

# Registry of Older South Australians

## Stage 1 Historical Cohort Report



**Permanent Residential Aged Care Facility Operators and Locations:**

- STATE GOVERNMENT
- CHARITABLE
- COMMUNITY-BASED
- RELIGIOUS
- PRIVATE INCORPORATED BODY
- LOCAL GOVERNMENT

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# I. Executive Summary

The Registry of Older South Australians (ROSA) is the product of the Healthy Ageing Research Consortium, a cross-sectoral partnership of researchers, clinicians, aged care providers and consumer advocacy groups. ROSA is a unique data resource that will support evidence-driven decision-making to improve the lives of all South Australians accessing aged care services.

ROSA was designed to monitor the health, service utilisation, medication use, mortality, and other outcomes of people receiving aged care services in South Australia. ROSA's efficient model leverages existing information and was designed to roll out in 3 stages due to data availability and data access approvals. These are:

- **Stage 1 (1997-2014) has historical national aged care data (from the National Aged Care Data Clearinghouse; NACDC) and mortality (from the National Death Index; NDI) obtained from the Australian Institute of Health and Welfare (AIHW). Stage 1 data was received by the ROSA Research Team in January 2018 and is the subject of this report.**
- Stage 2 (2002-2016) will expand the Stage 1 reporting period and link its data to additional national data sources, including the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS). ROSA anticipates receiving Stage 2 data in August 2018.
- Stage 3 (April 2018-onwards) is the prospective ROSA, which monitors all South Australians who had an Aged Care Assessment Team (ACAT) assessment from April 2018 onwards. Stage 3 links national and state-based data, including data from the: NACDC, NDI, MBS, PBS, Integrated South Australian Activity Collection (ISAAC), Emergency Department Data Collection (EDDC), and SA Ambulance Services (SAAS). These data are expected to be available for analyses in January 2019.

We are excited to present ROSA's Stage 1 Report based on national aged care data from 2003-2014 received from the AIHW. Our report provides an overview of the key characteristics of the historical cohort of **955,439 people** who had a first time ACAT assessment across Australia during this period.

This report is meant to introduce ROSA, its population, volume, main captured data elements, and also the capabilities of the ROSA team. We show in this report just a few examples of the characteristics that influence the outcomes of older Australians accessing aged care across our nation based on our review of these data. Over the coming months, the ROSA team will conduct in-depth analyses using Stage 1 data to achieve ROSA's aims to start monitoring the quality of ageing over time and to guide evidence-driven decision making for quality, coordinated, efficient and age-friendly services and practices.

Professor Steve Wesselingh

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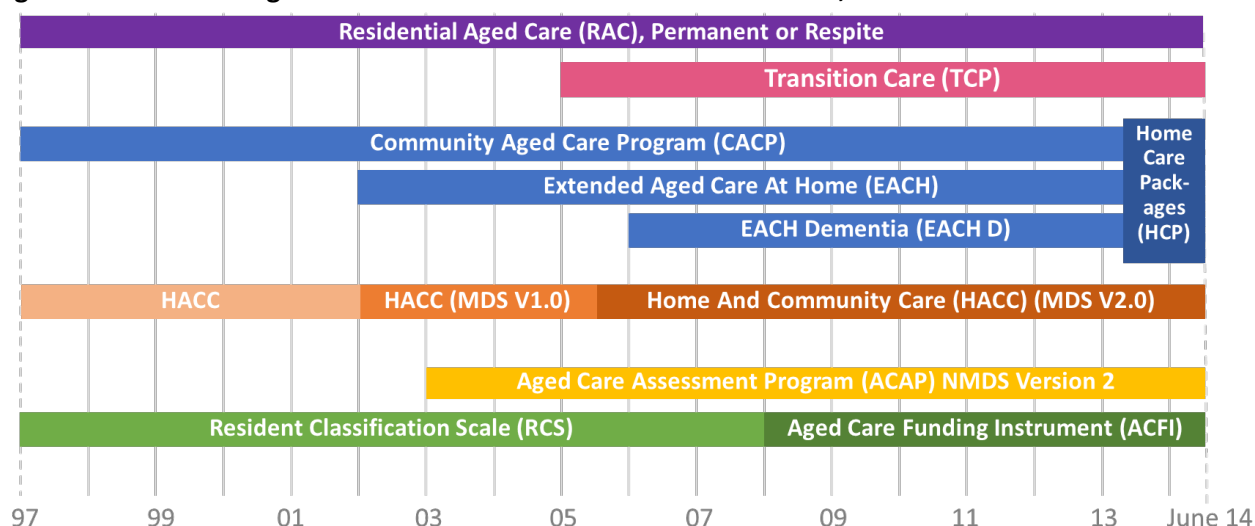
ROSA Executive Committee

## II. Data Received from the Australian Institute of Health and Welfare (AIHW)

We received 9 datasets from the AIHW for Stage 1 of ROSA. These data included the national cohort of people who were assessed for and/or received residential aged care services (Permanent and Respite), Home Care Packages and Transition Care services, and those that only ever received Home and Community Care (HACC). These data included **2.9 million unique people with 1.8 million ACATs, who had 1 million Aged Care Funding Instrument assessments (ACFIs), 1.9 million Residential Classification Scale (RCS) assessments, and received 6.3 million services.**

Aged care service preferences, laws, and the complexity of the aged care case mix have changed dramatically over the last 20 years. The timeline shown in **Figure 1** provides an overview of the key services and programs relevant to this Stage 1 report. Detail on each dataset received is included in **Table 1** and in ROSA’s Stage 1 Data Dictionary (Appendix G).

**Figure 1. Timeline of Aged Care Services and Assessments in Australia, 1997-June 2014**



**Table 1. Datasets Received from AIHW for Stage 1 ROSA.**

Name	Date range	Individual Records	N Variables
<i>Demographics</i>	1997-2014	2,938,132	6
<i>Pathways in Aged Care</i>	1997-2014	2,963,513	222
<i>Aged Care Assessment Program</i>	2003-2014	1,860,912	138
<i>Residential Classification Scale</i>	1997-2008	1,901,774	7
<i>Aged Care Funding Instrument</i>	2008-2014	1,037,622	13
<i>Home Care Package Information</i>	1997-2014	337,289	15
<i>Residential Care Information</i>	1997- 2014	2,109,770	14
<i>Home and Community Care</i>	2001-2005 (v1.0)	1,290,177	51
	2005-2014 (v2.0)	2,586,132	65

## *Dataset notes/descriptions*

### **DEMOGRAPHICS**

This file was created by the AIHW to describe the basic information (i.e. age, language, sex, indigenous status) on all recipients of aged care services.

### **PATHWAYS IN AGED CARE (PIAC)**

This file was created by the AIHW Pathways in Aged Care (PIAC) study, which linked all services provided to people in the aged care sector. This file maps the temporal sequence of aged care assessments/services for someone. This file also contains the mortality status of the people in the aged care datasets, which was obtained from the **National Death Index**.

### **AGED CARE ASSESSMENT PROGRAM (ACAP)**

Introduced in 2003 the ACAP is a cooperative working arrangement between the Commonwealth and state and territory governments to operate ACATs across Australia. The core objective of the ACAP is to comprehensively assess the care needs of frail older people and to assist them to gain access to the most appropriate types of care, including approval for Commonwealth Government subsidised care services.

### **RESIDENTIAL CLASSIFICATION SCALE (RCS)**

RCS was the classification used to discriminate care needs among residents of residential aged care facilities prior to (1997-2008) the Aged Care Funding Instrument (ACFI).

### **AGED CARE FUNDING INSTRUMENT (ACFI)**

The ACFI was introduced in 2008 as the means of allocating Australian Government subsidies to residential aged care providers. It focuses on the main areas that discriminate care needs among residents.

### **HOME CARE PACKAGE INFORMATION**

This table contains basic information on the home care package that recipients received. It includes information on the entry level for the care package, departure information, and organisation type.

### **RESIDENTIAL CARE INFORMATION**

This table contains basic information on the residents of residential aged care. It includes information on the organisation type, departure information, type of packages, and if transitional care, the functional capacity assessments of care recipients.

### **HOME AND COMMUNITY CARE (HACC)**

The HACC Minimum Data Set is a collection of data about HACC clients (such as their age and living arrangements) and the amount and types of assistance being provided to them through the Commonwealth HACC Program. The HACC Program provides funding for services which support frail older people and their carers, who live in the community and whose capacity for independent living is at risk of premature or inappropriate admission to long term residential care.

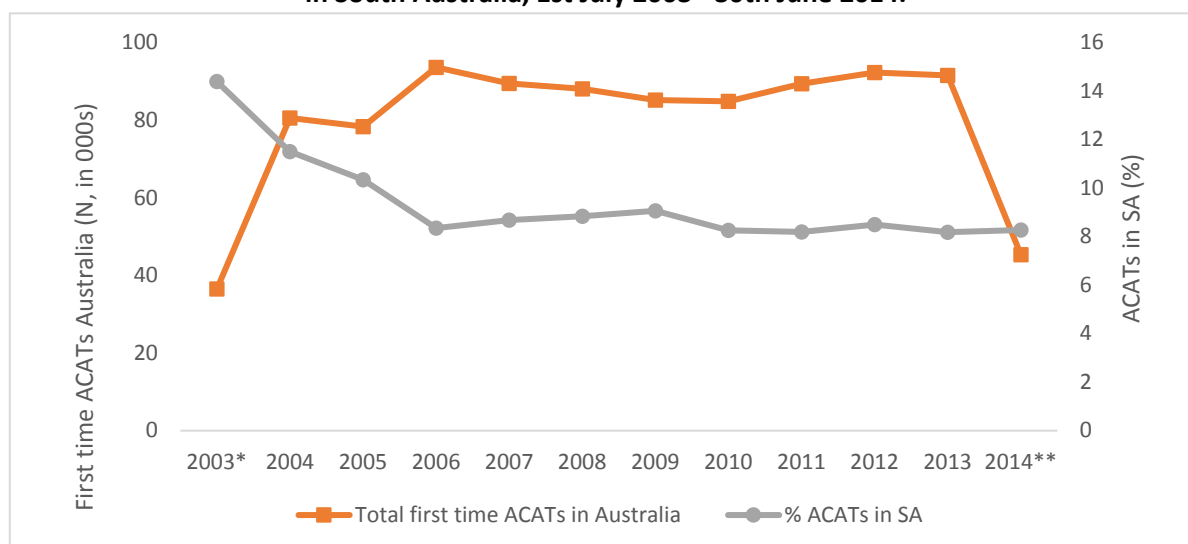
### III. Select Report on National Stage 1 Historical Cohort from the Registry of Older South Australians (ROSA), 1st July 2003 – 30th June 2014

#### A. VOLUME OF AGED CARE ASSESSMENTS

Our Stage 1 report population is Australians (aged 65 years or older or 50 years or older and of Aboriginal or Torres Strait Islander descent) who were assessed for aged care services eligibility between 1<sup>st</sup> July 2003 and 30<sup>th</sup> June 2014. During this timeframe there were on average 88,000 first time *Comprehensive Assessments* by ACATs each year nationally (**Figure 2**). Within this cohort, 87,183 ACATs were conducted in South Australia, which constitutes 9% of the national total of 955,439. While the Stage 1 report focuses on the national data, **key data on the South Australian cohort can be found in Appendix E.**

Assessment level data for ACAP were collected under the ACAP Minimum Data Set Version 2 (MDS V2) from 1 July 2003 and 30 June 2014. However, the implementation of ACAP MDS V2 data collection was staggered across the country – it was completed during 2003–04 for all jurisdictions except for New South Wales and Queensland which were completed by the end of 2005–06. This staggered collection is reflected by the apparent increase in volume of first time ACATs from 2003-2006 in **Figure 2**. The steep increase from 2003-2004 and decrease from 2013-2014 is due to only capturing 6 months rather than 12 months of data in 2003 and 2014.

**Figure 2. Volume of People Having First Time ACATs Nationally and % of Total ACATs undertaken in South Australia, 1st July 2003 - 30th June 2014.**



\*Half year from 01 July 2003, \*\*Half year to 30 June 2014.

There are 955,439 ACATs included in our report. Of these 27% were conducted in a hospital or inpatient setting and 73% included an assessor with nursing training as part of the team. The most commonly approved services after an ACAT were Respite (62%), Permanent Residential Aged Care (51%), and Home Care Package (26%) services. At least 2.6% of the people who had an ACAT were not approved for any services. See **Table 2** for details.

**Table 2. ACATs Settings, Assessors, and Approval Details.**

		N	%
<b>Total First Time ACATs</b>		955,439	100.0
<b>First Face-to-Face Contact Setting</b>	<i>Other</i>	588,830	61.6
	<i>Hospital (acute care)</i>	187,150	19.6
	<i>Missing/not stated</i>	92,797	9.7
	<i>Other inpatient setting</i>	74,911	7.8
	<i>Residential aged care service</i>	11,751	1.2
<b>Assessor Training<sup>1</sup></b>	<i>Medical practitioners</i>	444,051	46.5
	<i>Nursing professionals</i>	697,044	73.0
	<i>Health professionals</i>	465,794	48.8
	<i>Social welfare professionals</i>	445,830	46.7
<b>Approved Services after ACAT<sup>2</sup></b>			
<b>Residential Care (Respite)</b>	<i>Low</i>	417,621	43.7
	<i>High</i>	173,034	18.1
<b>Residential Care (Permanent)</b>	<i>Low</i>	292,711	30.6
	<i>High</i>	199,405	20.9
<b>Transition Care</b>		73,708	7.7
<b>Community Care (CACP)<sup>3</sup></b>		251,013	26.3
<b>Extended Aged Care at Home (EACH)<sup>3</sup></b>		36,342	3.8
<b>Extended Aged Care at Home/Dementia (EACHD)<sup>3</sup></b>		12,284	1.3
<b>Flexible Care</b>	<i>EACH package<sup>3</sup></i>	3,209	0.3
	<i>Other</i>	1,385	0.1
	<i>Multi-purpose service</i>	1,195	0.1
	<i>Transition Care</i>	407	<0.1
<b>Emergency Care<sup>4</sup></b>		2,143	0.2
<b>No Approval</b>		24,590	2.6

1. Multiple assessors can be part of the assessment.
2. The same person can be approved for multiple services.
3. These data include ACATs that were done before 2013. In August 2013 Community Care (or Home Care Package Program) replaced the 3 community packaged programs (CACP, EACH, and EACHD). Note: all of these are types of Home Care Packages.
4. Emergency care is selected as a qualifier to another service.

## B. CHARACTERISTICS OF COHORT

### *Summary:*

There were 955,439 people with first time ACAT Comprehensive Assessments in this reporting period (1<sup>st</sup> July 2003 – 30<sup>th</sup> June 2014) across Australia. People seeking aged care services vary greatly according to their needs and the paths they take through the aged care system. Due to the complexity of the cohort receiving aged care services, this report focuses on the national historic cohort of people with first time ACAT assessments and their subsequent main services, thus allowing it to be eventually compared to the Stage 3 ROSA Prospective Cohort (2018-onwards).

The overall cohort from this report was grouped into the following six main groups, which will be referred to throughout this Report:

**(1) PERMANENT RESIDENTIAL AGED CARE (PERMANENT).** People who went into Permanent Residential Aged Care first and never accessed a Home Care Package within the reporting period, N=392,853 (41.1% of total). People in this group may or may not have also received Respite or Transition Care.

**(2) HOME CARE PACKAGE (HOME CARE).** People who received a Home Care Package first, and never accessed Permanent Residential Aged Care within the reporting period, N=101,275 (10.6% of total). People in this group may or may not have also received Respite or Transition Care.

**(3) BOTH HOME CARE PACKAGE & PERMANENT RESIDENTIAL AGED CARE (BOTH).** People who received both Home Care Packages and Permanent Residential Aged Care support within the reporting period, N=98,386 (10.3% of total). The majority of people in this group accessed a Home Care Package before Permanent Residential Aged Care, but there are exceptions, including some people who may have moved between Home Care Packages and Permanent Residential Aged Care multiple times. People in this group may or may not have also received Respite Care or Transition Care.

**(4) NO SERVICES (NOTHING).** People with an assessment who received no services during the study period, N=271,935 (28.5% of total).

**(5) RESPITE CARE (RESPITE).** People who received Respite Care, but never received Permanent Residential Aged Care or a Home Care Package N=51,382 (5.4% of total). They may or may not have also accessed Transition Care.

**(6) TRANSITION CARE (TRANSITION).** People who received Transition Care, but never received Permanent Residential Aged Care or a Home Care Package N=43,419(4.5% of total). They may or may not have also accessed Respite Care.

The groupings total more than 100% as there is minor overlap between the Respite Care and Transition Care groups (N=959,250, 100.4%).

### *Sociodemographic Characteristics:*

Of the 955,439 people in this report, the majority were females (60%), the most common age group was 80-84 years old (27%), and 67% assessments were conducted for people who lived in a major city. The majority of people lived in private residences that they owned (66%) at the time of their assessment and 54% lived with someone (family or otherwise). See **Table 3** for detail on cohort characteristics. The age distribution at first service entry for people accessing Permanent Residential Aged Care or Home Care Packages is shown in **Figure 3**.

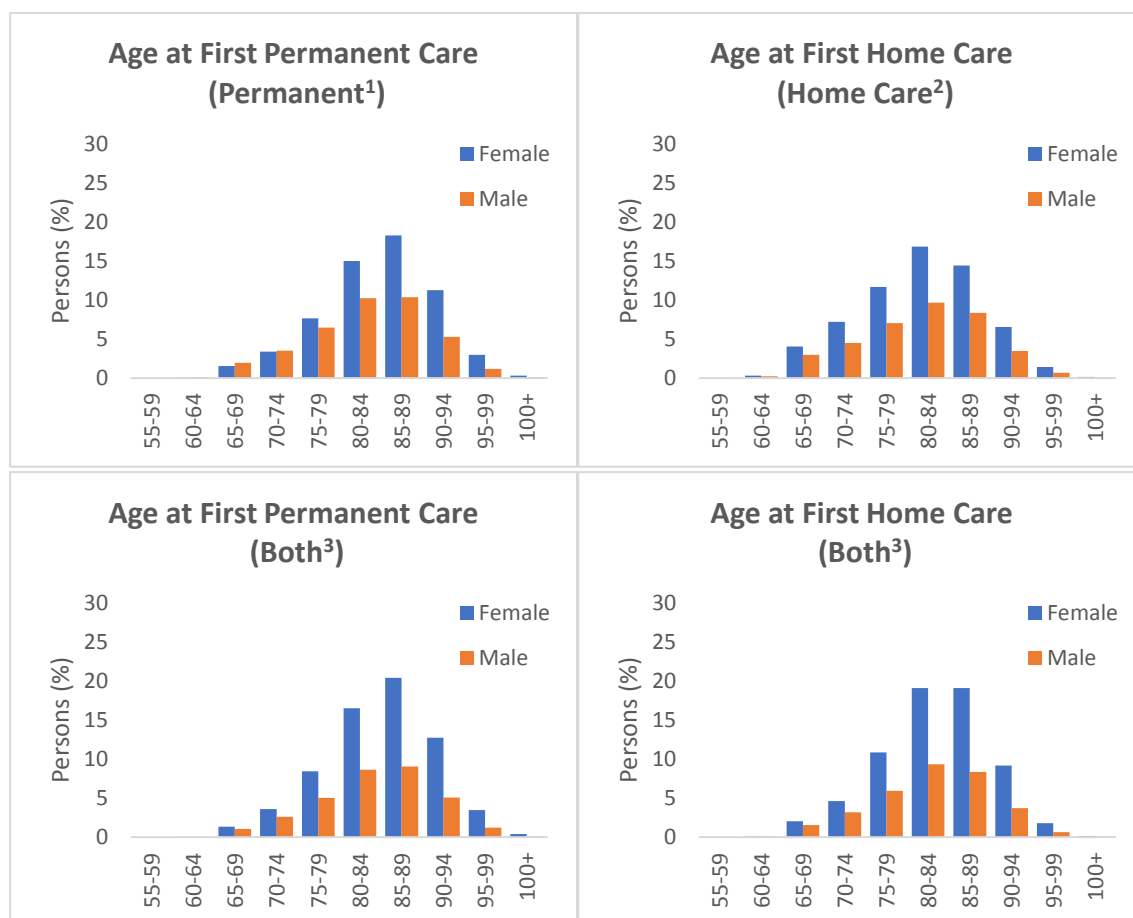


**Table 3. Socio-Demographic Characteristics of Overall Cohort and by Service Group.**

		Total ACATs		Permanent <sup>1</sup>		Home Care <sup>2</sup>		Both <sup>3</sup>		Nothing <sup>4</sup>		Respite <sup>5</sup>		Transition <sup>6</sup>	
		N	%	N	%	N	%	N	%	N	%	N	%	N	%
	<i>All</i>	955,439	100.0	392,853	41.1	101,275	10.6	98,386	10.3	271,935	28.5	51,382	5.4	43,419	4.5
<b>Sex<sup>7</sup></b>	<i>Female</i>	575,359	60.2	238,318	60.7	63,668	62.9	65,987	67.1	153,932	56.6	28,603	55.7	27,275	62.8
	<i>Male</i>	379,919	39.8	154,482	39.3	37,594	37.1	32,387	32.9	117,925	43.4	22,774	44.3	16,144	37.2
<b>Deceased at 30th June 2014</b>	<i>Deceased</i>	524,866	54.9	272,672	69.4	39,933	39.4	60,462	61.5	108,824	40.0	31,241	60.8	13,457	31.0
	<i>Not Deceased</i>	430,573	45.1	120,181	30.6	61,342	60.6	37,924	38.5	163,111	60.0	20,141	39.2	29,962	69.0
<b>Age at End of First ACAT</b>	<i>55-59</i>	91	<0.1	16	<0.1	47	<0.1	10	<0.1	15	<0.1	2	<0.1	1	<0.1
	<i>60-64</i>	584	0.1	63	<0.1	266	0.3	55	0.1	169	0.1	23	<0.1	11	<0.1
	<i>65-69</i>	48,938	5.1	14,727	3.7	7,664	7.6	3,947	4.0	16,732	6.2	2,584	5.0	3,490	8.0
	<i>70-74</i>	89,285	9.3	28,477	7.2	12,359	12.2	7,941	8.1	30,244	11.1	4,500	8.8	6,152	14.2
	<i>75-79</i>	164,347	17.2	58,929	15.0	19,944	19.7	17,449	17.7	51,118	18.8	8,438	16.4	9,169	21.1
	<i>80-84</i>	255,054	26.7	103,690	26.4	27,136	26.8	28,358	28.8	72,327	26.6	13,174	25.6	11,341	26.1
	<i>85-89</i>	246,038	25.8	111,479	28.4	22,387	22.1	26,466	26.9	64,171	23.6	13,621	26.5	8,898	20.5
	<i>90-94</i>	122,002	12.8	60,169	15.3	9,373	9.3	11,840	12.0	30,218	11.1	7,289	14.2	3,580	8.2
	<i>95-99</i>	26,416	2.8	13,951	3.6	1,902	1.9	2,153	2.2	6,195	2.3	1,595	3.1	702	1.6
	<i>100+</i>	2,684	0.3	1,352	0.3	197	0.2	167	0.2	746	0.3	156	0.3	75	0.2
<b>State</b>	<i>NSW</i>	331,280	34.7	134,574	34.3	33,762	33.3	32,627	33.2	93,516	34.4	21,641	42.1	16,774	38.6
	<i>VIC</i>	258,947	27.1	111,532	28.4	24,501	24.2	23,093	23.5	78,816	29.0	13,351	26.0	8,647	19.9
	<i>QLD</i>	144,614	15.1	58,348	14.9	17,377	17.2	16,962	17.2	36,681	13.5	5,751	11.2	9,940	22.9
	<i>SA</i>	87,183	9.1	40,819	10.4	7,968	7.9	8,811	9.0	20,699	7.6	5,268	10.3	4,029	9.3
	<i>WA</i>	89,476	9.4	31,045	7.9	11,971	11.8	12,057	12.3	29,866	11.0	2,855	5.6	1,821	4.2
	<i>TAS</i>	27,406	2.9	12,474	3.2	2,546	2.5	2,571	2.6	6,905	2.5	1,773	3.5	1,265	2.9
	<i>NT</i>	4,087	0.4	518	0.1	1,175	1.2	509	0.5	1,512	0.6	184	0.4	217	0.5
	<i>ACT</i>	12,446	1.3	3,543	0.9	1,975	2.0	1,756	1.8	3,940	1.4	559	1.1	726	1.7
<b>Carer Availability<sup>7</sup></b>	<i>Has carer</i>	757,116	79.2	313,644	79.8	79,192	78.2	78,460	79.7	213,832	78.6	43,418	84.5	31,646	72.9
	<i>Has no carer</i>	170,888	17.9	65,220	16.6	20,567	20.3	17,804	18.1	49,785	18.3	6,911	13.5	11,284	26.0
<b>Remoteness<sup>7</sup></b>	<i>Major City</i>	640,079	67.0	269,452	68.6	67,775	66.9	66,798	67.9	179,250	65.9	32,038	62.4	27,198	62.6
	<i>Other</i>	309,875	32.4	120,781	30.7	33,113	32.7	31,200	31.7	91,287	33.6	19,067	37.1	15,772	36.3

1. Permanent Residential Aged Care 2. Home Care Package 3. Accessed both Permanent Residential Aged Care and Home Care Package 4. Did not access any aged care services 5. Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package 6. Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package. 7. *Missing/not stated*: Sex (N=161, <0.1%), Carer Availability (N=27,425, 2.9%), Remoteness (N=5,485, 0.6%).

**Figure 3. Cohort Age at First Service Entry.**

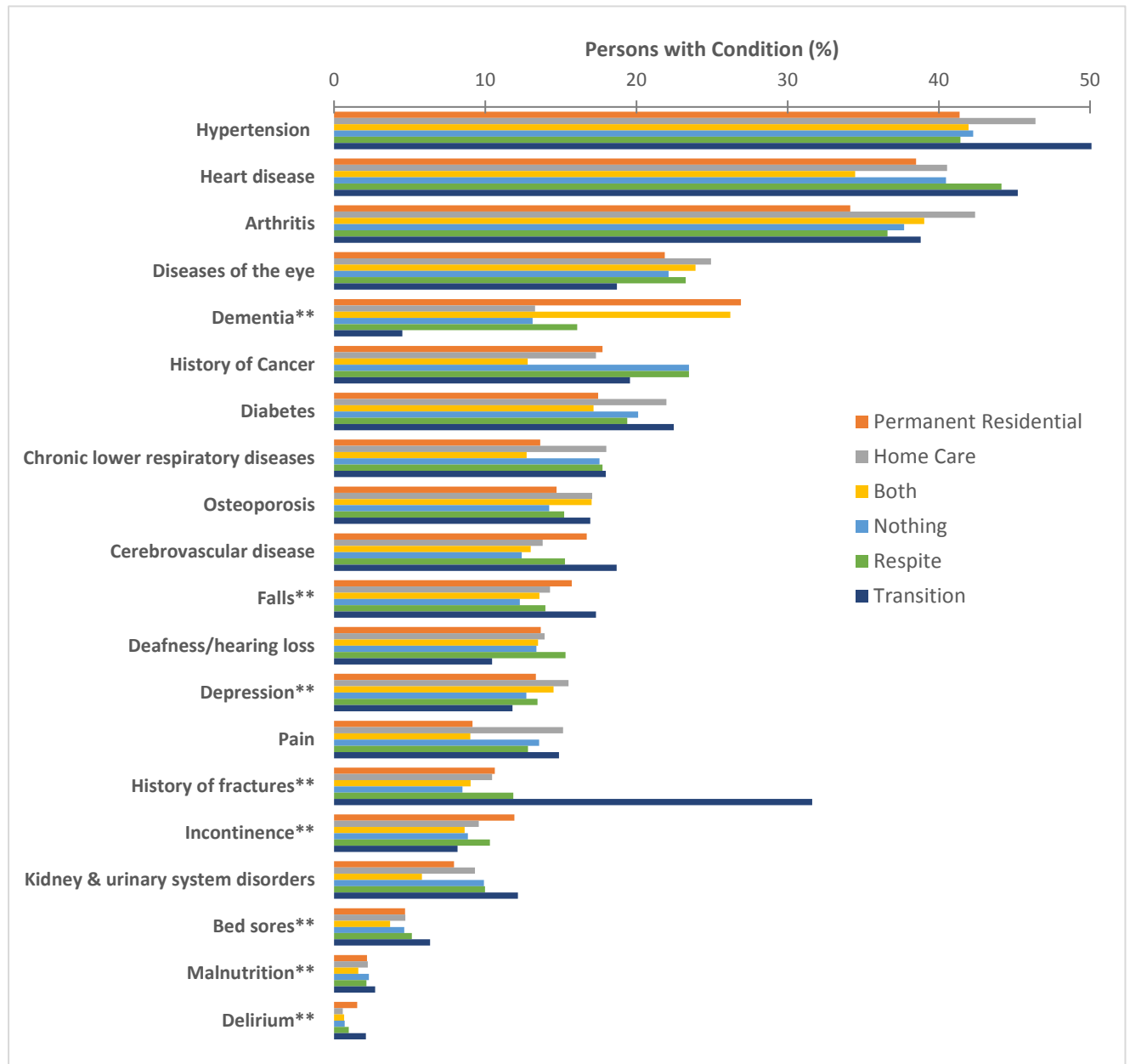


1. Permanent Residential Aged Care 2. Home Care Package 3. Accessed both Permanent Residential Aged Care and Home Care Package.

**Health Conditions:**

There were 211 conditions individually listed during ACATs as health concerns for the people having the assessments. The most prevalent conditions reported were: hypertension (43%), heart disease (39%), arthritis (37%), diseases of the eye (22%), dementia (20%), history of cancer (19%), and diabetes (19%). Of the common geriatric syndrome conditions reported, falls were the most prevalent, reported in 14% of the cohort, followed by history of fractures in 11%, incontinence in 10%, and delirium in 1% (**Figure 4**). There were differences in the prevalence of health conditions depending on the type of services people received. For example, history of fractures is higher in the group that received Transition Care (32%) services. Prevalence of dementia was higher in people who received Permanent Residential Aged Care first (27%), or who received both a Home Care Package and Permanent Residential Aged Care services (26%) and was lower in people who received Transition Care (4%).

**Figure 4. Prevalence of Common Health Conditions and Geriatric Syndrome Conditions by Service Received\*.**



\*Original conditions recorded by ACAT were grouped in some instances for reporting purposes (e.g. diabetes type 1 and 2 are reported together, all 'heart disease' conditions are grouped).

\*\*Geriatric Syndrome conditions.

Permanent Residential Aged Care (orange); Home Care Package (grey); Accessed both Permanent Residential Aged Care and Home Care Package (yellow); Nothing - did not access any aged care services (light blue); Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package (green); Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package (dark blue).



### *Activity Limitations:*

Part of the required data collected by the ACAT during the assessment is an evaluation of the aged care seekers' activity limitations and the current support they receive for that limitation.

Additionally, the ACAT assessment includes information on the recommended assistance after the evaluation. As shown in **Figure 6**, over 70% of people having ACATs report activity limitations in the areas of domestic support, transport, meals, and activities involving social and community participation.

### *Activity Limitation Categories:*

**WALKING.** Refers to assistance or supervision of another person with walking and related activities, either around the home or away from home (excludes needing assistance with transportation).

**TRANSPORT.** Refers to assistance or supervision of another person with using public transport, getting to and from places away from home or driving.

**SOCIAL.** Refers to assistance or supervision of another person with shopping, banking, participating in recreational, cultural or religious activities, attending day centres, managing finances and writing letters.

**SELF-CARE.** Refers to assistance or supervision of another person with daily self-care tasks such as eating, showering/bathing, dressing, toileting and managing incontinence.

**MOBILITY/MOVEMENT ACTIVITIES.** Refers to assistance or supervision of another person with activities such as maintaining or changing body position, carrying, moving and manipulating objects, getting in or out of bed or a chair.

**MEALS.** Refers to assistance or supervision of another person with meals, including the delivery of prepared meals, help with meal preparation and managing basic nutrition.

**HOME MAINTENANCE.** Refers to assistance or supervision of another person with the maintenance and repair of the person's home, garden or yard to keep their home in a safe and habitable condition, for example, changing light bulbs and basic gardening.

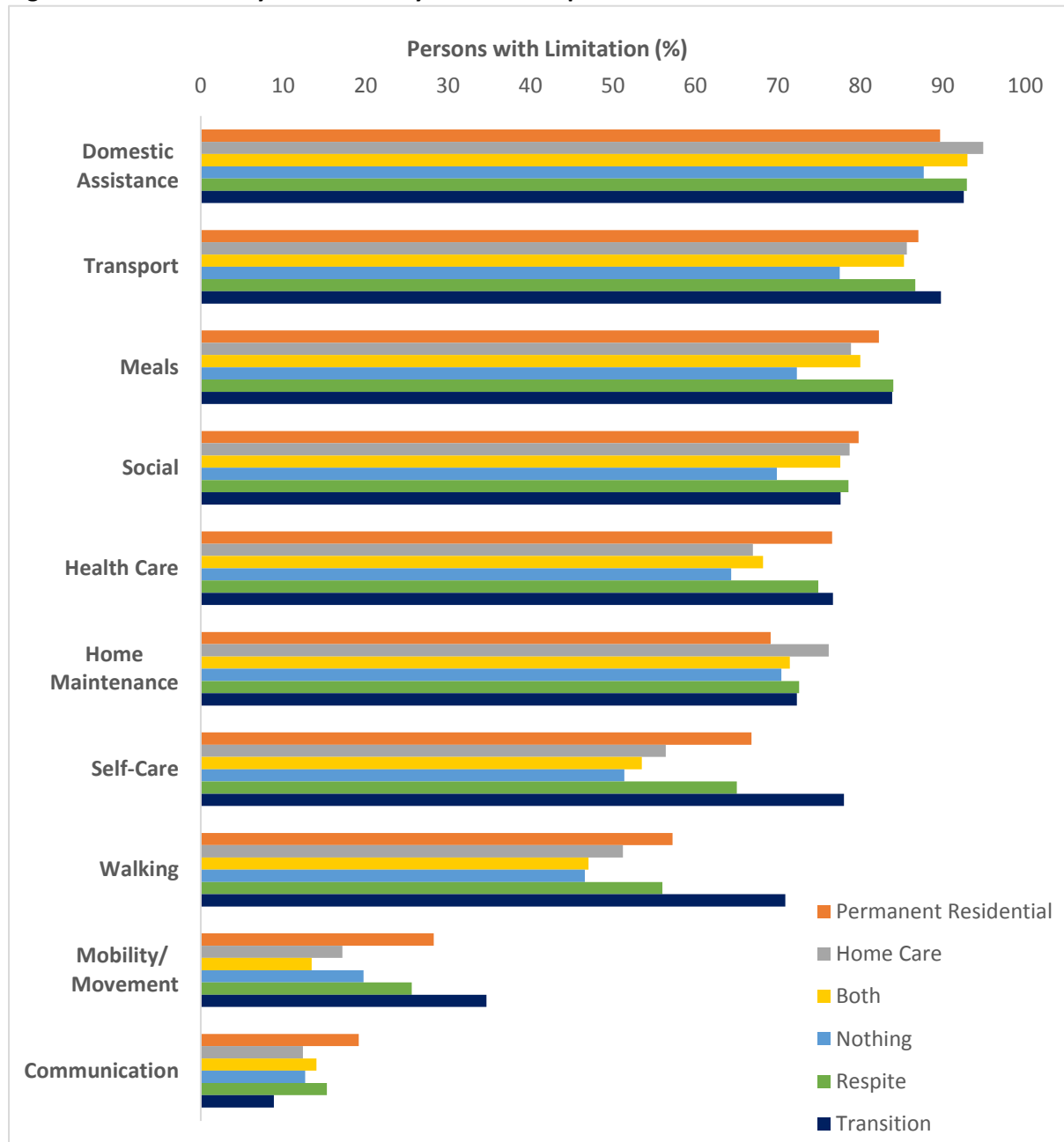
**HEALTH CARE TASKS.** Refers to assistance or supervision of another person with taking medication or administering injections, dressing wounds, using medical machinery, manipulating muscles or limbs, taking care of feet (includes a need for home nursing and allied health care).

**DOMESTIC ASSISTANCE.** Refers to assistance or supervision of another person with household chores such as washing, ironing, cleaning and formal linen services.

**COMMUNICATION.** Refers to assistance or supervision of another person with understanding others, making oneself understood by others.

When characterising main service groups by their activity limitations (**Figure 6**), we see that the highest proportion of people with walking limitations are found in the Transition Care group (71%), compared to the lowest proportion (46%) in the group of people who have not accessed any services. People in the Permanent Residential Aged Care group have the highest proportion of communication limitations (19%), which is double that of people in the Transition Care group (9%). Mobility limitations were more common in the Transition Care (35%), Permanent Residential Aged Care (28%) and Respite (26%) groups, but less common in the groups of people accessing no services (20%), Home Care Packages (17%) or both Home Care Packages and Permanent Residential Aged Care services (13%).

**Figure 6. Cohort Activity Limitations by Service Group.**



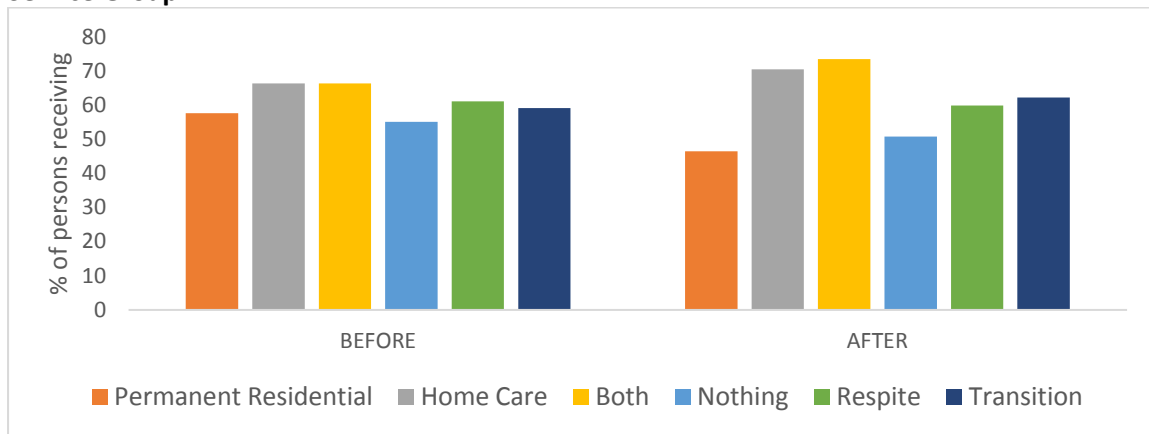
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### C. AGED CARE SERVICE UTILISATION

One of ROSA’s main goals is to evaluate the types of services someone receives, both within the aged care and health care system. With Stage 1 ROSA data we can evaluate the utilisation of aged care services. Of the total cohort of 955,439 people, 28% had 2 ACATs and 21% had 3 or more. 26% of people who received no services had 2 or more ACAT assessments.

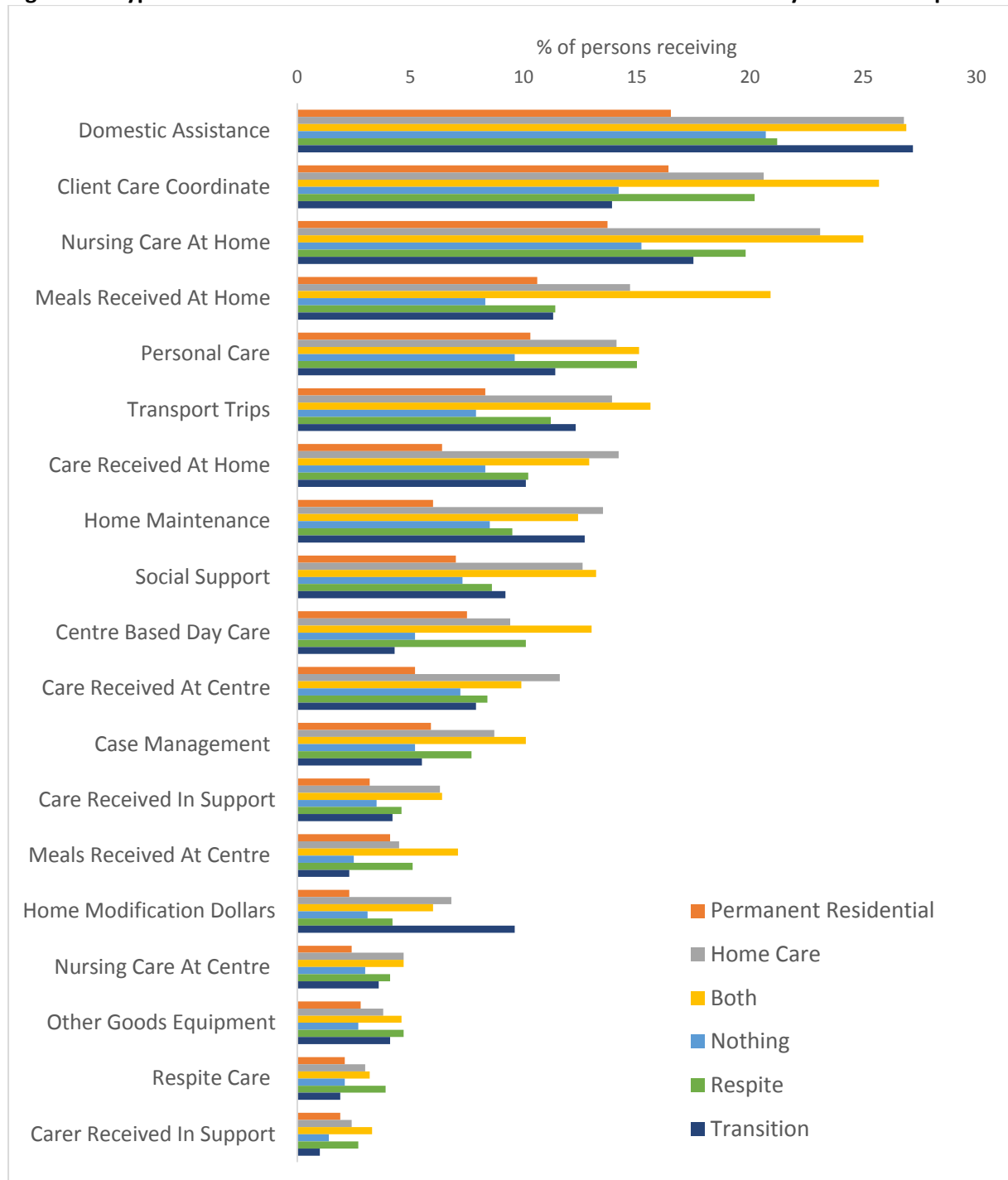
The use of HACC services, which are formal and informal aged care services (e.g. hours of nursing support, transport support, meals services, home repairs), before a first time ACAT was common (59% of people had at least 1 service) but it was less common after their ACAT (54%). People who went into Permanent Residential Aged Care first had a lower usage of HACC services after their first ACAT (47%), compared to people who received Home Care Packages after their first ACAT (71%). See **Figure 7a** for the proportion of people receiving HACC services before and after a first time ACAT, by service group they received after their ACAT, and **Figure 7b** for type of HACC services people obtained by service grouping.

**Figure 7a. Proportion of People Receiving HACC Services Before and After a First Time ACAT by Service Group\*.**



\*This figure includes any use of HACC services ever over the reporting period, they do not differentiate by length of time accessing the service(s), or frequency of access. Permanent Residential Aged Care (orange); Home Care Package (grey); Accessed both Permanent Residential Aged Care and Home Care Package (yellow); Nothing - did not access any aged care services (light blue); Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package (green); Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package (dark blue).

**Figure 7b. Type of HACC Services Received in the Year After First Time ACAT by Service Group\*.**



\*This figure includes any use of HACC services ever over the reporting period, they do not differentiate by length of time accessing the service(s), or frequency of access. Permanent Residential Aged Care (orange); Home Care Package (grey); Accessed both Permanent Residential Aged Care and Home Care Package (yellow); Nothing - did not access any aged care services (light blue); Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package (green); Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package (dark blue).



## D. COHORT MORTALITY AND FOLLOW-UP

The median follow-up of the cohort included in this report was 1.7 years (interquartile range 0.4-3.8 years). Of the entire cohort, 45% were alive at the end of the study period (**Table 4** and **Figure 8**) and this varied by the types of service that they received.

Please note that the survival estimates presented in this report are purely for descriptive purposes regarding the survival patterns of the cohort. We have not evaluated the associations between uptake of any of the aged care services with risk or likelihood of mortality and we are not suggesting causal associations between aged care service utilisation and survival.

For someone having a first time ACAT the 30-day crude survival rate was 97% and the 5-year survival rate was 43%. The survival of people after entry into aged care services was different based on the service they received. The highest 1-year survival rate was observed in those who had both Permanent Residential Aged Care and Home Care Packages (91%) compared to 67% in those that had only Permanent Residential Aged Care, and 79% of those that had only Home Care Packages. Those who were in the Transition Care group had a 79% survival rate and those who received Respite Care had 56% survival at 1 year.

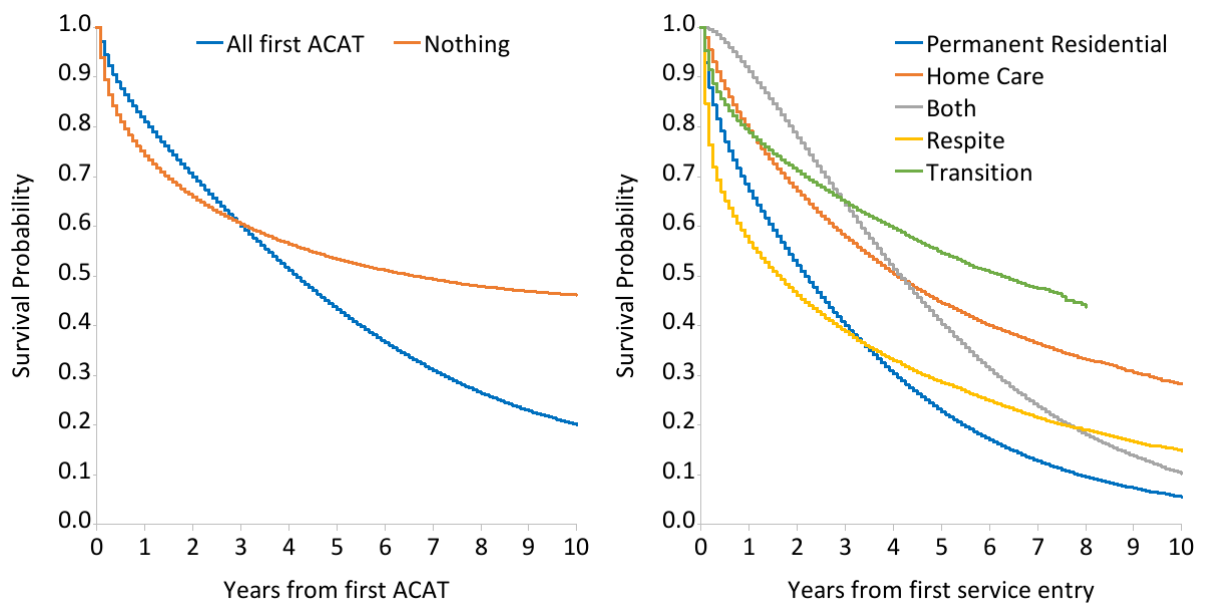
**Table 4. Summary Follow-up and Crude Survival Estimates for Overall Cohort and by Service Group.**

Group	Persons N	Deceased at 30 <sup>th</sup> June 2014 N (%)	Follow-up, years (median, IQR) <sup>7</sup>	Years to Death (median, IQR) <sup>7</sup>	30 Day Survival (%, 95%CI) <sup>7</sup>	90 Day Survival (%, 95%CI) <sup>7</sup>	1 Year Survival (%, 95%CI) <sup>7</sup>	5 Year Survival (%, 95%CI) <sup>7</sup>
Overall	955,439	524,866 (54.9)	2.5 (0.9,4.8)	1.9 (0.6,3.9)	97.3 (97.2-97.3)	92.3 (92.3-92.4)	80.9 (80.8-81.0)	43.1 (43.0-43.2)
Permanent <sup>1</sup>	392,853	272,672 (69.4)	2.7 (1.2,4.8)	2.3 (0.9,4.2)	92.9 (92.8-93)	84.4 (84.3-84.5)	66.9 (66.8-67.1)	22.5 (22.3-22.6)
Home Care <sup>2</sup>	101,275	39,933 (39.4)	2.6 (1.2,4.7)	2.0 (0.9,3.7)	98 (97.9-98)	93.1 (92.9-93.3)	78.9 (78.6-79.2)	44.2 (43.7-44.6)
Both <sup>3</sup>	98,386	60,462 (61.5)	4.2 (2.6,6.2)	3.8 (2.3,5.5)	99.9 (99.9-100)	99.2 (99.1-99.2)	91.1 (90.9-91.2)	40.1 (39.7-40.4)
Nothing <sup>4</sup>	271,935	108,824 (40.0)	1.6 (0.4,4.6)	0.6 (0.2,1.8)	93.9 (93.8-94.0)	86.5 (86.3-86.6)	74.1 (73.9-74.2)	53.2 (53.0-53.4)
Respite <sup>5</sup>	51,382	31,241 (60.8)	1.7 (0.5,3.7)	1.0 (0.3,2.5)	84.6 (84.2-84.9)	71.7 (71.3-72.1)	56.4 (56-56.9)	28.2 (27.7-28.7)
Transition <sup>6</sup>	43,419	13,457 (31.0)	1.9 (0.7,3.6)	1.0 (0.3,2.5)	95.3 (95.1-95.5)	88.7 (88.4-89)	78.7 (78.3-79.1)	54.2 (53.4-54.9)

IQR=Interquartile Range. CI=Confidence Intervals.

1. Permanent Residential Aged Care 2. Home Care Package 3. Accessed both Permanent Residential Aged Care and Home Care Package 4. Did not access any aged care services 5. Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package 6. Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package 7. Follow up, time to death and survival all calculated from first ACAT for overall and for the group not receiving services, calculated from first entry into service for all other groups.

**Figure 8. Kaplan Meier Curve of Cohort Survival by Age Care Service Group.**



## E. REFERENCES

### *Reference Data Manuals Used:*

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<https://www.aihw.gov.au/reports/aged-care/aged-care-assessment-program-data-dictionary-versi/contents/table-of-contents>
2. Aged Care Funding Instrument (ACFI) User Guide  
[https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/10\\_2014/acfi\\_user\\_guide\\_1\\_july\\_2013.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/10_2014/acfi_user_guide_1_july_2013.pdf)
3. HACC Data Dictionary Version 1.0  
<https://www.aihw.gov.au/reports/adoptions/home-community-care-hacc-data-dictionary-v-1/contents/table-of-contents>
4. HACC Program National MDS User Guide Version 2.0 (Update 2.01), January 2006  
[https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/11\\_2014/prov\\_4b1\\_hacc\\_md\\_s\\_user\\_guide.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/11_2014/prov_4b1_hacc_md_s_user_guide.pdf)
5. Australian Institute of Health and Welfare 2017. Pathways in aged care 2014: technical guide. Cat. no. AGE 82. Canberra: AIHW.  
<https://www.aihw.gov.au/reports/aged-care/pathways-in-aged-care-2014-technical-guide/contents/table-of-contents>
6. Australian Institute of Health and Welfare 2014. Patterns in use of aged care 2002–03 to 2010–11. Data linkage series no.18. CSI 20. Canberra: AIHW.  
<https://www.aihw.gov.au/reports/aged-care/patterns-in-use-of-aged-care-2002-03-to-2010-11/contents/table-of-contents>
7. Classification principles 1997  
<https://www.legislation.gov.au/Details/F2005C00536>

## F. ACKNOWLEDGEMENTS

We would like to acknowledge the Healthy Ageing Research Consortium Investigator Team\* and ROSA's South Australian Health and Medical Research Institute (SAHMRI) Research Team for ensuring the success of ROSA and support with this project. We also acknowledge the South Australian Government who provided us with support through the Premier's Research and Industry Fund (2017-2021) to conduct this work and the Australian Institute of Health and Welfare (AIHW) for the provision of the raw data used in ROSA. ROSA has also received one-year funding through approved disbursements from the Medical Research Future Fund (MRFF) Rapid Applied Research Translation Program.

### **\*Healthy Ageing Research Consortium Investigator Team (from 2016 SA Premier's Research and Industry Fund Grant):**

Prof Steve Wesselingh (SAHMRI)  
A/Prof Caroline Miller (SAHMRI and University of Adelaide)  
Ms Liddy Griffith (SAHMRI)  
Dr Carol Davy (SAHMRI)  
Prof Renuka Visvanathan (SA Health and University of Adelaide)  
A/Prof Craig Whitehead (SA Health and Flinders University)  
Prof Paddy Phillips (SA Health)  
Ms Jeanette Walters (SA Health)  
Dr Patrick Russell (SA Health)  
Prof Jon Karnon (University of Adelaide)  
Dr Tiffany Gill (University of Adelaide)  
Dr Linley Denson (University of Adelaide)  
Dr Lynn Ward (University of Adelaide)  
Prof David Roder (University of South Australia)  
Prof Andrew Beer (University of South Australia)  
Prof Mark Daniel (University of South Australia)  
Mr Andrew Stanley (SA NT DataLink)  
Prof Libby Roughead (University of South Australia)  
Prof Julie Ratcliffe (University of South Australia)  
Prof Karen Reynolds (Flinders University)  
Prof Keith Evans (Silver Chain)  
Ms Amber Watt (ECH)  
Ms Jane Mussared (Council on the Ageing SA)  
Ms Kirsty Rawlings (Council on the Ageing SA)  
Ms Megan Corlis (Helping Hand)  
Ms Ali Krollig (Country SA Primary Health Network)  
Ms Carmel McNamara (Adelaide Primary Health Network)  
Ms Simone Champion (Adelaide Primary Health Network)  
Ms Ellen Kerrins (Health Consumers Alliance of SA)

## IV. Appendices

### A. ROSA'S STAGE 1 AND 2 GOALS

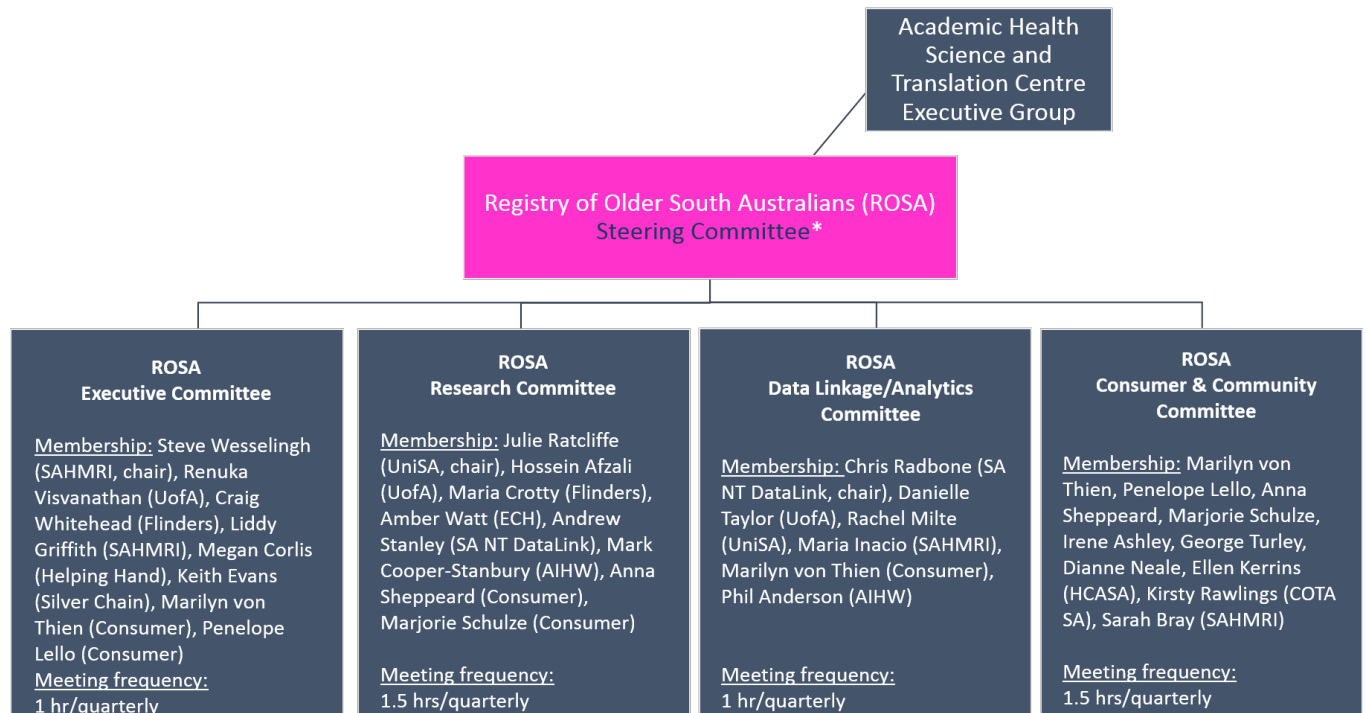
1. Who are the recipients of aged care services care services? We will define aged care seekers/recipients per their demographics, geographic location, socioeconomic status, general health status, social support, psychosocial profile, and specific important determinants of health for this population (e.g. home safety status, risk of vulnerability, cognitive impairment, functional capacity, and depression). How have the recipients changed over the study period (1997 - 2017)?
2. What changes in aged care services have occurred during the study period and how they have affected ageing in Australia?
3. What are the factors associated with specific aged care services (e.g. type of service, level of service, specific therapies) provided and subgroups of aged care recipients?
4. How do the aged care clients' characteristics affect the types of services provided to them and access to these services?
5. What are the factors associated with progression from one type of aged care service/package type to the next (e.g. determinants of clients change from aged care package program to transition care program, to residential aged care)?
6. What are the factors associated with mortality and/or other health events (e.g. falls, pain, fractures, health services utilisation) in aged care seekers/recipient?
7. What are the successful areas and areas in need of improvement in the delivery of health services for aged care?
8. What are the existing evidence-based health promotion strategies and guidelines in the delivery of aged care services?
9. What are the factors associated with successful industry innovations/opportunities that can benefit older Australians?
10. What are the opportunities to deliver cost-effective services to aged care recipients?

## B. ROSA'S GOVERNANCE STRUCTURE

The governance of ROSA includes (Figure 9):

- **Steering Committee** with membership comprising representative members from each of the Healthy Ageing Research Consortium partner organisations. This includes 13 organisations: SAHMRI, University of Adelaide, University of South Australia, Flinders University, Helping Hand, Silver Chain, Adelaide PHN, Country SA PHN, ECH, COTA SA, HCASA, SA NT DataLink and SA Health. Purpose: Overall direction and strategy for ROSA.
- **Executive Committee** with membership of consumers, SAHMRI, researchers, universities and industry representatives. Purpose: Direction, strategy and facilitation.
- **Research Committee** with membership of consumers, SAHMRI, researchers, universities, data integrating authorities (SA NT DataLink and AIHW) and industry representatives. Purpose: Review and make recommendations to the Steering Committee about study proposals.
- **Data Linkage and Analytics Committee** with membership of consumers, data integrating authorities (SA NT DataLink and AIHW), universities, SAHMRI and industry representatives. Purpose: Facilitate and assist with the establishment of the registry and reporting.
- **Consumer and Community Committee** with membership of consumer representatives from the other Committees, members from the wider community, representatives from the consumer advocacy organisations (COTA SA and HCASA), and SAHMRI researchers. Purpose: Facilitate and advise on consumer engagement activities, involvement, and direction.

Figure 9. ROSA's Governance Structure.



## C. ACCOMPLISHMENTS AND COLLABORATION

### **Publications:**

Harrison S, Milte R, Bradley C, Inacio M, Crotty M. The acceptability of participating in data linkage research: Research with older Australians. *Australian & New Zealand Journal of Public Health*. Accepted for publication 9 April 2018.

### **Scientific Presentations:**

Harrison S, Lang C, Whitehead C, Crotty M, Ratcliffe, Wesselingh S, Inacio M. Prevalence of dementia and survival with dementia in people entering residential aged care in Australia: trends from 2008 to 2014. Accepted to the 3rd Australian Dementia Forum of the NHMRC National Institute for Dementia Research. 2018 June 3-6.

Inacio M, Bray S, Whitehead C, Corlis M, Visvanathan R, Evans K, Griffith L, Wesselingh S. The Registry of Older South Australians (ROSA): Framework, Current Cohort, and Expected Impact. Shandong Symposium 2018. Shandong, China; May 9-10, 2018.

### **Grant funding received:**

Australian Government National Health and Medical Research Council, Medical Research Future Fund *Targeted Call for Research on Antimicrobial Resistance in residential aged care facilities*. APP1152268. Project grant: "Using metagenomics and the Registry of Ageing South Australians to understand carriage and transmission of antimicrobial resistance in the elderly." South Australian Health and Medical Research Institute. Chief Investigators: Geraint Rogers, Steve Wesselingh, David Gordon, Maria Crotty, Maria Inacio, Craig Whitehead, David Lynn, Richard Woodman, Lito Papanicolas, Lex Leong. Award: \$1,400,000. Funding period: 03/2018-03/2020.

Theo Murphy (Australia) Initiative. For the *Theo Murphy Frontiers of Science Healthy Ageing Symposium*. Chief Investigator: Stephanie Harrison. Award: \$31,745. Funding period: 03/2018-06/2019.

Australian Government National Health and Medical Research Council, Medical Research Future Fund *Rapid Applied Research Translation Program*. Chief Investigators: Steve Wesselingh. Award: \$125,000. Funding period: 01/2018-12/2019.

## D. ROSA RESEARCH TEAM

**Table 5. Current ROSA Research Team at SAHMRI.**

Project Management/ Research Support	Postdoctoral Researchers	Analytical Staff
<b>Director:</b> A/Prof Maria Inacio	<b>Psychometrics/Health Economics:</b> Dr Jyoti Khadka (University of South Australia)	<b>Programmer:</b> Ms Catherine Lang
<b>Senior Research Officer &amp; Consumer Engagement Officer:</b> Dr Sarah Bray	<b>Dementia and Cognitive Decline:</b> Dr Stephanie Harrison (Flinders University)	
<b>Research Assistant:</b> Ms Angela Barr	<b>Musculoskeletal:</b> Dr Tiffany Gill (University of Adelaide)	
	<b>Statistics:</b> Dr Azmeraw Amare	



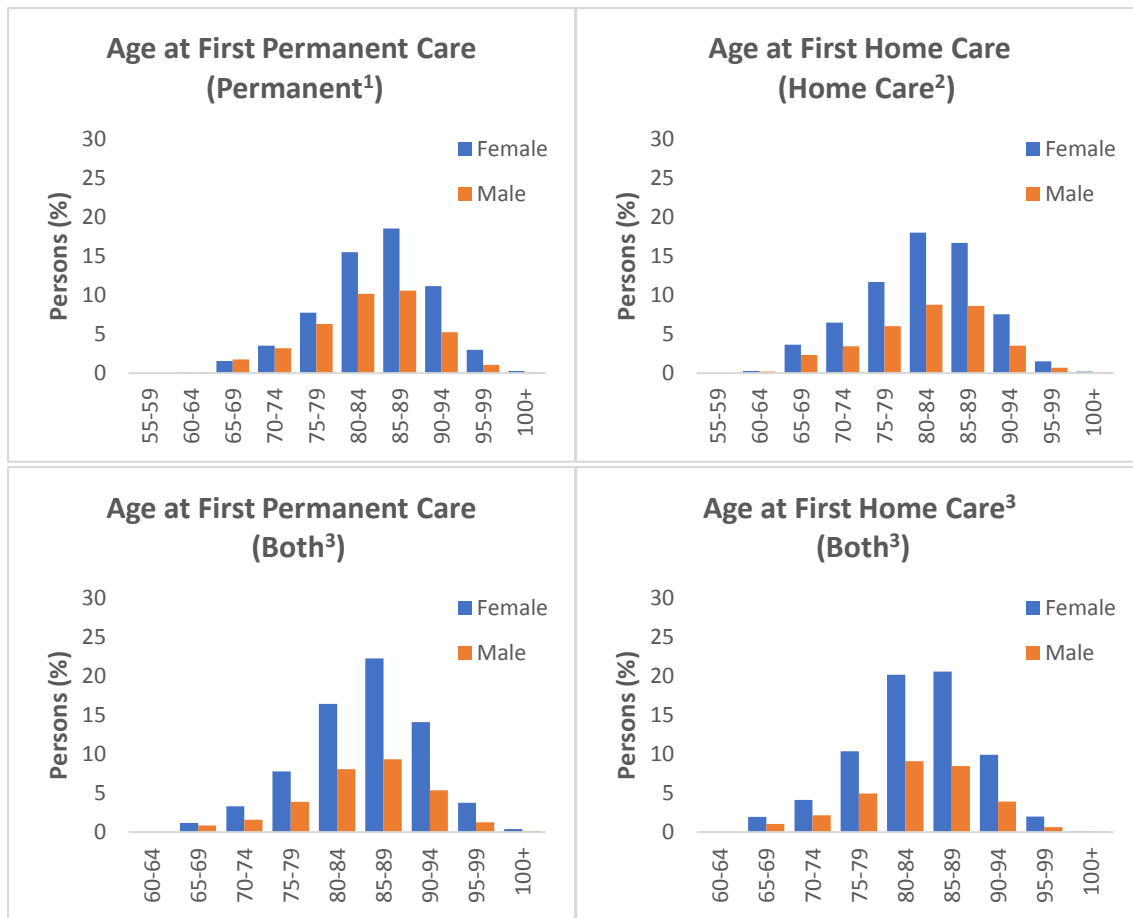
## E. ROSA STAGE 1 SOUTH AUSTRALIAN COHORT

**Table 6. SOUTH AUSTRALIAN COHORT: Socio-Demographic Characteristics of Overall Cohort and by Service Group.**

		Total ACATs		Permanent <sup>1</sup>		Home Care <sup>2</sup>		Both <sup>3</sup>		Nothing <sup>4</sup>		Respite <sup>5</sup>		Transition <sup>6</sup>	
		N	%	N	%	N	%	N	%	N	%	N	%	N	%
	<i>All</i>	87,183	100.0	40,819	46.8	7,968	9.1	8,811	10.1	20,699	23.7	5,268	6.0	4,029	4.6
<b>Sex<sup>7</sup></b>	<i>Female</i>	53,174	61.0	25,096	61.5	5,280	66.3	6,117	69.4	11,467	55.4	2,917	55.4	2,559	63.5
	<i>Male</i>	34,005	39.0	15,722	38.5	2,688	33.7	2,694	30.6	9,229	44.6	2,351	44.6	1,470	36.5
<b>Deceased at 30th June 2014</b>	<i>Deceased</i>	51,269	58.8	29,180	71.5	3,038	38.1	5,469	62.1	8,905	43.0	3,550	67.4	1,329	33.0
	<i>Not Deceased</i>	35,914	41.2	11,639	28.5	4,930	61.9	3,342	37.9	11,794	57.0	1,718	32.6	2,700	67.0
<b>Age at End of First ACAT</b>	<i>55-59</i>	11	<0.1	4	<0.1	6	0.1	0	0.0	1	<0.1	0	0.0	0	0.0
	<i>60-64</i>	51	0.1	4	<0.1	24	0.3	3	0.0	18	0.1	2	<0.1	0	0.0
	<i>65-69</i>	3,821	4.4	1,384	3.4	504	6.3	282	3.2	1,092	5.3	258	4.9	321	8.0
	<i>70-74</i>	6,928	7.9	2,728	6.7	804	10.1	553	6.3	1,939	9.4	440	8.4	505	12.5
	<i>75-79</i>	14,014	16.1	5,952	14.6	1,480	18.6	1,444	16.4	3,628	17.5	865	16.4	716	17.8
	<i>80-84</i>	23,628	27.1	10,911	26.7	2,173	27.3	2,630	29.8	5,595	27.0	1,360	25.8	1,068	26.5
	<i>85-89</i>	23,944	27.5	11,915	29.2	1,968	24.7	2,544	28.9	5,285	25.5	1,423	27.0	928	23.0
	<i>90-94</i>	11,957	13.7	6,349	15.6	845	10.6	1,125	12.8	2,535	12.2	733	13.9	412	10.2
	<i>95-99</i>	2,587	3.0	1,444	3.5	143	1.8	215	2.4	549	2.7	174	3.3	69	1.7
<b>Carer Availability<sup>7</sup></b>	<i>Has carer</i>	71,033	81.5	33,347	81.7	6,363	79.9	7,222	82.0	16,721	80.8	4,549	86.4	3,167	78.6
	<i>Has no carer</i>	11,740	13.5	4,849	11.9	1,461	18.3	1,326	15.0	2,791	13.5	568	10.8	814	20.2
<b>Remoteness<sup>7</sup></b>	<i>Major City</i>	62,327	71.5	32,186	78.9	5,182	65.0	6,130	69.6	12,692	61.3	3,675	69.8	2,778	69.0
	<i>Other</i>	24,729	28.4	8,574	21.0	2,780	34.9	2,675	30.4	7,966	38.5	1,585	30.1	1,244	30.9

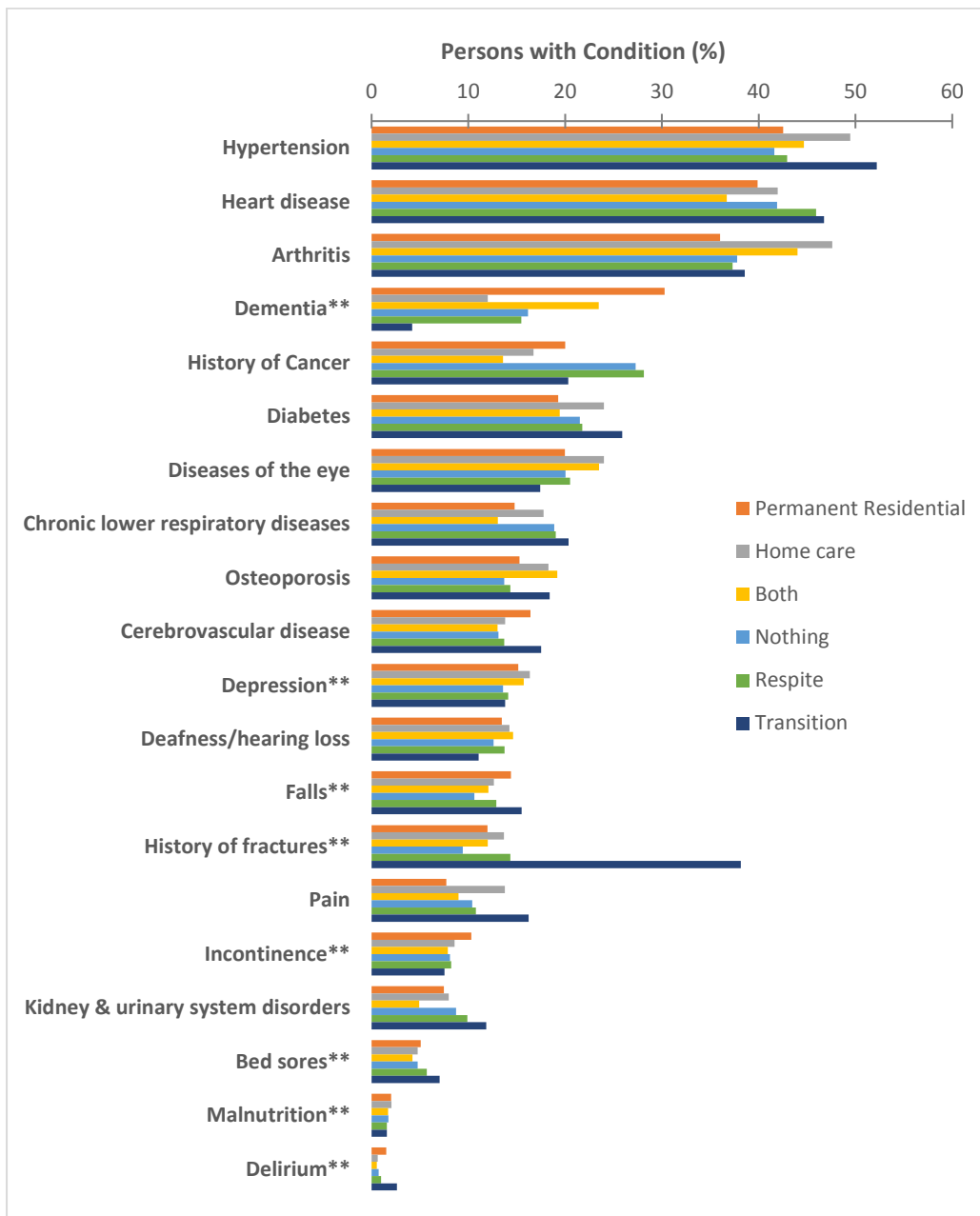
1. Permanent Residential Aged Care 2. Home Care Package 3. Accessed both Permanent Residential Aged Care and Home Care Package 4. Did not access any aged care services 5. Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package 6. Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package. 7. Missing/not stated records not included in table: Sex (N=4, <0.1%), Carer Availability (N=4410, 5.1%), Remoteness (N=127, 0.1%).

**Figure 10. SOUTH AUSTRALIAN COHORT: Cohort Age at First Service Entry.**



1. Permanent Residential Aged Care 2. Home Care Package 3. Accessed both Permanent Residential Aged Care and Home Care Package.

**Figure 11. SOUTH AUSTRALIAN COHORT: Prevalence of Common Health Conditions and Geriatric Syndrome Conditions by Service Received\*.**

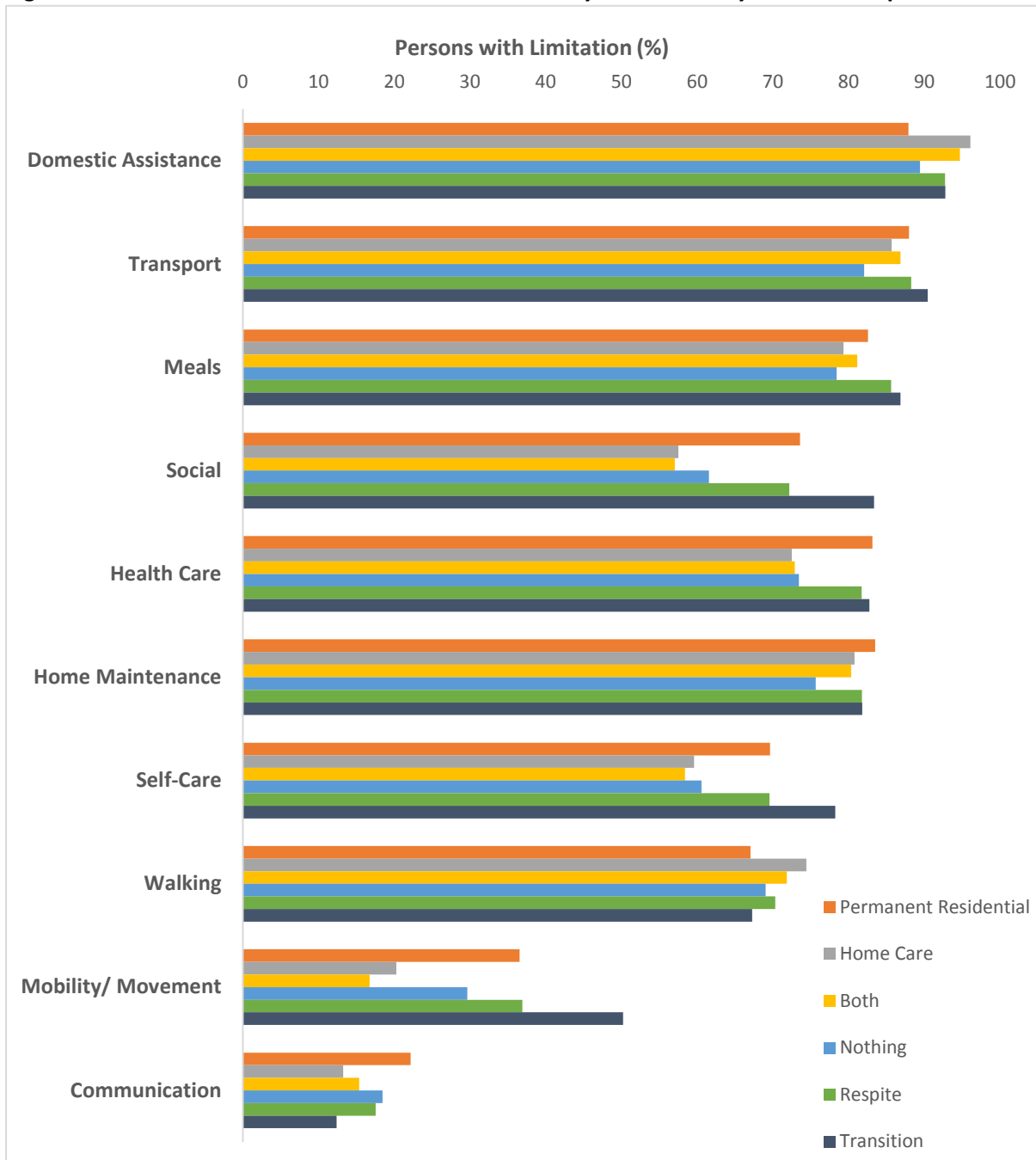


\*Original conditions recorded by ACAT were grouped in some instances for reporting purposes (e.g. diabetes type 1 and 2 are reported together, all 'heart disease' conditions are grouped).

\*\*Geriatric syndrome conditions.

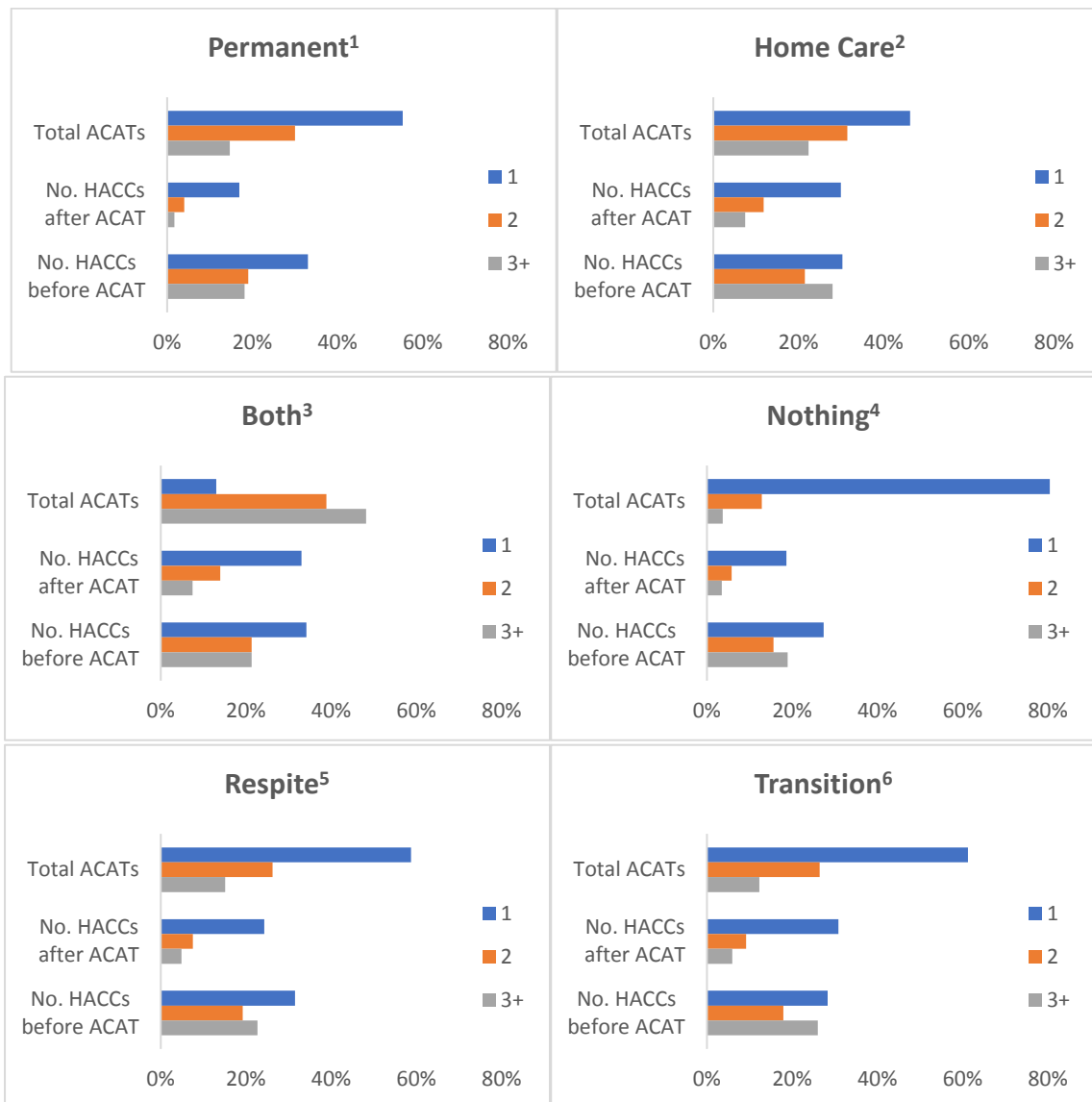
Permanent Residential Aged Care (orange); Home Care Package (grey); Accessed both Permanent Residential Aged Care and Home Care Package (yellow); Nothing - did not access any aged care services (light blue); Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package (green); Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package (dark blue).

**Figure 12. SOUTH AUSTRALIAN COHORT: Cohort Activity Limitations by Service Group.**



Permanent Residential Aged Care (orange); Home Care Package (grey); Accessed both Permanent Residential Aged Care and Home Care Package (yellow); Nothing - did not access any aged care services (light blue); Received Respite Care +/- Transition care but not Permanent Residential Aged Care or a Home Care Package (green); Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package (dark blue).

**Figure 13. SOUTH AUSTRALIAN COHORT: Proportion of People Receiving Multiple ACATs and Home and Community Care (HACC) Services by Group\*.**



1. Permanent Residential Aged Care 2. Home Care Package 3. Accessed both Permanent Residential Aged Care and Home Care Package 4. Did not access any aged care services 5. Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package 6. Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package. \*These figures include any use of HACC services ever over the reporting period, they do not differentiate by length of time accessing the service(s), or frequency of access.

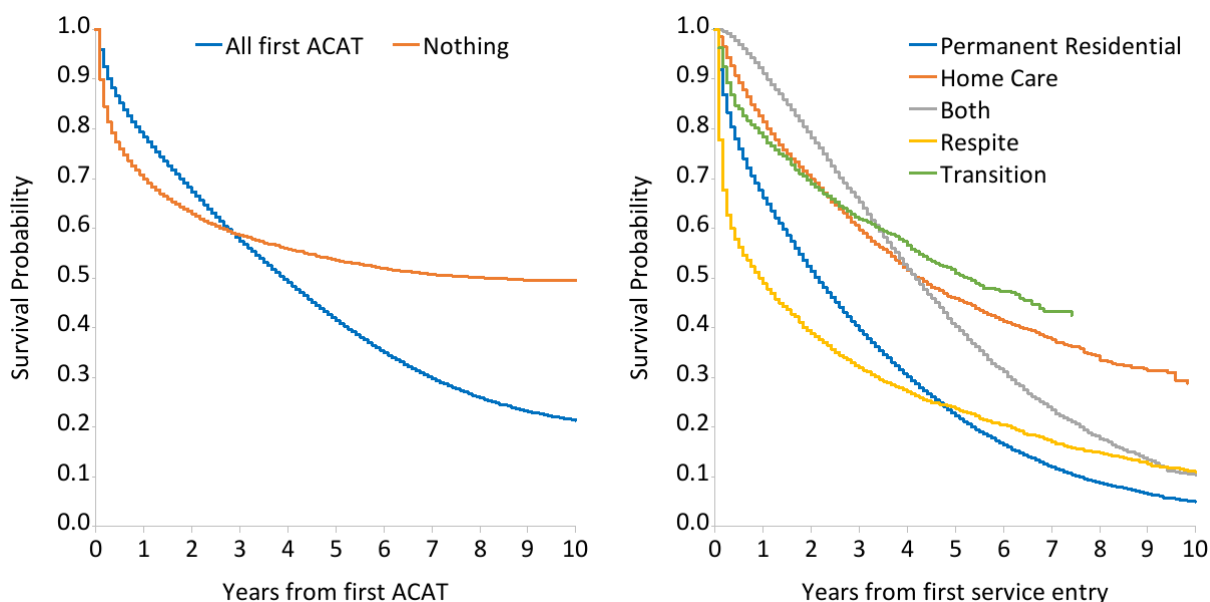
**Table 7. SOUTH AUSTRALIAN COHORT: Summary Follow-up and Crude Survival Estimates for Overall Cohort and by Group.**

Group	Persons N	Deceased at 30 <sup>th</sup> June 2014 N (%)	Follow-up, years (median, IQR) <sup>7</sup>	Years to Death (median, IQR) <sup>7</sup>	30 Day Survival (%, 95%CI) <sup>7</sup>	90 Day Survival (%, 95%CI) <sup>7</sup>	1 Year Survival (%, 95%CI) <sup>7</sup>	5 Year Survival (%, 95%CI) <sup>7</sup>
Overall	87,183	51,269 (58.8)	1.8 (0.5,3.9)	2.5 (0.8,4.9)	96.0 (95.9-96.1)	90.1 (89.9-90.3)	78.2 (78-78.5)	41.3 (40.9-41.7)
Permanent <sup>1</sup>	40,819	29,180 (71.5)	1.2 (0.3,2.9)	1.5 (0.4,3.3)	91.9 (91.6- 92.2)	83.4 (83-83.7)	66.0 (65.6-66.5)	22.1 (21.6-22.6)
Home Care <sup>2</sup>	7,968	3,038 (38.1)	1.2(0.5,2.6)	1.6 (0.6,3.3)	98.5 (98.2-98.7)	94.4 (93.8-94.8)	81.2 (80.3-82.1)	45.5 (43.9-47.1)
Both <sup>3</sup>	8,811	5,469 (62.1)	2.9 (1.6,4.5)	3.2 (1.8,5)	99.9 (99.8-100)	99.3 (99.1-99.4)	91.2 (90.6-91.8)	40.0 (38.8-41.2)
Nothing <sup>4</sup>	20,699	8,905 (43)	0.4 (0.1,1.5)	1.8 (0.3,6.2)	90.0 (89.5-90.4)	81.4 (80.8-81.9)	69.7 (69.1- 70.3)	53.4 (52.7-54.2)
Respite <sup>5</sup>	5,268	3,550 (67.4)	0.2 (0.1,1.2)	0.5 (0.1,2)	90.0 (89.5-90.4)	81.4 (80.8-81.9)	69.7 (69.1-70.3)	53.4 (52.7-54.2)
Transition <sup>6</sup>	4,029	1,329 (33.0)	0.6 (0.2,1.7)	1.4 (0.4,2.8)	77.6 (76.4-78.7)	62.4 (61.1-63.7)	48.5 (47.1-49.9)	23.4 (22-24.9)

IQR=Interquartile Range. CI=Confidence Intervals.

1. Permanent Residential Aged Care 2. Home Care Package 3. Accessed both Permanent Residential Aged Care and Home Care Package 4. Did not access any aged care services 5. Received Respite Care +/- Transition Care but not Permanent Residential Aged Care or a Home Care Package 6. Received Transition Care +/- Respite Care, but not Permanent Residential Aged Care or a Home Care Package 7. Follow up, time to death and survival all calculated from first ACAT for overall and for cohort not receiving services, calculated from first entry into service for all other cohorts.

**Figure 14. SOUTH AUSTRALIAN COHORT: Kaplan Meier Curve of Cohort Survival by Age Care.**



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## F. TECHNICAL REPORT ON ROSA STAGE 1 PREPARATION

Separate document available on request.

## G. ROSA STAGE 1 DATA DICTIONARY

Separate document available on request.