conjunction with a 4-digit Statistical Local Area; or suburb/town/locality in conjunction with postcode*	Usual address and Current address (both of which include suburb and postcode)	No change	Current collection of address information already supports MDS reporting. However, agencies will need to determine which address to use as the MDS data element refers to area of residence 'while receiving services' and this could relate to either a usual or a current address. Agencies wishing to report SLAs directly can derive this from address information included in the CIARR.

(continued)

Table C1 (continued): Mapping the CIARR and the HACC MDS—data elements requiring minimal modifications

HACC MDS	CIARR current	CIARR recommended	Reason for recommending change
Accommodation setting Private residence—owned/purchasing Private residence—private rental Private residence—public rental Independent living unit within a retirement village Boarding house/private hotel Short-term crisis, emergency or transitional accommodation facility (e.g. night shelters, refuges, hostels for the homeless, halfway houses) Supported independent living facility (e.g. group home for people with a disability) Supported accommodation facility (e.g. hostels for people with disabilities, Special Residential Services (Vic and SA)) Residential aged care facility (nursing home or aged care hostel) Psychiatric/mental health community care facility Public place/temporary shelter Other Not stated/inadequately described	Home owner Private tenant Public tenant	*Include full code list.*	Tenancy only relates to private residences, yet HACC clients live in a wide range of accommodation settings. If the CIARR is to be used as a general data collection instrument for HACC clients it should reflect the variety of accommodation settings in which they live. HACC coding list incorporates both accommodation setting and tenure. Would need to clarify some of the more confusing options in the guidelines to the CIARR (e.g. the inclusion of residential aged care facilities in such a context).
Government pension/benefit status Aged pension Veterans Affairs Pension Disability Support Pension Carer Payment (Pension) Unemployment-related benefits Other government pension or benefit No government pension or benefit Not stated/inadequately described	Source of income Pension type Number Other (specify) Unable to determine Pensioner concession card number	*Include code list for pension/benefit. May wish to include other options but maintain mappability. Will still need other information.* Also HACC MDS item does not relate to main source of income. Rather it relates to any income from government pensions/ benefits (both part and full pension/benefit receipt attract concessions and indicate some level of financial disadvantage). *Recommendation to maintain Domiciliary Nursing Care Benefit as a separate item as this is not a means tested entitlement.*	Enables mapping to HACC MDS.

HACC MDS	CIARR current	CIARR recommended	Reason for recommending change
Source of referral	Source of referral	*Include code list for source of referral. Will still need other information.*	Enables mapping to HACC MDS.
Self Family, significant other Internal agency referral GP/medical practitioner—community-based Specialist aged or disability assessment team/service (e.g. ACAT) Comprehensive HACC Assessment Authority Community nursing service Other community service—health Other community service—non-health Acute care hospital Psychiatric/mental health service or facility Extended care/rehabilitation facility Palliative care facility/hospice Residential aged care facility (nursing home/hostel) Other Not stated/inadequately described (not for use in primary data collections)	Name Contact no. Organisation (if applicable) Reason for referral and type of assistance being sought		

Table C2: Mapping the CIARR and the HACC MDS—information about carers.

HACC MDS	CIARR current	CIARR recommended	Reason for recommending change
Carer availability Has a carer Has no carer Not stated/inadequately described	*Not included. Does ask generally about informal assistance available and has an option to specify first the contact person as the carer.*	Carer availability Has a carer Has no carer (*Or:* Does the person have a carer? Yes/No) *Could still ask about availability of other informal assistance, and whether the first contact person is the carer (though need to be careful not to conflate contact persons with carers).* *Also need to acknowledge where the client is a carer.*	Specifically identifies the presence or absence of a carer. Enables coding to the MDS Relates to wider problems in the way carers/clients are dealt with in the CIARR.
Carer residency status Co-resident carer Non-resident carer Not stated/inadequately described	*Not included.*	Carer residency status Co-resident carer Non-resident carer	Specifically identifies whether a carer lives with the person for whom they care. Enables coding to the MDS. Relates to wider problems in the way carers/clients are dealt with in CIARR.
Relationship of carer to care recipient Wife/female partner Husband/male partner Mother Father Daughter Son Daughter-in-law Son-in-law Other relative—female Other relative—male Friend/neighbour—female Friend/neighbour—male Not stated/inadequately described	*Not specifically included. Does ask relationship for first contact/emergency contact or carer; second important contact and third important contact with no specified options.*	Include full code list in relation to carer. If carer's sex is also asked then could collapse the code list to the following: Spouse/partner Mother/father Daughter/son Daughter-in-law/son-in-law Other relative Friend/neighbour Not stated/inadequately described May be able to leave unchanged for contact persons.	Enables mapping to HACC MDS.

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