

Part B: Developing Australian contingence data standards

1 Introduction

1.1 Purpose

In 2001–02 the AIHW was commissioned to undertake a review of existing health and community care data sets, to identify data items that could contribute to the monitoring of incontinence and its treatment and management (AIHW 2002b). This review concluded that variation in the definition of incontinence, and the range and definitional variation of incontinence-relevant data items included in Australian data collections, limit the useability of incontinence data for benchmarking or monitoring prevalence and treatment of incontinence.

In 2004 the Australian Government Department of Health and Ageing again commissioned the AIHW to undertake the present study (Part B of this report) including another review of continence-relevant data collections, this time with the aim to inform and make recommendations for harmonising established and future continence program data. This work is being conducted alongside other established incontinence projects, and other work on dementia, to ensure cross-fertilisation and comparable outcomes. It was proposed that recommendations be presented as areas of information and options for potential data item sets considered vital to collecting informative and comparable data on incontinence prevalence estimates, management and outcomes.

1.2 Data standards and data dictionaries

The international and national standards used to inform this report are the International Classification of Functioning, Disability and Health (ICF) (see Section 1.3) and the national data dictionaries. Adherence to data standards ensures there is mutual understanding of the meaning of underlying concepts between different parties, and promotes consistency and comparability of data for analysis and interpretation.

To facilitate the development of data for reporting purposes, the relevant policy agencies of the Commonwealth, states and territories and the two statistical agencies (the ABS and the AIHW) have signed four national information agreements for the fields of health, community services, housing and Indigenous housing. Two of the main products resulting from the national information agreements relevant to this report are the *National Community Services Data Dictionary* (NCSDD Version 3, AIHW 2003a) and the *National Health Data Dictionary* (NHDD Version 12, AIHW 2004b). These data dictionaries are compiled by the respective information management groups established under the information agreements and are published by the AIHW. The dictionaries are major pieces of Australian national information infrastructure. They contain national information models, and associated data elements, specified in accordance with International Organization for Standardization (ISO) standards. The dictionaries provide a menu of standard data elements, from which national minimum data sets can be specified, for the major national collections in the fields of health, community services, housing and Indigenous housing. Minimum data sets established under the community services, health and housing agreements are obligatory for all to report on,

and all signatories are obliged to use the relevant national data dictionaries. The dictionaries are also intended to assist a much broader audience, e.g. service providers developing their own information systems, and researchers.

The data dictionaries provide information necessary to understand the meaning of the data elements and ensure consistency in application of the definitions and classifications.

In addition, METeOR, or the Metadata Online Registry, has been developed by the AIHW as the Institute's online registry of nationally endorsed metadata standards. This has involved restructuring of national metadata presented in the NCSDD and NHDD in line with the latest version of the international standard for metadata identification and recording. These metadata standards allow information to be consistently defined, so that information can be compared across different service delivery settings and sectors. METeOR is available at <<http://meteor.aihw.gov.au/content/index.phtml/itemId/181162>>.

1.3 International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) was endorsed by the World Health Assembly in May 2001 (WHO 2001). The ICF has been widely accepted as a framework for conceptualising disability and has been used in a range of applications (AIHW 2003b). For example, the ABS has used the ICF framework and its main concepts in Australian disability surveys (e.g. ABS 1999).

The ICF is an international and national standard for classifying functioning and disability and is part of the Australian Family of Health and Related Classifications endorsed by the Australian Health Ministers Advisory Council. The ICF has proven to be a useful framework for comparing data collections and measurement tools, e.g. a recent study comparing dependency information across aged and community care programs (see AIHW 2004c).

Disability is a multidimensional concept, relating to the body functions and structures of people, the activities they do, the life areas in which they participate, and the factors in their environment that affect these experiences (WHO 2001). The conceptual framework of the ICF consists of three components: body functions and structures, activities and participation, and environmental factors (Figure 1.1). These components are defined 'in the context of health' to distinguish disability from other circumstances, such as poverty, that may contribute to restricting a person's participation in society. Within each component a classification structure is provided, which can be used to organise information on various domains¹ of the disability experience. For example, the activities and participation component consists of nine broad areas of life, such as self-care, mobility and communication. The first two components – body functions and structures, activities and participation – can be expressed in two ways. They can indicate neutral or positive aspects of health states summarised under the umbrella term 'functioning' or they can be used to indicate problems (impairment, activity limitation or participation restriction); these are summarised under the umbrella term 'disability' (AIHW 2003b). Impairments are 'problems in body function or structure such as significant deviation or loss' in, for example, hearing or vision. Activity limitations are 'difficulties an individual may have in executing activities' such as eating or drinking.

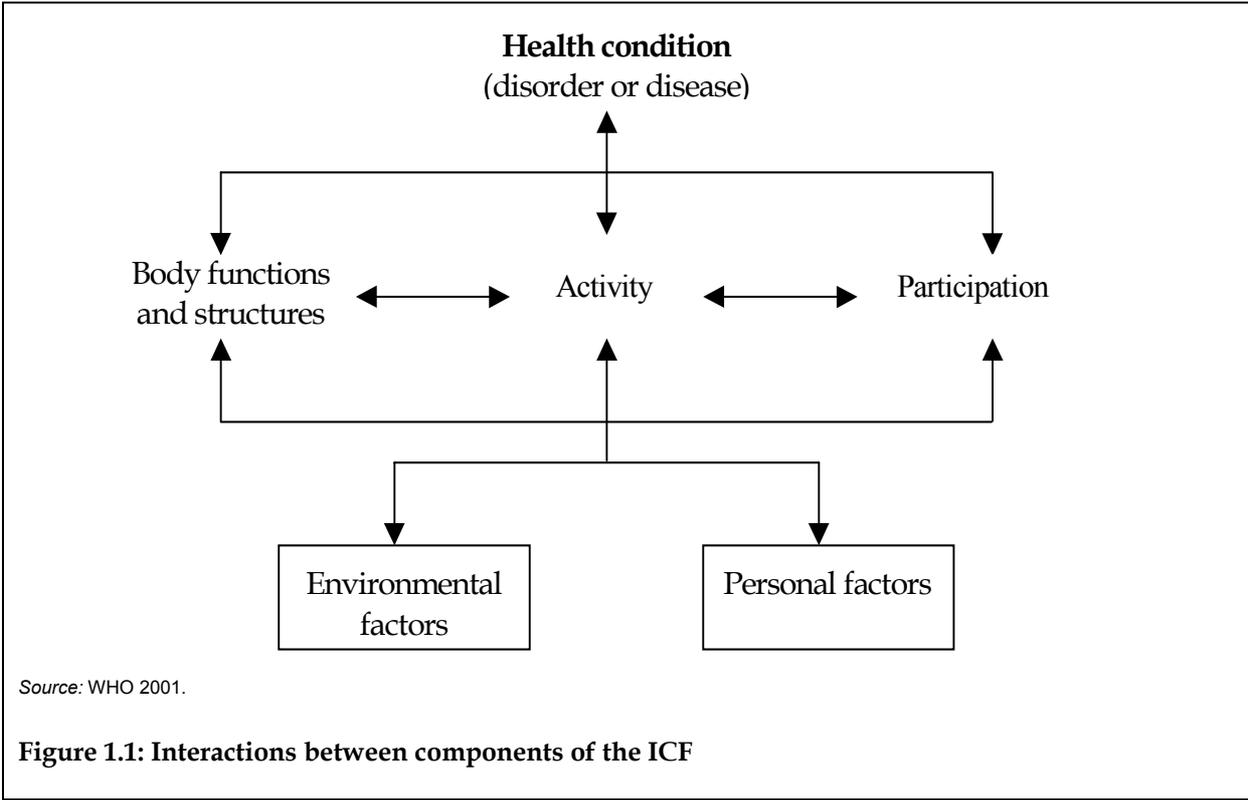
¹ A domain is a practical and meaningful set of related physiological functions, anatomical structures, actions, tasks, or areas of life (WHO 2001:3).

Participation restrictions are ‘problems an individual may experience in involvement in life situations’ such as participation in education and employment (WHO 2001:7-10).

Environmental factors and personal factors represent an important new component of the ICF in recognition of their effects on functioning and disability. Personal factors are not part of the classification because of the large social and cultural variance associated with them. Environmental factors ‘make up the physical, social and attitudinal environment in which people live and conduct their lives’. Personal factors are ‘the particular background of an individual’s life and living’ (WHO 2001:16-17).

All the ICF components are distinct but interrelated. On the one hand, an individual’s negative experience relating to any one domain of a component may be considered to constitute disability. On the other hand, the experience of disability is often complex and multidimensional. In the ICF framework, a person’s functioning in a specific domain of a component is considered as a dynamic interaction between the health condition and environmental and personal factors (WHO 2001:18-19).

It should be noted that ICF does not cover situations that are not health related, such as participation restrictions due solely to socioeconomic factors (WHO 2001). This therefore distinguishes disability from disadvantage or exclusion unrelated to health.



1.4 Method

A search was first undertaken for Australian data collections currently collecting information on incontinence. Once assembled, these collections were investigated for all data items

pertaining to (in)continence, managing incontinence and toileting. Chapter 2 provides a description of these data collections, their scope and all incontinence-relevant data items.

Data items were grouped and mapped with reference to the International Classification of Functioning, Disability and Health (ICF). These items were compared, to determine the underlying themes in Australian incontinence data, and the sorts of data items consistently included in these collections.

A review of incontinence assessment or outcome tools was also undertaken with reference to the Continence Outcomes Measurement Suite project (Thomas et al. 2005), so to compare the type of information collected using these tools with that found in Australian data collections. Again, these items were grouped and mapped with reference to the ICF, and compared with data collection items for conceptual comparability and consistency.

The results of these mapping exercises, and reference to the content of incontinence assessment tools, were used to construct a menu of recommended data item options for use in the redevelopment of future data collections.

1.5 Outline of Part B

The rest of Part B of the report comprises three chapters:

- Chapter 2 summarises the scope, purpose and content of identified Australian data collections and a brief description of data items related to (in)continence, managing incontinence and toileting.
- Chapter 3 describes, with reference to the ICF, the sorts of (in)continence-related data items currently collected in Australian data collections, and discusses key themes and the comparability of data items. Information collected using continence outcome assessment and utility index tools is also investigated, primarily to compare continence information collected in clinical and epidemiological research contexts against Australian data collection items.
- Chapter 4 recommends a composite of data themes and items for inclusion in administrative data collections, based on the results presented in Chapter 3.

2 Australian continence data collections

2.1 Population health and disability surveys

Survey of Disability, Ageing and Carers (SDAC)

The ABS Survey of Disability, Ageing and Carers is Australia's primary source of national population data on disability. Data are gathered from both households and cared accommodation and cover both rural and urban areas in all states and territories. Information is collected on three population groups – people with a disability, older people (i.e. those aged 60 years and over), and carers or persons who provide assistance to older people and those with disabilities. Five surveys have been conducted, in 1981, 1988, 1993, 1998 and 2003.

A person is defined by the survey screening questions, as having a disability if they have any limitation, restriction or impairment which has lasted, or is likely to last, for at least 6 months and restricts everyday activities (ABS 2004b). A person with a disability may have a specific limitation or restriction, either a restriction in one or more core activities (self-care, mobility and communication) or a schooling or employment restriction. The severity of disability experienced is measured by the need for assistance with one or more activities. Therefore:

- Profound – a profound core activity restriction refers to a person who is unable to do, or always needs help with, a core activity task.
- Severe – a severe core activity restriction refers to a person who sometimes needs help with a core activity, or has difficulty understanding or being understood by family or friends, or can communicate more easily using sign language or other non-spoken forms of communication.
- Moderate – a moderate core activity restriction refers to a person who has difficulty performing a core activity but does not need assistance.
- Mild – a mild core activity restriction refers to a person who has no difficulty performing a core activity but uses aids or equipment because of their disability.

Self-care, as defined as a core activity in the SDAC, includes showering or bathing, dressing, eating, toileting, and bladder or bowel control (ABS 2004b). Incontinence-related data items collected in the SDAC include:

- impairment or restriction as a result of head injury, stroke or other brain damage (Table 3.1a) (collected in 1998 but not in 2003);
- impairment or restriction which causes the most problems (not collected in 2003 SDAC) (Table 3.1a) (collected in 1998 but not in 2003);
- condition producing most restriction impairment (not collected in 2003 SDAC) (Table 3.1a) (collected in 1998 but not in 2003);
- self-care: level of assistance needed with bladder or bowel control (Table 3.1b);

- uses aids for incontinence (Table 3.1c)
- type of assistance primary carers usually provides: managing incontinence (Table 3.1c) (ABS 2004a).

National Health Survey (NHS)

The National Health Survey is a population survey designed to obtain national benchmark information on a range of health-related issues, and to enable changes in health to be monitored over time. Surveys so far completed were conducted in 1989–90, 1995, 2001 and 2004; the 2001 and 2004 surveys are the first two surveys in a new series of triennial ABS health surveys. The broad topics covered in the 2001 and 2004 surveys are similar to those included in the 1995 survey.

The content of the surveys in the NHS series has differed between surveys, around a common (or core) data set. The 2001 survey covered five main areas:

- Indicators of health status and injuries (e.g. self-assessed health status, health transition, quality of life scale, K10 scale to indicate psychological distress, long-term conditions focusing in particular on asthma, diabetes, cardiovascular and cancer).
- Health-related actions taken (visits to hospitals and day clinics, consultations with doctors, dentists and other health professionals, use of medications (for national health priority area conditions only), days away from work and other days of reduced activity).
- Health risk factors (e.g. smoking, alcohol consumption, diet, exercise, body mass, sun protection, breastfeeding, immunisation).
- Supplementary women's health items (e.g. breast and cervical cancer screening practices, contraceptive/protective behaviours, hormone replacement therapy, breastfeeding history).
- Demographic and socioeconomic characteristics (ABS 2002).

The NHS collects information on urinary incontinence as a long-term health condition; faecal incontinence is collapsed into the category 'Diseases of the digestive system', and the sub-category 'Symptoms and signs involving the digestive system' (ABS 2002, 2003).

Women's Health Australia (WHA)

The Australian Longitudinal Study on Women's Health, or Women's Health Australia, is a large, longitudinal population-based survey of 40,000 Australian women over a 20-year period, which commenced in 1995. Researchers based at the University of Newcastle and University of Queensland are responsible for the management of the survey and dissemination of project results (see www.newcastle.edu.au/centre/wha/index.html for further information). The study was commenced in response to initiatives arising from the National Women's Health Policy and aims to collect women's health information relevant to the development of policy and best practice by Australian and State Government Departments of Health.

Three base year survey cohorts representing young (18–23 years), middle-aged (45–50 years) and older (70–75 years) women are surveyed every three years. Information is collected on five main themes – use of and satisfaction with health care services, life stages and key events, time use, weight and exercise, and violence. The study also links social, environmental and personal factors in women's lives to health care use data, by record linkage with the Medicare database.

Continence information is collected using the following question (Table 3.1a):

In the last 12 months have you had any of the following problems?

Leaking urine: Never/Rarely/Sometimes/Often

Data on the efficacy of health service intervention for treating incontinence are also collected, based on the respondent's self-rated satisfaction with health services available to help the problem (Table 3.1c).

South Australian Health Omnibus Survey (SAHOS)

The South Australian Health Omnibus Survey was first conducted in 1990 and has run yearly since, primarily to assess health planning, delivery and evaluation. The survey is demand driven, where health organisations can purchase questions for inclusion in respective surveys (Wilson et al. 1992). General results stemming from each survey are provided to all clients, but responses to survey questions owned by different clients are not provided unless permission has been granted.

The population in scope are South Australians aged 15 years and over living in private dwellings (Wilson et al. 1992). Information is collected on health conditions, risk factors and demographics. Also included are a series of questions derived from utility measures such as the EuroQOL, AQOL and HUI-III, such as items on ease or limitation associated with executing activities (e.g. mobility, communication) and feelings of community connectedness.

The SAHOS incontinence module comprises questions on experience of frequent urination and urine leakage, and leakage or loss of control of stools and gas (Table 3.1a). Data on the need to wear continence pads for faecal incontinence are also collected (Table 3.1c).

2.2 Administrative data collections

Home and Community Care National Minimum Data Set (HACC NMDS)

The Home and Community Care Program, which is jointly funded by the Australian, state and territory governments, provides community care services to frail older people and their carers (around 80% of the HACC client population) and people of all ages with a disability, and their carers. The aim of the program is to enhance the independence of these people and avoid their premature admission to long-term residential care.

The HACC NMDS is client-based and collected nationally by HACC agencies every 3 months. Data are forwarded to the HACC National Data Repository at the Australian Government Department of Health and Ageing. HACC agencies include those organisations or organisational sub-units responsible for the direct provision of HACC-funded assistance to clients. Data collected per collection period are only on those clients who have received HACC-funded services from an agency within the 3-month reporting period. Therefore, not all clients may necessarily be included in each collection period nor the type(s) of assistance received from HACC-funded agencies (AIHW 2002b).

Incontinence is not separately identifiable in the HACC NMDS (V2.0) but it is subsumed within data items on assistance for personal care and self-care aids received respectively:

- primary type of assistance received: personal care (includes toileting);
- assistance with goods and equipment received: self-care aids (includes aids that assist with urinary incontinence, e.g. bag, incontinence pad, and faecal incontinence, e.g. colostomy bag, bowel pad) (Table 3.1c).

A new data item 'Functional status – additional items' includes a code for toileting, i.e. whether the person can manage the toilet, but no code for incontinence (Table 3.1b).

Ongoing Needs Identification (ONI) and Initial Needs Identification (INI)

The ONI and INI are two assessment tools developed by the Centre for Health Service Development at the University of Wollongong for use in various states and territories within HACC programs (see www.uow.edu.au/commerce/chsd/screening.html and www.health.qld.gov.au/hacc/ONInteractive.asp).

The ONI, developed for use in New South Wales and Queensland, includes items on continence and incontinence in the Health Conditions Profile. The ONI uses three incontinence items: experience of urine leakage, whether leakage events are related to coughing or sneezing, and experience of faecal soiling or change of bowel habit, which are documented in the Core ONI if identified as an issue for the client (Table 3.1a). The Queensland version of the ONI also uses a comment box to record any health conditions that may be associated with incontinence, and require further investigation.

A recent review of the ONI suggested use of alternative items on incontinence based on a review of relevant literature and current practice (CHSD 2005). These items record the frequency of urine leakage and faecal leakage or loss, the amount of urine loss, and a severity index for urinary incontinence derived from questions based on leakage and amount.

The INI, developed for Victoria and South Australia, does not include specific questions on continence although incontinence may be recorded within a section on (other) health conditions, where the client is asked to relate any relevant health problems experienced in the past that may relate to present problems or current conditions that are longstanding, persistent or recurrent. These health condition issues may be recorded as requiring action.

Aged Care Assessment Program Minimum Data Set (ACAP MDS)

The Aged Care Assessment Program (ACAP) is an Australian, state and territory government funded program to assess the needs of frail, older Australians and recommend and facilitate care services appropriate to a person's needs. ACATs, or Aged Care Assessment Teams, assess persons for recommended admission to residential care or residential respite, or the receipt of Community Aged Care Packages (AIHW 2002b).

The ACAP MDS specifies a collection of information on individual assessments. Between 1991 and 2001, the MDS underwent a review and then redevelopment, resulting in Version 2.0 of the data collection designed to report on the core work of ACATs (AIHW 2004c). The information collected by ACATs relates to client characteristics and circumstances, such as socio-demographic information, health status, functional abilities, current assistance from services, documentation of the assessment process, and components of the ACAT's care plan for the client, e.g. recommended long-term care setting.

Version 2.0 of the data collection includes data on incontinence, defined as a health condition and body function impairment:

- health condition, using ICD-10-AM codes: stress/urinary incontinence, bowel/faecal incontinence and unspecified urinary incontinence;
- body function impairment (based on ICF): defecation functions, urination functions (Table 3.1a);

and as an activity limitation, although management of incontinence is not separately identifiable and categorised within self-care (Table 3.1b).

Community Aged Care Packages (CACP)

The Community Aged Care Package (CACP) program was established in 1992 by the Australian Government to provide assistance to enable frail or disabled older people with complex care needs to continue living in the community (AIHW 2004c). Younger people with disabilities may also access a care package where there are no appropriate care options available in the area.

A CACP data dictionary was developed but has not been implemented as a national minimum data set. Information recorded regarding provision of CACPs is stored on ACCMIS, held by the Australian Government Department of Health and Ageing (AIHW 2004c).

A data item on core activity limitation, which collects information on the core activit(ies) in which an individual requires the help or supervision of another, includes codes for toileting and managing incontinence (Table 3.1b). Assistance received with personal care is captured in the data item 'Types of assistance received' but neither toileting nor managing incontinence can be identified separately (Table 3.1c).

Resident Classification Scale (RCS)

The Resident Classification Scale (RCS) data are collected on the care needs of clients residing in residential aged care facilities. Through information collected on the RCS form, all residents are categorised into a care category, which determines the level of subsidy an agency will receive in respect of that person (AIHW 2002b). RCS data are also stored on ACCMIS.

The appraisal used for the RCS does not consider all of a resident's care needs, just those that have been identified as contributing the most to differences in the total cost of residential care. New clients are assessed within 30 days of entering a residential aged care facility, and undergo reassessment every 12 months unless a significant change in care needs occurs.

The RCS uses two incontinence data items – bladder management and bowel management of the resident being assessed (Table 3.1b). These items record whether the resident is continent of urine or faeces, and if not, the level of support needed, in terms of use of continence aids and/or an individualised continence program.

A review of the RCS was commenced in 2002 with recommendations for the refinement of a reduced RCS question set, and development of complementary assessment tools. The Aged Care Funding Instrument (ACFI) is one product that has emerged from this process and is undergoing a national trial in 2005; it will be used to provide information on the care needs of residents in residential aged care facilities to determine government subsidy levels for each resident (see www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-rcspage-rcsreview.htm). The ACFI consists of 13 domains, of which domains 4 and 5 relate to toileting and continence respectively. The continence item consists of a checklist of 11

questions from which a person is rated as being continent (rating A), occasionally incontinent (rating B), frequently incontinent (rating C) or always incontinent (rating D) (Table 3.1b). The toileting item refers to use of a toilet and associated toilet hygiene; a person is rated as being independent, in need of supervision, or in need of physical assistance for each toileting care need.

National Continence Helpline (NCH)

The National Continence Helpline is a national telephone information, referral and counselling service, established under the National Continence Management Strategy and managed by the Continence Foundation of Australia. The helpline is staffed by continence nurse advisers and offers advice, information and clinic referrals to persons experiencing or caring for someone with urinary and/or faecal incontinence.

Information collected during each call is entered into the helpline database. Depending on the nature of the call, data may be collected on the:

- nature of the call (e.g. type of incontinence, aids and equipment);
- reason for call (e.g. product and surgical procedure information, financial assistance, educational literature, preventative measures);
- caller type (professional, carer or client);
- response to call (e.g. referral, literature sent);
- caller characteristics (e.g. age, gender, ethnicity) (Continence Foundation of Australia 2004, personal communication).

The Continence Foundation collates quarterly results for analysis and reporting to the Australian Government Department of Health and Ageing.

The NCH includes two relevant data items – continence issue, whereby the type of incontinence is recorded (Table 3.1a) and reason for call, where clients may be ringing for information on aids and equipment (e.g. their use, access) (Table 3.1c).

Continence Aids Assistance Scheme (CAAS)

The Continence Aids Assistance Scheme is an Australian Government program introduced in 1993 which aims to assist people of working age with permanent or ongoing incontinence resulting from a neurological condition or severe intellectual impairment to defray the cost of continence management. Clients receive a subsidy of \$470 per annum on continence aids ordered through Intouch.

Information collected by the contractor relates to client orders, client expenditure against their subsidy allocation, complaints and financial information. One data item on incontinence is included in the CAAS collection, i.e. type of incontinence experienced by the client. Incontinence is recorded as urinary, bowel or urinary and bowel (Table 3.1a). The aids received by a CAAS client are also recorded as a separate data item (Table 3.1c).

2.3 Health service data collections

Bettering the Evaluation and Care of Health (BEACH)

The BEACH project is a continuous collection of morbidity and treatment data from a random sample of 1,000 GPs across Australia, who provide information on approximately 100 GP-patient encounters. Approximately 20 GPs participate each week, 50 weeks a year (see www.fmrc.org.au/beach.htm).

The aim of BEACH is to provide a quality database of GP-patient encounter information from which general practice data can be used by government bodies, GP organisations, consumers, researchers, and the pharmaceutical industry, amongst others. BEACH uses three interrelated data collections: encounter data (e.g. reasons for encounter, problems managed, medications prescribed and other treatments); GP characteristics (e.g. age, sex, years in practice, practice size); and patient characteristics (e.g. age, sex, Aboriginal and Torres Strait Islander status).

Potential data items on incontinence from the BEACH collection include reasons for encounter and problems managed, coded using ICPC-2 PLUS (Table 3.1a). Medical interventions prescribed to alleviate incontinence are recorded in the data items clinical treatment, imaging and pathology tests ordered, and medications/vaccinations prescribed for diagnosis/problem (Table 3.1c).

Community Nursing Minimum Data Set Australia (CNMDSA)

The CNMDSA was developed by the Australian Council of Community Nursing Services (ACCNS) in 1994 and is based on domiciliary nursing services (through membership of the ACCNS) (AIHW 2002b). The purpose of the data set is to produce useable data for policy makers and to standardise data items on nursing for use in planning and monitoring at the clinical and management levels. Data have been collected by some domiciliary care services but collection is not mandatory and no national data set of all relevant agencies exists.

The CNMDSA collects data on both nursing diagnosis (based on the North American Nursing Diagnosis Association codes) and medical diagnosis (ICD-10-AM codes) for recipients of care, from which incontinence can be identified. An additional item on dependency in activities of daily living measures the severity of the incontinence as the frequency of incontinent episodes over a daily period.

National Hospital Morbidity Database

The National Hospital Morbidity Database is a compilation of electronic summary records collected in admitted patient morbidity data collection systems in Australian hospitals. Data related to admitted patients in almost all hospitals are included: public acute hospitals, public psychiatric hospitals, private acute hospitals, private psychiatric hospitals and private free-standing day hospital facilities (AIHW 2005b).

The database records information on 'hospital separations' and not patients, where a separation refers to the episode of care, which can be a total hospital stay, from admission to discharge, transfer or death, or a portion of a hospital stay beginning or ending in a change in type of care (AIHW 2005b). Diagnoses, procedures and external causes are recorded.

Incontinence may be recorded, using ICD-10-AM codes, as a principal or additional diagnosis responsible for a patient's episode of care in hospital. Data items on surgical and non-surgical procedures that are relevant to incontinence are also included, again based on ICD-10-AM codes. A list of procedure codes are given in AIHW (2002b).

Medicare Benefits Scheme (MBS)

The Medicare Benefits Scheme provides free or subsidised treatment by practitioners such as general practitioners, specialists, participating optometrists and dentists. These subsidies mostly cover out-of-hospital medical services but also apply to medical services delivered in hospitals to private patients. The Health Insurance Commission (HIC) is responsible for administering payments and information for the Medicare program.

MBS data collected by HIC cover only those services eligible for Medicare benefits, as listed in the Medicare Benefits Schedule. The MBS data include Medicare item number, Medicare benefit, date of service and processing, provider number, recipient of the service and an indication of whether or not the item was provided in a hospital. Eight Medicare item numbers refer to procedures and operations used specifically for urinary or faecal incontinence (Table 3.1c).

Pharmaceutical Benefits Scheme (PBS)

The Pharmaceutical Benefits Scheme (PBS) is also administered by the HIC and was set up to reimburse pharmacists who have dispensed eligible prescription pharmaceuticals at a cost greater than the patient's contribution. The PBS data collection includes information on prescriptions dispensed to general patients where a pharmacist is eligible for a reimbursement, prescriptions dispensed to persons who have been issued a health care card, or those who have reached the safety net threshold.

The HIC website contains aggregate statistics, based on PBS items and group categories, for each state and territory (see www.hic.gov.au/providers/health_statistics/statistical_reporting/pbs.htm). Data comprises drug codes as classified in the Pharmaceutical Benefits Schedule (Table 3.1c).

3 Mapping and comparability of continence data items

3.1 Definitions of incontinence

Definitions of incontinence used in the clinical and research fields vary; while all define incontinence as the loss of, or inability, to control urination or defecation, they differ as to what degree of loss constitutes incontinence *per se*. The 3rd International Continence Society defined urinary incontinence as the ‘complaint of any involuntary leakage of urine’ (Abrams et al. 2002a:168), whereas many clinical and research definitions focus on frequency or amount of loss over a given time period. This variation has produced a wide range of prevalence estimates, especially for urinary incontinence (see discussion in Part A, Chapter 3).

The ICF classifies continence either or both as a body function or a self-care activity. As a body function, it is classified as a urination function (urinary continence) or defecation function (faecal continence and flatulence), where incontinence is an impairment of that function. Continence as a component of self-care is classified as a toileting activity involving the regulation of urination or defecation. Regulating is defined in the ICF as ‘coordinating or managing’. A problem with regulating continence, or incontinence, is hence classified as an activity limitation.

3.2 Key themes

Continence data collected in Australia encompass two key themes – incontinence as an impairment or activity limitation, and the sorts of assistance or measures people experiencing incontinence need, rely on or have used to manage or alleviate their incontinence. Within these themes, four primary types of data items are routinely collected in Australian data collections – incontinence as an impairment, incontinence as an activity limitation, assistance needed to manage incontinence, and medical interventions to relieve incontinence, such as medications and surgical procedures.

Tables 3.1a, 3.1b and 3.1c maps these data items to the ICF. The first primary data item, incontinence as an impairment, maps broadly to the ICF component of Body functions, and more specifically to Urinary continence (ICF code b6202) and Faecal continence (ICF code b5253). The second primary data item, of incontinence as an activity limitation, maps to the ICF component of Activities and Participation, and the area of Toileting (ICF code d530), or Regulating urination and defecation (ICF codes d5300 and 5301 respectively).

The theme of assistance and intervention relates to Environmental factors, i.e. factors which make up the physical, social and attitudinal environment in which people live and conduct their lives (WHO 2001). The more general forms of assistance – personal assistance and aids and equipment used – map to the chapter headings of support and relationships (ICF code 3340 Personal care providers and personal assistants) and products and technology (ICF code 1151 Assistive products and technology for personal use in daily living) respectively.

Medical treatment and intervention map to both Products and technology (primarily, for medication prescription and use – ICF code e1101 Drugs) and services, systems and policies, or more specifically, health services (ICF code e5800 Health services).

Results from the mapping exercise presented in Tables 3.1a, 3.1b and 3.1c and are discussed below in Section 3.3.

3.3 Data item comparability

The scope and purpose of the data collections described in Chapter 2 determine the sorts of incontinence-related data items included in each collection, and hence the detail of incontinence information collected. This section compares the use and mix of primary incontinence data items in Australian data collections as tabulated in Tables 3.1a–c, and describes how comparable primary data items are between collections.

With few exceptions, most of the collections reviewed do not include data items corresponding to the ICF component of Body structures or other sub-components of Activities and Participation. The latter omission stands in contrast to the focus of many incontinence symptom and quality of life assessment tools (see Section 3.4 for further discussion).

Body function items

Incontinence (ICF codes b6202 Urinary continence and b5253 Faecal continence)

Continence data items included in most data collections characterise incontinence as an impairment of urinary or faecal continence (Table 3.1a).

The SDAC includes data items which describe incontinence as an impairment (and as a self-care activity limitation – see below) associated with a health condition. That impairment may be identified as the main restricting impairment associated with a health condition, the impairment causing the most problems, or a long-term impairment/restriction resulting from head injury, stroke or other brain damage.²

The population health surveys WHA and SAHOS use impairment-related data items derived from a series of questions on typical problems associated with incontinence, e.g. urine and faecal leakage and, in SAHOS, the bothersomeness and severity of that leakage. In SAHOS, up to 8 and 7 urinary and faecal continence questions respectively can be used to determine the experience and severity of incontinence.

Impairment data items from the population health and disability surveys are often used to estimate the prevalence of incontinence in Australia. However, the different definitional approaches used in these collections potentially produce varying estimates, and could make comparison between estimates difficult. This is further confounded by some data collections, such as the NHS and ACAP MDS, and the ONI and INI assessment tools using data items in

² The 1998 SDAC includes data items as described; the 2003 SDAC only includes incontinence in the data items on long-term impairment/restriction resulting from head injury, stroke or other brain damage.

Table 3.1a: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Body functions)

Body functions: Incontinence (ICF codes b6202 Urinary continence and b5253 Faecal continence)									
Collection	SDAC	NHS	WHA	SAHOS ^(a)		HACC (QLD ONI)	ACAP MDS	CACP	RCS/ACFI
Data item	Restriction or impairment causing the most problems Condition producing main restricting impairment Long-term restriction as a result of head injury, stroke or other brain damage		Experienced 'leaking urine' in the last 12 months?	Experienced following problems and how much bothered by them: (a) frequent urination (b) urine leakage (c) small amount of urine leakage Small amount of leakage (drops)?	Experienced urgent need to have a bowel movement that makes you rush to the toilet Experienced leakage, accidents or loss of control with (a) solid stool (b) liquid stool or (c) gas or (d) if you don't get to a toilet in time	2004: (i) Leaking urine? (ii) Is this related to coughing or sneezing? (iii) Faecal soiling/change of bowel habit? 2005: (i) Frequency of urine leakage (ii) Amount of urine lost (ii) Frequency of faecal leakage	Body function impairment		
Data domain or codes	17 Incontinence (bladder or bowel)		1 Never 2 Rarely 3 Sometimes 4 Often	1 Not at all 2 Slightly 3 Moderately 4 Greatly 5 Refused	1 Never 2 Rarely 3 Sometimes 4 Often or usually 5 Always 6 Refuse	See (b) in table notes	Four-digit code based on ICF: 6003: Defecation functions 7002: Urination functions		
Collection	NCH	CAAS	BEACH	CNMDSA		NHMD	MBS	PBS	
Data item	Continence issue	Continence type	Reasons for encounter Problems managed	Nursing diagnosis	Medical diagnosis	Principal diagnosis Additional diagnosis			
Data domain or codes	Faecal Urinary Faecal and urinary	1 Urinary 2 Bowel 3 Urinary and bowel	ICPC-2 PLUS codes	North American Nursing Diagnosis Association codes	ICD-10-AM codes	ICD-10-AM codes			

(a) Questions from 2004 SAHOS.

(b) Domain for 2004 QLD ONI: Leaking urine or faecal soiling: 1 Never 2 Sometimes 3 Often; Domain for 2005 QLD ONI (suggested): Frequency of urine leakage: 0 Never 1 Less than once a month 2 One to several times a month 3 One to several times a week 4 Every day and/or night; Amount of urine lost each time: 1 A few drops 2 A little 3 More; Frequency of faecal leakage or loss: 0 Never 1 Rarely (less than once in past 4 weeks) 2 Sometimes (less than once a week, but more than once in past 4 weeks) 3 Often or usually (less than once a day but more than once a week) 4 Always (more than once a day).

Note: Collection abbreviations can be found in Chapter 2 description of data collections.

Table 3.1b: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Activities and Participation)

Activities and Participation: Self-care (Toileting) (ICF codes d5300 Regulating urination and d5301 Regulating defecation)								
Collection	SDAC	NHS	WHA	SAHOS	HACC NMDS	ACAP MDS	CACP	RCS/ACFI
Data item	Level of assistance needed with bladder/bowel control				Functional status: ability to manage the toilet with or without help	Activity limitation: activity in which help or supervision of another individual is needed	Core activity in which the help or supervision of another individual is needed	RCS: Bladder management ^(a) , Bowel management ^(b) ACFI: Incontinence management
Data domain or codes	1 Always needs help or supervision 2 Sometimes needs help or supervision 3 Does not need help or supervision but has some difficulty 4 Has no difficulty with bladder or bowel control				Only toileting	Self-care Managing incontinence is not separately identifiable	4: Toileting 5: Managing incontinence	RCS: A Not applicable — continent B Some support C Major support D Extensive support ACFI: ^(c) A: Continent B: Occasionally incontinent C: Frequently incontinent D: Always incontinent
Collection	NCH	CAAS	BEACH	CNMDSA	NHMD	MBS	PBS	
Data item				Dependency in activities of daily living: a person's ability to carry out activities				
Data domain or codes				1 Continent 2 Incontinent less than daily 3 Incontinent once/24 h 4 Incontinent 2–6 times/24 h 5 Incontinent more than 6 times/24 h 6 Incontinent more than once a night only				

- (a) RCS Bladder management data domain: Not applicable—person is continent of urine; Some support—person would be occasionally incontinent but continence supported by prompting only or wears external continence aids occasionally; Major support—person wears continence aids at all times related to frequent incontinence that cannot be improved by a continence program but, for behavioural or other reasons, cannot use continence aids; Extensive support—person would be frequently incontinent but has individualised continence program in place to optimise continence level.
- (b) RCS Bowel management data domain: Not applicable—person is continent of faeces; Some support—person wears continence aids at all times related to frequent incontinence that cannot be improved by a continence program; Major support—person's constipation is prevented or continence level maintained by a bowel management program; Extensive support—person would usually be incontinent but has an individualised continence management program in place to optimise continence level.
- (c) Continent—continent of urine or faeces or self manages continence devices; Occasionally incontinent—incontinent of urine less than or equal to once per day, or incontinent of faeces less than or equal to once per week, or continent with regular prompting to manage occasional urinary and/or bowel incontinence or disorder; Frequently incontinent—incontinent of urine 2 to 3 times per day; or incontinent of faeces 2 to 3 times per week, or continent with a continence management program to manage frequent urinary and/or bowel incontinence or disorder; Always incontinent—incontinent of urine more than 3 times per day; incontinent of faeces more than 3 times per week, or continent with a continence management program to manage a person who is always incontinent of urine and/or faeces.

Table 3.1c: Mapping of data items from Australian incontinence-relevant data collections to the ICF (Environmental factors)

Environmental factors: Assistance (ICF codes e1151 Assistive products and technology for personal use in daily living and e340 Personal care providers and personal assistants)									
Collection	SDAC		NHS	WHA	SAHOS	HACC NMDS	ACAP MDS	CACP	RCS/ACFI
Data item	Uses aids for incontinence	Type of assistance primary carer usually provides to main recipient of care			Need to wear continence pad (bowel incontinence)	(i) Primary type of assistance received (ii) Assistance with goods and equipment received	Recommended formal assistance with activities	Type of assistance received	
Data domain or codes	1 Uses incontinence aid(s) 2 Does not use incontinence aid(s) but uses other aids(s) 3 Does not use aid(s)	1 Usually assists with managing incontinence 2 Does not usually assist with managing incontinence			1 Never 2 Rarely 3 Sometimes 4 Often or usually 5 Always 6 Refused	(i) 5: Personal care Toileting, not incontinence (i) Self-care aids Continence aids identified by the code (04) and (05) but are recorded as self-care aids	Self-care Incontinence is not separately identifiable	1: Personal care Personal care includes assistance with daily self-care tasks such as toileting and managing incontinence. Incontinence is not separately identifiable	
Collection	NCH		CAAS	BEACH	CNMDSA	NHMD	MBS	PBS	
Data item	Continence issue Reason for call	Product currently used ^(a)	Type of CAAS aids received						
Data domain or codes	Aids and appliances		List of Service Administrator's catalogue codes						

(a) NCH product codes include CISC, Commode, pan or urinal, Cones, Deodorant, Chair pad, Feminine hygiene pad, IDC or SP Catheter, Incontinence garments, Penile pad, Personal alarm, Plastic sheet, Anal or urethra plug, Anal/urethral or stoma pouches, Reused bed sheets or chair pads, Skin-care products, Towels/handkerchief/tissues, Urodome and Nil.

Table 3.1c (continued): Mapping of data items from Australian incontinence-relevant data collections to the ICF (Environmental factors)

Environmental factors: Medical interventions (ICF codes e1101 Drugs and e5800 Health services)								
Collection	SDAC	NHS	WHA	SAHOS	HACC NMDS	ACAP MDS	CACP	RCS/ACFI
Data item		Medications used	Satisfaction with health services available to help with problem					
Data domain or codes		0037: Other genitourinary	1 Yes 2 No 3 Not applicable					
Collection	NCH	CAAS	BEACH	CNMDSA	NHMD	MBS	PBS	
Data item			Drugs prescribed Imaging and pathology tests Clinical treatment	Procedure (surgical)	Procedures (surgical and non-surgical)	Procedures qualifying for Medicare Benefits	PBS drug items	
Data domain or codes			ICPC-2 codes	ICD-10-AM codes	ICD-10-AM codes	MBS item codes	PBS drug item codes	

which incontinence is described as a health condition. The ICF defines health conditions as a 'disease or disorder', and the context in which an impairment of a body function (or an activity limitation or participation restriction) exists and is affected. Further discussion on definition and prevalence estimates can be found in Part A of the report.

In the NHMD and CNMDSA collections, incontinence as an impairment is identified by 'principal' and 'additional diagnosis' (NHMD) and 'medical diagnosis' (CNMDSA) and coded using ICD-10-AM. CNMDSA also employs North American Nursing Diagnosis Association codes to code the data item 'nursing diagnosis'. Depending on the level and interpretation of the diagnosis, this data item can map to health condition or an impairment of urinary/faecal continence function. BEACH uses two data items to indicate impairment (or health condition) – reason for encounter and problem managed – coded using ICPC-2 PLUS.

All collections allow differentiation between the two forms of incontinence, except SDAC which groups bladder and bowel incontinence under incontinence.

Activities and Participation items

Toileting (ICF codes d5300 Regulating urination and d5301 Regulating defecation)

Incontinence associated with the activity of toileting, and the management of that activity, is a concept almost exclusively used in administrative data collections measuring the need for support in activities of daily living. Toileting and continence map to the ICF codes d5300 Regulating urination and d5301 Regulating defecation, where regulating is defined as 'coordinating and managing, such as by indicating need, getting into the proper position, choosing and getting to an appropriate place..., manipulating clothing before and after..., and cleaning oneself after...'. An individual who experiences difficulty in completing any aspect of this activity is considered to have an activity limitation, which may be relieved through reliance on some form of assistance.

Data items used in the ACAP MDS, CACP, RCS (and ACFI) and CNMDSA collections effectively define incontinence as an activity limitation, where the help or supervision of another individual is needed (Table 3.1b). The SDAC also includes a data item on activity limitation related to incontinence. How information on this limitation is collected differs between collections and data items do not map exclusively to Activities and Participation. This is particularly apparent for the incontinence items used in the SDAC, RCS and CNMDSA collections. While both the SDAC and RCS (and ACFI) items record limitation or difficulty managing incontinence, their data domains enlist assistance, support or equipment, i.e. environmental factors, as a means to measure that limitation or difficulty. For example, the SDAC data item refers to always, sometimes or not needing help or supervision with managing bladder and bowel control and the RCS items of bladder and bowel management support are defined by frequency of aid use and effect of a continence program (see Table 3.1b).

The CNMDSA data item focuses on 'dependency' in activities of daily living, in which remaining continent is defined as an activity. Unlike the SDAC and RCS collections, the data domain for this item does not reference environmental factors of assistance or support but

assesses how often an individual experiences episodes of incontinence over a 24-hour period i.e. a problem or impairment with the function of continence.

Environmental factors items

Assistance (ICF codes e1151 Assistive products and technology for personal use in daily living and e340 Personal care providers and personal assistants)

The concepts of assistance and equipment relate to the ICF component Environmental factors, and more specifically to the areas of Products and technology (for aid and equipment use) and Support and relationships (for personal assistance).

Information on the use of aids and equipment is collected in the NCH, CAAS, SDAC, SAHOS and HACC NMDS collections. The NCH and CAAS collections provide a more comprehensive picture of aid use, i.e. the sorts of aids used (and needed). Aid use and need are identified more simply in the SDAC and HACC NMDS collections – whether an individual uses aids for incontinence and the primary type of assistance received – although continence aids in the HACC NMDS are grouped with self-care aids and not separately identifiable. The SAHOS includes a data item on need to wear continence pads for faecal incontinence, and the frequency of the need to use pads. This data item complements the suite of data items used in SAHOS to measure severity of incontinence experienced.

While data items on personal assistance are collected in the administrative data collections HACC NMDS, ACAP MDS and CACP, data are collected about self-care, with no specific detail on continence-related activities. The SDAC, however, does include a data item on personal assistance for managing incontinence but, unlike the data item on aid use, this data item is collected from the perspective of the caregiver, not the individual experiencing incontinence.

Medical treatment and procedures (ICF codes e5800 Health Services and e1101 Drugs)

Data items on medical intervention are almost the sole focus in the health service collections BEACH, CNMDSA, NHMD, MBS and PBS. Medical treatment and procedures for alleviating incontinence map (roughly) to the area of Health services, systems and policies (ICF code e5800), and more specifically to Health services, or 'services and programmes at a local, community, regional, state or national level, aimed at delivering interventions to individuals for their physical, psychological and social wellbeing...' (WHO 2001:203). Procedures, however, more closely map to other classification systems, namely the Australian Classification of Health Interventions and ICPC-2. The range of procedures potentially used to alleviate incontinence are too numerous to repeat here.

BEACH includes data items on clinical treatment prescribed and any tests (e.g. pathology) requested by the general practitioner, which may be linked through analysis to problem treated (i.e. incontinence). Information on surgical and non-surgical procedures relevant to incontinence is collected in the CNMDSA and NHMD (using ICD-10-AM codes) and MBS (MBS item codes for procedures qualifying for Medicare Benefits) collections.

Drugs are another environmental factor that can alleviate an impairment or activity limitation such as incontinence. Three collections include data items on drugs prescribed or used to treat incontinence or related symptoms – BEACH (drug labels prescribed), PBS (drug

items prescribed under the PBS), and NHS (medications used for genitourinary conditions). However, identification of drugs used specifically to manage incontinence is complex.

3.4 Comparability with continence assessment tools

With few exceptions, most of the collections reviewed do not include data items corresponding to the ICF component of Body structures or other sub-components of Activities and Participation. The latter omission stands in contrast to the focus of many incontinence symptoms and quality of life assessment tools, discussed in this section.

The consequences of incontinence for general wellbeing are not only affected by the type and severity of incontinence but also by an individual's environment and psychosocial adjustment to the condition. Abrams et al. (2002b) have recommended that any assessment of an individual with incontinence should include:

- a history and general assessment, including questions on nature and duration of symptoms, previous surgical procedures, environment, mobility, cognitive status, and bowel function;
 - assessment of symptoms, such as frequency of incontinence, perceived quantity of leakage, and perceived impact of leakage;
 - measurement of symptoms (e.g. urodynamics), using bladder and bowel charts etc.;
- and when appropriate symptom indications are present:
- further symptom and quality of life assessment, using functional outcome validated questionnaires.

Standard clinical tests, such as urodynamics assessments, tend to associate poorly with symptoms and functional outcomes, and so a broad range of continence assessment tools have been developed to measure both symptoms and effects on wellbeing. These assessment tools comprise two main types – the assessment of symptoms of incontinence and the assessment of functional outcomes, or the effects of incontinence on quality of life. The latter group of tools are generally classified as either condition-specific or a more generic measure (Naughton et al. 2004).

Such tools are often used in concert to measure the effect of incontinence and the outcome of treatment methods, the latter through objective measures of reduction in the severity of incontinence (e.g. frequency of, and amount, leaked or voided) and subsequent assessment of improvement in quality of life.

Functional outcome assessment tool and utility index items

The number of functional outcome assessment tools (and utility indexes) in use is extensive. The Continence Outcomes Measurement Suite Project recently investigated this range of continence outcome measurement tools to recommend specific tools for use in Australia by (a) primary care practitioners involved in the delivery of health services to people with incontinence, (b) specialist incontinence practitioners and (c) incontinence researchers (Thomas et al. 2005). The recommended assessment tools followed a review of the research literature, consultations with practitioners and discussion with measurement experts. An extension of this project was the inclusion of five health-related quality of life instruments utility indexes in the 2004 SAHOS, for their evaluation of the effect of incontinence and

intervention on quality of life. The results indicated that while four of the five instruments produced similar scores and score variation, there were differences in sensitivity, and two instruments – AQOL and HU13 – proved to be better measures in terms of validity and reliability (Hawthorne & Sansoni 2004; Thomas et al. 2005).

Given the wide range of tools a select, but representative, group has been chosen for the present study, to assess comparability. The selection was based on recommendations made by Thomas et al. (2005) and an earlier evaluation conducted by the 2nd International Consultation on Urinary Incontinence (reviewed in Naughton et al. 2004).

Outcome assessment tool and utility index items are mapped to the ICF in Table 3.2. Continence assessment tools focus on symptoms and the effects of these symptoms. Items map mainly to the ICF components of Body functions and Activities and Participation respectively, and to a lesser extent Environmental factors.

Tools to assess the symptoms of urinary incontinence listed in Table 3.2 are the Urogenital Distress Inventory (UDI), including the UDI 6 short form, King's Health Questionnaire (KHQ), Incontinence Symptom Severity Index (ISSI), and ICS Male, and the Wexner Faecal Incontinence Score, for faecal incontinence. The urinary incontinence symptom tools focus specifically on frequency (KHQ and ISSI), amount of leakage (UDI and ISSI), type of incontinence (all except ISSI), voiding problems (UDI, KHQ and ICSmale) and pain (UDI and KHQ). The Wexner scores frequency of different forms of faecal incontinence (solid, liquid and gas), use of pads, and impact on lifestyle.

Condition-specific quality of life tools mostly focus on the impact incontinence has on a person's participation in various life areas. The most common life areas covered in the tools and mapped to the ICF are:

- domestic life (shopping, maintenance work, housework)
- interpersonal interactions and relationships (intimate and family relationships, and friendships)
- major life areas (employment)
- community, social and civic life (social life, recreational and religious activities).

These life areas relate to the more broadly defined participation groupings used in generic quality of life measures, e.g. 'social limitations', 'role limitations'.

Generic health-related quality of life (HRQOL) measures also, unlike most condition-specific HRQOL tools, measure the impact on activities, such as mobility and self-care (e.g. hygiene, eating and drinking) and a range of body functions such as cognition, vision, hearing and pain.

Emotional response to incontinence is another important item included in condition-specific and generic QOL measures, such as the experience of depression, anxiety, embarrassment and frustration. These responses are in part a result of the attitude of others towards incontinence (another environmental factor) but also the individual's feelings towards the manageability of the condition, especially for those with more severe forms.

With the exception of ICIQ and the Wexner, which include an item on protection use, there is little consideration of equipment and products used to manage incontinence or the sorts of environmental factors that could improve manageability of the condition. AQOL scores the frequency of use of medical aids and visits to health professionals.

Table 3.2: Mapping of items from continence assessment tools to the ICF

Body functions					
Chapter heading (ICF)	ICF code(s)	Item	Assessment tool		
			Symptom-specific	Condition-specific	Generic/utility index
Mental functions	b130 Energy and drive functions	Energy	KHQ		SF-36
	b134 Sleep functions		KHQ	MUSIQ	AQOL, SIP
	b152 Emotional functions		KHQ	IIQ, U-IIQ, MUSIQ, LIS	SIP, AQOL, HU13, EQ5D, SF-36
	b164 Higher-level cognitive functions	Cognition			HU13
Sensory functions and pain	b210 Seeing functions				AQOL, HU13
	b230 Hearing functions				AQOL, HU13
	b280 Sensation of pain	Discomfort and pain	UDI, KHQ		AQOL, HU13, EQ5D, SF-36
Functions of the digestive, metabolic and endocrine systems			WEX		
Genitourinary and reproductive functions	b610 Urinary excretory functions b620 Urination functions b630 Sensations associated with urination functions	Incontinence symptoms	KHQ, UDI, ICIQ, ISSI, ICS ^{male} , MUDI		
Activities and Participation					
Chapter heading	ICF code(s)	Item	Assessment tool		
			Symptom-specific	Condition-specific	Generic/utility index
Communication	d310 Communicating with—receiving—spoken messages and d330 Speaking				AQOL
Mobility	d440 Fine hand use	Dexterity			HU13
	d450–d469 Walking and moving	Ambulation			SIP, HU13, EQ5D
	d470–d489 Moving around using transportation	Travelling by car or bus		IIQ	AQOL
Self-care		Personal care and hygiene		LIS	SIP, EQ5D

Table 3.2 (continued): Mapping of items from continence assessment tools to the ICF

Activities and Participation (continued)					
Chapter heading	ICF code(s)	Item	Assessment tool		
			Symptom-specific	Condition-specific	Generic/utility index
	d550 Eating and d560 Drinking	Eating/drinking			SIP
Domestic life	d6200 Shopping	Shopping		IIQ, U-IIQ, MUSIQ, LIS	
	d640 Doing housework	Housework		IIQ, LIS	SIP, AQOL
	d650 Caring for household objects	Maintenance work		IIQ, U-IIQ	AQOL, SIP
Interpersonal interactions and relationships	d750 Informal social relationships	Relationships	KHQ	IIQ, U-IIQ, MUSIQ	
	d7500 Informal relationships with friends	Visiting friends		IIQ, U-IIQ	AQOL
	d760 Family relationships	Family life		LIS	AQOL
	d7702 Sexual relationships	Sexual activities	ICIQ	IIQ, MUSIQ, LIS	
Major life areas	d480–d859 Work and employment	Employment		IIQ, LIS	SIP
Community, social and civic life	d910 Community life	Voluntary work		IIQ	
	d920 Recreation and leisure	Recreational activities		IIQ, U-IIQ	SIP, AQOL
	d9200 Sports	Exercise		U-IIQ, MUSIQ	
	d9204 Hobbies	Hobbies		IIQ, MUSIQ, LIS	
	d930 Religion and spirituality	Religious activities		IIQ, U-IIQ	
	d9205 Socialising	Social life	KHQ, ICIQ	IIQ, U-IIQ, LIS	SIP

Table 3.2 (continued): Mapping of items from continence assessment tools to the ICF

Environmental factors					
Chapter heading	ICF code(s)	Item	Assessment tool		
			Symptom-specific	Condition-specific	Generic/utility index
Products and technology	e1101 Drugs	Use of prescribed medicine			AQOL
	e1151 Assistive products and technology for personal use in daily living	Protection use and type	ICIQ, WEX		AQOL
Support and relationships	e310 Immediate family	Stability of support		MUSIQ	
	e355 Health professionals	Medical treatment from doctor or health professional			AQOL

Notes

1. AQOL = Assessment of Quality of Life, EQ5D = EuroQOL 5D, HU13 = Health Utilities Index Mark 3, ICIQ = International Consultation on Incontinence Questionnaire, ICSmale = International Continence Society male questionnaire; IIQ = Incontinence Impact Questionnaire, ISSI = Incontinence Symptom Severity Index, KHQ = King's Health Questionnaire, LIS = Leicester Impact Scale, MUDI = Male Urogenital Distress Inventory, MUSIQ = Male Urinary Symptom Impact Questionnaire, SIP = Sickness Impact Profile, UDI = Urogenital Distress Inventory, U-IIQ = Urge-Incontinence Impact Questionnaire, WEX = Wexner Faecal Incontinence Score.
2. A small proportion of assessment tools assess impact on 'everyday life', 'lifestyle' or 'usual activities' etc. rather than defining specific activities, and these items therefore can not be mapped to the ICF. These include the Wexner Faecal Incontinence Score, ICIQ and EQ5D.

Sources: Avery et al. 2004c; Bergner et al. 1981; Donovan et al. 1996; Handa & Massof 2004; Hawthorne et al. 2000; Health Utilities Incorporated 2004; Kelleher et al. 1997; Lubeck et al. 1999; Naughton et al. 2004; Robinson & Shea 2002; Shaw et al. 2004; Thomas et al. 2005; van der Vaart et al. 2003

Comparability with Australian incontinence data items

Overall, there is some overlap between information collected in Australian data collection and incontinence assessment tools, after comparison of Tables 3.1a–c and 3.2. This overlap is largely at the Body function component with only minimal overlap at other components. Body function items used in assessment tools tend to be more detailed than those collected in data collections, reflecting the use of such tools to describe the symptoms of incontinence.

The most consistent difference between assessment tools and incontinence data collections is the coverage of participation, and to some extent activities, and environmental factors respectively. All the quality of life assessment tools, and some symptom-based tools, include activity and participation items and, while the breadth of these items varies between tools, most have items where respondents rate how incontinence has affected their domestic life, relationships, employment and community and social life. None of the data collections include data items on participation as affected by incontinence specifically, although generic participation items in collections such as the SDAC do allow analytical investigation of participation restrictions associated with incontinence.

In contrast, continence assessment tools tend not to look at the sorts of environmental factors that may affect a person's experience of incontinence, whereas many of the data collections do. The omission of equipment and assistance are conspicuous examples; ICIQ and the Wexner are the only assessment tools reviewed here which include an assistance item, in this case protection use and type. Assistance is not consistently covered in Australian data collections but some sort of relevant 'assistance' data item(s) are included in the four administrative data collections, and the national disability collection (SDAC).

4 Promoting consistency in continence data collections

4.1 A menu of data items

The differences in purpose and operational context of the data collections reviewed have produced varying 'interpretations' of incontinence (for example, incontinence as an impairment versus incontinence as an activity limitation). Hence the assemblage of data items used to collect information on incontinence also varies. An important finding of the review was that none of the collections contained a definition of incontinence. Some collections contained an implicit definition but most essentially offered items relevant to incontinence from which a user could create their own definition and estimate related prevalence numbers.

The purpose of this report is not to define incontinence but to outline key themes and options for potential data item sets useable in a wide range of collections and/or assessment tools. If these items are used as a standard 'menu', and if context and purpose is taken into account, this would promote greater consistency and comparability across the field, and greater quality in many collections and tools.

The recommendations listed below were developed with reference to both the general themes currently collected in Australian data collections and those in continence symptom and quality of life assessment tools.

In the process of developing these recommendations, it was essential that proposed data items were:

- independently valid yet retained a level of inter-relation and complementarity for more detailed analysis, and
- appropriate to the general context and scope of an administrative data collection.

A multidimensional concept

Australian data collections generally collect information about incontinence as an impairment of body function and/or as an activity limitation, and about the assistance and measures people experiencing incontinence use or need to manage or relieve their incontinence. The results from the review indicate that 'continence' and 'incontinence' are an multidimensional concept that may draw on different components of the ICF model.

A person's functioning is an amalgam of body functions, the activities they engage in, and their participation in life areas, influenced by environmental factors and their personal characteristics (WHO 2001). To collect concise information on functional status, a composite of data items capturing these components is essential. For information on the functional status of a person with incontinence, this composite of items may be categorised as:

- identification/'diagnostic'
- measure of severity

- assistance and aid use
- participation.

Such data items enable description of the prevalence and severity of incontinence amongst the collection's population, the support available or needed to manage the condition, and how participation in life areas may be affected by incontinence, and potentially improved when support is received.

This composite or menu of data items, however, needs to be flexible enough for inclusion in data collections with different focuses and purposes.

Functioning and Related Health Outcomes Module (FRHOM)

The AIHW is currently developing a Functioning and Related Health Outcomes Module, or FRHOM, which can be used to collect data on functioning, and to relate to other sources of functioning information gathered in assessment and other measurement tools. The FRHOM will provide summary level information on functioning with reference to body function impairments, activities and participation, and the influence of the environment (AIHW forthcoming). The information derived from the module can be used to describe a person's health status, outcomes of health interventions, and the need for assistance in areas of human functioning.

The FRHOM is to undergo pilot testing focusing on specific health conditions (e.g. acquired brain injury, cardiovascular disease). The final product may be used as an additional template for future refinement of the third incontinence module presented in Section 4.4.

4.2 Proposed data items

The proposed data items presented below are described with reference to the ICF components of Body functions, Activities and Participation, and Environmental Factors, and the concept of severity. Other demographic items relating to age, sex, Indigenous status of the respondent, and carer availability are available on METeOR (see Chapter 1 for URL).

Health condition ('Diagnosing' incontinence)

Incontinence as a health condition will not be discussed here, chiefly because incontinence does not appear to be an 'identifiable' health condition. Although ICD codes are used in health services collections, such as BEACH and the National Hospital MDS (see AIHW 2002b) to denote incontinence (Table 3.1a), this method may only be appropriate for the purposes of these sorts of collections. The very complexity of incontinence, incorporating the dimensions of body function, activity limitation and participation restriction, necessitates a method of identification that is broader than one based solely on body-related information.

Body functions

The ICF body function codes can be used in two ways, depending on the level of information required, and when using various data collections. First, directly relevant body function codes can assist in the 'identification' of continence impairments. Second, a list of body function codes can be used to record the range of other body functions that may be affected

by, or the related impairments that may coexist with, incontinence. These two approaches are discussed below.

'Identifying' incontinence

Incontinence can be identified using the ICF body functions codes for:

- Functions of 'control' – b6202 Urinary continence (functions of control over urination) and b5253 Faecal continence (functions involved in voluntary control over the elimination function);
- Functions of 'frequency' – b6201 Frequency of urination (functions involved in the number of times urination occurs) and b5252 Frequency of defecation (functions involved in the frequency of defecation).

The ICF also codes for Faecal consistency (b5251 – consistency of faeces such as hard, firm, soft or watery) and Flatulence (b5254 – functions involved in the expulsion of excessive amounts of air or gases from the intestines), which are more commonly collected in epidemiological and clinical studies, although the SAHOS does include related questions.

Since items on functions of control and frequency are collected in only a few Australian data collections reviewed, we need to look to the continence symptom assessment tools for guidance.

Many assessment tools record incontinence in terms of presence and severity.³The actual 'presence' of incontinence is normally identified as the experience of leakage. The simplest method, as used, for example, in the U-UDI (Urogenital Distress Inventory for Urge Incontinence), is to ask respondents whether they have experienced, in this case during the last 4 weeks, any episodes of urine leakage. A similar approach has been adopted by the WHA, where respondents were asked if urine leakage had been experienced in the last 12 months. A comparable data item based on this approach is given in Box 4.1 (data item 1a) and relates to the ICF codes 'functions of control'. An item based on experience of leakage may be a better identifier of incontinence in scenarios where information is collected solely or partly on a self-reporting basis – not all respondents who experience leakage may consider themselves incontinent, and may not identify as having either form of incontinence if simply asked whether they experience incontinence.

The data collected from data item 1a would provide a crude estimate of the population who experience some degree of incontinence, i.e. anyone who has had at least one episode of leakage over a given time period, and the type of incontinence they experience.

Data item 1b captures the population who experience 'urgency', defined by Abrams et al. (2002a:168), with reference to urinating, as '...a sudden compelling desire to pass urine, which is difficult to defer'. Urgency may or may not result in an incontinent event and does not necessarily occur periodically, but is related to functions of control and can require considerable management strategies to prevent an incontinence event occurring. Inclusion of urgency as a data item, alongside data on incontinence as a function of control, allows identification of persons experiencing incontinence, urgency or both.

The type of urinary incontinence experienced is detailed in data item 1c. Stress, urge and, to a lesser extent, mixed incontinence are the primary types of urinary incontinence

³ 'Bothersomeness' is a more recently introduced concept in the measurement of incontinence severity but will not be discussed here.

information collected in clinical and epidemiological surveys. Two additional categories are included – nocturnal enuresis, for urine leakage occurring during sleep, and ‘other’, which incorporates less common types of incontinence experienced. These categories may or may not be included in the completed data item depending on the level of detail required.

Faecal incontinence can manifest itself as incontinence of solid and/or liquid stool. Because the type of faecal incontinence does not impact on incontinence management, a data item is not suggested here.

Box 4.1: Identifying incontinence

Data item 1a: Incontinent of urine or faeces (control)

Definition: *Whether a person has experienced an episode or episodes of urine leakage or faecal soiling/loss over a defined time period.*⁴

Example value domain:

- 1 Urine leakage
- 2 Faecal leakage
- 3 Both urine and faecal leakage
- 4 Neither urine nor faecal leakage or a sense of urgency to urinate or defecate

Data item 1b: Urgency with urination or defecation

Definition: *Whether a person experiences a strong sense of urgency to urinate or defecate.*

Example value domain:

- 1 Sense of urgency to urinate
- 2 Sense of urgency to defecate
- 3 Sense of urgency to urinate and defecate
- 4 Neither a sense of urgency to urinate nor defecate

Data item 1c: Type of urinary incontinence

Definition: *The primary type of urinary incontinence a person experiences.*

Example value domain:

- 1 Stress urinary incontinence (urine leakage occurring on effort or exertion, or on sneezing or coughing)
- 2 Urge urinary incontinence (urine leakage accompanied by or immediately preceded by urgency)
- 3 Mixed urinary incontinence (urinary leakage associated with urgency and also with exertion, effort, sneezing or coughing)
- 4 Nocturnal enuresis (urinary leakage occurring during sleep)
- 5 Other (may include overflow incontinence, neurogenic or reflex incontinence and dribbling)

See Abrams et al. (2002a) for terminology of types of urinary incontinence.

⁴ Because differing time periods are used in various studies and assessment tools a specific time period is not given here.

Severity and body function impairment: interweaving presence and severity

Many assessment tools, and population health surveys such as the SAHOS, rarely use data items measuring general presence of incontinence but rely on items that incorporate severity scales to identify presence of leakage. The frequency of urination or defecation, often collected alongside, or sometimes instead of, leakage information, is also commonly structured against a point scale, which may be used to measure severity levels. This incorporation of a measure of severity within identifier items allows estimation of the overall population with incontinence, and the population experiencing more severe incontinence.

Severity of incontinence in clinical and epidemiological settings is often measured with a range of items but the frequency of (a) urination and (b) incontinence events (leakage), and the volume lost at each episode, are most commonly used. These are measures of severity related to body function impairments. Frequency of urination items, which relate to the ICF code 'functions of frequency', records how often an individual needs to urinate or defecate over a set time period – over 24 hours for urination, and usually a week for defecation. Incontinence events or frequency of leakage, which combines ICF codes 'functions of frequency' and 'functions of control', is regularly scored against a 4- or 5-point scale, whereby a respondent indicates how often they experience leakage over a given time period.

While these items are not mutually exclusive, they do provide different measures of incontinence. All indicate an impairment with control and/or frequency of need to urinate or defecate. An item on frequency of urination and defecation also allows an assessment of the regularity of incontinence events against actual frequency of urination or defecation, and may be an indicator of a body function (or structure) impairment associated with the overproduction of urine and faecal matter. Furthermore, frequent urination is a possible sign of future incontinence problems for those not yet reporting incontinence events. Box 4.2 details data items (data items 2a and 2b) to measure the severity of incontinence in terms of frequency of urine leakage and faecal leakage respectively, Box 4.3 includes an item on amount of urine lost during an incontinence event, and Box 4.4 presents data items on frequency of urination during the day and during the night, and frequency of defecation over the week (data items 4a, 4b and 5 respectively).

Box 4.2: Severity of incontinence – body function impairment (I)

Data item 2a: Incontinence – frequency of urine leakage

Definition: *How often a person experiences urine leakage.*

Example value domain:

- 0 Never
- 1 Less than once a month
- 2 Once or more times a month
- 3 Once or more times a week
- 4 More than once a day

Data item 2b: Incontinence – frequency of faecal leakage

Definition: *How often a person experiences faecal leakage.*

Example value domain:

- 0 Never
- 1 Less than once a month
- 2 Once or more times a month
- 3 Once or more times a week
- 4 More than once a day

Box 4.3: Severity of incontinence – body function impairment (II)

Data item 3: Incontinence – amount of urine lost

Definition: *The amount of urine lost when a person experiences urine leakage.*

Example value domain:

- 0 Does not experience urine leakage
- 1 A few drops
- 2 More than a few drops

Box 4.4: Severity of incontinence – body function impairment (III)

Data item 4a: Incontinence severity – frequency of urination (day)

Definition: *The frequency with which a person urinates during the day, or while awake.*

Example value domain:

- 1 1–3 times a day
- 2 4–6 times a day
- 3 7–10 times a day
- 4 10 or more times a day

Data item 4b: Incontinence severity – frequency of urination (night)

Definition: *The frequency with which a person urinates during the night, i.e. when sleeping.*

Example value domain:

- 1 1–2 times a night
- 2 3–4 times a night
- 3 5 or more times a night

Data item 5: Incontinence severity – frequency of bowel movements

Definition: *The frequency with which a person defecates on a weekly basis.*

Example value domain:

- 1 Once or less
- 2 Twice
- 3 3–4 times
- 4 5–12 times
- 5 13–21 times
- 6 22–26 times
- 7 27 or more times

Related body function impairments

Incontinence may occur with, or contribute to, other body function impairments. Examples of impairments that coexist with incontinence, as regularly collected in assessment tools, include impairments of mental functions, such as energy, sleep and emotional functions (e.g. depression, frustration, anxiety), mobility, and sensory functions, such as pain (see Table 3.2). Revealing other body function impairments associated with incontinence provides a broader understanding of a person's functional status, including the additional health or other forms of care a person may need, or the possible combined effect on participation.

The ICF provides an extensive list of body functions, which can be used at various levels. The chapter headings listed in Box 4.5 represent the highest level of body functions domains in data item 6; more specific body functions fall within these chapters. Depending on the purpose of the item, and the collection itself, value domains for a data item on body function impairment will differ depending on level of detail needed. It is recommended that the user

refer to the *National Community Services Data Dictionary* (Version 3.0) or METeOR for further guidance on value domain development.

Box 4.5: Identifying body function impairments associated with incontinence

Data item 6: Incontinence – co-existent body function impairments

Definition: Other body function impairments reported by a person experiencing incontinence. Impairments of body functions are problems in body functions such as a loss or significant departure from population standards or averages.

Example value domain (categories 1–8 are based on ICF chapter headings):

- 1 Mental functions
- 2 Sensory functions and pain
- 3 Voice and speech functions
- 4 Functions of the cardiovascular, haematological, immunological and respiratory systems
- 5 Functions of the digestive, metabolic and endocrine systems
- 6 Genitourinary and reproductive functions
- 7 Neuromusculoskeletal and movement-related functions
- 8 Functions of the skin and related structures
- 9 Cognitive functions*

* Dementia is generally not included within mental function categories in Australian administrative data collections, and therefore an additional domain 'Cognitive functions' has been added.

Activities and participation

Incontinence as an activity limitation

Continence, or the management of bladder and bowel control, can also be conceptualised as an activity of self-care, and incontinence then as an activity limitation. An activity limitation is defined as 'difficulties an individual may have in executing activities'. The ICF codes management of bladder and bowel control under 'Toileting' (d530) or the activity of 'planning and carrying out the elimination of human waste..., and cleaning oneself afterwards'. The relevant codes for urinary and faecal continence are:

- d5300 Regulating urination
- d5301 Regulating defecation

Data on the difficulties associated with executing an activity such as regulating urination or defecation are often collected in Australian population and administrative data collections with reference to the need for assistance or supervision. In this context the presence of incontinence is not the activity limitation (difficulty) itself, it is the inability to manage the incontinence without some sort of external assistance that is limiting. A data item solely focused on need for assistance, however, does not capture the whole population experiencing difficulty managing their incontinence, and hence an item must distinguish between, and collect information on, persons who experience difficulty but can still manage on their own, and those who require assistance. The SDAC includes such an item. Data item

7, presented in Box 4.6, is based on this SDAC item and incorporates the concepts of difficulty and need for assistance so to differentiate between three population groups: persons who experience difficulty and need assistance at least sometimes to manage their incontinence, persons who do have some difficulty but do not currently need assistance, and those who generally do not experience problems with incontinence. The first group targets the population who use or may need formal interventions to manage their incontinence; the latter group a proportion of individuals who may, with age or a worsening of their incontinence, require assistance in the future.

The level of assistance needed to manage incontinence complements this data item, and is addressed in the following section on severity and activity limitation.

Box 4.6: Incontinence as an activity limitation (severity of incontinence – activity limitation I)

Data item 7: Incontinence – difficulty and need for assistance

Definition: Whether an individual experiences difficulty and the level of assistance needed to manage their urinary or faecal incontinence (i.e. bladder or bowel control).

Example value domain:

- 1 Always needs assistance to manage incontinence
- 2 Sometimes needs assistance to manage incontinence
- 3 Does not need assistance but has some difficulty managing incontinence
- 4 Has no difficulty with bladder or bowel control

Severity and activity limitation

Severity can also be measured through assessing a person's management of their incontinence with relation to need for assistance. This severity data item considers incontinence as an activity limitation. Some of the data collections reviewed already employ variations on this measure, ranging from whether any support is needed to the amount of support needed. The former method is partly captured in data item 7 if a person reports they experience difficulty managing their incontinence and need assistance to manage the incontinence. To measure severity more precisely, measuring the level of assistance needed is clearly the preferred option.

The 'activity limitation' question used in the SDAC is a template from which such an item may be developed. The level of assistance needed relates, in the SDAC, to the impact of a disabling condition – 'always needing' assistance is defined as profound, 'sometimes needing' assistance as severe, and 'does not need' assistance but 'has difficulty' as moderate. It is generally information on the more severe end of the spectrum (i.e. always and sometimes needing assistance) where support and service-based administrative data collections are focused, and hence data on this group are pertinent to policy development and distribution of monies.

How much assistance a person needs is another measure of severity. The SDAC also uses an item whereby the respondent indicates the frequency of assistance needed over a defined time period. This data item (data item 8) can be collected alongside the data item on need for assistance to create a broader picture of the personal assistance needs a person uses to manage their incontinence.

Box 4.7: Severity of incontinence – activity limitation (II)

Data item 8: Incontinence – frequency of need for assistance

Definition: *The frequency of assistance needed to manage incontinence (bladder or bowel control).*

Example value domain:

- 0 Does not need assistance
- 1 Less than once a month
- 2 1–3 times a month
- 3 1–6 times a week
- 4 1–2 times a day
- 5 3–5 times a day
- 6 6 or more times a day

Incontinence and participation restrictions/other activity limitations

The absence in most data collections reviewed of measures of participation restriction contrasts to its standard inclusion in continence assessment tools. Data items regarding impact on lifestyle add a further dimension to the assessment of severity and need for assistance (see below), and contribute to the understanding of a person's functional status.

The ability to participate in various life areas, or undertake activities, is the most frequently used measure in condition-specific assessment tools but the SAHOS and SDAC are the only population surveys that collect information on the impact of incontinence on a person's life. Depending on the level of detail required, participation may focus on the effect incontinence has on lifestyle generally (as asked in SAHOS: *Does bowel or stool leakage cause you to alter your lifestyle?*) or on a specified list of activities and life areas pertinent to the population in scope. The ICF component of activities and participation lists the following broad activity and participation domains;⁵ domains commonly used in continence-specific assessment tools are bolded (see Table 3.2).

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility (moving around using transportation)
- Self-care
- **Domestic life**
- **Interpersonal interactions and relationships**
- **Major life areas**
- **Community, social and civic life** (WHO 2001).

⁵ There is as yet no consensus amongst ICF developers and users how to best split this list into specified activities and participation domains, and one option suggested is to retain it as a single list (AIHW 2003b).

The ICF provides an extensive list of activities and life areas within these chapter headings which can be used to guide selection of relevant life areas. As for impairments of body function, it is recommended that the user refer to the 'Activities and participation domains' data item in the *National Community Services Data Dictionary* (Version 3.0).

Box 4.8 presents an example data item, based on the sorts of activities and life areas included in continence assessment tools. This item may be used to identify the effect that the presence (and severity) of incontinence has on a person's ability to participate and to assess improvements in a person's participation related to current assistance or interventions.

Box 4.8: Incontinence and activity limitations/participation restrictions

Data item 9: Incontinence – associated activity limitations/participation restrictions

Definition: The activities and life situations in which a person experiences limitations or restrictions associated with or affected by their incontinence.

Example value domains:

- 1 Self-care
 - 1.1 Washing oneself
 - 1.2 Caring for body parts
 - 1.3 Dressing
 - 1.4 Eating
 - 1.5 Drinking
 - 1.6 Looking after one's health
- 2 Mobility
 - 2.1 Walking and moving around
 - 2.2 Moving around using transportation
- 3 Domestic life
 - 3.1 Shopping
 - 3.2 Housework
 - 3.3 Maintenance work
- 4 Interpersonal interactions and relationships
 - 4.1 Informal social relationships, including with friends
 - 4.2 Family relationships
 - 4.3 Sexual relationships
- 5 Major life areas
 - 5.1 Education
 - 5.2 Work and employment
- 6 Community, social and civic life
 - 6.1 Community life, such as volunteering
 - 6.2 Recreation and leisure
 - 6.3 Sports
 - 6.4 Hobbies
 - 6.5 Religion and spirituality
 - 6.6 Socialising

Environmental factors

Environmental factors are often neglected in data collections despite their sometimes profound effect on a person's experience or management of a health condition, disability or impairment, and hence their functioning. The management of incontinence often relies on personal assistance, the use of aids, or a combination of the two. Aids are a critical means for managing incontinence, particularly for those persons still living and interacting with the community. A number of Australian data collections include, to some extent, items on environmental factors, often incorporated within questions on support or assistance needed. Personal assistance is the primary or only form of support normally considered in these collections. Therefore, a more complete approach would include reference to aids.

The key purpose of many health and community service data collections is to determine what assistance is needed and can be accessed by a person. This requires clear delineation of actual use, additional need and the sorts of assistance or support used and needed. A simple template for an item on use of aids to manage incontinence is given in data item 10 (Box 4.9). The type of continence aids that might be used by a person experiencing incontinence are listed in data item 11 (Box 4.10). The aids listed reflect aids and equipment specific to the management of incontinence and exclude more generic items, such as gloves or creams that may be used in conjunction with these aids to manage incontinence.

Box 4.9: Incontinence – use of aids

Data item 10: Incontinence – use of aids

Definition: *Use of aids and equipment to manage incontinence (bladder or bowel control).*

Example value domain:

- 1 Uses aids or equipment to manage incontinence
- 2 Does not use aids to manage incontinence

Medical interventions and prevention

A record of interventions provides an indication of the extent of potentially more severe forms of incontinence in Australia, by virtue of the need for medical intervention. Some information on additional interventions is available from collections such as the Medicare Benefits Schedule and BEACH collections, but data are difficult to reconcile because of the differences between populations in scope. Data item 12 provides a method by which information on these alternative forms of intervention can be collected (Box 4.11).

Box 4.10: Incontinence – type of continence aids**Data item 11: Incontinence – type of aids used**

Definition: *Type of aids and equipment used to manage incontinence (bladder or bowel control).*

Example value domain:

- 1 Continence pads
 - 1.1 Disposable
 - 1.2 Reusable
- 2 Continence pants
 - 2.1 Disposable
 - 2.2 Reusable
- 3 Drainage bags and accessories
- 4 Bottles and urinals
- 5 Catheters and catheter accessories
- 6 Condom drainage systems/protective sheaths/external catheters
- 7 Urethral plugs/vaginal bows/penis clamps
- 8 Anal plugs/anal tampons/anus bags
- 9 Stomal appliances
- 10 Faecal softeners and suppositories
- 11 Enemas and suppositories
- 12 Continence sheets and waterproof seat covers
- 13 Other

Box 4.11: Incontinence – interventions**Data item 12: Incontinence – other interventions**

Definition: *Other forms of support or intervention used or undertaken to manage incontinence.*

Example value domain:

- 1 Preventative measures, such as pelvic floor exercises
- 2 Management strategies, such as time voiding, double voiding, bladder retraining
- 3 Medications
- 4 Surgical procedures
- 5 Diagnostic tests
- 6 Other interventions

Additional support

As stated earlier, items on support should be able to ascertain actual use from additional need for support. Data item 13 (Box 4.12) serves as a basic template for identifying additional

need for support or interventions to manage incontinence, from which more detailed items may be developed, such as frequency of need for particular forms of assistance.

Box 4.12: Incontinence – need for intervention or additional support

Data item 13: Incontinence – need for intervention or additional support⁶

Definition: *The need for intervention or additional support to manage incontinence (bladder or bowel control).*

Example value domain:

- 1 Additional need for personal assistance
- 2 Additional need for aids and equipment
- 3 Additional need for other interventions
- 4 Does not need additional assistance or intervention methods

Additional items

Effect on carer wellbeing

The physical and emotional effects of caring for a person with incontinence, particularly someone with severe incontinence, can be substantial. Analysis presented in Part A, Chapter 4 showed that some carers who assisted another person with their incontinence had felt a negative impact on their physical and emotional wellbeing.

Two data items that may be used to indicate the effect on carer wellbeing are given in Box 4.13. These items are modelled on data items used in the primary carer component of the SDAC. Data item 14 ascertains the time, in hours, a carer spends assisting a person with their incontinence over a weekly period. Two value domains are suggested: one where the carer estimates the total hours spent on a daily or a weekly basis, without reference to value domain prompts, the second based on the value domain used in the SDAC to measure the number of hours a carer assists a person with self-care. The latter option is the least preferable as it is based on the sorts of hours that may be spent assisting on any combination of self-care activities. Further work would be required to estimate the sorts of hours a carer may need to spend assisting a person with their incontinence so as to develop an appropriate value domain.

Data item 15 allows the carer to indicate the physical and emotional consequences, if any, of caring for someone with incontinence. Each of the values in the value domain are drawn from questions directed to primary carers in the SDAC, and refer to the carer's physical and emotional response to the caring role, and the effect of the caring role on their relationship with the person being cared for, other family members and friends. This value domain will require further development, and may need to be split into two items.

⁶ Respondent may indicate need for more than one support type or intervention.

Box 4.13: Incontinence – effect on carer wellbeing

Data item 14: Incontinence – hours of caring

Definition: *Number of hours a carer spends in a week assisting a person in managing their incontinence OR Number of hours a carer spends on a daily basis assisting a person in managing their incontinence.*

Carer to estimate number of hours.....

Example value domain:

- 1 <20 hours per week
- 2 20–39 hours per week
- 3 40+ hours per week

Data item 15: Incontinence – effects on carer physical and emotional wellbeing

Definition: *The effects on a carer's physical and emotional wellbeing associated with assisting a person to manage their incontinence.*

Example value domain:

- 1 Feels weary or lacks energy due to caring role
- 2 Sleep frequently interrupted due to caring role
- 3 Feels worried or depressed due to caring role
- 4 Feels angry or resentful due to caring role
- 5 Relationship with person being cared for affected due to caring role
- 6 Relationships with other family members affected due to caring role
- 7 Relationships with friends affected due to caring role

Risk factors

A range of risk factors identified for urinary and faecal incontinence are described in Part A, Chapter 3 and include:

- constipation
- lower urinary tract symptoms
- mobility, cognitive and neurological impairments (and related health conditions)
- pregnancy, childbirth and parity
- menopause
- obesity
- surgeries, such as prostatectomies, prolapse repair, hysterectomies.

Including a data item on risk factors provides some indication as to the health conditions, life events or other factors associated with incontinence. However, any recommendation for a data item on risk factors is somewhat premature, particularly given the variable relationship of these factors to the development and experience of incontinence, i.e. some of these factors can be defined as precursors to incontinence, as influencing incontinence and/or associated with incontinence. As such, an item is not proposed here, with the recommendation that any future data item rely on a very clear definition of what constitutes a risk factor *per se*, and, in turn, a risk factor for incontinence.

Toileting and incontinence

Toileting, in its very broadest sense, may be considered as both the ability to perform tasks associated with using the toilet and the ability to manage bladder and bowel control.

Australian population surveys and various administrative collections, however, tend to differentiate between the two by including data items on ability to manage toileting (i.e. tasks associated with using the toilet) alongside, or in place of, items on ability to manage incontinence. For example, the SDAC collects information on the need for assistance with toileting, which refers to any difficulty associated with using a toilet, and the need for assistance with bladder and bowel management, or difficulty associated with bladder and bowel control. The CACP dictionary also separates toileting (use of toilet) from managing incontinence as an activity of self-care, although it is coded together under personal care. In contrast, Version 2.0 of the HACC NMDS does not include managing incontinence as an item of functional status, relying solely on the activity of toileting as the ability to 'manage the toilet...without or with some help' or complete inability 'to manage the toilet without help', as an indicator of the population with incontinence. This item is used to identify activities where a person may require assistance and the extent of assistance they may need.

While the ability to use or manage the toilet and the ability to manage incontinence are related, they are not one and the same; thus the use of an item on toileting alone is not necessarily a good indicator of the population who experience incontinence, or who need assistance with their incontinence. Careful question wording clearly defining that toileting includes bladder and bowel control as well as the ability to get to and perform tasks associated with using the toilet may encourage better reporting. However, this approach ultimately masks two very different aspects of toileting, and, hence, the different needs of the individual and the sorts of assistance appropriate to their needs. A suggested method, depending again on purpose of the collection, is to include two items that clearly separate tasks of toileting from the management of bladder and bowel control as activities of self-care. Further investigation is needed to test suitable question wording and sequential placement of items.

4.3 Interrelationship of themes and data items

The data themes and data items described fulfil two purposes, i.e. that each data item stands alone to provide crucial information on an aspect of incontinence, and that the data items together provide a more detailed account of the experience of people with incontinence. Listed in Table 4.1 are the sorts of information that can be derived from individual data items and data item combinations.

These data items may also be used to monitor changes, over successive collection years, regarding improvements in management of incontinence, and effect on participation, in relation to changing environmental factors.

Table 4.1: Incontinence themes and proposed data items

Themes	Proposed data items and related estimates	Status of development
Estimate of prevalence of urinary and faecal incontinence	Item 1a: Broad estimate based on body function impairment.	For further development
	Item 7: Narrower estimate based on activity limitation (difficulty with managing incontinence and need for assistance).	See metadata item 'Activity—level of difficulty' in NCSDD.
	Item 1c: Estimate of population experiencing different types of urinary incontinence.	For further development
Estimate of prevalence of persons experiencing sense of urgency	Item 1b: Broad estimate of population experiencing sense of urgency.	For further development
Estimate of population experiencing more severe forms of incontinence		
Severity, as measured by body function impairment	Item 2a/b: Estimate of population experiencing frequent (as defined by user) episodes of urine or faecal leakage, in combination with:	For further development
	Item 3: Estimate of population experiencing more than a few drops of urine leaked during an incontinence event.	For further development
	Items 4a/b and 5: Estimate of population experiencing overly frequent (as defined by respondent) need to urinate or defecate.	For further development
Severity as measured by activity limitation and need for assistance	Item 7: Estimate of population who need assistance to manage their urinary or faecal incontinence and the level of assistance needed.	See ABS SDAC 'need for assistance' data item
	Item 8: Estimate of how much personal assistance a person needs, over the week, to manage their incontinence.	ABS SDAC 'frequency of need for assistance' data item
The environmental factors persons with incontinence rely on to manage their incontinence	Items 7 and 8 as above for personal assistance.	ABS SDAC 'need for assistance' data item ABS SDAC 'frequency of need for assistance' data item
	Item 10: Estimate of population who use continence aids to help manage their incontinence.	ABS SDAC 'use of continence aids' data item
	Item 11: Types of aids used for incontinence.	For further development
Other interventions used to manage or alleviate incontinence	Item 12: Estimate of population who use alternative interventions, e.g. preventive measures, medications, surgical procedures, to alleviate or manage incontinence.	For further development
The need for additional assistance or interventions	Item 13: Estimate of population who need additional personal assistance or aids, or interventions to manage incontinence.	For further development
The potential effect of incontinence on participation	Item 9: Estimate of population whose lifestyle has been affected by incontinence, and the sorts of life areas impacted upon.	See metadata items 'Activity and participation domains' and 'Participation extent' in the NCSDD
Associated or coexistent body function impairments	Item 6: Types and commonality of body function impairments associated with or related to incontinence.	See metadata item 'Body functions' in the NCSDD
Effect on carer	Items 14 and 15: Total number of hours spent per week assisting someone with their incontinence, and the physical and emotional effects of that caring role.	ABS SDAC various items on effect of the carer role (see ABS 2004a).

4.4 Summary and recommendations

Part B of this report reviewed Australian data collections which included continence relevant data items, alongside continence assessment tools, to determine the sorts of information on incontinence currently collected in Australia and to guide the development of draft items for possible inclusion in future collections.

This chapter provides 19 data items that may be used to collect information on the prevalence and severity of incontinence amongst Australians, and the sorts of assistance and support they need or use to manage their incontinence. If these items are used as a standard 'menu', and if context and purpose are taken into account, this approach would promote greater consistency across the field and greater quality in many incontinence-related collections and tools.

This report recommends three 'incontinence modules', which differ in terms of complexity of item usage and sorts of information collected, and for inclusion depending on the underlying purpose of the collection.

Module 1 How many Australians have incontinence

For collections that simply require an estimate of the population experiencing incontinence, use data item 1a (Incontinent of urine or faeces (control)). Data item 1a captures the broadest possible group, i.e. all persons who may have experienced an episode of incontinence over a defined time period. For a better estimate of the population who experience more severe incontinence, then data items based on data items 2a (Incontinence – frequency of urine leakage) and 3 (Incontinence – amount of urine lost) for urinary incontinence and data item 2b (Incontinence – frequency of faecal leakage) for faecal incontinence are essential.

Module 2 Population needing assistance—the experience of 'severe' incontinence

The second module is appropriate for collections focusing on the population experiencing more severe incontinence – those who may require formal service intervention now or in the future.

Most incontinence-related administrative collections, and some population surveys such as the SDAC, currently collect information on incontinence as an activity limitation. This method of determining severity is recommended here, in part because many administrative collections reviewed use a similar data item to identify incontinence (Table 3.1b). The combination of items to collect such information would therefore include:

- data item 7 (Incontinence – difficulty and need for assistance), to determine prevalence estimates of those who need assistance to manage their incontinence (severe incontinence) and those who do not need assistance but have difficulty managing their incontinence (mild/moderate incontinence). This data item can also be used to estimate the amount of assistance the population with severe incontinence need. This item probably mostly relates to assistance from informal care, and therefore provides information on (a) in which cases formal services are needed and (b) the demands on primary carers.
- data item 8 (Incontinence – frequency of need for assistance), to estimate the frequency of need for assistance (e.g. separating 'profound' from 'severe').

- data item 10 (Incontinence – use of aids), to estimate the population who rely on continence aids. This item, in combination with data item 7, provides estimates of the population relying solely on personal assistance, the population relying solely on continence aids, and the population using both forms of support.
- data item 13 (Incontinence – need for intervention or additional support), to estimate the degree of additional support needed, and the sort(s) of additional support required. This item can be collected not just for people who report needing personal assistance, but also those experiencing difficulty managing their incontinence.

Since most epidemiological studies tend to focus on incontinence as a body function impairment, data items 2a and 2b (Incontinence – frequency of urine leakage and Incontinence – frequency of faecal leakage), 4a and 4b (Incontinence – frequency of urination (day/night)), 5 (Incontinence – frequency of bowel movements) and 1c (Type of urinary incontinence) may also be considered for inclusion, at least for comparative purposes. If data items 2a, 2b, 4a, 4b and 5 are collected alongside data items 7 (Incontinence – difficulty and need for assistance) and 8 (Incontinence – frequency of need for assistance), it is recommended that there be some examination and mapping of responses to these two sets of items, to assess how well the different measures of severity relate to one another.

Module 3 A complete picture: incontinence as a multidimensional concept

For a complete picture of the population experiencing incontinence, it is recommended that the whole suite of items be used, and this may be more appropriate for a collection focusing solely on the incontinent population. Some of the additional information that is collected using this module includes:

- the type of aids needed and use of alternative interventions to manage incontinence;
- a better understanding of the types of body function impairments that may be associated with incontinence generally, and more severe forms of incontinence, and hence the additional support and other intervention measures this population does or may require;
- the impact of incontinence on lifestyle, participation and the pursuit of specific activities;
- the effect on carers caring for persons with incontinence.

The data items in this module ensure comparability with the sorts of information collected using assessment tools and in epidemiological research; the data items relate to national data standards where available. Most importantly, it provides a whole-of-person description of the experience of incontinence, which is generally unavailable from most collections, and many epidemiological studies, and is essential for a whole-of-person approach to assisting people with incontinence.