

2020 Integrated Atlas of Care for Multiple Sclerosis in the Australian Capital Territory



Disclaimer:

This report has been prepared through a consultancy process using specific methods outlined in the Framework section of this report. The Project Team has relied upon the information obtained as being accurate with every reasonable effort made to obtain information from service providers providing services to people with Multiple Sclerosis (MS) across the region. Information related to utilisation of services has not been included in this report.

The information, statements, statistics and commentary (together the “information”) contained in this report have been prepared by the project team from publicly available information as well as information provided by the care service providers as described above across the Australian Capital Territory catchment area.

The language used in some of the service categories mapped in this report (e.g. outpatient, day care, non- acute) reflect the category nomenclature employed within the Description and Evaluation of Services and DirectoriEs for Long Term Care (DESDE-LTC) classification system rather than a description of services. The consistent application of standardised category labels, which have been used for some years in Europe for health service mapping studies, provides a common language for meaningful comparisons of service across regions (nationally and internationally).

Suggested citation

Tabatabaei-Jafari H., Bagheri N., Salinas-Perez JA., Furst M., Mendoza J., Salvador-Carulla L. (2021) *The Integrated Atlas of Care for Multiple Sclerosis in the Australian Capital Territory*, Research School of Population Health, The Australian National University, 2021.

DOI: 10.13140/RG.2.2.27184.28167

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Acknowledgement

This Atlas was funded by Our Health in Our Hands (OHIOH), a strategic initiative of the Australian National University created in partnership with ACT Health, which aims to transform health care by developing new personalized health technologies and solutions in collaboration with patients, clinicians, and health-care providers. The authors wish to specially thank the researchers and consumers of OHIOH group, who provide invaluable comments regarding the MS care in ACT: Dr Jane Desborough, Dr Anne Bruestle, Dr Anne Parkinson, Dr Vanessa Fanning, Ms Janet Drew, Ms Hellena Paul, Ms Katrina Chisholm, Ms Mary Webb, and Mr Mark Elisha.

Additionally, this work was also funded by Incubator Grant funded by MS Research Australia (application number: 19-0656). Title of the project: Analysis and mapping of service availability and pattern of care for multiple sclerosis in the Australian Capital Territory region.

Content

Executive Summary	1
1 Introduction.....	2
1.1 Context.....	2
1.2 Health system in ACT	2
1.2.1 ACT Regional Health Hub.....	2
1.2.2 The ACT Primary Health Network	3
1.3 NDIS and Multiple Sclerosis in ACT	5
1.4 Integrated Health Atlases	5
1.4.1 Ecological approach.....	7
1.4.2 Layers of services	8
1.6 The Atlas of Multiple Sclerosis Care	9
2 Methodology.....	10
2.1 DESDE-LTC.....	10
2.1.1 Basic Stable Inputs of Care	10
2.1.2 Classification of BSIC	11
2.1.3 Other Care Teams (OCT).....	19
2.2 Inclusion Criteria	20
2.3 Atlas Development Process	21
2.4 Glossary	26
3 Description of Services Providing Support for People with Multiple Sclerosis in the ACT Region	29
3.1 Socio demographic and health related indicators of Australian Capital Territory Primary Health Area	29
3.2 General Description.....	37
3.3 Health vs. Social services	37
3.4 Workforce Capacity	40
3.5 Description of the pattern of care.....	41
3.5.1 Subspeciality vs. Speciality services	41
3.5.2 Public vs. private services	42
3.6 Capacity of the System	42
4 Discussion.....	44
4.1 Overview and the gaps.....	44
4.2 Comparing MS care with mental health care in ACT	47
4.3 Conclusion	48
References	49

Abbreviations

Abbreviation	Definition
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
BSIC	Basic Stable Input of Care
CALD	Culturally and Linguistically Diverse
DESDE	Description and Evaluation of Services and DirectoriEs
DESDE-LTC	Description and Evaluation of Services and DirectoriEs for Long-Term Care
FTE	Full Time Equivalent
GIS	Geographical Information System
HREC	Human Research Ethics Committee
ICD-10	International Classification of Diseases, Tenth Revision
ICF	International Classification of Functioning, Disability and Health
IRSD	Index of Relative Socio-economic Disadvantage
LGA	Local Government Area
LHD	Local Health District
MH	Mental Health
MTC	Main Type of Care
MS	Multiple Sclerosis
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation (or community service provider)
NMHC	National Mental Health Commission
PHIDU	Public Health Information Development Unit
PHN	Primary Health Network
SEIFA	Socio Economic Indexes for Areas

Executive Summary

This study aimed to evaluate and describe the pattern of service provision for people with multiple sclerosis (MS) in the Australian Capital Territory. A healthcare ecosystem approach has been followed using an internationally standardised service classification instrument--the Description and Evaluation of Services and Directories- Long Term Care (DESDE-LTC) -- to typify and describe all services for MS care in the study area. Available services were classified according to the target population into those specifically provided to people living with MS and those providing generic neurological services, both public and private, and across social and health sectors.

A limited variety of services were available. Facilities providing or coordinating multidisciplinary integrated care specific to MS were missing. Services specific to MS (sub-speciality services) were limited in number (six of the 27 services) and use of services in the nearby states was reported in the interviews. Additionally, there were few services outside the core health sector (4%). Care system was fragmented and relied heavily on generic neurology services with restricted access due to copayment. Using standardised methods of service classification will facilitate comparisons with other local areas, monitor changes over time and enable comparison with other health conditions (e.g. dementia, mental disorders).

Lack of local availability of sufficient and equitable care may be less problematic if the service that are provided incorporate experiential and social outcomes of the disease and the preservation of valued social roles into case management and clinical planning. Therefore, even if the establishment of further services is not practical because of insufficient demand, coordinating the available local and adjacent services can improve the efficacy of the whole system.

1 Introduction

Multiple sclerosis (MS) is an autoimmune disease, and the most common disabling neurological condition of young adults globally. Most people are diagnosed between the ages of 20 and 40, during their most productive years. Global prevalence of MS was estimated to be 2–2.5 million cases in 2016, an increase of 10.4% since 1990. In addition to genetic profile, environmental and lifestyle factors are also important in the development of MS [1]. Geographical Information Systems (GIS) and spatial analysis play a relevant role in the understanding and management of health-related outcomes in chronic diseases with a complex course, as in MS. The GIS tools, including Atlases of care, have become essential in supporting evidence-informed planning and prioritisation and resource allocation, as well as in understanding service availability and capacity, accessibility, equitability and gap analysis. A recent systematic review showed the broad application of GIS in this area, although most studies have been conducted in Europe and North America. In Australia the authors identified two GIS studies focused on the analysis of latitudinal gradient of first demyelinating events [2], and the use of prescription data to estimate and map MS prevalence [3]. Unfortunately there has not been any analysis of service provision and variation of healthcare use in this population group in Australia. None of the 4 Atlases of Healthcare Variation published by the Australian Commission on Safety and Quality in Healthcare has provided information on neurological conditions including MS [4].

1.1 Context

The Australian Capital Territory is an Australian federal territory with a population of around 429,000. Geographically an enclave within the state boundaries of New South Wales, it is home to Canberra, the territory's only city and the nation's capital. The ACT population is resoundingly urban, with close to 400,000 people, or over 90% of its population, living in one of Canberra's seven districts, and smaller numbers living in rural and semi-rural areas to Canberra's south and west. The ACT also has a strong functional link with the small city of Queanbeyan in New South Wales (population around 65,000) due to its proximity to the territory's eastern border.

1.2 Health system in ACT

1.2.1 ACT Regional Health Hub

The role of ACT Health as a regional hub closely connected with the South Eastern NSW PHN is another salient characteristic. Canberra's area of influence covers a region of 220,000 km², with 1.2 million people living in a diverse geographical region incorporating the ACT, Southern

NSW, Murrumbidgee, and Illawarra Shoalhaven Local Health Districts. It includes desert and beachside towns, Aboriginal communities, drought-stricken farms, retirement communities, a major population centre (Canberra) and other urban clusters (Wollongong and Wagga Wagga). The ACT health system is an established system of general practitioners (GPs), specialists, nurses, allied health and hospital staff, and emergency/retrieval services in a range of organisational models: from single-doctor general practices to large tertiary hospitals where the region's nurses, doctors and allied health workers are trained [5]. Canberra Health Services provide all healthcare services in the ACT, including the 672-bed Canberra Hospital, Centenary Hospital for Women and Children, ACT-based community health services, and the outpatient University of Canberra Hospital. The ACT Health Directorate sets policy, plans health services to meet community needs, and funds a range of Non-Government Organisations (NGOs) to provide services to people in the ACT and surrounding region [5].

The region has entrenched low doctor: patient ratios in primary care, with a patient: GP ratio of 1:1350 in the ACT (compared with 1:982 for metropolitan NSW). The entire region also suffers from specialist workforce shortages in surgery, medicine, obstetrics, and paediatrics. Population flow data indicate frequent cross-jurisdictional travel to access tertiary health care provided by Canberra Health Services in the ACT, supplemented by specialist outreach services from the ACT to the region. As a result of these factors, the region faces challenges in delivering and sustaining effective and equitable care, including reducing variations in care across the region, ensuring equitable access for all, integration of primary, secondary and tertiary care; effective referral and retrieval practices, workforce recruitment and retention, and service delivery to ageing and marginalised populations [5].

1.2.2 The ACT Primary Health Network

Capital Health Network, the ACT Primary Health Network is one of 31 PHNs in Australia and covers the whole territory. It is a rapidly growing and diversifying region, with a relatively young population. Planned infrastructure growth to accommodate the needs of this swelling population includes the building of more schools and housing, with areas in Gungahlin and Molonglo expected to be the fastest growing, and the development of transport links, in particular the expansion of the light rail.

The territory is relatively socio-economically advantaged: its SEIFA (Socio-Economic Index for Areas) score at 1075 is the second highest of all Primary Health Network regions in Australia after Northern Sydney, and only 2.4% of its population rely on unemployment benefits for income (compared to 4.6-5.8% in Perth, 6.5% in Adelaide, 4.5-5% in Brisbane, 3-4.9% in

Melbourne, 3.7% in Western Sydney). It has the second highest rate in Australia of young people still in fulltime education at age 16 [6].

Despite this, it has areas of great disadvantage. Canberra's story has been referred to as "a tale of two cities" [7], its overall relative affluence and education masking pockets of significant and entrenched disadvantage. For example, a relatively high percentage of people in the ACT live in social housing (6.5% compared to 3-3.6% in Perth metropolitan areas, 3.5-4.2% in Brisbane, 1.8-3.7% in Melbourne, 2-4.7% in Central, Eastern and Northern Sydney), and this varies significantly across the region: while only 2.2-2.8% of people in Gungahlin live in social housing, in the inner north the figure is 10.6% [6]. Historically, ACT's "salt and pepper" public housing strategy has been one of dispersal rather than congregation. This strategy locates smaller scale public housing throughout Canberra's suburbs and town centres, in order to support the development of diverse local communities, and to achieve positive social and economic outcomes for tenants and the broader community. However, a change in urban planning policy from a greenfield focus to one of urban renewal has also meant planning for redevelopment of the inner urban infrastructure, including the relocation of some inner area public housing further out into the suburban areas [8]. Planning and infrastructure changes such as the development of new public transport corridors and the relocation of public housing to more distant suburbs of the city have implications for population mental health through, for example, changes to people's experiences of social isolation or of their accessibility to services.

The ACT PHN has the challenging task of commissioning appropriate and adequate health services to meet the needs of its fast growing, dynamic and diverse population. Coupled with the impact of chronic health diseases, this presents great challenges for service planning to meet current and anticipated community need. Running alongside the challenge of chronic care, PHNs are also having to negotiate the ways in which they and their services will engage with the NDIS. The NDIS is one of Australia's most significant social policy changes, and its roll out has impacted both disability and care service provision. The impact of these two major government policies on PHN service commissioning cannot be underestimated, and is explored in further detail in the respective sections below.

PHNs were established in 2015. Part of their role is to develop and commission new services to meet the needs of people with, or at risk of, chronic illness who can be appropriately managed in the primary care setting. They also have a key role in supporting integration and partnerships between health services (including state and territory funded services, NGOs and private practitioners), education providers and other relevant support services.

1.3 NDIS and Multiple Sclerosis in ACT

The National Disability Insurance Scheme (NDIS) launched in July 2013, after years of discussion about the need for a major reform of disability services in Australia. The NDIS is a new way of funding individualised support for people with disability (including psychosocial disability) that involves more choice and control, and a lifetime approach to a person's support needs. To be eligible for the NDIS, people need to meet age and residence requirements (e.g. hold Australian citizenship, permanent visa or a Special Category Visa) as well as disability or early intervention requirements.

As of 31 December 2016, a total of 5,541 people had approved NDIS plans in ACT, and 3% of these people (about 166) had MS diagnosis (compared with 2% nationally)[9].

However there are unclear roles and responsibilities within the scheme implementation; concerns about planners' understanding of the nature of chronic illness and needs of people with disabilities; issues around funding and appropriately skilled staffing; the downgrading of services, in particular those providing outreach support too hard to reach populations; and fears for people not eligible for the scheme, or for whom current services may no longer be available [10].

In this context, it is crucial to provide policy and service decision makers with every tool and opportunity to make better, more informed choices about future planning and investments in MS care. This report will be a resource providing a point in time assessment of how services have changed over time, and whether these changes have led to increased levels of care in locally identified areas of need.

1.4 Integrated Health Atlases

A number of international organisations have called for an integrated model of health care, covering specific interventions for different disorders, and including a complex array of service provision settings including homecare, community, hospital, and other residential settings [11]. This will be important for improving the productivity and quality of care services, and in fully integrating the health care and social elements of long-term care provision, especially for people with MS, in order to boost efficient and equitable care provision[12]. However, there are still major challenges for producing standard and valid comparisons of the patterns of care to people with MS across different jurisdictions. National and international comparisons are hindered by ambiguity and inconsistency in service definition and description; differences in organisational

structure; inconsistency in service definition and description; and differences in the definition of the target population. Hence using a common assessment and coding system allows harmonisation of service data, can inform equitable allocation of care resources, programmes, and treatment across different health districts, and facilitate linkages of health networks.

In addition, all health system approaches require the broader perspective of health care ecosystem analysis, that also takes into account the spatial–temporal variation across regions in the patterns of care and related impacts [13, 14]. Understanding the complex intersection of contextual factors is fundamental to implementation, provision, modelling, and improvement of services [15]. Specific approaches to local service coding and mapping are therefore required to address local impacts of service use. Integrated atlases provide a demonstrated method of categorising services which recognise contextual factors [16, 17]. The utility of integrated atlases has been demonstrated in describing single location service systems, treatment responses and workforce capacity; visualising variations and gaps in health systems, providing a broader perspective (e.g. multi-sectorial), and showing differences in the availability and diversity of services across geographic locations [18].

Geographical variations in health service provision and utilisation were first observed (1973) by Wennberg and Gittelsohn [19], and continue to be documented in research articles [20, 21], and in atlases of healthcare such as the Ontario Atlas of Care [22], the Dartmouth Atlas [23, 24], the WHO Atlas of Neurology, and the Australian Atlas of Healthcare Variation. These Atlases of health provide healthcare information for a region or regions. They are however susceptible to two major biases that could impact on the translation of healthcare findings into regional and local planning and resource allocation: the ecological fallacy bias, which derives from an assumption that national averages apply directly to individuals or to local area services [25, 26]; and the terminological unclarity bias, which refers to ambiguity and vagueness in the naming and definition of the services [27] and interventions [28]. They also focus on the provision of medical services, rather than taking an integrated approach. Information is sourced from experts, in a “top down” model.

In order to avoid these pitfalls in the analysis of service provision in local systems, it is necessary to use a common reference framework [29], a validated glossary of terms [30], and a standard classification system [31] for coding and mapping local services. Integrated Atlases such as the Integrated Atlas of Mental Health of ACT, the Integrated Chronic Care Atlas of Dubbo and Coonamble [32] and The Integrated Mental Health Atlas of Western Sydney [27] have used an innovative service classification instrument, the Description and Evaluation of Services and

Directoris for Long Term Care (DESDE-LTC) in combination with Geographic Information Systems (GIS), to gain detailed local information about service provision and availability from local service managers in a “bottom-up” approach. This data has revealed gaps in service provision, and identified differences between what services are expected to do and what they actually do, as well as problems with the stability of service provision. This is highly relevant information for health policy. Additionally, GIS aid in communication of complex data to decision makers (GIS) by providing visual geographical maps of the data [33].

The Description and Evaluation of Services and Directoris for Long Term Care (DESDE-LTC) [31] tool is a well defined classification system that can be used for the standardised description of health services available in a defined area using common units of analysis in service assessment, allowing comparisons across different health districts [31, 34, 35]. DESDE-LTC has previously been used for describing care provision in over 34 countries [36]. It uses an international terminology and coding system to overcome the problem of local and national variation in the names of services.

1.4.1 Ecological approach

The modified Thornicroft and Tansella matrix of care delivery [37] and related ecological production of care model [38] provide the main model for research within the area of health care systems. Thornicroft and Tansella combined the model of production of healthcare developed by Avedis Donabedian [39] to describe health systems in terms of structure, process, and outcomes with an ecological approach, stratifying the decision-making levels within health services, and describing these as “micro” (between patient and clinician-level); “meso” (community level, including healthcare services) and “macro” (governmental-level) . The Thornicroft and Tansella matrix enabled a more holistic and systemic analysis of integrated care across the different components of the system. The DESDE classification system and its earlier version, the European Service Mapping Schedule (ESMS) [36] added “services” at the “micro level” in the spatial axis (quadrant 3A) and a “nano” level to describe the patient -clinician level (quadrant 4A). In integrated atlases we are looking specifically at the care service delivery system at the meso level (quadrant2A), and the aggregation of information from the micro level to the meso level (quadrant 2A) and from meso level to macro level (quadrant1A).

	INPUT	THROUGHPUT	OUTPUT
MACRO Country/region	1A	1B	1C
MESO Local <i>Health districts, catchment areas</i>	2A	2B	2C
MICRO Service <i>Settings, facilities, care teams</i>	3A	3B	3C
NANO Individual agents <i>Users, carers, profs.</i>	4A	4B	4C

Figure 1-1 Extended Tansella and Thornicroft Care Matrix. Comparison of NMHSPF and DESDE-LTC. Adapted from Tansella & Thornicroft, 1998. **Modified from Thornicroft & Tansella (1999) The Mental Health Matrix, Cambridge Univ. Press**

1.4.2 Layers of services

The complex array of service provision for any given diseases/disorders are provided at different levels of speciality. At the highest level, sub-specialised services are allocated to a specific disease/ disorder. In this level, the service provider targets the specific needs of that particular group of patients. In specialised services, the service provider targets a category of specific diseases/disorders such as neurologic diseases. In the case of very rare diseases, this is the main level of specialised care available to patients. The next layers of care are generic services (such as general practitioners, and paediatric and geriatric services) and expanded supply services (such as dietitians, dentists, ophthalmologists, podiatrists and pharmacologists). These layers of care are responsible for a large proportion of available services in each health care system.

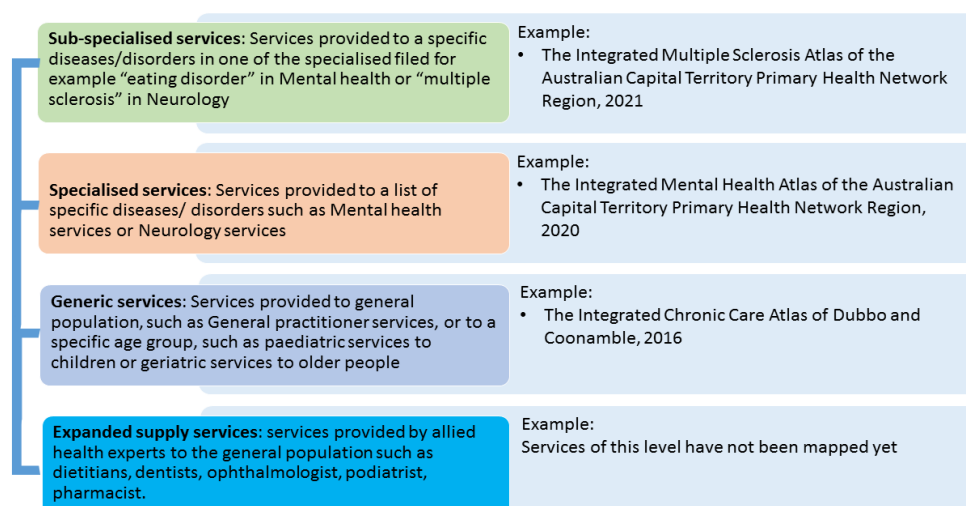


Figure 1-2 layers of health services

1.6 The Atlas of Multiple Sclerosis Care

The Integrated Atlas of Multiple Sclerosis (MS) services is an essential tool for planners of MS service provision in ACT. This Integrated Atlas includes detailed information on social and demographic characteristics and health-related needs, as well as data on service availability and care capacity. The maps and graphics which are used as a main form of presenting the data allow policy planners and decision makers to build bridges between the different sectors. The information in the Atlas enables us to assess strengths and gaps in the health system, and provides the opportunity to assess the impact of policy decisions in the system. This information is vital for future integrated care planning.

The "Description and Evaluation of Services and DirectoriEs for long-term care" (DESDE-LTC) was used to code MS services. Annex 1 provides a description of the types of services found in Australia in relation to the DESDE coding system. The DESDE system classifies services based on actual service activity (i.e. what the service does) rather than on the service's name. The DESDE- LTC system is a classification system which uses a standardised coding methodology based on common terminology and a standardised procedure for data collection. This standardised approach allows service planners and researchers to complete meaningful comparisons of service systems across and within countries. Such comparisons allow for service gap analysis and monitoring of health systems. The use of the DESDE model has allowed comparison of "like for like" services and thus has provided a unique opportunity to assess longitudinal change within a given health system.

In a recent review of the use of the DESDE system it was observed that the DESDE (and the earlier ESMS system) have been used in 585 catchment areas and 34 different countries to describe services at local, regional and national levels. Authors of the review note that the DESDE/ESMS-system's metric properties have been extensively analysed, and the usability of the system has been demonstrated around the world [36].

2 Methodology

Typically, atlases of health are formed through lists or directories of services, and the inclusion of services is based on their official or everyday titles. This is particularly problematic for several reasons:

- the wide variability in the terminology of services and programs even in the same geographical area;
- the lack of relationship between the names of services and their actual functions (e.g. day hospitals, day clinic), as the service name may not reflect the actual activity performed in the setting; and,
- the lack of a common understanding of what a service is. The word 'service' is an umbrella term that is used to describe very different components of the organisation of care. It merges permanent, highly structured services, with clinical units, or even short-term programs and interventions.

2.1 DESDE-LTC

To overcome these limitations, in this project, the "Description and Evaluation of Services and DirectoriEs for Long-Term Care" (DESDE- LTC) has been used (Salvador-Carulla et al., 2013). This is an open-access, validated, international instrument for the standardised description and classification of services for Long Term Care. It was originally developed for health issues requiring long term care such as its application in The Integrated Chronic Care Atlas of Dubbo and Coonamble in Australia [40], which identifies services across a spectrum of care intensity and duration for people with chronic diseases.

The DESDE-LTC includes a taxonomy tree and coding system that allows the classification of services in a defined catchment area, according to the main care structure/activity offered, as well as to the level of availability and utilisation. It is based on the activities, not the name, of the service provider. The classification of services based on the actual activity of the service therefore reflects the real provision of care in a defined catchment area.

It is important to note that in research on health and social services there are typically different units of analysis, but comparisons should be made across a single and common 'unit of analysis' group. Different units of analysis include: macro- organisations (e.g. Local Health Networks), meso-organisations (e.g. Hospitals), and micro- organisations (e.g. Services). They could also include smaller units within a service: main types of care, care modalities, care units, care intervention programs, care packages, interventions, activities, micro- activities or philosophy of care.

Analysis based on DESDE-LTC is focused on the evaluation of the service delivery teams or Basic Stable Inputs of Care (BSIC).

2.1.1 Basic Stable Inputs of Care

A Basic Stable Input of Care (BSIC) is best described as a team of staff working together to provide care for a group of people. It could also be described as a service delivery or care team.

These teams must have time stability (typically they have been funded for more than three years or have funding secured for three years) and structural stability. Structural stability means that they have administrative support, and two of the following: their own space (which can be in a shared office); their own finances (for instance a specific cost centre); and their own forms of documentation (i.e. they collect data and produce reports on their service activities). There are several criteria that help to define a BSIC (Table 2-1).

Table 2-1 Basic Stable Input of Care Criteria

Criterion	
A	Has its own professional staff
B	All activities are used by the same clients
C	Time continuity
D	Organisational stability
D.1	The service is registered as an independent legal organisation (with its own company tax code or an official register). If NOT:
D.2	The service has its own administrative unit and/or secretary's office and fulfils two additional descriptors (see below). If NOT:
D.3	The service fulfils three additional descriptors
D3.1	It has its own premises and not as part of other facility (e.g. a hospital)
D3.2	It has separate financing and specific accountability (e.g. the unit has its own cost centre)
D3.3	It has separated documentation when in a meso-organisation (e.g. end of year reports)

2.1.2 Classification of BSIC

Once BSIC are identified using the above criteria, the Main Types of Care (MTC) they provide are examined and classified.

Each BSIC is classified by using one or more codes based on the MTC they deliver. Some services might include a principal structure or activity (for example a 'Residential' code) and an additional one (for example, a 'Day Care' code).

There are six main classifications of care within the DESDE-LTC, as described below (Figure 2-1).

Residential Care - Used to classify facilities which provide beds overnight for clients for a purpose related to the clinical and social management of their health condition. These include inpatient hospital wards, crisis shelters, residential rehabilitation services and inpatient withdrawal units. Residential Care is divided into Acute and Non- Acute branches (Figure 2-2).

Day Care - Used to classify facilities which: (i) are normally available to several clients at a time (rather than delivering services to individuals one at a time); (ii) provide some combination of treatment for problems related to long-term care needs (e.g. providing structured activities or social contact/and or support); (iii) have regular opening hours during which they are normally available; and (iv) expect clients to stay at the facility beyond the periods during which they have face to face contact with staff: these include the more traditional long-stay day programs (Figure 2-3).

Outpatient Care - Used to code care provided by service delivery teams which: (i) involves contact between staff and clients for some purpose related to the management of their condition and associated clinical and social needs; and (ii) is not provided as a part of delivery of Residential or Day services (Figure 2-4). These include outreach services. Quite often, Outpatient Care also involves the provision of information and support to access other types of care.

Accessibility to Care - Classifies service delivery teams whose **main function** is to facilitate access to care for clients with long- term care needs. These services do not provide any therapeutic care, and include Care Co-ordination services (Figure 2-5).

Information for Care - Used for service delivery teams whose **main function** is to provide clients with information and/or assessment of their needs. Services providing information are not involved in subsequent monitoring/follow- up or direct provision of care. These include many telephone information and triage type services (Figure 2-6).

Self- Help and Voluntary Care - Used for BSIC which aim to provide clients with support, self- help or contact, with un- paid staff that offer any type of care as described above (i.e. Residential, Day, Outpatient, Accessibility or Information) (Figure 2-7).

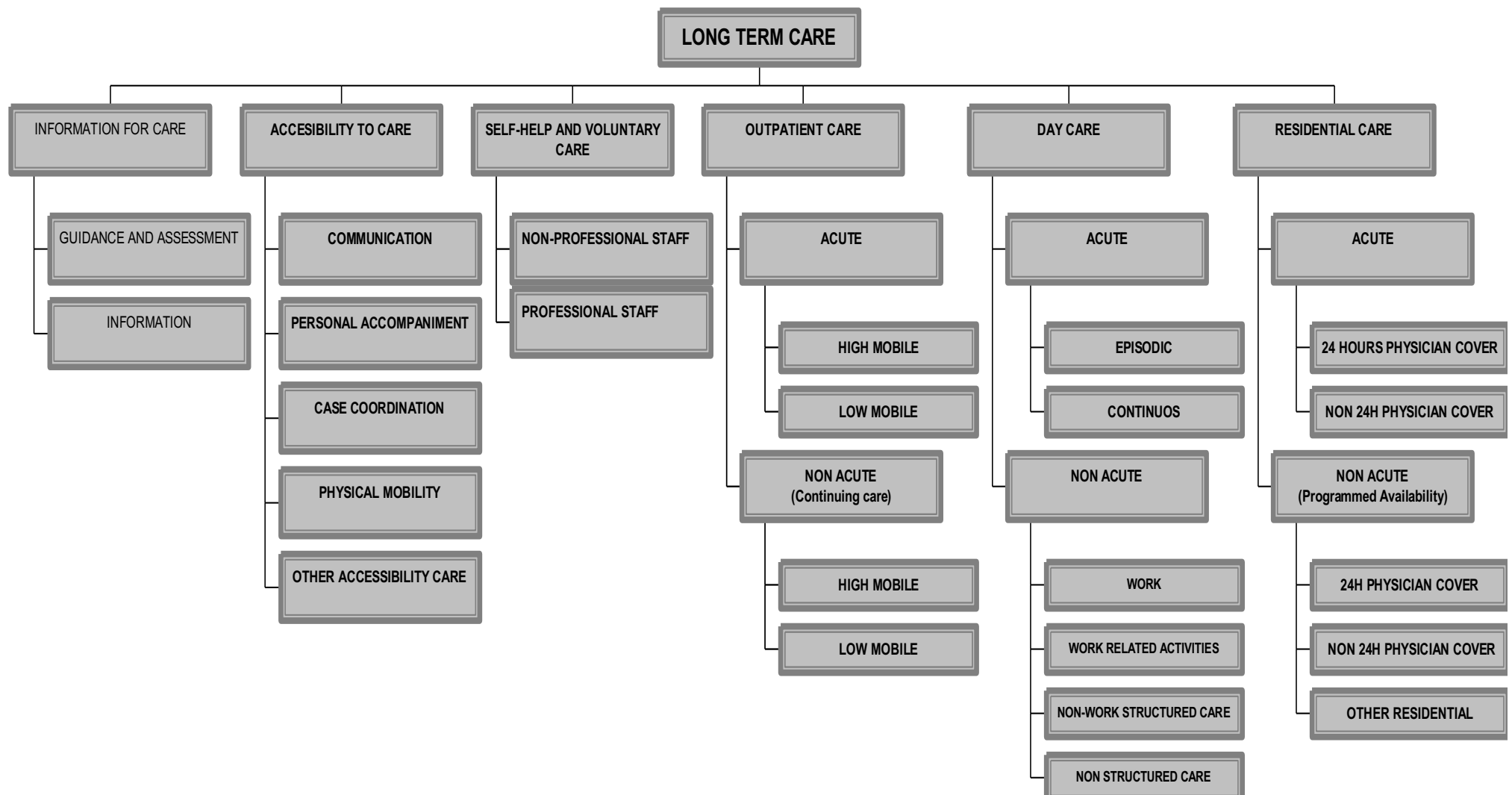


Figure 2-1 Long Term Care Main Branches of Care

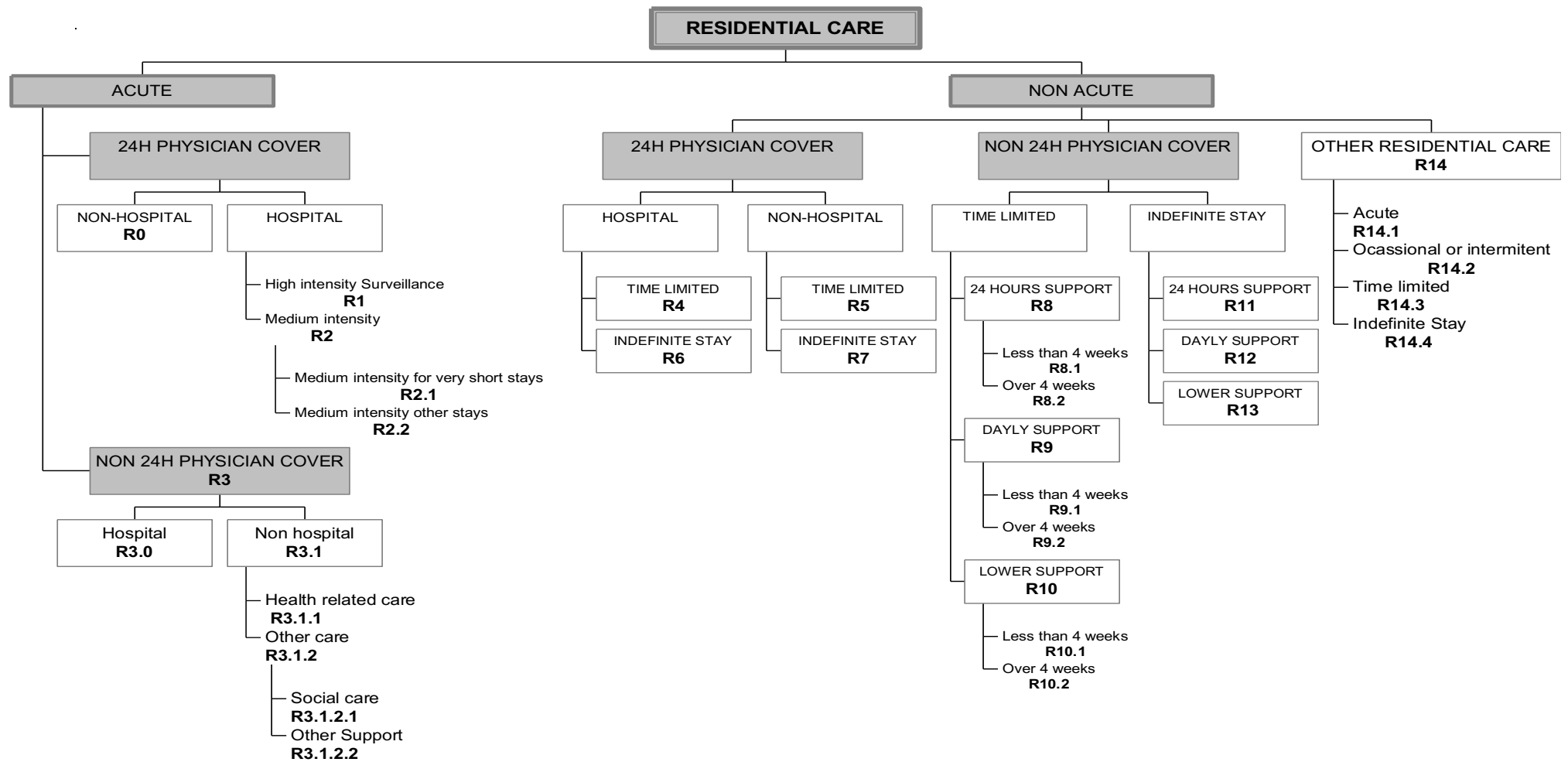


Figure 2-2 Residential Main Branch of Care

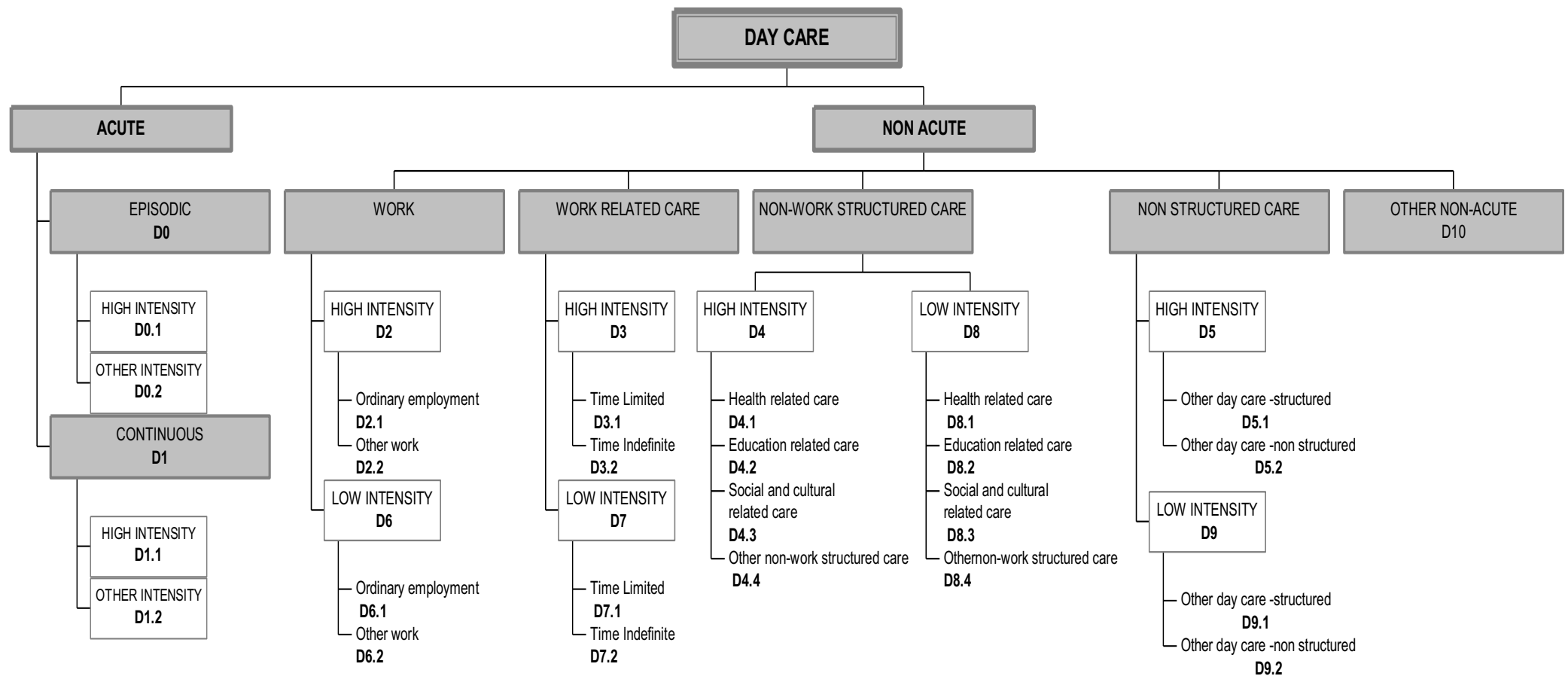


Figure 2-3 Day Care Main Branch of Care

Integrated Atlas of Care for Multiple Sclerosis in the ACT region-2020

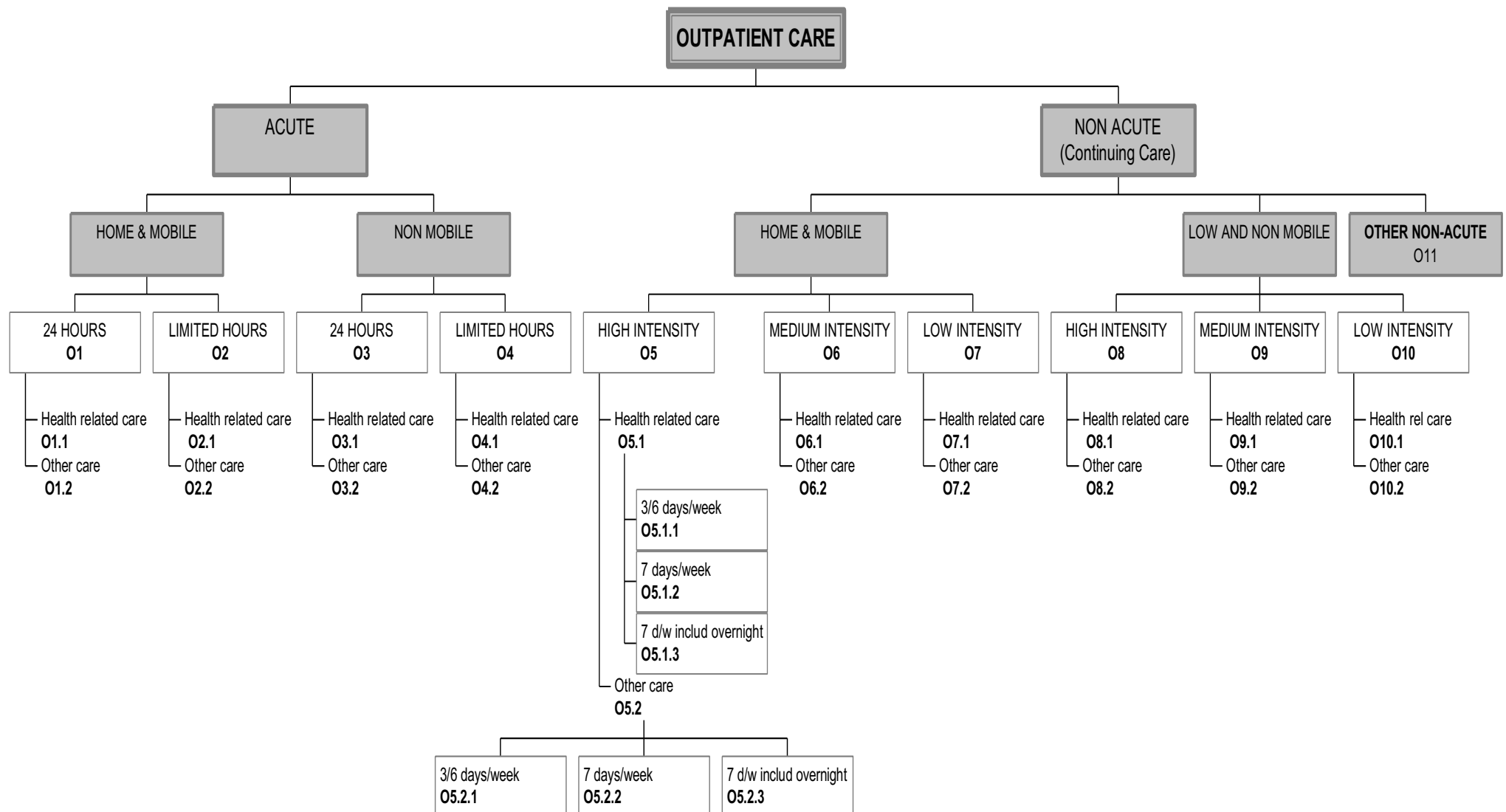


Figure 2-4 Outpatient Main Branch of Care

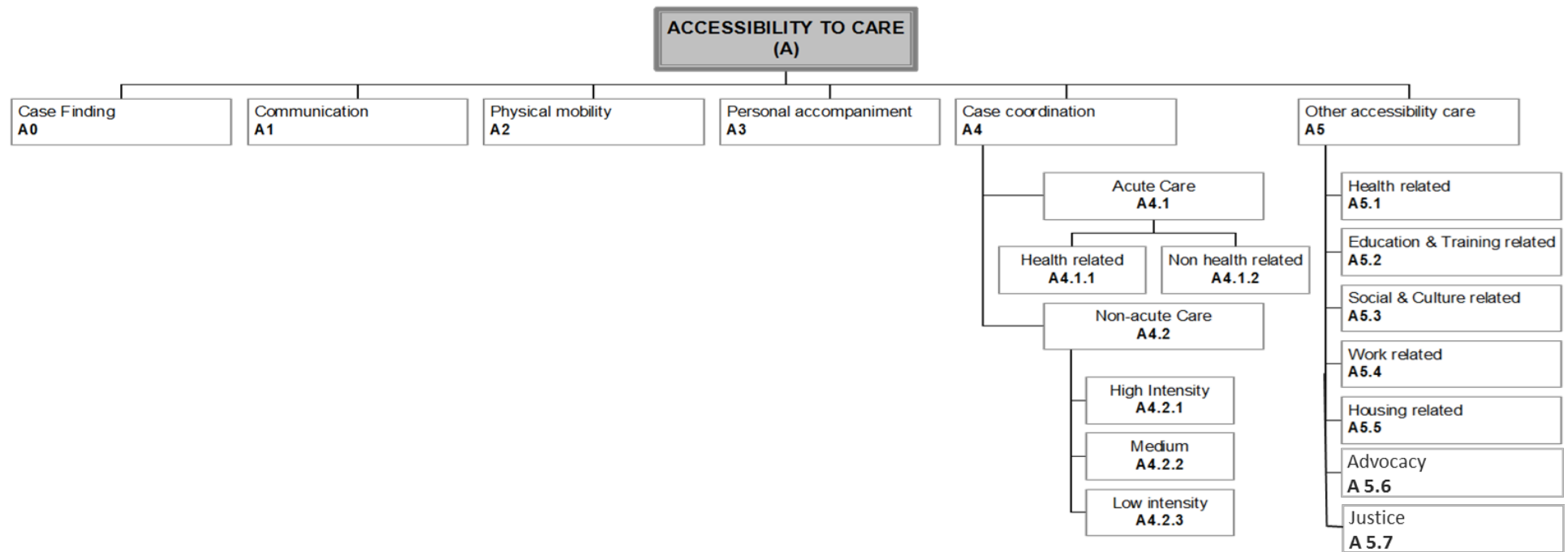


Figure 2-5 Accessibility Main Branch of Care

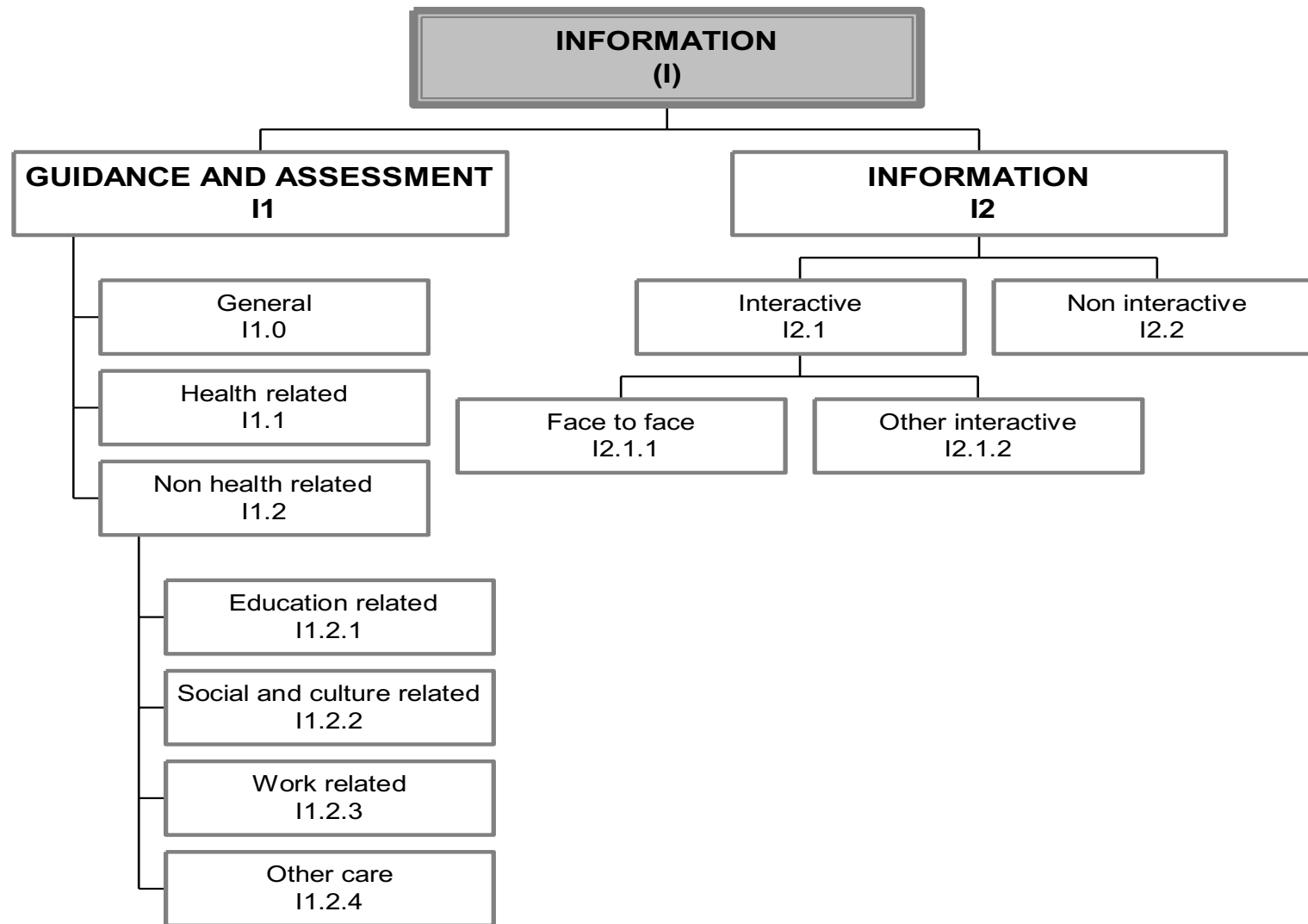


Figure 2-6 Information for Care Main Branch of Care

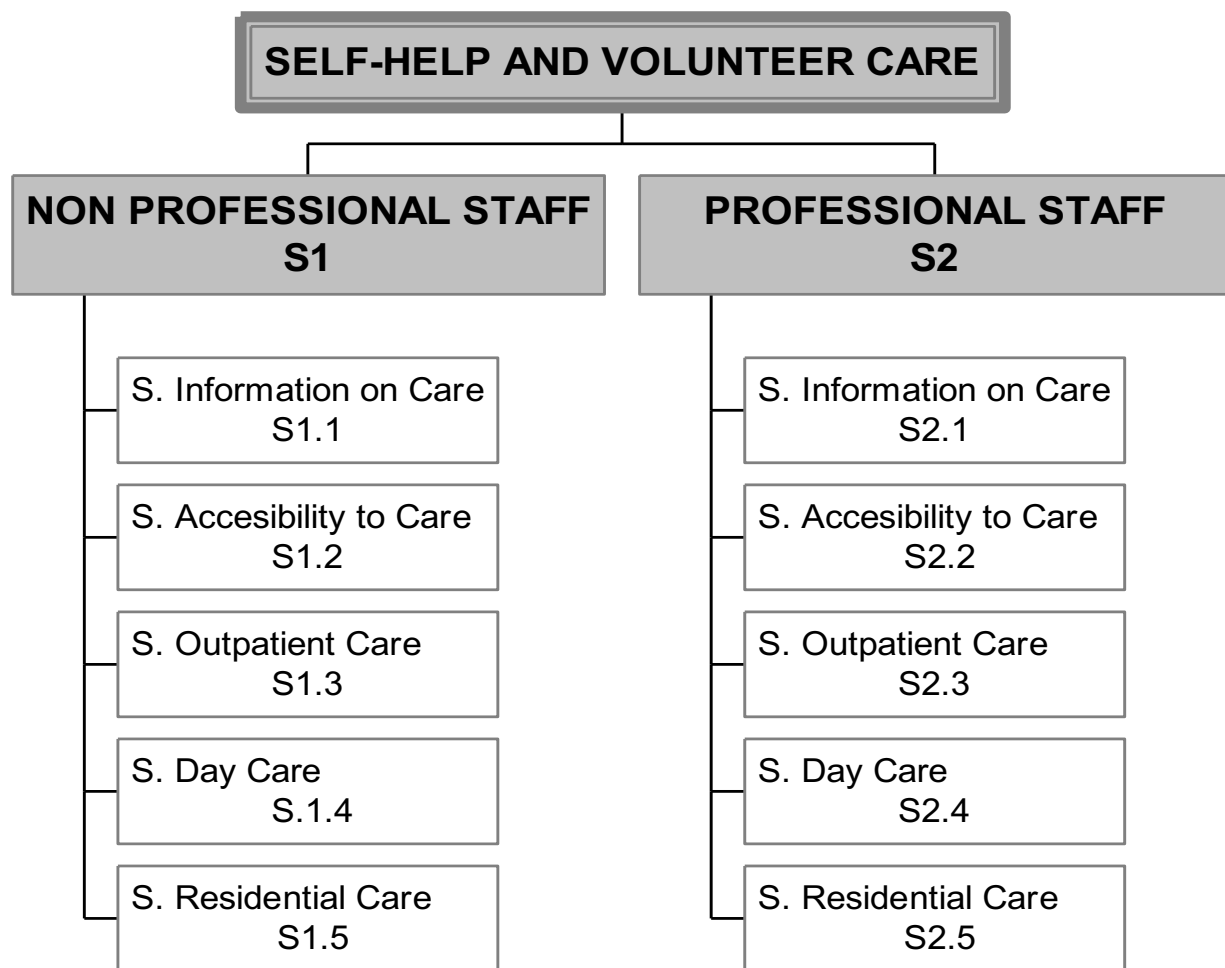


Figure 2-7 Self-help and Volunteer Main Branch of Care

2.1.3 Other Care Teams (OCT)

These are a minimal set of inputs organised for delivering health-related care characterised by time continuity which does not fulfil the organisational stability criteria or attributes described for a BSIC. An example are stable clinical units financed with earmarked funding under a policy provision programme separated from the general financing system of the micro-organisation (e.g. early psychosis intervention in Catalonia) and using a separate documentation due to specific monitoring by the local health agency).

A typical case of OCT are 'clinical units' within 'care teams' of general hospitals or other health-related meso-organisations (e.g. a Multiple Sclerosis program or clinical unit within a broader care unit such as the acute neurology ward in a general hospital, or the acute emergency care function provided by the staff of the neurology care team at the emergency room). These are coded with lower case mtc (d1.1 etc.) to differentiate them from MTCs of BSICs.

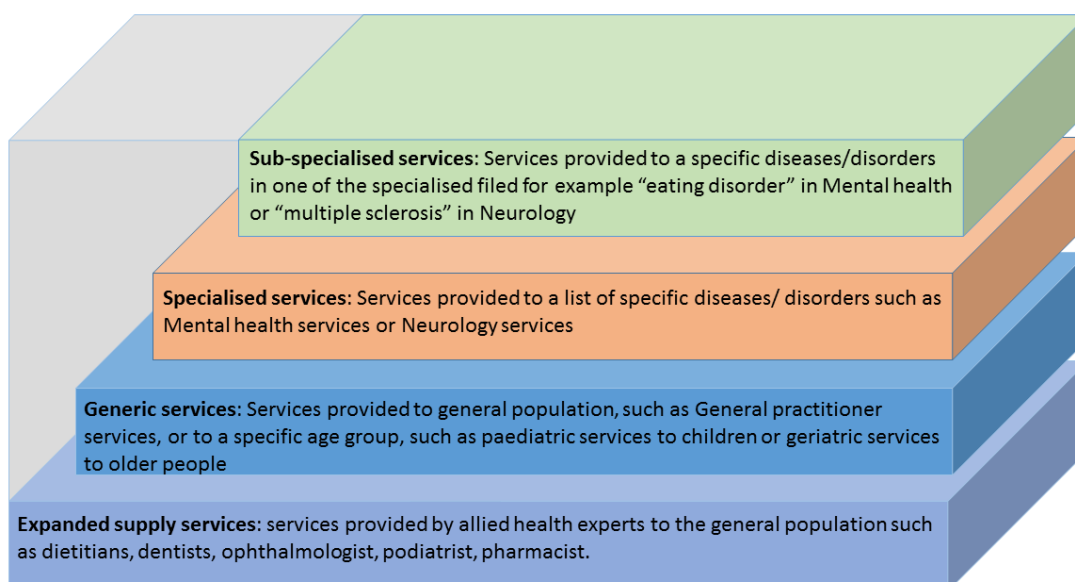
2.2 Inclusion Criteria

The Integrated Atlas has clear inclusion criteria to ensure consistency and comparability across Atlases created using the DESDE methodology, both internationally, and across Australia.

To be included in the Atlas a service has to meet certain inclusion criteria:

The service is specialised - the service must specifically target people with a diagnosis of MS. That is, the primary reason for using the service is for treatment of MS or its complications. This includes subspecialty services that only provide care to people with MS, and generalised speciality services that provide services to people with all neurologic disorders including MS (Sub-specialised and Specialised layers in figure 2.8).

Figure 2-8 layers of services provided to a specific disease



The service is universally accessible - the Atlas focuses on services that are universally accessible, regardless of whether they are publicly or privately funded. Access to most private mental health services in Australia requires private health insurance coverage, higher income or savings, or having NDIS support in cases such as people with MS.

The service is 'stable': that is, it has, or will, receive funding for more than 3 years - the inclusion of stable services guarantees that the mapping reflects the robustness of the system as a basis for evidence- informed planning. As such, services that are pilot projects or are provided through short term grants are excluded. However, there is an appreciation that the current environment is one where there is significant uncertainty around the continuation of funding streams at both state and federal level. Thus, an additional qualifier "v" has been added to the classification to identify services that do not have this stability of funding but whose exclusion would skew the information provided.

The service is within the boundaries of ACT-the inclusion of services that are within the boundaries of ACT is essential to have a clear picture of the local availability of resources.

The service provides direct care or support to clients - services that were only concerned with the co-ordination of other services or system improvement, without any type of direct contact with people with a lived experience of mental ill- health, were excluded

2.3 Atlas Development Process

Phase 1: There were five key steps involved in the creation of the Integrated Atlas of Multiple Sclerosis

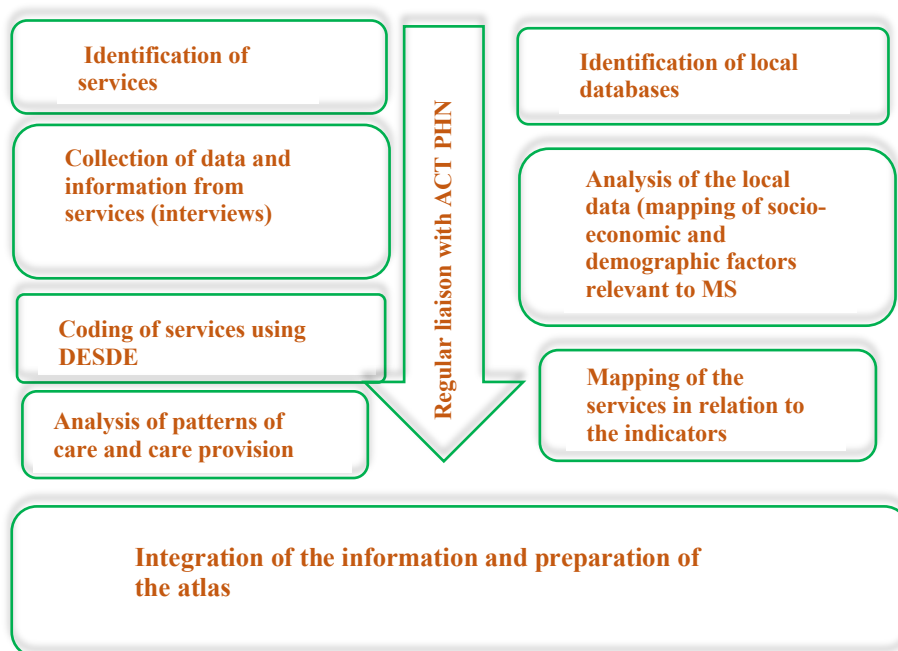


Figure 2-9 Atlas Development Process

Step 1 – Ethics and Governance Approval

The project obtained ethical approval from the HREC at Australian National University (ethics protocol 2019/456).

Step 2 - Data Collection

Initial search identifying eligible services: A preliminary list of organisations was drawn up to verify and pre-qualify where possible their appropriateness for inclusion in the Atlas. Online, telephone directory, and official service directories were searched, and people with MS and experts in the field were consulted to identify and list eligible services providing MS care in the ACT reference area (ACT Primary Health Network).

Webpage content extraction: information related to MS care services were extracted from webpages of identified service providers. The Integrated Atlas methodology provides the framework and template for the information that needed to be gathered. This included:

- basic service information (e.g. name, type of service, description of governance);
- location and geographical information about the service (e.g. service of reference, service area);
- service data (e.g. opening days and hours, staffing, management, economic information, legal system, user profile, number of clients, number of contacts or admissions, number of days in hospital or residential accommodation, number of available beds or places, links with other services); and
- additional information (e.g. name of coder, date, number of observations and problems with data collection).

Contacting organisations and arranging interviews: To collect further needed information, which was not available on websites, organisations were contacted to arrange interviews with their representatives. A determination was made on how best to contact each organisation for the purposes of gathering the information necessary to create the Atlas.

Interviewing representatives: representative of each identified organisation was interviewed through face-to-face meeting, via video conference, or through phone connection using the DESDE-LTC service inventory questionnaire. An open-ended question was asked at the end of the interview about the overall sufficiency of the MS care services in ACT. Following the initial interview, additional information was on occasion sought in order to support and verify classification decisions.

Meeting with focus group: An expert panel was established comprising five consumers (people with MS) and four health service researchers and collected data was presented to them to get meaningful feedback and external validation.

Step 3 – Codification

Information gathered in step one was entered into a master spreadsheet, analysed, and allocated a DESDE code (where the service delivery team meets the inclusion criteria). The work of each service delivery team was coded following the criteria defined in the DESDE-LTC, according to the MTC provided. Codes can be split into four different components and follow a standard format.

(i) Client age group: This represents the main target group for which the service is intended or currently accessed by, using capital letters.

GX All age groups

CX Child & Adolescents (e.g. 0-17)

CC Only children (e.g. 0-11)

CA Only adolescent (e.g. 12 – 17)

CY Adolescents and young adults (e.g. 12-25)

AX Adult (e.g. 18-65)

TA Transition from adolescent to adult (e.g. 16-25)

In this case only services for the general population (GX) and for Adults (AX) have been considered

(ii) ICD-10 Code: ICD-10 codes appear in brackets after the age group code but before DESDE-LTC code in order to describe the main diagnostic group covered by the service. For generalist neurology services, the code [G0-99] is used, which means that the service includes all types of neurological disorders rather than a specific disorder. For the sub-specialised services for MS the code [G35] is used. If the service is not targeting neurological ill-health, but other problems (for instance exercise, functional rehabilitation) ICD codes between Z56- Z65, and International Classification of Functioning (ICF) codes are used. Homelessness services use the code [Z59] and AOD services use [F10-F19]. If the client of the service is a child, but the professional is working with the family, or if the service is for carers, or the family, the code [e310] (immediate family or carers) from ICF is used.

The key diagnostic codes used in this Atlas are:

Table 2-2 ICD codes used in Integrated Atlas of MS Care of ACT Region

ICD Code	Diagnosis
G0-99	All types of neurological disorders
G35	Multiple Sclerosis
ICF	Used where the service is for any functional diagnosis
ICD	Used where there is not a specific diagnostic group for this service

(ii) DESDE-LTC code: The third component of the code is the core DESDE-LTC code which is the MTC. As explained above, the services were classified according to their main type of care. This care can be related to: a) Residential care (codes starting with R); b) Day care (codes starting with D); c) Outpatient care (codes starting with O); d) Accessibility to care (codes starting with A); e) Information for care (codes starting with I); and f) Self-help and voluntary care (codes starting with S).

(iv) Qualifiers: In some cases, a fourth component may be incorporated to facilitate a quick appraisal of those characteristics of the services which may be relevant to local policy. Not all available qualifiers have been relevant for use in this Atlas. The qualifiers used in this Atlas are:

Table 2-3 Qualifiers used in Integrated Atlas of multiple sclerosis care in ACT Region

Qualifier	Description
b	This qualifier describes episode-related care provision, usually provided for non-acute patients within a time limited plan (e.g. three months of brief rehabilitation). The 'b' qualifier is only assigned when at least 80% of the care provided in the facility is short- time limited and episode-related.

e	Technology based services; eg phone or online
g	This qualifier is applied to Outpatient services that provide predominantly group activities and do not meet the criteria for a Day Care service (Typically 80% of their activity is through the provision of groups);
h	This qualifier describes non-residential MTCs (outpatient, Day care) provided in an organisation registered as a hospital.
l	Liaison – use for liaison neurology services such as to oncology patients
m	Used where counselling is provided with management such as planning and care coordination.
q	This qualifier indicates that the main attribute of the MTC (e.g., mobility, intensity) is significantly higher/greater than for other care teams coded in the same MTC. For example, a “q” qualifier in a “closed “ MTC indicates that the security provided by the closed status of the care team is of a higher level than that which may be provided by other teams within the “closed”” group.
s	Specialised – for specific sub-group of population.
t	Tributary-refers to a satellite team: may be a second permanent location for the team or a team that travels to more than one location.
v	This qualifier is used when the code applied at the moment of the interview could vary significantly in the near future (from example from acute outpatient care to non- acute). This depends on the capacity of the service to provide the type of care described by the code due to fluctuations in the demand or the supply capacity. This variability in the pattern of service provision is independent of the time continuity of the service. For example, a continuous service can have a ‘v’ code due to a health reform while a care program limited to two years may show organisational stability during the period when it is funded.
u	This qualifier describes single-handed SCTs where care is typically delivered by a single health professional.

Example:

A Non-Acute Non-Mobile Outpatient unit in a hospital for adults with neurologic diseases including MS will receive the following code: AX [G00-G99] – O8.1h (2-10).

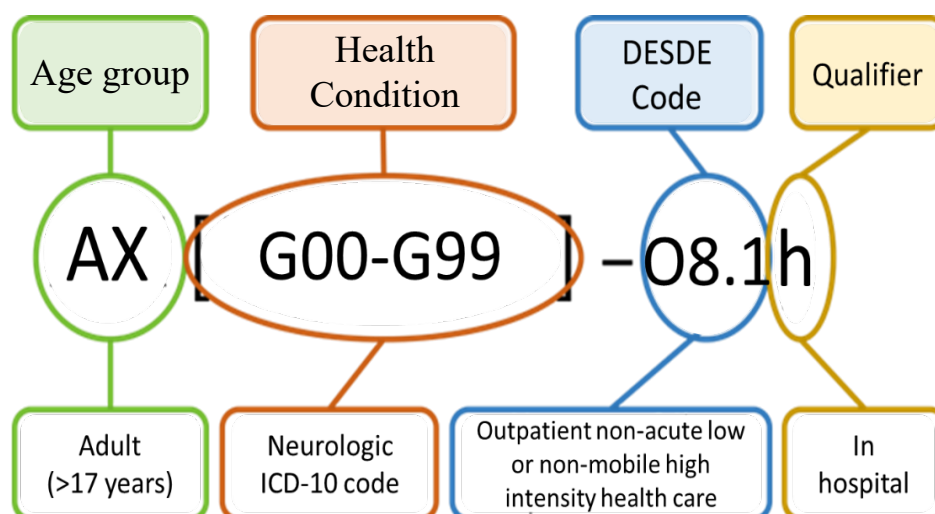


Figure 2-10 Code Components

Step 4 - Mapping the BSIC

The next step in the construction of the Atlas was to map the supply of MS services in relation to indicators of potential demand within the ACTPHN area. To achieve this step, the BSIC data was exported into a Geographic Information System (GIS) for visualisation.

Step 5 - Description of the Pattern of Care - Service Availability and Capacity

The availability of services was analysed according to their MTC, as well as their capacity.

Availability - defined as the presence, location and readiness for use of service delivery teams in a catchment area at a given time. A service is available when it is operable or useable upon demand to perform its designated or required function. The availability rate for the MTC is calculated per 100,000 of the target population.

Placement Capacity – this is the maximum number of beds in Residential care, and places in Day Care in a care delivery organisation or catchment area at a given time. Rates are also calculated per 100,000 of the target population.

Spider Diagrams – to understand the balance between the different types of care offered in an area, a radar chart tool, also referred to as a spider diagram, is used. The spider diagram is essentially a tool to visually depict the pattern of care in an area. Each of the 21 points on the radius of the diagram represents the number of MTC for a particular type of care per 100,000 population.

This analysis allows for comparisons of the availability and capacity rates with other areas, and to estimate whether the provision of services is adequate with regard to the population's needs.

Following the coding of the services and development of a draft Atlas (Phase 1, or Alpha version), the Atlas is presented to planners in order for them to review and adjust the data and codes presented where necessary (Phase 2, or Beta Version). A Version for Comments is then

prepared by the research team for release to stakeholders. Time is allowed for stakeholders to review the service data and coding, and provide any further comment. After further revision based on the received feedback, a Final Version is released to the planners. In the case of ACT, this Atlas represents the results of Phase 2 of the process (Beta Version): that is, the revision of the Alpha version by the planners, and subsequent adjustment to data and codes carried out by the team from Australian National University (ANU) (Figure 2-11).

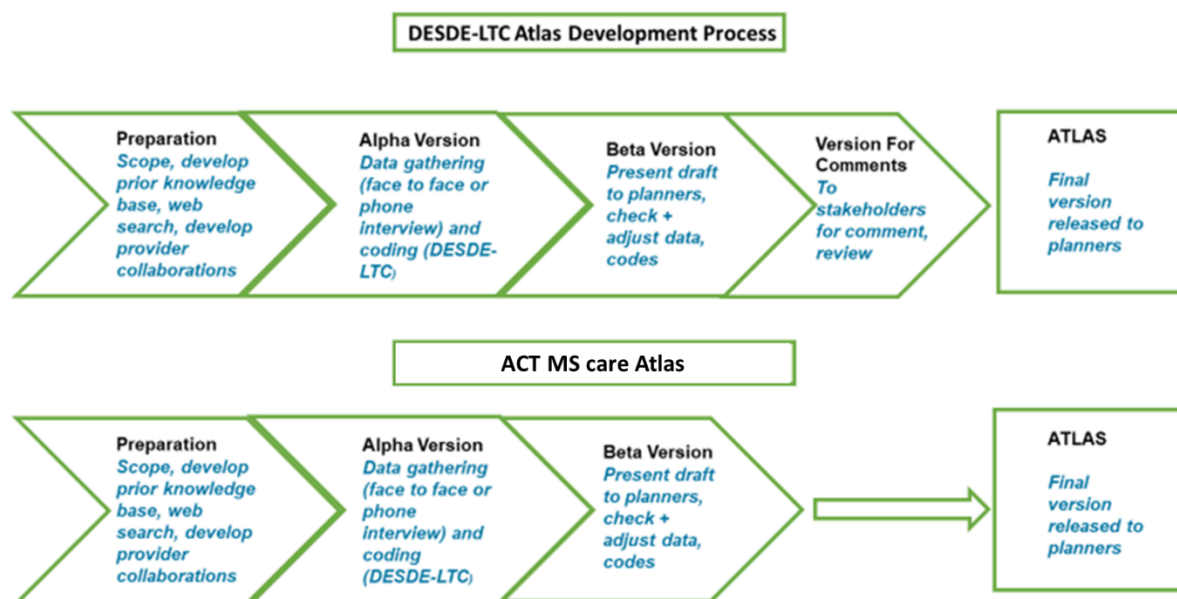


Figure 2-11 Development of the Integrated Atlas of MS Care in ACT PHN Region

2.4 Glossary

DESDE Code and Australian Health Care Descriptors

The following table lists the DESDE Main Types of Care shown in the radar or spider diagrams. The variations in terminology for similar types of care in different Australian jurisdictions is a feature of the Australian health care structures. Further complicating the analysis of Australian services, is that within the same state-wide program there may be a great deal of variation in the intensity of care provided. DESDE allows consistent comparisons based on the level of input of care and setting, not localised descriptors.

Table 2-4 Service group for pattern of care analysis

DESDE main Types of Care by Group and sub-type	Examples of Australian Health Care Descriptions
RESIDENTIAL	Accommodation, Hospital, Residential
R: ACUTE HOSPITAL	High Dependency Inpatient; Acute Care Unit; Intensive Care Unit; Assessment and Planning Unit
R: NON ACUTE HOSPITAL	Sub-acute; Community Care Units; Extended Care Health Rehabilitation Unit; Extended Treatment
R: ACUTE NON HOSPITAL	Hospital in the Home; Crisis homes (almost complete absent in Australia)
R: NON ACUTE NON HOSPITAL	Step up-Step Down (SUSD)
R: OTHER NON HOSPITAL	Hostel; Group Houses; Supported Accommodation; Crisis accommodation (e.g. Common Ground)
R: HIGH INTENSITY NON HOSPITAL	Housing Supported Care (e.g. HASI, HASP)
DAY CARE	Rehabilitation or Recovery
D: ACUTE HEALTH	Day Hospital services
D: NON ACUTE HEALTH	Some limited, specialist services such as neuro-rehabilitation services
D: WORK RELATED	Disability Enterprises; Social firms; Workers Coop
D: OTHER	Social Clubs; Club Houses
OUTPATIENT	Community or ambulatory care
O: ACUTE MOBILE HEALTH	Police & Acute Care Response; Crisis and Treatment Team; Assertive Community Treatment
O: ACUTE NON MOBILE HEALTH	Emergency Depts,
O: NON ACUTE MOBILE HEALTH	Mobile Support and Treatment Team; Community Outreach
O: NON ACUTE NON MOBILE HEALTH	Outpatients; Clinic services, Dual Diagnosis; Community Care/Continuing Care
O: NON ACUTE NON MOBILE NON HEALTH	Daily Living
O: NON ACUTE MOBILE NON HEALTH	Personal Helpers and Mentors; Psychosocial support

O: ACUTE NON MOBILE NON HEALTH	Family and sexual violence crisis services (e.g. Yarrow Place, Adelaide)
O: ACUTE MOBILE NON HEALTH	No services identified in Australia
ACCESSIBILITY	
A: OTHER	Advocacy services
A: CARE COORDINATION	Partners in Recovery; Care Navigator; Access and Support
A: EMPLOYMENT	Disability Employment Service or DES; some Partners in Recovery
A: HOUSING	No services identified in Australia
INFORMATION	
I: GUIDANCE & ASSESSMENT	Telephone triage; Intake & Assessment
I: INFORMATION	Information services

3 Description of Services Providing Support for People with Multiple Sclerosis in the ACT Region

3.1 Socio demographic and health related indicators of Australian Capital Territory Primary Health Area

Health indicators are tools designed to measure the health status of people and the functioning of health care system through the various factors that influence them (demographic, economic, and social) [41, 42]. These factors can be simple or composite factors. Composite synthetic indicators demonstrate a composite score by integrating individual variables using PCA/factor analysis. Researchers and policy planners could investigate the association between composite indices and health care outcomes. For example, social fragmentation is one kind of those synthetic indicators which represents how communities are homogenous (high level of cohesion) or fragmented and how it influences health status of residences in those highly fragmented communities. Therefore, health indicators provide the basic information for contextual analyses and understanding the process in health care ecosystem and they help policy makers to quantify context and design interventions health management.

The following maps show the distribution of some MS related health indicators in ACT.

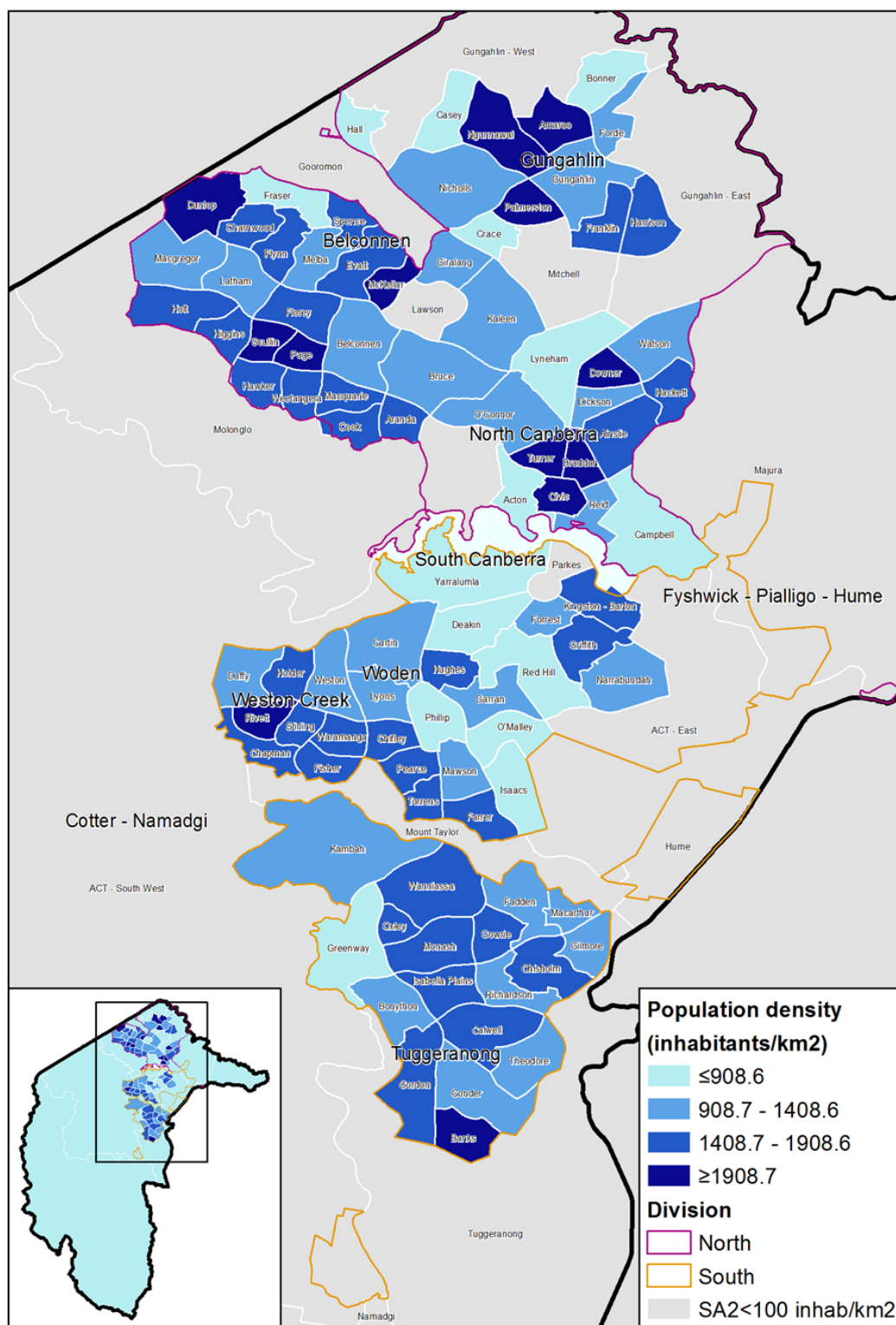


Figure 3-1 Population density in Australian Capital Territory

Source: 2011 Census of Population and Housing

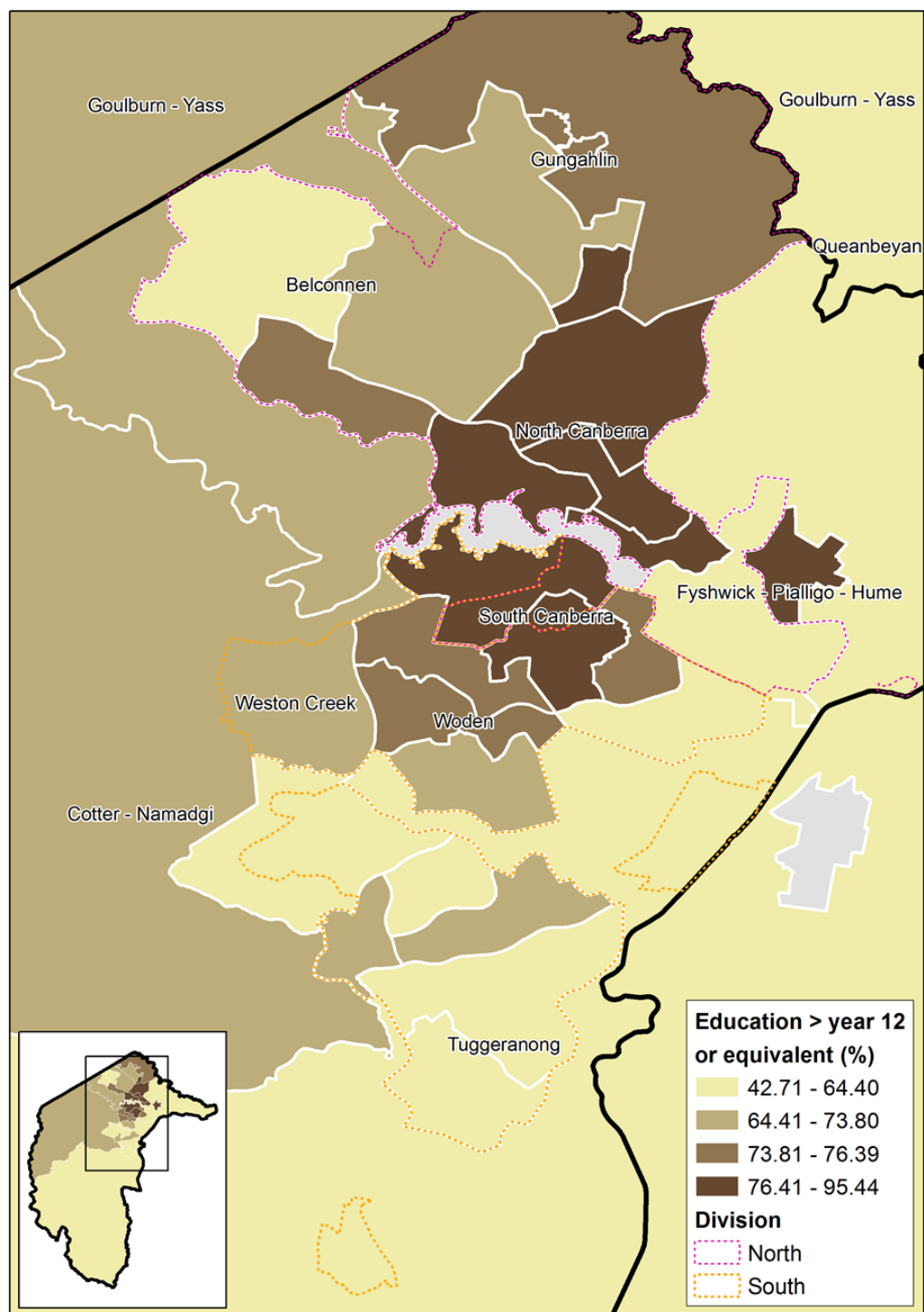


Figure 3-2 rate of people with education higher than 12 years or equivalent

Source: 2011 Census of Population and Housing

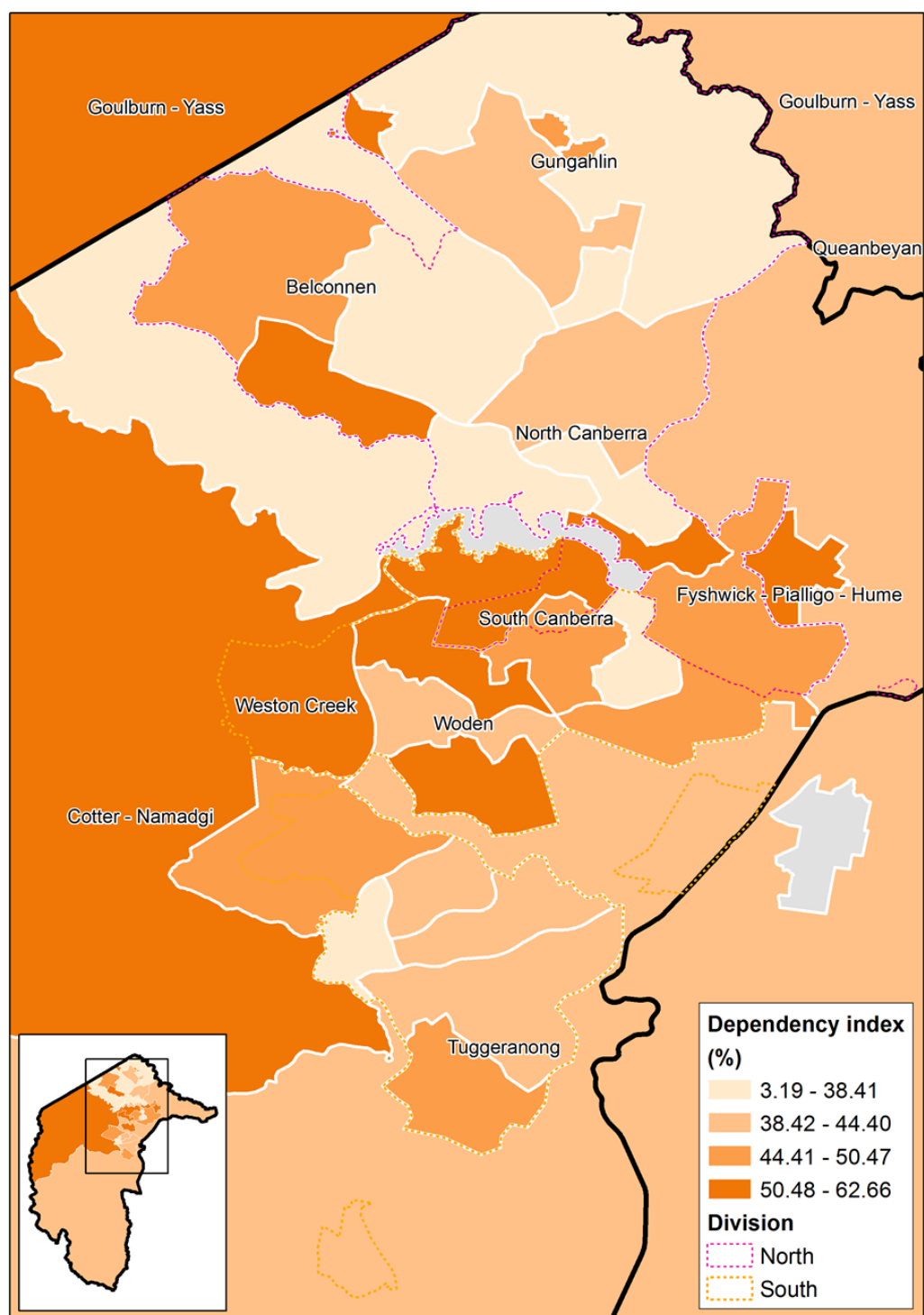


Figure 3-3 Dependency Index:

Source: 2011 Census of Population and Housing

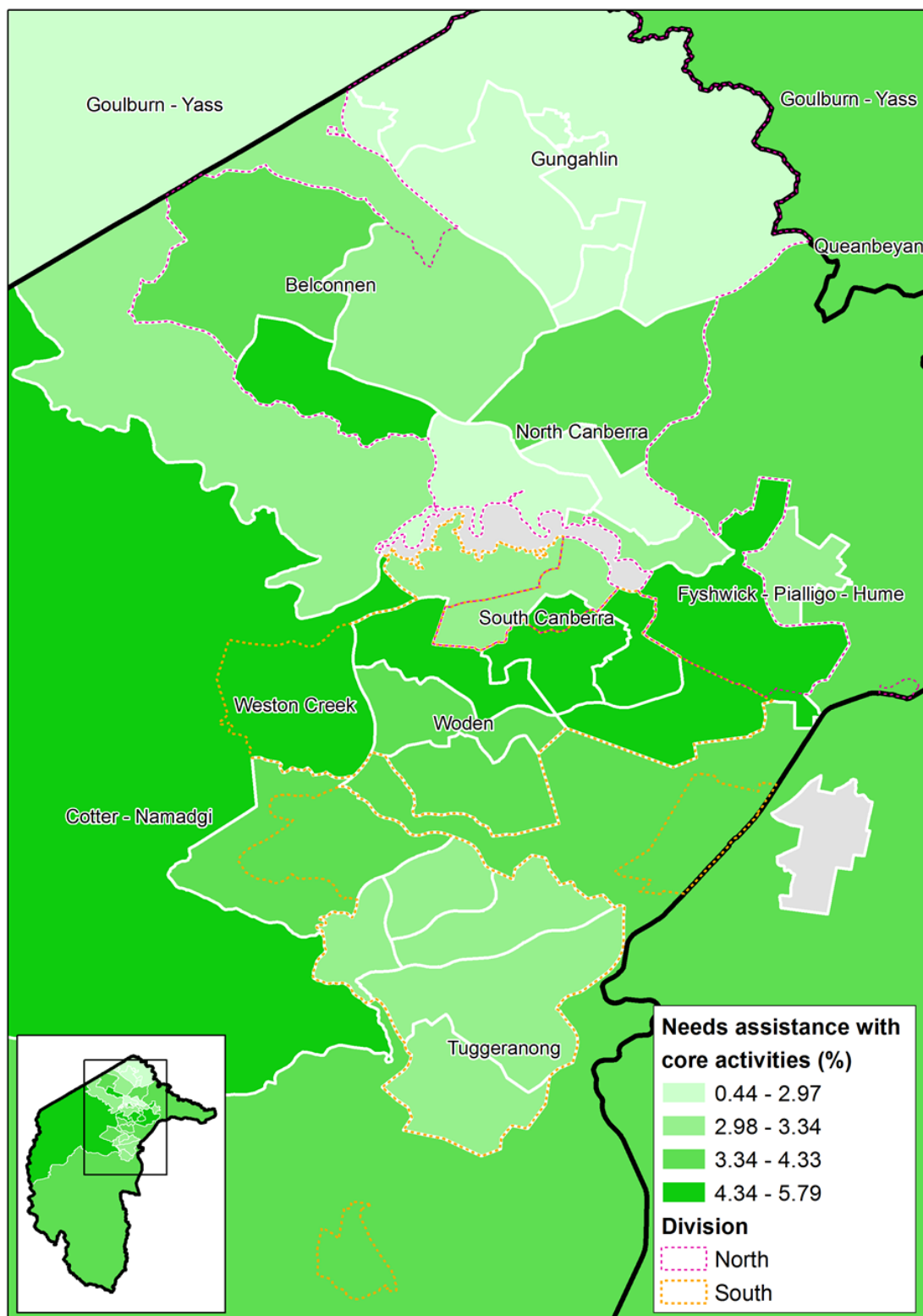


Figure 3-4 rate of people who need assistance with core activities

Source: 2011 Census of Population and Housing

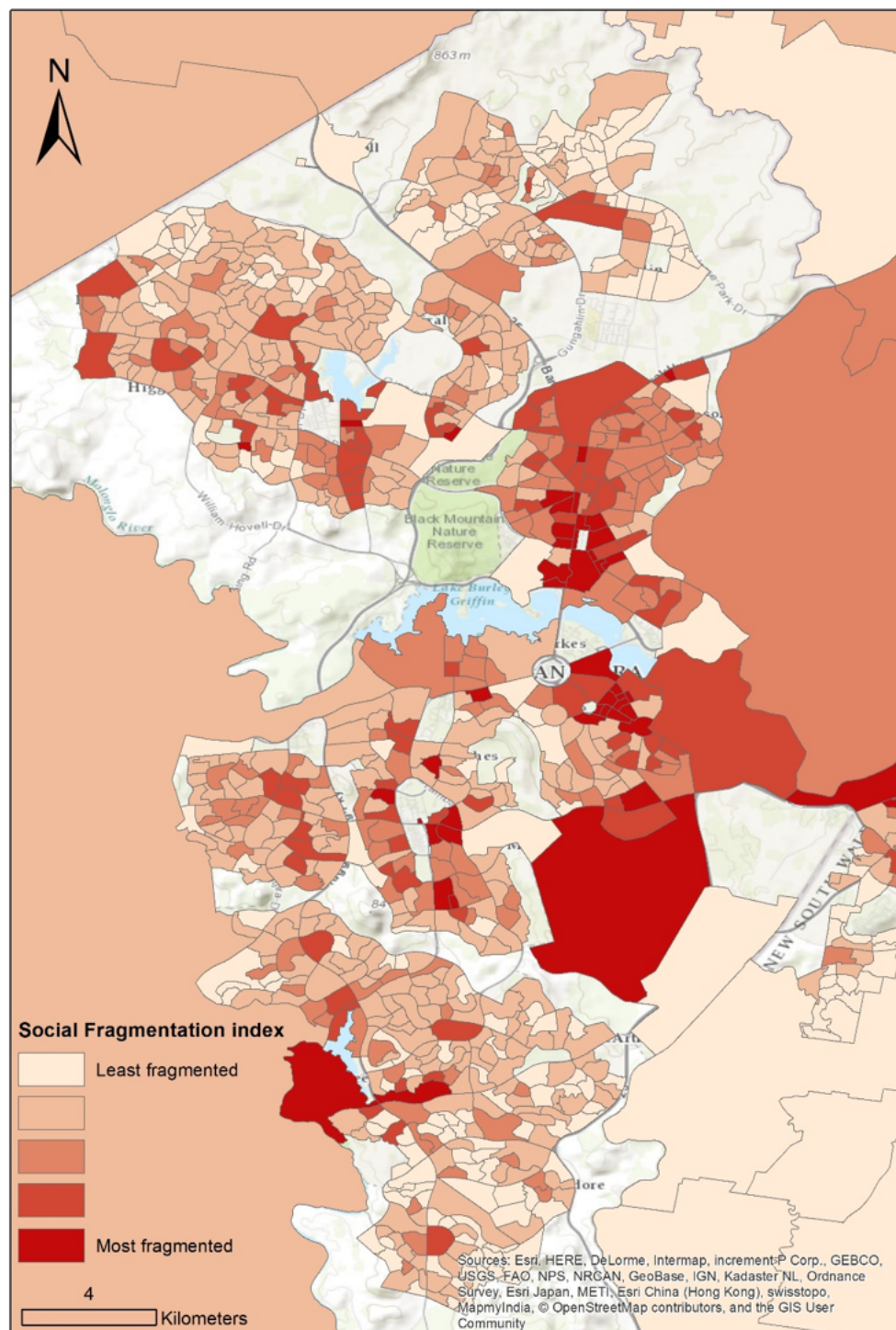


Figure 3-6 Social Fragmentation Index ACT 2018

Source: 2011 Census of Population and Housing

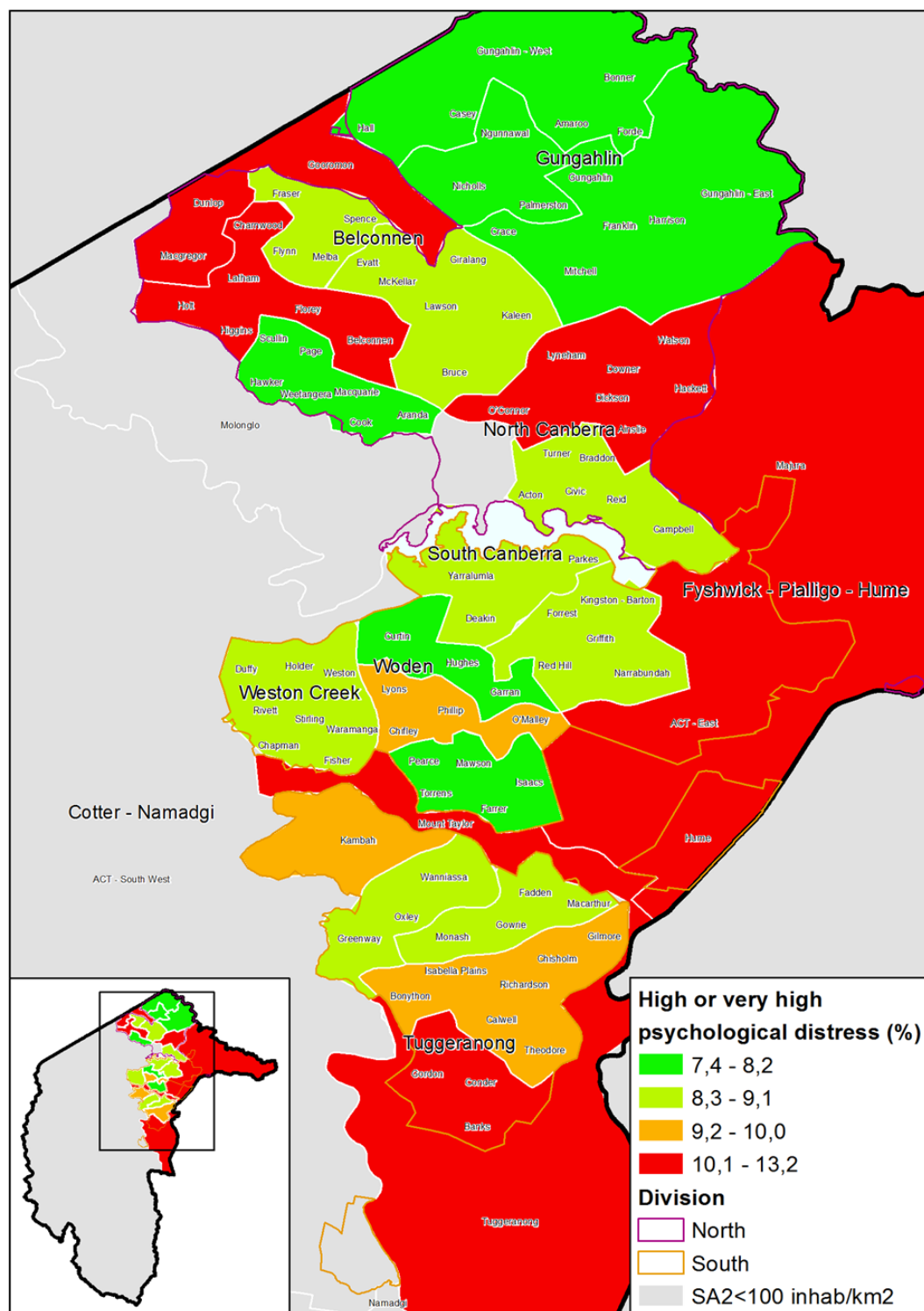


Figure 3-7 Areas of high or very high psychological distress ACT 2018

Source: PHIDU, 2011-2012.

3.2 General Description

Data on services providing care for people with multiple sclerosis in the ACT PHN region were collected from the 15th May to the 1st August 2021. Data were collected via face to face, zoom or telephone interviews. A total of 25 “care clusters”, provided by 16 organisations and comprising 25 Basic stable Inputs of Care (BSICs or individual care teams) providing 27 Main types of Care (MTCs) was identified. All the services, except one, were in the health sector of care and provided by health professionals, i.e., neurologists, nurses, physiotherapists and exercise therapists. Of the five categories of type of care, outpatient care provided a total care of 67%, residential care as the next most common type of care with 11%, day services with 11%, accessibility services with 7%, and self-help volunteer care provided 4% of MS care (Table 3-1). There were no services for the category of information. Four of the BSICs provide 5 MTCs sub-specialised MS services and 21 of them provide 23 MTCs specialised services to people with neurologic or musculoskeletal problems including people with MS.

3.3 Health vs. Social services

Except for one self-help and volunteer service, all the available care was provided by the health sector and core health professionals, i.e., neurologists, nurses, physiotherapists, and exercise therapists.

Table 3-1 Sub-speciality and speciality services provided to people with MS in ACT

Provider	Name	DESDE Code(s)*	Public/ private	FTE** For MS	Town / Suburb	Area of Coverage
Sub-speciality services (multiple sclerosis)						
MS Ltd	MS Ltd	AX[G35]-A4.2.1 e g v AX[G35]-A5.6 e	Public	7.0	Deakin	ACT
Canberra Hospital (ACT health)	MS Clinic	AX[G35]-O8.1 hw	Public	0.9	Garran	ACT- Southern NSW
MS nurse	MS Nurse	GX[G35][GZ3]-O10.1 es	Private	0.5	Sydney (NSW)	ACT- Southern NSW
NeuroSpace	NeuroSpace	AX[G35][ICF]-O8.1 b	Private	3.0	Phillip	ACT

People with MS taking control group	People with MS taking control group	Gx[G35]-S1.3ge	Public	NA	Deakin	ACT-Southern NSW
Speciality services (neurology)						
Canberra Hospital (ACT health)	Acute neurology ward	AX[G0-99][G49]-R2 AX[G0-99][G49]-o3.1	Public	NA	Garran	ACT-Southern NSW
Canberra Hospital (ACT health)	Day treatment Services	GX[ICD]-D0.1 h GX[ICD]-D4.1 h	Public	NA	Garran	ACT-Southern NSW
Canberra Hospital (ACT health)	Hospital in the home	GX[ICD]-O1.1	Public	NA	Garran	ACT-Southern NSW
Calvary Hospital	Acute ward Neurology unit	GX[G0-99]-R2	Public	NA	Bruce	ACT-Southern NSW
Calvary Hospital	Outpatient Neurology unit	AX[G0-99]-O9.1 hl	Public	NA	Bruce	ACT-Southern NSW
University of Canberra Hospital	Neurological rehabilitation ward	AX[G0-99][ICF]-R4	Public	NA	Bruce	ACT
University of Canberra Hospital	Day program	AX[ICD]-D4.1 h	Public	NA	Bruce	ACT
University of Canberra Hospital	Ambulatory team	AX[ICD]-O8.1 hg	Public	NA	Bruce	ACT
University of Canberra Hospital	Home based rehabilitation	AX[ICD]-O5.1.1 h	Public	NA	Bruce	ACT
University of Canberra Health Hub	UC Neurophysiotherapy	AX[G0-99][ICF]-O9.1 gb	Private	NA	Bruce	ACT
Canberra Dizziness Clinic (Neurologist #1)	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Holder	ACT

Neurologist #2	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Deakin	ACT
Neurologist #3	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Deakin	ACT
Neurologist #4	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Bruce	ACT
Neurologist #5	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Bruce	ACT
Neurologist #6	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Bruce	ACT
Neurologist #7	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Lyneham	ACT
Neurologist #8	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Barton	ACT
Neurologist #9	Private neurologic clinics	GX[G0-99]-O9.1 u	Private	NA	Fisher	ACT

*DESDE codes' description: GX; all age group, AX; adult (between 17 and 65 years old), G35; people diagnosed with multiple sclerosis, G0-99; people diagnosed with any neurologic diseases, ICF; International Classification of Functioning, Disability and Health, GZ3; the code for only medication management, A 4.2.1; Accessibility to care-high intensity case coordination, A5.6; Accessibility to care- advocacy, D0.1;high intensity episodic acute day care, D4.1;health intensity health related non-acute day care, O1.1;health related acute outreach outpatient care, o3.1; centre-based health related acute outpatient care (low capital because it is not the main service), O5.1.1;health related high intensity outreach non-acute outpatient care for 3 to 6 days per week, O8.1;high intensity health related centre-based non-acute outpatient care, O9.1;health related medium intensity centre-based non-acute outpatient care, O10.1; low intensity health related centre-based non-acute outpatient care, R2;medium intensity acute hospital care, R4;time limited non-acute residential care with 24 hours physician cover, S1.3;Self-help and Volunteer care- outpatient care by non-professional staff.

Qualifiers: b; when at least 80% of the care provided in the facility is short, time limited, and episode g; services with group activities, e; technology based services such as phone or online services, h; non-residential care that provided in a hospital, l; liaison services provided to people admitted to other speciality services, s; providing specialised care to specific sub-group of the clients, u; care is typically delivered by a single health professional, v; the type of provided care could vary over time due to different reason such as financial reasons or system reforming, w; the service is wholly limited to the described activity with no variation. For more detail see Appendix A.

**FTE; number of fulltime equivalent health professionals allocated to people with MS

Table 3-2 DESDE codes according to types of service

Group	DESDE codes
R: ACUTE HOSPITAL	R2
R: NON ACUTE HOSPITAL	R4
R: ACUTE NON HOSPITAL	
R: NON ACUTE NON HOSPITAL	
R: OTHER NON HOSPITAL	
R: HIGH INTENSITY NON HOSPITAL	
D: ACUTE HEALTH	D0.1
D: NON ACUTE HEALTH	D4.1
D: WORK RELATED	
D: OTHER	
O: ACUTE MOBILE HEALTH	O1.1
O: ACUTE NON MOBILE HEALTH	O5.1.1, o3.1
O: NON ACUTE MOBILE HEALTH	
O: NON ACUTE NON MOBILE HEALTH	O8.1, O9.1, O10.1
O: NON ACUTE NON MOBILE NON HEALTH	
O: NON ACUTE MOBILE NON HEALTH	
O: ACUTE NON MOBILE NON HEALTH	
O: ACUTE MOBILE NON HEALTH	
O: OTHER NON ACUTE	
A: OTHER	A5.6
A: CARE COORDINATION	A4.2.1
A: EMPLOYMENT	
A: HOUSING	

3.4 Workforce Capacity

The workforce capacity specifically allocated to people with MS was limited. There were only 0.4 FTE neurologist, 0.5 FTE registrar, 2.5 FTE nurses, 3 FTE physiotherapists, 2 FTE support coordinators, and 1 FTE support worker available in services providing speciality care to people with MS. However, most service providers used their workforces, providing services to a range of neurological disorders, of which MS diagnosis was only one of them. Additionally, neurologists and physiotherapists comprised the majority of this workforce.

3.5 Description of the pattern of care

To understand the balance between the different types of care offered in an area, a radar tool is used to visually depict the mix of service types (pattern of care) in the area. Each of the 24 points on the radius of the diagram represents the number of MTC for a particular group of care types per 100,000 adults.

3.5.1 Subspecialty vs. Speciality services

Five care teams provided six sub-specialised services specifically for people with MS, while 19 care teams provided 21 specialised services which were for people with neurological problems in general, including MS (Table 3-1).

Figure 3-8 shows the pattern of MS care (MTCs per 100,000 of the population) in the ACT region in 2021. The brown line shows the pattern of sub-speciality services specific to people with MS and the blue line shows speciality services that people with MS may use but it is not limited to them and all people with neurologic and musculoskeletal disorders may also use them. As the figure shows, sub-speciality services are limited to health-related non-acute outpatient services and accessibility services, whereas acute outpatient, day care services and residential hospital services are provided by speciality services.

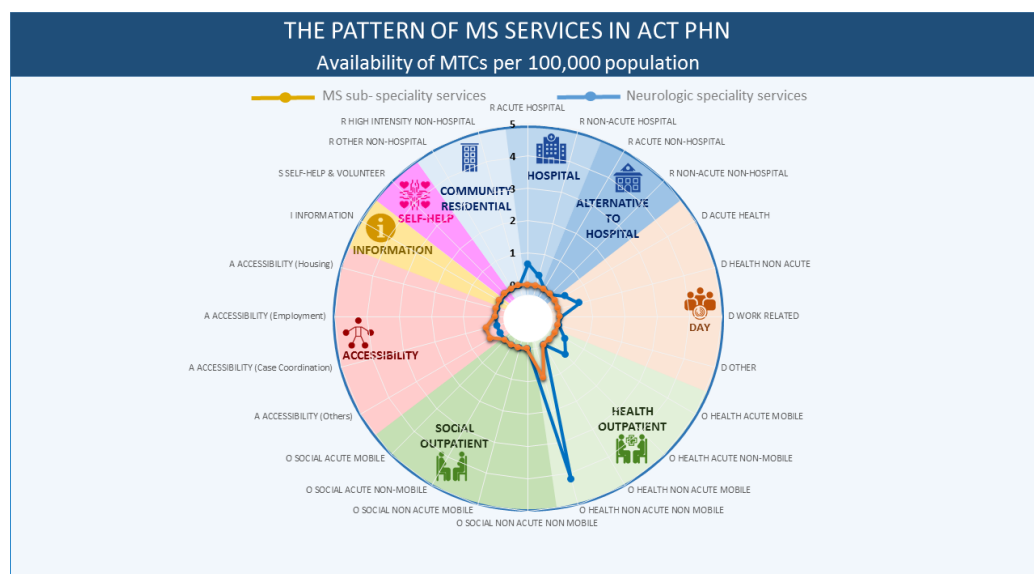


Figure 3-8 Availability of specific MS services (brown) and neurologic MS services (blue) MTCs per 100,000 adult population

Overall, the highest rate of services was in non-acute non-mobile outpatient health care, followed by non-acute mobile social type outpatient care, with low rates of service provision in acute health-related outpatient care and accessibility services, and very low rates of service provision in day services and alternatives to hospital care.

3.5.2 Public vs. private services

Of the 16 organisations identified, five (comprising nine BSICs and 11 MTCs) provide free of charge public services, while for the other 11 organisations (comprising 15 BSICs and 16 MTCs), clients need to provide private insurance, have a special governmental funding aid (e.g. DVA or National Disability Insurance Scheme) or pay out of pocket. As figure 3-9 shows, the private sector only provides outpatient centre-based services (the blue line), whereas the public sector provides a wider range of services (the green line) from residential to self-help volunteer services. However, as detailed in table 1, private services were mostly provided by neurologists in their offices.

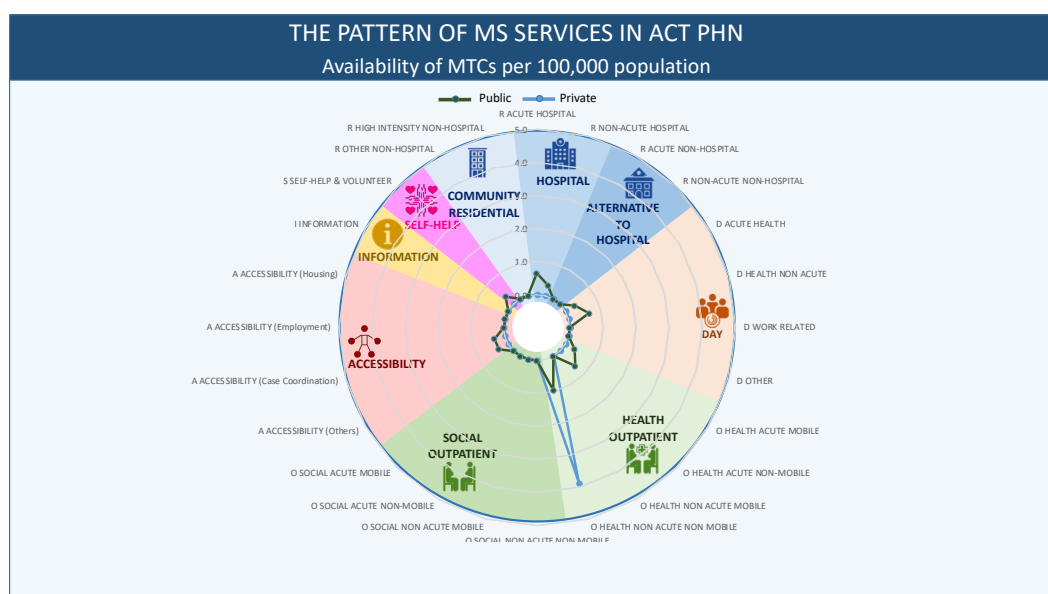


Figure 3-9 Availability of public services (green) and private (blue) services MTCs per 100,000 adult population

3.6 Capacity of the System

Less than 550 people with MS live in ACT [43, 44]. Specialist medical services are mostly provided by the Canberra Hospital. MS Ltd is the main organisation supporting people with

MS for access to social and disability services. There is a gap in medical services, and thus some people with MS choose to go to NSW for medical MS speciality services.

At the end of interviews by an open question service managers were invited to provide information or comment about MS service provision in ACT (table 3-3). Some issues raised echoed those expressed by service managers in our interviews with mental health service providers in ACT [10].

Table 3-3 comments from service providers regarding gaps in MS services in ACT

Interview Themes	Comments
Challenges for MS workforce	Difficult to recruit neurologists and MS nurses and loss of current staff (1 provider). The role of pharmaceutical companies in employing nurses to provide medication could be associated with conflict of interest (one provider).
Service access and delivery	Access to specialised MS services in ACT is patchy, uncoordinated or poorly coordinated, particularly in the medical aspect of it. According to standards provided by the “Brain Health’ organisation, Canberra is in very low standard (one provider). A lot of people with MS in ACT choose to go to NSW for medical services (two providers). There is a gap in allied health services such as infusion services, sexual counselling and so on (one provider). There is no actual MS clinic in ACT (one provider)

4 Discussion

4.1 Overview and the gaps

The main aim of this project was to investigate the pattern of available MS care services in the Australian Capital Territory. This included all speciality and sub-speciality services, public and private care as well as health and social care. The findings revealed that services specific to MS (sub-speciality services) were few and predominantly health related. Social and coordination services were missing. A limited variety of professionals, comprising 11.5 fulltime equivalent neurologist, registrar, nurse professionals, case managers and social workers, and rehabilitation professionals, provided 11 of the 24 clusters of type of care for people with MS in ACT. However, these limited resources were also fragmented and poorly coordinated. Overall, the service provision in ACT was lower than the standard care provision recommended for people with MS. This is important because this situation provides no choices for people with MS except to use generic neurology services, which mostly require out of pocket payment, or to seek MS specific services in the nearby states (e.g., the New South Wales).

MS has become a subspecialty within neurology, as it is becoming difficult for general neurologists to keep pace with the increasing complexity of the diagnostic and treatment strategies for this condition [45]. In this context the patterns of care provision and the profile of care teams for treating MS have been described by the US Framework Taskforce which comprised 13 clinician-experts from the Consortium of Multiple Sclerosis Centers [46, 47]. According to this taskforce, the core team of the MS Care Unit should include neurologists sub-specialised in MS, nursing professionals, physiatrist, mental health professionals, social worker, urologist, rehabilitation professionals, physician assistant, orthopaedist, patient advocate, primary care clinician, and pharmacist. This core team should collaborate in an expanded network with a group of different specialists such as dietitian, speech therapist, and continence specialist [45]. Moreover, social related care should also be included in the MS care system [48].

The need for an integrated/person-centred model of care has also been identified as a major global priority for chronic care by the World Health Organisation [49]. The application of the person-centred care model in Australia was revised in a report to the National Commission of

Safety and Quality in 2016 [50]. In the case of MS, the need for an integrated-person centred approach has been accentuated by changes in the pattern of care delivery mainly due to the major improvement of treatment during the last two decades. Many disease-modifying therapies are available that can reduce symptoms, relapse frequency, and limitations in functioning. Most of these treatments modify immunity and are administered variously via oral, intramuscular, subcutaneous, and intravenous routes. These treatments also carry side effects, including pervasive flu-like symptoms as a direct consequence of treatment (type 1 interferons), heightened susceptibility to infections as a result of immune suppression, and drug hypersensitivity and injection site reactions, which can impact people's willingness to use them [48]. In any case the treatment improvement has resulted in a dramatic reduction of the rates and reasons for hospitalisation and acute care in MS [51]. This change has had a major impact on the demand for personalised care and the need for better community care alternatives. However, the shift in the patterns of treatment for MS was not accompanied with a similar shift in the design and planning of provision.

The deinstitutionalisation of mental health care and shift to community care in the 1960's-1980's was also related to a major improvement in treatment alternatives during this period. However, this shift opened an intensive debate on the needs, planning, and transfer of funding from hospital to community care in mental health and related cost of illness and cost-effectiveness studies [52, 53]. However, the shift in patterns of treatment for MS has been silent, and an equivalent planning of community non-acute care and tentative reallocation of resources from acute hospital care to community care has not happened. Community care is less expensive but more complex and fragmented than hospital care. This creates new types of inefficiency and difficulties in case management and navigation of service availability, and creates new challenges both for patients and for professionals. A recent meta-synthesis analysis of the experiences and approaches to self-management of people with MS identified five experiential themes: (a) the quest for knowledge, expertise and understanding, (b) uncertain trajectories (c) loss of valued roles and activities, and the threat of a changing identity, (d) managing fatigue and its impacts on life and relationships, and (f) adapting to life with MS [48]. Surprisingly, local availability of sufficient and equitable care was not an issue for this population group.

There could be several explanations for the lack of awareness of issues related to service availability identified in this study. One of them could be the relative lack of models of care for MS, the comparative analysis of service provision across different jurisdictions. The literature on integrated models of care for MS is quite recent. Another explanatory factor could be the heterogeneity of clinical manifestations and subgrouping of patients and the large differences in the course of the disease. People with MS need a multidisciplinary comprehensive and integrated care approach, but the specific type of care needed may vary between individual MS patients, and thus the lack of availability of some types of service may draw less attention than that of others.

MS services in ACT are provided at four levels: 1) sub-speciality neurology services dedicated specifically to people with MS; 2) neurologic speciality services that people with MS can use but the target population is not limited to people with MS; 3) generic services aimed for the general population or other broader groups such as primary care, physiotherapy, or disability care; and 4) other ancillary and supply services (Fig 2.8) The Atlas of MS care provision in ACT is focused on subspecialised and specialised care.

Sub-speciality services are limited to those provided by the MS clinic, and accessibility services provided by MS Ltd., which mainly supports and coordinates connection between people with MS and allied health professionals and other governmental support systems. Services at speciality level are mainly health related (medical), and consist of residential non-acute hospital services, day care, and health related outpatient services.

According to MS Ltd.'s expert opinion, the capacity of medical services in ACT is not enough for people with MS, and most patients prefer to use services available in New South Wales. Consistent with MS Ltd.'s comment, the director of the neurology unit of Canberra Hospital, which provides the only available residential care, believes that their organisation needs at least two more neurologists and a nurse to fulfil the current demand.

Taking into account the gaps in MS services identified in the atlas, and the importance of a multidisciplinary care approach supportive of individual disparity in need for services, concerns may arise about the practicality of having a comprehensive MS care system in ACT with the relatively small number of people with MS. A possible solution could be a well

organised connection between health system services in ACT and nearby interstate health systems, especially with metropolitan's health systems.

4.2 Comparing MS care with mental health care in ACT

Comparing the pattern of MS services with mental health services (for adults) in ACT reveals that there is greater variation in the type of services providing support for people with mental health issues than for people with MS (figure 3-8 and 3-10). There are no community residential and alternatives to hospital residential services, self-help volunteer, information, and social outpatient services available for people with MS in ACT, compared with the availability of all of these types of care to people with mental health issues.. However, given that the number of people with MS is relatively fewer than that of people with mental health issues, ACT has a proportionately greater availability of health-related outpatient care, hospital residential and accessibility services for people with MS than is the case for people with mental health needs.

Another important difference between the provision of MS and mental health services is the stability of services in MS care. The service provided by some mental health services had potential to vary significantly in weeks after the interview due, for example, to fluctuations in demand, or to health system reform, or to a change in the whole financing system or social care, or to the development of a new disability scheme such as the NDIS. These services have been specified by the qualifier “v”. Only one of the services interviewed for people with MS demonstrated this type of instability in the service they provided.

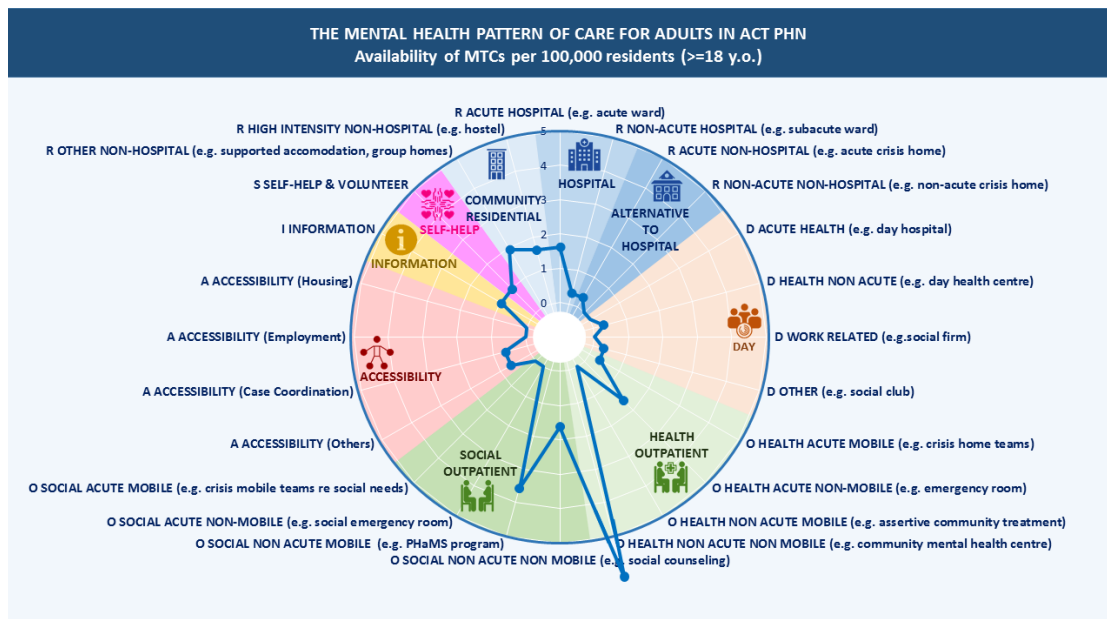


Figure 3-10 Availability of mental health MTCs per 100,000 adult population. From the integrated mental health atlas of the ACT primary health network region 2020

4.3 Conclusion

The MS care system in ACT is quite insufficient when compared to the international standards and recommendations mentioned above. This insufficiency in the system may leave no choice for people with MS but to use non-specific generic neurologic services, or to seek MS specific services in other jurisdictions. Indeed, in interviews with professionals and meeting with consumers, it repeatedly came up that many people with MS opt to go to nearby states (mostly New South Wales) for MS specific care. However, it is important to consider that the lack of local availability of sufficient and equitable care may be less problematic if the services that are provided incorporate experiential and social outcomes of the disease and the preservation of valued social roles into case management and clinical planning [48]. Therefore, even if the establishment of further services is not practical due to insufficient demand, coordination of the available local and adjacent services could improve the efficacy of the whole system.

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