



EXCELC

Exploring Comparative
Effectiveness and Efficiency
in Long-term Care

EXCELC – Exploring Comparative Effectiveness and Efficiency in Long-term Care:

Study Design and Descriptive Statistics for the Austrian Sample of Adult Users of Home Care Services

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EXCELC-project aim

To meet societal and economic challenges, health and care welfare regimes will need to become much more focused on the outcomes that matter to people and deliver these programs effectively and efficiently. Central to this goal is the need to accurately measure outcomes and reflect the value of those outcomes.

EXCELC (Exploring Comparative Effectiveness and Efficiency in Long-term Care) was a cross-country study whose core purpose was to assess the comparative effectiveness and efficiency of community and home-based long-term care (LTC) for older adults and their informal carers in Austria, England and Finland. EXCELC was using the care-related outcome tool, ASCOT, to measure the outcomes of LTC. The study has produced a German and Finnish version of the ASCOT service user and informal carer instruments.

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For the **German ASCOT instruments** for long-term care service users and for informal carers see <https://www.pssru.ac.uk/ascot/translations/> and <https://www.wu.ac.at/en/altersoekonomie/ascot> or <https://www.wu.ac.at/altersoekonomie/ascot> (information in German)

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1 INTRODUCTION

The **EXCELC project** (4/2015-8/2018) had two main analytical aims. First, it aimed to explore the effectiveness of home care service provision by comparing quality-of-life outcomes of home care service users and informal carers across three European countries, Austria, England and Finland. Second, a cost-effectiveness analysis should give insights into the efficiency of service use and provision in the three countries. In order to generate the results, data on home care service users and carers needed to be collected. In total, we aimed for 450 long-term care (LTC) service users and 225 informal carers to be involved in the study in Austria.

The purpose of this document is to provide details on both the **study design of the Austrian data collection** and the main characteristics of the **Austrian home care service-user sample**¹. For information on the study design and the sample description of the Austrian *informal carer data*, see (Trukeschitz/Litschauer et al. 2018)

The document consists of two parts. The first part describes the study design used for data collection of long-term care service users in Austria (Chapter 2). The second part compares the sample to the population of home care service users in Austria and contains descriptive statistics of core variables. The descriptive data cover socio-demographic characteristics (Chapter 3.2), the outcome measure (Chapter 3.3), information on service receipt (Chapter 3.4) and other factors influencing quality of life outcomes. (Chapter 3.5 – 3.8). Finally, we also report on survey administration and completion to give insights into data quality (Chapter 4).

2 STUDY DESIGN

The aim of the data collection in Austria was to generate long-term care service user data that can be compared to the data of the English IIASC study conducted by PSSRU, University of Kent in 2013/2014 (Forder/Malley et al. 2016). The study design for the data collection in Austria drew on the English IIASC study and was developed in collaboration with the research team at the PSSRU, University of Kent. We adapted their approach to the institutional setting in Austria.

The following sections give insights into the definition of the target group (section 2.1) and the data collection process (section 2.2).

2.1 TARGET GROUP OF THE AUSTRIAN SERVICE USER EXCELC-SURVEY

The Austrian part of the EXCELC study included a survey of adult long-term care service users across all nine regions (Laender) in Austria. In order to gain comparative data to the English sample, data collection focused on people aged 55 or older who live at home and receive long-term care services (i.e. home care, home nursing, visiting services and additional support services, such as day care or Meals on Wheels). We also included 24-hour care, i.e. care by a live-in-caregiver, which has gained importance in Austria during the last years. However, people meeting all criteria were excluded from

¹ For information on the study design and characteristics of the Austrian informal carer

the study if they lacked the capacity to participate (e.g. due to cognitive impairments or inability to give their informed consent – ‘beschwaltete Personen’).

2.2 DATA COLLECTION

This section describes the recruitment strategy (section 2.2.1), type and processes of data collection (section 2.2.2) and gives an overview of the topics of the questionnaire (section 2.2.3).

2.2.1 RECRUITMENT STRATEGY FOR SERVICE USERS

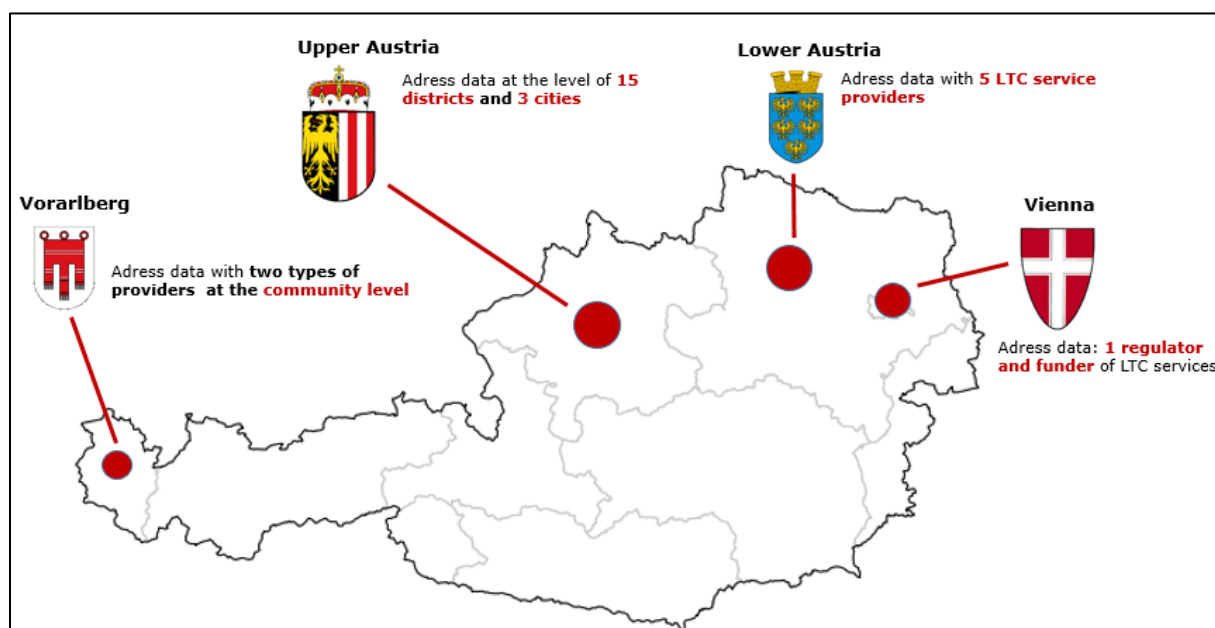
The Austrian long-term care system is characterized by shared responsibilities at the regional and national levels of government. The national level is responsible for the long-term care allowance (‘Pflegegeld’), a universal cash benefit, while nine regions (‘Laender’) regulate and publicly co-fund LTC services (for detailed information see Kieninger/Trukeschitz 2018). These shared responsibilities have led to a significant heterogeneity in long-term care service regulations and institutional arrangements across the nine Laender. Consequently, the diverse institutional setups affected the way of accessing service users for the purpose of this study.

As there are no national records of home care service users in Austria and also no standardized access to home care service users in all nine provinces, the Austrian part of the EXCELC study used two main recruitment approaches. First, we collected data in cooperation with the Austrian Federal Ministry of Labor, Social Affairs and Consumer Protection by drawing on a **national sample** from the Austrian Home Visit and Counseling Program (HVCP). In the HVCP, each year a random sample of some 20,000 LTC allowance recipients living at home are visited by a graduate nurse who assesses the care situation and offers advice and counseling. The HVCP-data contain, amongst others, information on LTC service receipt, age and cognitive capacity of the care recipient. Thus, the data were suitable to draw a sample for the 2014-2016 data for the EXCELC data collection. The sampling guidance was developed in close collaboration with the Federal Ministry of Social Affairs to ensure feasibility and compliance with data protection and ethical standards. The invitation letters and reminder letters were sent out on behalf of the research team.

According to the HVCP-data, only about a quarter to a third of LTC allowance recipients in Austria take up LTC services. Thus, and to ensure that a sufficient number of home care service users participated in the study, the second recruitment approach involved regional governments, administrative units and care organizations (**region-specific approaches**). Data collection at the regional level had to account for the different institutional arrangements in the nine Laender. For example, and as illustrated in Figure 1, access to collaboration partners who sent out invitation letters to home care users differs across the Laender. Whereas in Vienna just one organization holds address data of home care recipients, each of the five providers in Lower Austria, and 15 district administrations and 3 city administrations in Upper Austria needed to be approached and asked for consent. In Vorarlberg, address data of home care and health home care users are stored with different organizations at the community level. The governments of five Laender were approached to discuss regional modes of long-term care service administration and to work out a strategy for

data collection. In four Laender, we directly collaborated with long-term care organizations that cover the majority of the market to discuss options for involving their clients in the EXCELC-study.

Figure 1. Four examples for the diverse institutional setup of home care in Austria



The **local cooperation partners**, comprising non-profit care organizations, local authorities, district administrations, regulators, etc., that agreed to support the study, sent out invitation letters and, when necessary, reminder letters to their home care clients on behalf of the research team. Preferably, and if supported by their data processing systems, invitation letters were personally addressed the home care clients. As was the case in the English IIASC-study (Forder/Malley et al. 2016), in Austria the majority of the letters were also sent by post, only some were distributed via care staff. It was just the regulator and funder of long-term care services in Vienna that only agreed to add an invitation card to a written bi-annual survey to home care clients in Vienna. For this approach, a stratified random sample (the strata was age group) based on the criteria the EXCELC study (age, service receipt and general ability to make decisions) was drawn.

The **invitation letters** (and cards) introduced the EXCELC study, invited the care service users to participate and offered a toll-free telephone number to contact the research team at the WU, the Vienna University of Economics and Business. A brief audio message informed the participants that their phone number was stored successfully and they will be called back within two working days. Calling back, the researchers explained the study aims to the respondents and asked them to answer short screening questions, covering information about the care setting, the contact details, availability of an informal carer who might be interested to be also involved in the study, and whether the potential survey participant agreed that the researchers passed on the information to the interviewers. The details were logged. The researchers answered the questions of the potential study participants during and at the end of the phone call. The research team contacted the interviewer living closest to the LTC service user and passed on the contact details and core information about the potential study participant. The interviewer arranged time and location for the interview that was convenient for the LTC service user.

To cope with the number of potential study participants and the training of interviewers, the **recruitment** was done province by province. The recruitment process started in Vienna in May 2016 and took 18 months in total. Data collection was completed in Upper Austria and Vorarlberg in April of 2017, in Carinthia, Vienna, Lower Austria and Burgenland in summer 2017, and in Styria, Salzburg and Tyrol in fall 2017.

In total, 26,606 letters were sent out by the councils and home care providers (19,070 initial letters plus 7,536 reminder letters). Additionally 111 letters were distributed via care staff. A total of 1,813 contacted the research team (9.5% response rate). Of these, in 99 cases the research team was unable to contact the LTC service user, 623 were out of scope, i.e. did not meet the study inclusion criteria (lacked mental capacity, no service use, living in nursing home) and another 369 did not want to participate in the study. In total, 722 indicated an interest in participating in the study and met the study inclusion criteria. A total of 645 valid interviews were included in the final dataset. (see Table 1)

Table 1. Fieldwork outcomes

Outcome	n
Number of letters sent out or distributed personally	26,717
Number of LTC service users in contact with research team	1,813
Number of positive return (i.e. met inclusion criteria and interested in study)	722
Number of valid interviews with users of LTC care services	645
Out of scope (lacked mental capacity to participate or in nursing/residential care)	623
LTC service user declined to participate when contacted by research team	369
Research team unable to contact the LTC service user during fieldwork period	99
LTC service user declined to participate when contacted by fieldworker	74
Not available during fieldwork period	2
Retrospective request to remove data from the study after interview completed	1

Source: EXCELC INT SU AUT 2016/2017

In six of the nine Laender reminder letters were sent out. In general, reminder letters resulted in a much higher response rate: for example, in the region of Salzburg, 2,282 LTC service users were approached by the home care provider. The initial invitation letter resulted in 31 contacts with the research team (1.4% response rate), whereas the reminder letter resulted in 177 contacts (7.8% response rate).

Addressing the home care clients personally in the invitation letters did make a difference. In the case where the regulator of long-term care services only added our invitation card to their survey to home care clients (5,000 letters) this resulted in only 22 interviews. The 400 personally addressed letters from a provider resulted in 37 interviews.

2.2.2 CONDUCTING THE INTERVIEWS WITH LTC SERVICE USERS

Data were collected through computer-aided personal standardized interviews (CAPI) with tablet computers. The research team applied the online survey software 'Qualtrics' (<https://www.qualtrics.com/de/>) to program the questionnaires. To account for the regional

differences in long-term care service availability and service names, a questionnaire was programmed for each of the regions. To assure that the software also runs smoothly in remote and mountainous areas with no or unstable internet connection, we bought a license for the Qualtrics offline-App. In addition, show cards were used to facilitate the interview process.

Members of the research team at the Vienna University of Economics and Business conducted the 34 interviews of the pilot study in Vienna and Lower Austria to gain experience with the software, the questions, and the respondents. Their experiences contributed to improving the questions and the flow of the survey.

63 interviewers conducted the majority of fieldwork. The interviewers had a background in social science (sociology, social work, pedagogics, business administration, economics, health sciences and law). Some were still in education. The interviewers were between 22 and 60 years old, most of them young adults. More than two-thirds were women. We recruited interviewers who were able to speak the regional dialects of the LTC service users we planned to approach. Thus, our interviewers came from all nine Austrian regions (Laender).

To prepare the interviewers for their task, we organized interviewer-training sessions. In total, we conducted 15 interviewer training sessions in five Austrian cities. Most sessions, however, took place in Vienna. The interviewer training lasted 3.5 hours each and covered the aims of the EXCELC-study, information about the collaboration and the contract, tips for working with the tablet and the survey offline app, briefings about interviewing older people, the importance of obtaining the interviewees' voluntary agreement to participate prior to the interviews (signed informed consent), region-specific explanations about long-term care services and a briefing about the questionnaire.

On average, one interviewer conducted 14 interviews (min. 1 and max. 28 interviews). For details see section 4.2 The interviewers were asked to keep close contact with the regional coordinator of the research team at the WU Vienna University of Economics and Business to report on the arranged dates for the interviews and interesting details of the interview, covering process and results. Before the interview started, the interviewers explained the purpose of the study and the processing of the data, handed over the information sheet, answered questions, ensured that the interviewee had comprehended the information and obtained written informed consent. The interviewees received a copy of both the information sheet and informed consent. The length of an interview was between 1 and 2 hours, depending on the chats in between and the answering speed of the respondent (for details on the survey delivery see section 4).

2.2.3 THE EXCELC-SERVICE USER QUESTIONNAIRE

The relevant parts of the English IIASC-questionnaire were either translated into German or existing German instruments (e.g. EQ5D) were taken. The data collected in the interviews addressed:

- socio-demographic information
- support needs
- service receipt and informal support
- social care related QoL using the German version of ASCOT for service users

- quality of life (QoL) and health
- suitability of home and local environment for mobility needs
- control and autonomy
- social contact and support
- questions to check for interviewee behavior

3 THE LTC SERVICE USER SAMPLE FOR THE AUSTRIAN EXCELC STUDY

In total, 645 interviews with LTC service users were conducted. 11 were excluded because of young age and 1 because of no service receipt at time of the interview – the final number of LTC service users in the sample is 633.

The following sections contain descriptive statistics of the core variables and quality of life outcomes of the home care service user sample.

3.1 COMPARISON TO POPULATION OF LONG-TERM CARE SERVICE USERS

Information on the number and characteristics of home care service users in Austria is limited. Since 2012, the Laender (regions) have been obliged to forward information on home care service users to the national statistical office, called Statistics Austria. According to Statistics Austria, information on home care is only available for the total number² and regional distribution of home care users, by care level, age and sex. The comparison of the sample to the population builds on these three characteristics.

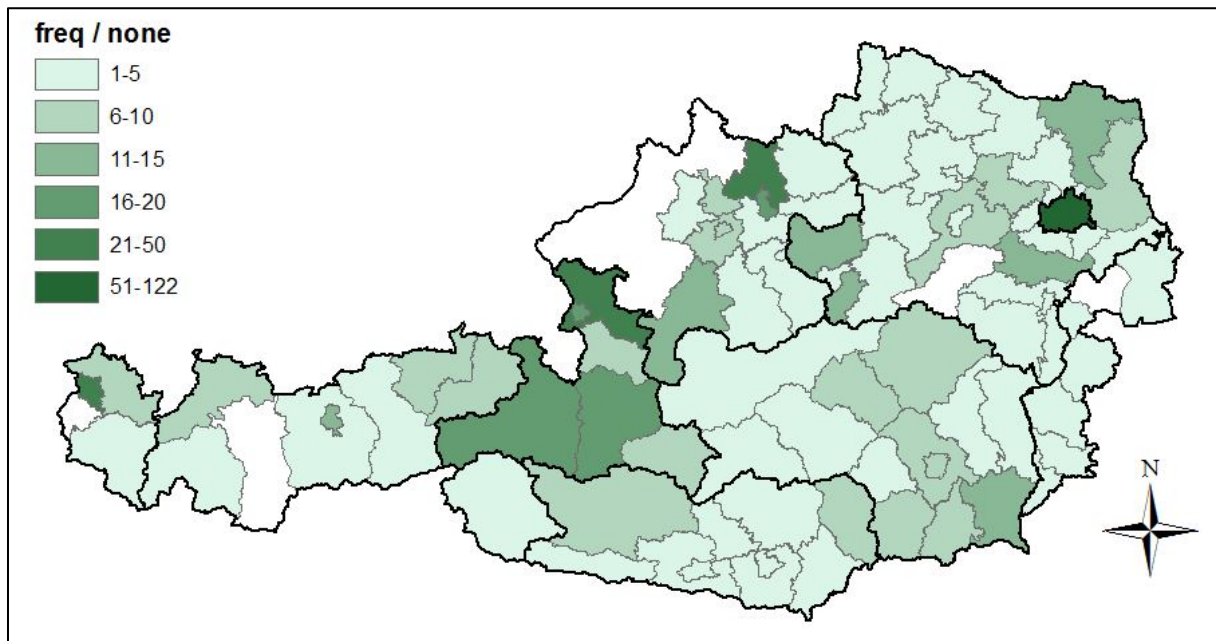
Overall, the Austrian sample of home care service users reflects the characteristics of LTC service users in Austria.

3.1.1 REGIONAL DISTRIBUTION OF INTERVIEWS

Overall, 633 recipients of home care services from all nine Austrian Laender and almost all 79 districts of Austria were interviewed (see Figure 2 and Figure 3). The nationwide distribution was important for the study to cover the heterogeneity of the country and to capture the regional differences across the country with respect to its topography and the variety of regulation, provision and organization of services that still prevail. As presented in Figure 2, the highest number of interviews took place in the capital of Vienna, followed by Salzburg and the surrounding area, and the Western city of Dornbirn. There are also some rural areas, like the south-western districts in the province of Salzburg and the northern surrounding of Linz with a higher share of interviews.

² In 2016 and 2017 the exact number of total home care services were not available as some Laender could only provide a tentative number of service recipients (see BMASK 2017).

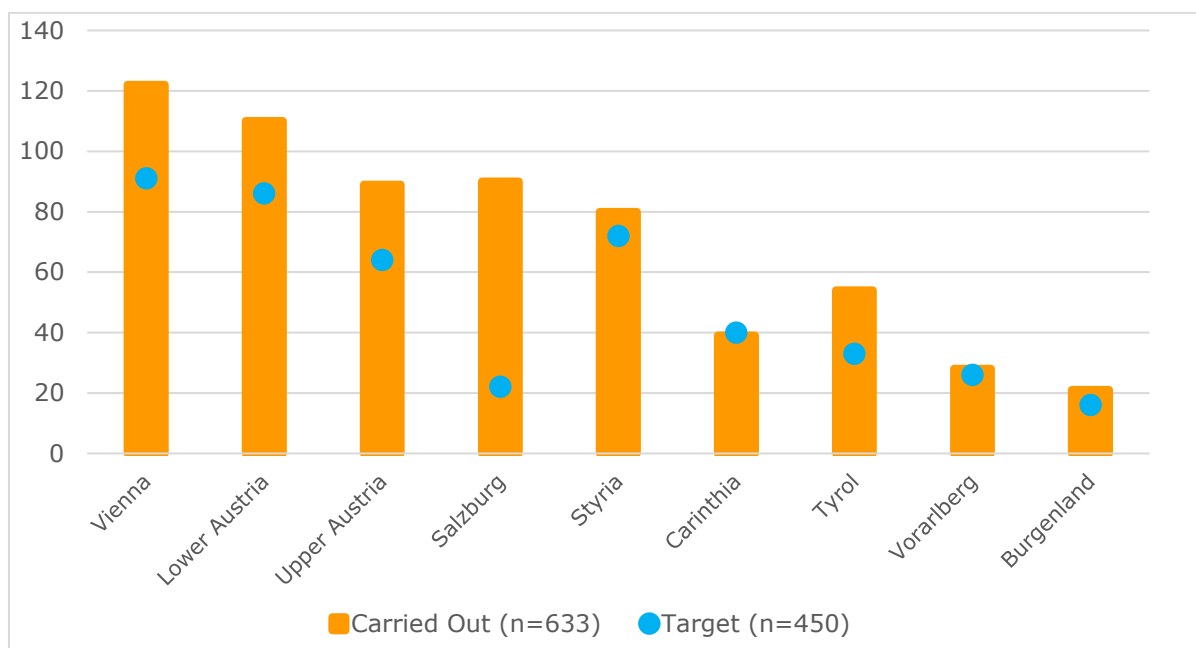
Figure 2. Interviews by district



Source: EXCELC INT SU AUT 2016/2017

Figure 3 illustrates the home care service users divided by regions and compares the target numbers to the actual sample. The targets for the LTC service user interviews in each province were derived from the number of LTC service users per region (BMASK 2015). In Vienna, a total of 122 interviews were carried out, exceeding its target by almost a third. In all other regions, except for the two smallest and outlying provinces of Vorarlberg and Burgenland, the actual sample was also higher than the targets. For Salzburg, the province with the third smallest population, the target was exceeded threefold due to a very successful recruitment process.

Figure 3. Home care service users by region (Land), (Target and EXCELC SU sample)



Source: EXCELC INT SU AUT 2016/2017 and BMASK (2015: 101 ff.)

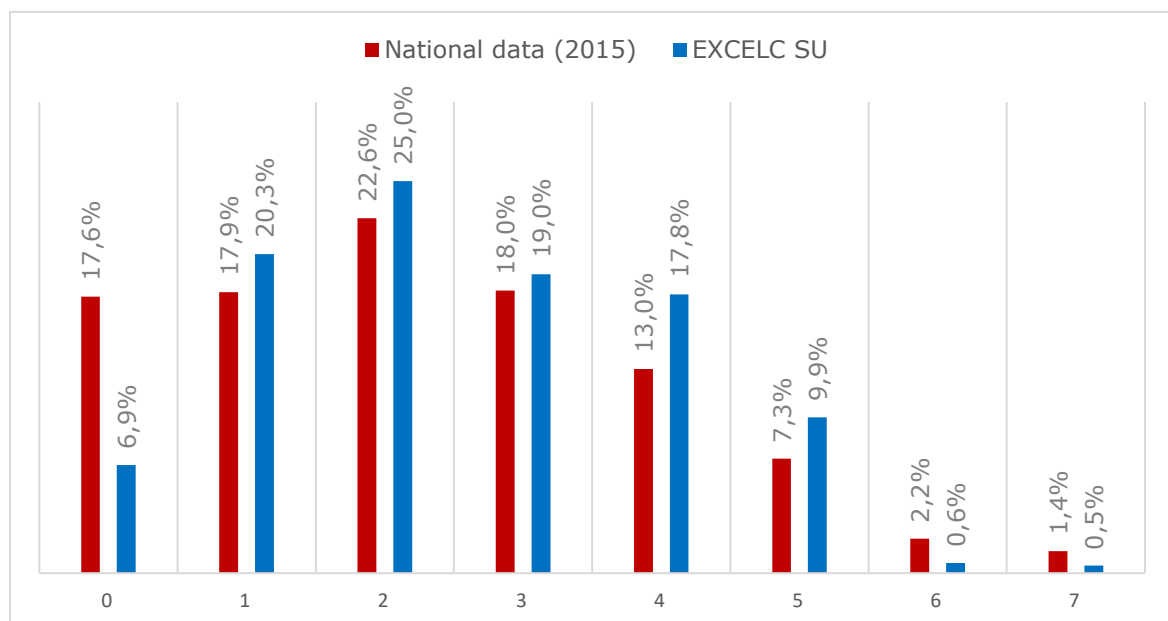
3.1.2 LONG-TERM CARE ALLOWANCE LEVELS

The long-term care allowance is a national universal cash benefit for people in need of long-term care for more than 65 hours per month. Seven levels reflect the intensity of need. The lowest LTC allowance level supports care-dependent people with EUR 157.30 per month for people who require support between 65 and 95 hours per month. People who are in need of more than 180 hours of support per month and are unable to move their legs and arms intentionally are eligible for an LTC allowance level 7 with EUR 1,688.90 per month.

Figure 4 shows that the participants in our sample categorized by the level of LTC allowance correspond to the national data except for the subgroup of clients that did not receive LTC allowance at the time of the interview. This number is not representative of national statistics because the study focuses on publicly funded care services for people in need of care. Participants who were not eligible for LTC allowance and did not have access to public support for LTC services (out-of-pocket clients) were not part of the target group. However, people who were in the process of applying for LTC allowance or still received publicly funded LTC services (because of a low household income) were included in the sample.

According to national data, the majority of people in need of long-term care received LTC cash benefits within the first three levels, which was represented by our sample. The number of participants that are granted LTC allowance at level 6 or 7 was smaller due to higher physical and mental restrictions that affected these subgroups and limited their capacity to participate in the survey.

Figure 4. Home care service users by LTC allowance level (national data and EXCELC SU sample)

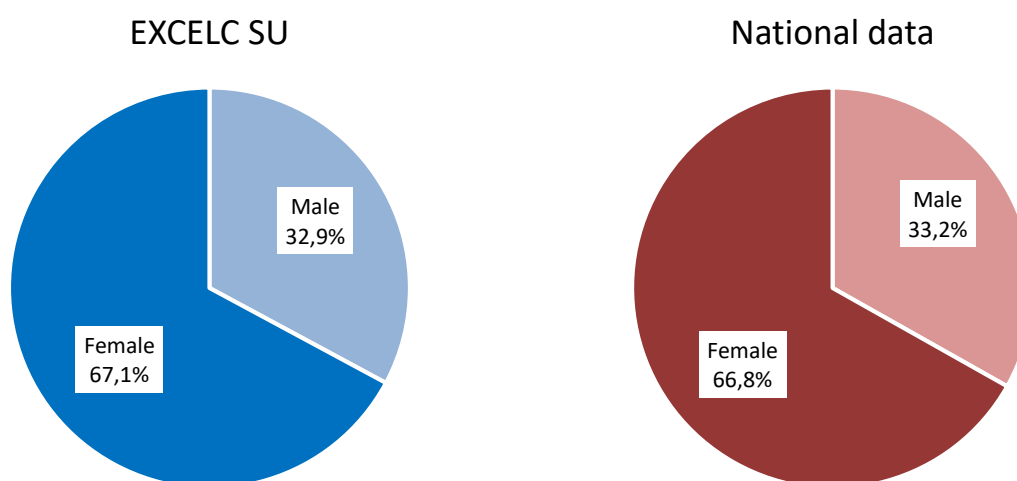


Source: EXCELC INT SU AUT 2016/2017 (n=625) and Statistik Austria (2017a) (n=452,601)

3.1.3 GENDER

Consistent with the national data, the LTC service user sample has more than twice as many women as men (illustrated in Figure 5). However, this does not mean higher support needs for women in general since the healthy life expectancy in Austria is nearly the same for men and women aged 65 (Eurostat 2017). Two other factors may yet provide an explanation. On one hand, the shorter life expectancy of men leads to a higher share of widowed women, who consequently have to rely more on professional help. Another explanation lies with the unequal distribution of informal care that is still borne by more women than men (Arbeiterkammer Wien 2014) and may substitute for professional LTC services. Hence, there are more women taking care for their husbands than the other way around and consequently fewer men who depend on formal care.

Figure 5. Home care service users by sex (national data and EXCELC SU sample)



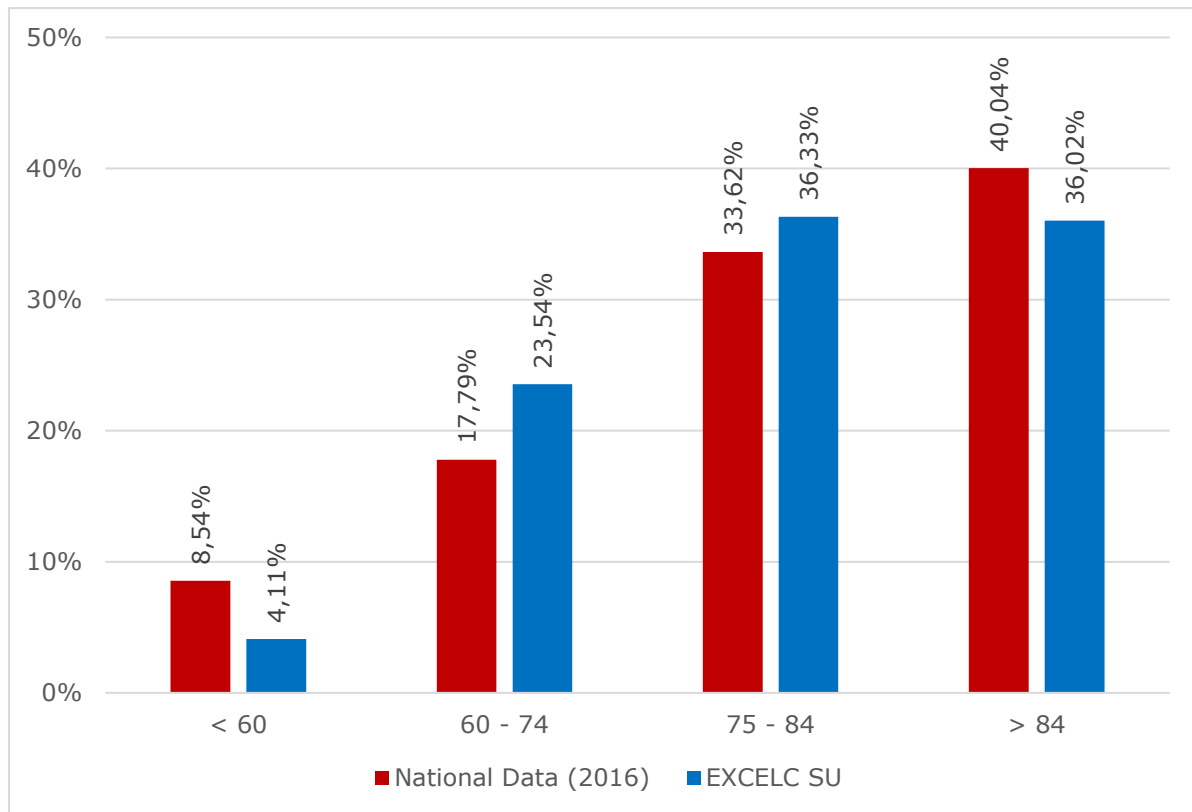
Source: EXCELC INT SU AUT 2016/2017 (n=633) and BMASK (2017: 194) (n=93,058)

3.1.4 AGE GROUPS

Looking at the age groups of home care service users in Figure 6, the data reflects a similar distribution between the national data of our target group. The two age groups on the edges, however, differ to varying degrees from the national data. The subgroup of service recipients below the age of 60 is underrepresented compared to the national sample, due to the fact that we excluded LTC service user recipients below the age of 55.

The number of LTC service users aged 85 and over is slightly smaller in our sample as it was more difficult to find potential participants who were eligible for the survey and willing to participate in the study. Reasons for this may include limited mental capacities but also added reluctance by the invited participants who reported feeling too old, too tired or too weak to participate in the study or were more stressed and upset concerning the idea of an interview situation.

Figure 6. Home care service users by age group (national data and EXCELC SU sample, n=633)



Source: EXCELC INT SU AUT 2016/2017 (n=633) and BMASK (2017: 195) (n=91,248)

3.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF LTC SERVICE USERS IN THE SAMPLE

Distribution of the LTC service user sample according to the socio-demographic characteristics, including age, sex, marital status, living arrangement and long-term care allowance is shown in Table 2. In total 633 LTC service users were interviewed. The sample has more females than males, and a skewed distribution of respondents across the age groups 55 to 64, 65 to 74, 75-84 and 85 and over with more older respondents (75 and older).

Almost 50% of the LTC service users in the sample were widowed, 15% were separated, another 15% had never married and just over 20% were currently married. In line with this picture, just over 20 percent reported living with a spouse or partner and slightly over ten percent reported living with other adults or children. The majority, namely three-quarters of the sample, stated living alone. Only a small proportion of respondents had missing data for these variables.

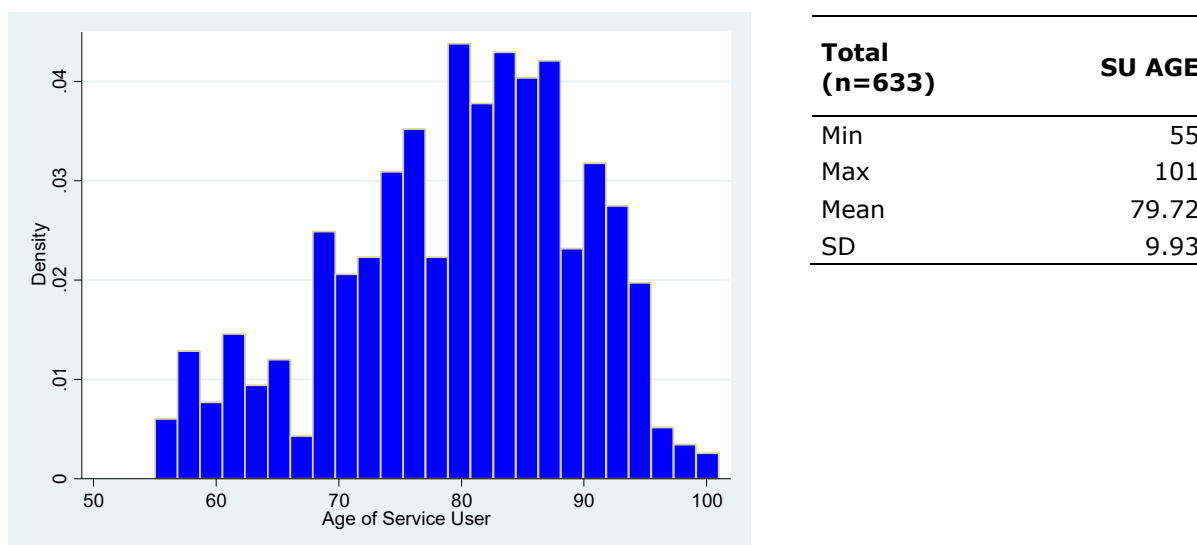
Table 2. Socio-demographic characteristics of the home care service user sample, Austria

	n	%
Age group		
55-64	59	9.32
65-74	116	18.33
75-84	230	36.33
85 and over	228	36.02
Sex		
Female	425	67.14
Male	208	32.86
Education		
Lower secondary and below	269	42.50
Upper secondary, post-secondary and short-cycle tertiary	290	45.81
BA/MA/PhD	74	11.69
Marital Status		
Never married	92	14.53
Married	130	20.54
Divorced	95	15.01
Widowed	314	49.61
Missing	2	0.32
Living arrangement		
Lives alone	410	64.77
Lives with partner	132	20.85
Lives only with adults who are not partner	74	11.69
Lives only with children	4	0.63
Missing	13	2.05
Long-term care allowance level		
Level 0	43	6.79
Level 1	127	20.06
Level 2	156	24.64
Level 3	119	18.80
Level 4	111	17.54
Level 5	62	9.79
Level 6	4	0.63
Level 7	3	0.47
Missing	8	1.26
TOTAL	633	100.00

Source: EXCELC INT SU AUT 2016/2017

Figure 7 illustrates a detailed picture of the age distribution of the LTC service user sample with ages of ranging from 55 (required minimum age) to 101 (no maximum age fixed) and an average age close to 78.

Figure 7. Age distribution of the home care service user sample, Austria



Source: EXCELC INT SU AUT 2016/2017

3.3 QUALITY-OF-LIFE OUTCOMES USING ASCOT FOR SERVICE USERS

To measure the effects of social care interventions on quality of life the Adult Social Care Outcome Toolkit for service users (ASCOT) was used. The instrument was originally developed at the University of Kent and was now for the first time used in Austria within the course of the study. It focuses on those areas of life of a person that can be influenced by LTC services and includes eight domains of Social Care Related Quality of Life (SCRQoL). ASCOT for service users comprises basic needs (*Personal cleanliness and comfort, Food and drink, Accommodation and Personal safety*) and higher order needs (*Control over daily life, Social participation and involvement and Occupation*). For each of the eight domains information was collected on the current and the expected SCRQoL. The current SCRQoL measures the current situation with services in place whereas the expected SCRQoL estimates what QoL would be in absence of services (Netten/Forder et al. 2011). Respondents were asked to rate their current and expected situation on a four-point scale (high needs, no needs, some needs, high level needs).

Overall assessment of one’s quality of life was measured using the variable of life satisfaction.

3.3.1 OVERALL QUALITY OF LIFE OF LTC SERVICE USERS

The distributional statistics for the overall quality of life reported by the care service recipients - including all the good things and bad things in a person’s life - are shown in Table 3. Data shows that the majority (over 40%) of care service recipients reported a good quality of life and for more than 85% overall quality of life seemed to be at least alright or better. Close to 8% of the respondents indicated a bad quality of life and less than 3.5% reported that their life satisfaction was very bad or even worse.

When participants were asked to compare life satisfaction with the life situation experienced six months ago the responses show quite a symmetric distribution (see Table 3): more than half of the respondents indicated that nothing changed in comparison with the reference period, while the rest is quite evenly distributed between the two other categories showing 22.75% of respondents who indicated a worsening and 20.38% an improvement of their quality of life.

Table 3. Quality of life at present and compared with 6 months ago

	n	%
Quality of life		
So good it can't be better	30	4.74
Very good	83	13.11
Good	261	41.23
Alright	183	28.91
Bad	51	8.06
Very bad	11	1.74
So bad it couldn't be worse	10	1.58
Missing	4	0.63
Quality of life compared with 6 months ago		
Better	129	20.38
Much the same	355	56.08
Worse	144	22.75
Missing	5	0.79
TOTAL	633	100

Source: EXCELC INT SU AUT 2016/2017

3.3.2 HOME CARE AND LTC SERVICE USERS' QUALITY OF LIFE USING ASCOT FOR SERVICE USERS

Figure 8 (on page 16) illustrates the social care-related quality of life of home service users for each domain comparing the current state (with LTC services) and the expected state (without LTC services) captured with ASCOT for informal carers.

The dignity domain differs in regard to current versus expected outcomes: the first situation reflects how LTC services affect the individual's self-esteem (*The fact I need help*) and a second question assessed how the way care is delivered impacts an individual's self-esteem (*The way I am helped*). This subchapter contains results in detail. For the cobweb diagrams see Trukeschitz/Hajji et al. (2018).

Considering the current situation with support of LTC services, LTC service users reported a high quality of life for the domains related to basic needs, that is: *Personal cleanliness, Food and drink, and Accommodation and comfort* (see Figure 8). In all three domains, more than 90% of LTC service users reported that they were completely or sufficiently satisfied in their situation with services. In detail, greater than 66% of the sample reported having as much to eat and to drink as they want, whenever they want, and 28% reported having enough food at adequately timed intervals. 65% of LTC service users stated feeling clean and comfortable and being dressed in the way they want and 32% reported feeling sufficiently clean and appropriately dressed. Similarly, 59% of the LTC service

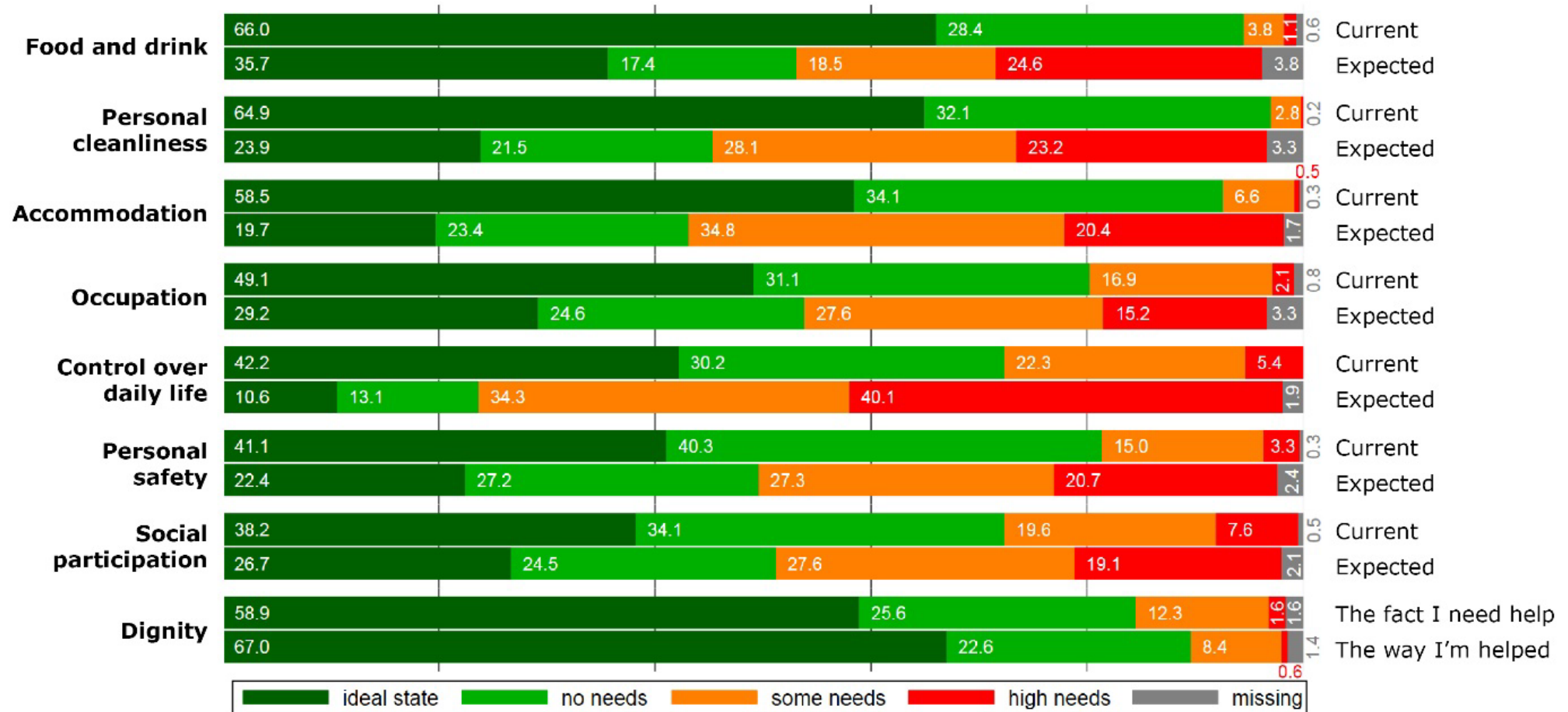
users reported living in a home environment that is as clean and comfortable as they can imagine and 34% reported a sufficiently clean accommodation.

Quality of life in the other domains capturing higher-order needs, such as *Personal safety*, *Social participation*, *Control over daily life*, and *Occupation* was lower, but there were still between 72 and 80% of LTC service users reporting an ideal state or no needs for these domains. *Control over daily life* and *Social participation* rendered the lowest outcome with about 72% each.

Figure 8 also shows the expected quality of life for all domains in an imagined situation without LTC services. For all domains, the situation would be worse without support of LTC services and quality of life would be lowest for *Control over daily life*: only 24% reported that they would have as much or adequate control over their daily lives without professional help. 40% reported that they would have no more control over their daily lives (high needs). Quality of life would also be much more limited for *Accommodation* and *Personal Cleanliness*, for which more than 50% of LTC service users reported some needs or high needs without the use of services. For the remaining domains, *Food and Drink*, *Occupation*, *Personal safety* and *Social participation*, between 42 and 46% of LTC service users reported some needs or high needs in a situation without services.

With regard to *Dignity*, the majority of LTC service users reported a positive influence of receiving help on their well-being (59%) and 26% indicated no impact of help. An even higher percentage of LTC service users reported a positive impact of the way LTC services are carried out on their self-esteem: 67% reported that the way they are helped makes them think and feel better about themselves. 22% of LTC service users reported no influence of professional support on their self-esteem. Fewer than 10% were unhappy with the way they were treated and occasionally experienced negative influence on their self-esteem.

Figure 8. Current and expected LTC-service related quality of life using ASCOT for service users



Source: EXCELC INT SU AUT 2016/2017, n=633

The ratings of LTC service users' current QoL was on average higher than the expected QoL in absence of services, indicating an impact of LTC services on people's quality of life (see Table 4). The difference between the current SCRQoL and the expected SCRQoL is the SCRQoL gain that measures the impact of home care services on the quality of life related to the single domains. The impact of LTC services on QoL were highest for the domains related to basic needs which already performed best with respect to current outcomes. The domains related to higher-order needs show on average lower impacts on SCRQoL with the exception of the *Control of daily life* domain, which had the highest LTC-service induced gain. The lowest gain was reported on average for the domain of *Personal Safety* and *Social participation*. On average, home care services seem to have a bigger impact on physiological needs, such as personal cleanliness and accommodation and food but to a bit lower extent on social and safety needs.

The majority of LTC service users reported a positive impact of LTC services on their QoL. This is in particular the case for *Control over daily life*, *Personal cleanliness and comfort* and *Accommodation and comfort* with the mean exceeding the standard deviation. For the five other domains, the difference between mean and standard deviation can be negative, indicating that some LTC service users may experience a negative impact of LTC services on this specific aspect of their QoL.

Table 4. Distributional statistics for current and expected ASCOT scores and ASCOT domains for the service user measure

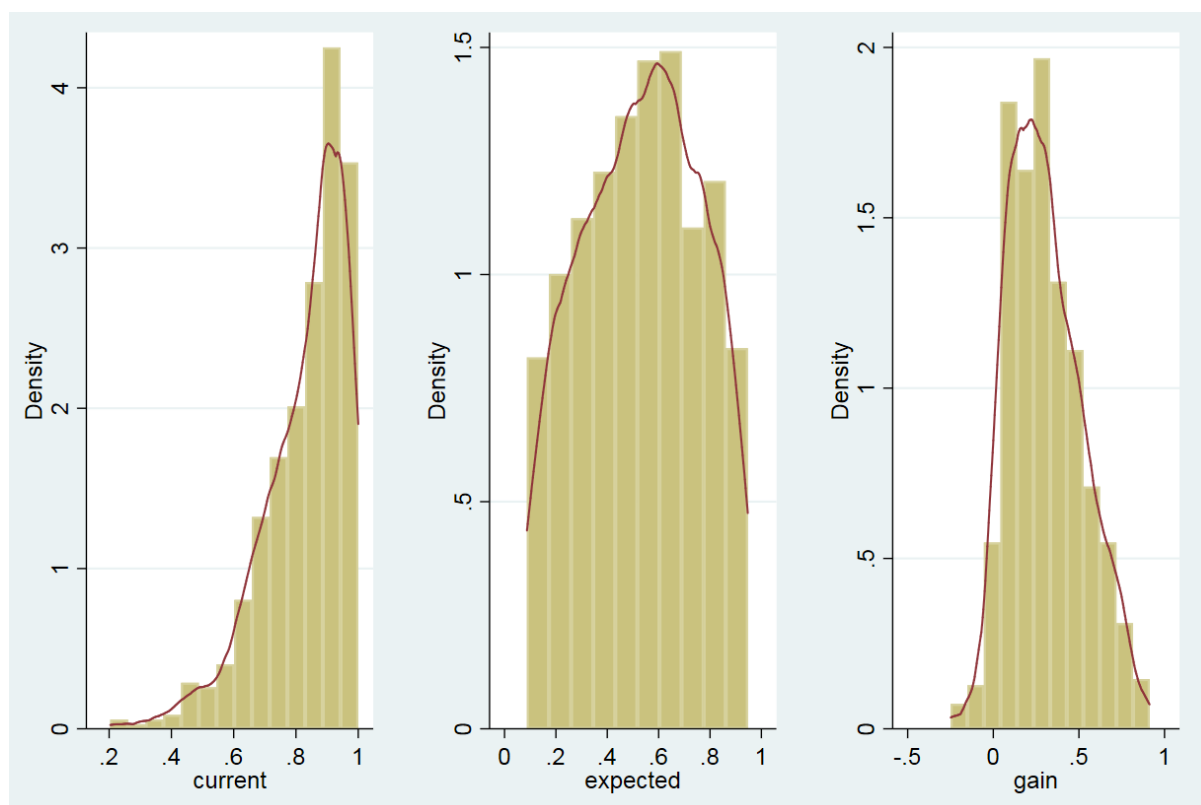
	Current Mean (SD)	n	Expected Mean (SD)	n	Impact Mean (SD)	n
ASCOT: index	18.92 (3.38)	612	12.97 (5.21)	569	5.97 (4.58)	567
ASCOT: preference-weighted ^a	0.83 (0.14)	612	0.53 (0.23)	569	0.30 (0.22)	567
Control over daily life	2.09 (0.92)	633	0.94 (0.99)	621	1.15 (1.07)	621
Personal cleanliness and comfort	2.62 (0.55)	633	1.48 (1.11)	612	1.14 (1.10)	612
Food and drink	2.60 (0.62)	629	1.67 (1.22)	609	0.93 (1.16)	609
Accommodation and comfort	2.51 (0.64)	631	1.43 (1.03)	622	1.07 (1.05)	621
Personal safety	2.19 (0.81)	631	1.53 (1.07)	618	0.66 (0.99)	617
Social participation	2.03 (0.94)	630	1.60 (1.09)	620	0.44 (0.84)	618
Occupation	2.28 (0.82)	628	1.70 (1.06)	612	0.58 (0.95)	612
Dignity ^b	2.58 (0.67)	624	n/a		n/a	

Notes: ^a preference-weighted index uses weights derived directly from the best-worst scaling experiment conducted in the EXCELC project; the score ranges between 0 and 1. ^b 'the way I'm helped'

Source: EXCELC INT SU AUT 2016/2017, own calculations

Figure 9 illustrates the distribution of LTC service users' QoL. The density values on the x-axis account for the relative frequency of QoL states. The graphs show a negatively skewed and peaked distribution for the current score but an approximately normal distribution for the expected and gain index. The ASCOT current index reflecting the current situation of Austrian home care service users has its peak close to 1 (maximum value for the index) which represents a relatively high share of LTC service users reporting an ideal state of current QoL. The gain index has a peak around 0.3 which reflects the average effect of LTC services on quality of life across all eight domains.

Figure 9. Preference weighted score for ASCOT for service users



Source: EXCELC INT SU AUT 2016/2017, n=612|569|567

3.3.3 FEASIBILITY OF THE ASCOT-SURVEY FOR LTC SERVICE USERS

To have some evidence for the feasibility of using ASCOT for service users we used self-ratings by the participants and ratings by the interviewers of the understanding of ASCOT with regard to the expected situation in absence of services. In almost 70% of the cases, the interviewer reported that the participant had a complete understanding of the ASCOT or understood a great deal of the task (shown in Table 5).

According to the interviewers' perception, also 60% of the participants appeared to have very carefully or carefully reflected on the hypothetical question about a situation in absence of services. Only slightly more than 50% of the participants, however, reported that they found it very easy or quite easy to answer the hypothetical questions and 50% of the participants also reported difficulties in assuming that no one else would step in when thinking of the hypothetical situation. It has to be considered that the hypothetical questions demand a rather high cognitive ability and some respondents seemed to lack the capacity to have the right understanding of the task. However, the results of the cognitive interviews on ASCOT for service users showed that rating the answering of the expected questions as difficult had different meanings. Some respondents said they found the expected situation difficult to imagine because it would not be possible to handle anymore (but they were able to imagine it) and other respondents simply had difficulties to imagine it without thinking of other family members to step in.

Table 5. Understanding of ASCOT for service users

	n	%
Understanding of ASCOT (recorded by interviewer)		
Understood completely	256	40.44
Understood a great deal	178	28.12
Understood a little	137	21.64
Did not understand very much	54	8.53
Did not understand at all	8	1.26
Reflection on expected question (recorded by interviewer)		
Very careful consideration	163	25.75
Careful consideration	226	35.70
Some consideration	160	25.28
Little consideration	73	11.53
No consideration	10	1.58
Missing	1	0.16
Answer the expected questions		
Very easy	181	28.59
Quite easy	166	26.22
Neither difficult nor easy	82	12.95
Quite difficult	112	17.69
Very difficult	66	10.43
Missing	26	4.11
Assume that no other help would step in		
Very easy	86	13.59
Quite easy	99	15.64
Neither difficult nor easy	75	11.85
Quite difficult	167	26.38
Very difficult	153	24.17
Missing	53	8.37
TOTAL	633	100

Source: EXCELC INT SU AUT 2016/2017

3.4 SERVICE RECEIPT AND INTENSITY OF PROVISION

This section focuses on the amount of help people need in their everyday life as measured by the amount of help needed with the (instrumental) activities of daily living (I)ADLs and the sufficient or lack of support through informal and formal help with the individual tasks. It also includes information on the frequency of receipt of different publicly-funded services and their intensity of provision.

3.4.1 FORMAL OR INFORMAL SUPPORT BY TASK AND ADDITIONAL SUPPORT REQUIRED

Table 6 lists all (I)ADLs people received help or needed more help with. When looking at the results, it is useful to keep in mind that two thirds of the participants in our study received LTC allowance level 3 or below and only 1.1% had an LTC allowance level 6 or 7, therefore needing a higher level of support.

Table 6 shows that the tasks most of the people need and receive help with are instrumental tasks, such as *Housekeeping or laundry* (87%), *Shopping* (80%), *Getting out of the house* (66%) and *Managing paperwork and finances* (58%). The two basic tasks most people got support with were *Personal hygiene* (66%) and *Dressing or undressing* (47%). Three quarters stated receiving help with *taking medicines* and *Getting up and down the stairs*. More than a quarter of the respondents also reported receiving help with *Eating or cutting food* and *Getting in and out of bed*.

On average, home care recipients in Austria seemed to be satisfied with the amount of support they received for their activities of daily living (Table 6). For 9 out of the 13 (I)ADLs, only few people (between 1 and 7%) wanted more help than they received, the rest seemed satisfied. More help, however, was required for routine housekeeping and laundry tasks, where close to 20% reported that they wanted more help with this activity. Another 14% seemed to prefer more help with transport or getting out of the house, which is a limiting factor when participating in social or cultural activities out of the house. The only basic task that is mentioned by a higher number of service recipients to prefer more help with is taking a bath or a shower (10%).

Table 6. Help with (instrumental) activities of daily living of the home care service user sample, Austria

Total (n=633)	Received help		Wanted more help	
	n	%	n	%
Routine housework or laundry	549	86.73	126	19.91
Shopping	508	80.25	65	10.27
Taking a bath or shower	419	66.19	65	10.27
Getting out of the house	418	66.03	87	13.74
Paperwork or paying bills	370	58.45	34	5.37
Dressing or undressing	300	47.39	45	7.11
Taking medicine	220	34.76	8	1.26
Getting up and down the stairs	209	33.02	37	5.85
Getting in and out of bed	183	28.91	19	3.00
Eating, including cutting up food	163	25.75	15	2.37
Getting around indoors	143	22.59	13	2.05
Using the toilet	142	22.43	17	2.69
Washing hands and face	103	16.27	10	1.58

Source: EXCELC INT SU AUT 2016/2017

3.4.2 MET & UNMET NEEDS, ADDITIONAL SUPPORT REQUIRED

Table 7 shows the distribution of ADL and IADL met and unmet needs that on average show a low percentage of unmet needs in relation to each (I)ADL. Met and unmet needs are defined according whether the respondent reporting a need is receiving help or not. A need is defined as either being able to complete the task with help or being unable to do the activity. Unmet needs appeared to be by far the greatest when it comes to getting up and down the stairs with more than 23% of the sample reporting that they do not receive help but need it. Looking at this number, however, it has to be considered that respondents were asked to exclude any equipment or mechanical devices, such as a stair lift or elevator they may use for mobility activities (for data on the use of equipment by tasks see section 3.5.2). The same applies for another activity related to mobility: getting out of the

house, where close to 10% appeared to have unmet needs. For all basic activities the help needed matched quite well with the help received and on average only around 3% of the ADLs seem to show an unmet need.

Table 7. (Un)met needs with (instrumental) activities of daily living of the home care service user sample, Austria

Total (n=633)	Unmet need		Met need		No need		Missing	
	n	%	n	%	n	%	n	%
Getting up/down the stairs	137	21.64	146	23.06	334	52.76	16	2.53
Getting out of the house	61	9.64	312	49.29	258	40.76	3	0.32
Shopping	50	7.90	428	67.61	143	22.59	12	1.90
Taking a bath or shower	40	6.32	379	59.87	213	33.65	1	0.16
Paperwork or paying bills	37	5.85	281	44.39	303	47.87	12	1.90
Routine housework/laundry	36	5.69	433	68.40	152	24.01	12	1.90
Dressing or undressing	26	4.11	218	34.44	389	61.45		
Getting around indoors	20	3.16	50	7.90	563	88.94		
Taking medicine	15	2.37	153	24.17	461	72.83	4	0.63
Using the toilet	18	2.84	92	14.53	522	82.46	1	0.16
Eating, incl. cutting up food	15	2.37	83	13.11	534	84.36	1	0.16
Washing hands and face	10	1.58	51	8.06	572	90.36		
Getting in and out of bed	10	1.58	115	18.17	508	80.25		

Source: EXCELC INT SU AUT 2016/2017

3.4.3 FORMAL SUPPORT – TYPES OF SERVICES

There is a variety of publicly-funded home care services (such as home care, home nursing, 24-hour care and visiting services), region-specific home care services (e.g. housekeeping service) and support services (such as Meals on Wheels, day center, patient transport, sheltered housing) available for people in need of care (Kieninger/Trukeschitz 2018). As a result of our sampling strategy (see chapter 2) the majority received home care services. Looking at the frequency of service-receipt, the majority received home care services followed with a larger margin by the 24-hour home care service (see Table 8). Regarding additional support services, a quarter of the sample used Meals on Wheels, a delivery service that brings meals in peoples' households. Another support service that is widely used among people in need of care is the personal alarm service that allows people to call for assistance when they have an accident or fall at home. Nearly 44% of all sample members reported the use of this service.

Table 8. Utilization of services by type of service

Total (n=633)	n	%
Home Care Worker	387	61.14
Alarm	276	43.60
Home Nurse	261	41.23
Meals on Wheels	161	25.43
Patient transport	120	18.96
24h Care	82	12.95
Special regional home care services	44	6.96
<i>Specialized social work for older people (FSBA)</i>	31	4.90
<i>Housekeeping Service</i>	11	1.74
<i>Blocked Care</i>	2	0.32
Volunteer / Visiting Service	33	5.21
Day center	31	4.90
Other	10	1.58
Personal Assistant	9	1.42
Warden/sheltered house manager	7	1.11

Source: EXCELC INT C AUT 2016/2017

3.4.4 INTENSITY OF HOME CARE SERVICE PROVISION

Intensity of publicly-funded care services can be captured by number of care hours provided per week or by an indicator reflecting the cost-weighted use of care services.

3.4.4.1 HOURS OF CARE SERVICE PROVISION

The intensity of all types of care services provided at older people's homes is shown in Table 9. The intensity of the two most widely used care services, home care and home nursing, is about the same with an average of 4 hours (4.17/3.83) per week. The average provision of FSBA, a regionally specific form of home care, is a bit lower at around 3.25 hours per week. Visiting services that are mainly run by charities and staffed by volunteers are provided for 1.9 hours per week, on average. Personal assistance, a service granted to people with disabilities, is provided for on average of 12 hours per week. However, only 8 respondents reported the use of personal assistance. Not surprisingly, the intensity of care provision is highest for 24-hour home care with an average of 165.3 hours per week and a maximum of 168 hours (care provided 24/7). Although most respondents reported a general attendance time of 24/7 the net working hours are usually lower considering sleeping time and breaks.

Table 9. Intensity of all types of social care services: care hours per week

	mean	min	median	max	SD	skew	kurtosis	n	miss
Home care total ^a									
users only	4.87	0.00	3.0	47.5	5.16	3.38	20.62	528	105
all	4.23	0.00	3.0	47.5	5.08	3.34	20.71	609	24
Home Care									
users only	4.17	0.33	3.0	33.0	4.13	3.08	16.71	360	273
all	2.48	0.00	1.4	33.0	3.78	3.26	19.24	606	27
Home Nurse									
users only	3.83	0.25	2.5	30.0	4.11	2.60	12.51	236	397
all	1.49	0.00	0.0	30.0	3.16	3.74	22.49	608	25
FSBA ^b									
users only	3.24	0.25	2.5	15.0	3.12	2.11	8.43	27	606
all	0.14	0.00	0.0	15.0	0.91	10.01	131.28	629	4
HWD ^c									
users only	1.66	0.50	1.5	5.0	1.23	1.95	6.21	11	622
all	0.03	0.00	0.0	5.0	0.27	13.05	210.92	633	0
Blocked care ^d									
users only	14.00	8.00	14.0	20.0	8.49	0.00	1.00	2	631
all	0.04	0.00	0.0	20.0	0.86	21.36	480.62	633	0
Visiting Service									
users only	1.89	0.50	2.0	4.0	1.07	0.84	2.65	23	610
all	0.07	0.00	0.0	4.0	0.41	6.97	56.28	623	10
Pers. Assistant									
users only	11.78	0.25	5.5	45.0	15.48	1.45	3.65	8	625
all	0.15	0.00	0.0	45.0	2.10	18.31	364.13	632	1
24h Care									
users only	165.30	84.00	168.0	168.0	14.17	-5.22	28.97	82	551
all	21.41	0.00	0.0	168.0	55.79	2.23	6.01	633	0
Sheltered house									
users only	4.00	0.50	2.0	14.5	5.91	1.45	3.19	5	628
all	0.03	0.00	0.0	14.5	0.59	23.62	577.63	631	2
Other ^e									
users only	12.12	1.00	7.0	42.0	14.97	1.30	3.26	7	626
all	0.13	0.00	0.0	42.0	1.94	18.52	373.76	630	3

Note: ^a Home care total includes home care, home nurse, FSBA and HWD

^b FSBA (*FachsozialbetreuerIn Schwerpunkt Altenarbeit*) is a region-specific form of home-care provided in 2 provinces only

^c HWD (*Hauswirtschaftsdienst*) is a region-specific form of home help provided in 2 provinces

^d Blocked care is a specific care service providing 4-8 hours a day (max.30 hours per month) and is available in one province only

^e Other is just a catch-all in case people do not find their service in the list (e.g. small rural care associations)

Source: EXCELC INT SU AUT 2016/2017

3.4.4.2 COST-WEIGHTED USE OF HOME CARE SERVICES

A different approach to compare the intensity of publicly-funded services is the provision of a common currency (EUR per hour). These 'unit costs' are a cost-weighted utilization measure that can be used as an indicator of service intensity. The numbers were calculated based on national data.

Unit costs in Austria – national data

In England, unit costs of long-term care services are published on a regular basis (Curtis 2013). In Austria, no such data are available. Thus, unit costs for home care services have been calculated using data from Austria's long-term care service statistics 2016 provided by Statistics Austria

(Statistik Austria 2017b). The *gross* unit costs of home care services reflect the regional *total* expenditures for LTC service provision per hour, including public costs, private contributions and other income of the Laender (e.g. health care fund – ‘Landesgesundheitsfonds’).

The comparability of cost data, however, is limited due to differences in the financial support and billing systems across the Austrian regions. Apart from varying data quality, the regional variations in overall gross expenditures also reflect different LTC service types, a different frequency of use of each type, and the employment of more or less qualified staff. Moreover, the structure of LTC service provision varies across the country and the Laender-specific regulations of support of LTC result in different modes of private and public cost sharing (see Kieninger/Trukeschitz 2018). Table 10 thus only gives a rough idea about gross unit costs per hour of home care service in Austria 2016. For economic evaluations, however, reliable data are required that allow comparison of unit costs across regions.

Table 10. (*Estimated) gross unit costs per hour of home care service 2016

Region	EUR/hour
Styria	56.55
Burgenland ^a	48.42
Carinthia ^a	45.61
Upper Austria	43.00
Lower Austria ^a	40.10
Tyrol	39.80
Salzburg ^a	39.32
Vorarlberg	29.40
Austria	41.66

Notes: In the four marked Laender – Burgenland, Carinthia, Lower Austria and Salzburg – the administrative authority does not collect any information on private co-payments and thus is unable to provide complete gross unit costs. For better comparability, we have included LTC service user contributions that are based on averages in the gross unit costs of the four Laender concerned. These figures are however only a rough estimate.

Source: EXCELC INT SU AUT 2016/2017

Unit costs for 24-hour care have been calculated for a 24-hour home care arrangement with 2 self-employed carers (bi-weekly rotation) using approximate values of the Federal Ministry of Finance (Bundesministerium Finanzen (BMF) 2018) and Caritas, a nonprofit care service provider (Caritas 2018). The gross unit costs comprise the public expenditure per recipient in 2016 (financial support for 24-hour care) and the private costs covered by the client (fees for the care worker, travel expenses, costs for board and lodging, agency costs). The costs of 24-hour home care may vary considerably depending on the placement agencies, the fee agreed to by the client (there is no statutory minimum wage for self-employed workers), the travel costs (migrant workers come from different countries), etc. Moreover, 24 hour care can also be provided by one care worker for 14 days. The other half of the month is then covered by the family. For our calculations, however, the monthly estimated public and private costs (EUR 3,131.88) were divided by hours per month which

results into gross unit costs per hour of EUR 4.66 (tied to the use of around the clock care for a month).

The gross unit costs of day care centers reflect the total expenditures for day centers per day, including client contributions, private co-payments and other income sources of the Laender. The data were derived from Austria's long term care service statistics (Statistik Austria 2017c) but differences concerning data collection across the country affected the accuracy of the unit costs per day. Although some regions provided information on costs of day care centre visits per hour, e.g. Vorarlberg, such data were not available for all regions. Thus, unit costs for day care center visits could only be calculated per day and were again just a rough estimate. Dividing the gross expenditures of daytime care centers per year by the accounted days and adjusting them for private contributions resulted into unit costs per day of EUR 77.16 (own calculations, Statistik Austria 2017c).

For Meals on Wheels no national data is available. The service is usually privately paid and prices ranged between EUR 7 and EUR 9 per meal delivered to the household. In most communities recipients of a minimum pension could get subsidised meals.

Cost-weighted use of long-term care services – sample descriptives

Table 11 provides descriptive statistics for three variants of the intensity of provision of publicly-funded services indicator:

- Home care hours: the sum of the hours per week of care received from care workers, including home care, home nursing and regional home care services.
- Cost-weighted use of home care: cost-weighted utilization of home care services.
- Cost-weighted use of all community care: cost-weighted total use of any of the following: home care (care workers), day care, and 24-hour-care – meals and equipment are excluded because they are specified in a different unit.

Comparing the cost-weighted average figures, home care (care workers) comprised just over 80% of the total use of all services.

As is common for service use, the distribution of usage across individuals was skewed to the right. This means that more people received services of lower intensity. Consequently, we used (natural) log-transformed care service use totals. This transformation substantially reduced the skewedness of this data.

The average total hours of home care provided per week was 4.87 for a home care service user. The high intensity of 47.50 hours per week (maximum) referred to a case where two home care services (home help and home nurse) were provided 7 days a week.

Table 11. Intensity of provision of publicly-funded services: cost-weighted use of home care

		mean	min	median	max	SD	skewness	kurtosis	n
Home care * - total hours per week	per week	4.87	0	3.00	47.50	5.16	3.38	20.62	528
	ln (+1)	1.53	0	1.39	3.88	0.66	0.54	3.06	528
Cost-weighted use of home care (EUR)	per week	176.06	0	124.98	1978.85	211.55	3.37	20.71	609
	ln (+1)	4.27	0	4.84	7.59	1.87	-1.36	3.94	609
Cost-weighted use of care services at home, incl. 24h care and day care centers (EUR)	per week	285.81	0	166.64	1978.85	284.21	1.61	6.23	611
	ln (+1)	5.13	0	5.12	7.59	1.19	-1.26	7.16	611

Note: *incl. all types of home care

Source: EXCELC INT SU AUT 2016/2017

3.5 EQUIPMENT

Apart from personal support through care workers, nurses and other professionals, older people may use special equipment, such as a manual or electric wheelchair, walking sticks or a walking frame, etc. In addition, there is a variety of other equipment and adaptations to the home that help to better cope with daily activities and improve safety at home. These items ranged from bath boards, shower chairs and raised toilet seats to adjusting beds and different forms of handles.

3.5.1 MOBILITY EQUIPMENT

As shown in Table 12, the great majority (85%) of LTC service users in our sample used one of these devices to improve mobility and to help in carrying out activities, whereby the most common equipment was a walking frame, used by more than 46% and a walking stick that eases mobility for almost 40% of the people in the sample. The use of a manual wheelchair (23%) is three times higher than the use of an electric wheelchair (7%).

Table 12. Use of mobility equipment

Total (n=633)	Mobility equipment	
	n	%
Any mobility equipment	535	84.52
Walking frame	297	46.92
Walking stick	245	38.70
Manual wheelchair	143	22.59
Elbow crutches	112	17.69
Electric wheelchair	45	7.11
Mobility scooter	14	2.21
Other mobility equipment	24	3.79

Source: EXCELC INT SU AUT 2016/2017, own calculations

3.5.2 EQUIPMENT BY TASK

Table 13 lists the use of equipment by task, showing that almost half of the people in the sample used equipment for getting around indoors and getting out of the house. Daily living equipment seemed to be quite common for bathrooms and more than one third of the respondents reported to have some form of equipment that assisted with having a bath or a shower. Another quarter of the sample used some equipment when going to the toilet. This, as an example, may include mobility aid to go to the toilet but also grab bars near the toilet, a movable toilet or catheter.

Table 13. Use of equipment by task

Total (n=599)	Use of equipment	
	n	%
Equipment to help with daily activities	443	73.96
Getting around indoors	285	47.58
Getting out of the house	258	43.07
Taking a bath or shower	205	34.22
Getting in and out of bed	177	29.55
Getting up and down the stairs	176	29.38
Using the toilet	155	25.88
Shopping	112	18.70
Dressing or undressing	58	9.68
Routine housework or laundry	53	8.85
Washing hands and face	48	8.01
Taking medicine	41	6.84
Paperwork or paying bills	29	4.84
Eating, including cutting up food	19	3.17

Source: EXCELC INT SU AUT 2016/2017

3.6 NEEDS AND HEALTH OF LTC CARE SERVICE USERS

Health conditions and functional limitations as measured by the ability to cope with (I)ADLs are important indicators of long term care needs.

3.6.1 FUNCTIONAL NEED

As shown in Table 14, functional need was the greatest for activities related to mobility and physical strength, such as shopping and routine housework, followed by getting up and down the stairs. More than one third of the LTC service users in the sample was unable to do the shopping and close to 40% was only able to do it with help from someone. Similar figures apply to routine housework and laundry. A quarter of the respondents reported that they were unable to get up and down the stairs and another 20% were dependent on the help of others to do the task. Greater limitations that are also related to cognitive functioning can be observed with financial management, including paying the bills and paperwork as well as medication management. A quarter of the sample was no longer able to manage bank balances and paying bills and another quarter reported having to rely on help of someone else to do this. Support might refer to the physical part of the activity, given that most

older people still use payment slips for paying their bills that have to be brought to the bank. A quarter of the people in the sample stated to also be dependent on help when it comes to keeping medication up to date, taking medicine on time, and in the right dosage. Concerning the basic activities, functional need was lower on average for most of the activities with the exception of personal hygiene. Close to 60% of the participants could only take a bath or shower with the help of someone else, followed by the activity of dressing and undressing that more than a third of the sample could not do without help.

Table 14. Functional need

Total (n=633)	Can do without help		Have difficulty		Can only do with help		Unable to do		Missing	
	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%
Routine housework or laundry	59	9.32	93	14.69	243	38.39	226	35.70	12	1.90
Shopping	81	12.80	62	9.79	249	39.34	229	36.18	12	1.90
Getting up and down the stairs	112	17.69	222	35.07	127	20.06	156	24.64	16	2.53
Taking a bath or shower	144	22.75	69	10.90	373	58.93	46	7.27	1	0.16
Getting out of the house	152	24.01	106	16.75	302	47.71	71	11.22	2	0.32
Dressing or undressing	213	33.65	176	27.80	210	33.18	34	5.37	0	0.00
Paperwork or paying bills	235	37.12	68	10.74	165	26.07	153	24.17	12	1.90
Getting around indoors	351	55.45	212	33.49	53	8.37	17	2.69	0	0.00
Getting in and out of bed	359	56.71	149	23.54	102	16.11	23	3.63	0	0.00
Using the toilet	408	64.45	114	18.01	88	13.90	22	3.48	1	0.16
Taking medicine	420	66.35	41	6.48	155	24.49	13	2.05	4	0.63
Eating, including cutting up food	443	69.98	91	14.38	87	13.74	11	1.74	1	0.16
Washing hands and face	509	80.41	63	9.95	52	8.21	9	1.42	0	0.00

Notes: Impairment/functional limitations indicators:

Activities of daily living (ADLs) or instrumental activities of daily living (IADLs) as a total count; number of I/ADLs with difficulty; and number of I/ADLs cannot do alone. Either as a scale with the eight I/ADLs in the ASCS (all client groups) or thirteen I/ADLs from the older people (65+ years) social care questionnaire (Blake/Gray et al. 2010) (PSI and MH client groups only), or alternatively considered as individual I/ADL items.

Source: EXCELC INT SU AUT 2016/2017

3.6.2 HEALTH INDICATORS

Health condition and health status, measured by long-term illnesses, self-reported health status and reported change in health status seemed to be another important indicator of quality of life and care needs. When asked about whether they suffer from a long-term illness, more than 86% respondents answered in the affirmative, however, this did not seem to go along with a self-reported bad health status (see Table 15). Almost half of the sample reported fair health and more than one quarter reported good health. Less than one fifth reported bad health and less than 4% reported very good or very bad health condition. Concerning the change in health status more than half of the sample reported constant health over the past six months and around two fifth even reported an improving health. Still more than fourth of the sample reported declining health.

Table 15. Short-term memory problems, long-term-illness and general health

	n	%
Short-term memory problem (recorded by interviewer)		
Yes	80	12.64
No	545	86.10
Missing	8	1.26
Long-term illness		
Yes	549	86.73
No	82	12.95
Missing	2	0.32
Self-rated health		
Very good	22	3.48
Good	165	26.07
Fair	310	48.97
Bad	113	17.85
Very bad	22	3.48
Missing	1	0.16
Health compared to 6 months ago		
Better	119	18.80
Much the same	352	55.61
Worse	161	25.43
Missing	1	0.16
TOTAL	633	100

Source: EXCELC INT C AUT 2016/2017

3.6.3 HEALTH RELATED QUALITY OF LIFE (HRQOL)

To measure health-related quality of life the EQ-5D-instrument was applied (EuroQol Group 1990). Participants of the study had to rate their situation across 5 dimensions, i.e. mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. As expected for this sample and shown in Table 16 for all dimensions, the majority reported health states that were not ideal, whereby the most prevalent problems were reported for the mobility domain with more than 85% of the LTC service

users indicating some problems. Around one third reported problems with their usual activities and one third suffered from moderate pain or discomfort.

Table 16. Health-related quality of life using EQ-5D

	n	%
EQ-5D mobility		
No problems	71	11.22
Some problems	540	85.31
Confined to bed	13	2.05
Missing	9	1.42
EQ-5D self-care		
No problems	190	30.02
Some problems	295	46.60
Unable	145	22.91
Missing	3	0.47
EQ-5D usual activities		
No problems	126	19.91
Some problems	390	61.61
Unable	111	17.54
Missing	6	0.95
EQ-5D pain/discomfort		
No pain/discomfort	90	14.22
Moderate pain/discomfort	400	63.19
Extreme pain/discomfort	140	22.12
Missing	3	0.47
EQ-5D anxiety/depression		
Not anxious/depressed	296	46.76
Moderately anxious/depressed	288	45.50
Extremely anxious/depressed	42	6.64
Missing	7	1.11
TOTAL	633	100

Source: EXCELC INT SU AUT 2016/2017

3.6.4 NEEDS-RELATED SUMMARY SCORES

The scores of EQ-5D were converted into a single index, as shown in Table 17, ranging from 1 (full health) to 0 (a state regarded as similar to being dead). Weights were used for the German population (see Claes/Greiner et al. 1999) as there are no weights for Austria available. The average EQ-5D score lied in the very middle at 0.54, indicating a moderate health-related quality of life profile of the sample population.

Responses to the I/ADL questions have been summarized in two indices: (i) I/ADLS with need, including all the answers where the respondent reported either difficulties, need of help or incapacity to complete a task. (ii) I/ADLs failed, including all the answers where the respondent reports either needing help or being unable to do the I/ADL.

On average, people in the sample reported that they could not do 7.3 I/ADLs out of 13 without help or have difficulties doing (i.e. I/ADLs with need) and that they definitely needed help with or were unable to do 5 I/ADLs (i.e. I/ADLs failed). There were a few outliers in the sample reporting that

they did not have any difficulties or need help with the I/ADLs (minimum = 0) and another few indicating that they do not need help with any I/ADL but may have difficulties with some I/ADLS (minimum = 0). There is some variation in the sample, as the standard deviation for both indices amounts up to nearly 3.5 tasks.

Table 17. EQ-5D utility index and distribution of I/ADL indices

Total (n = 633)	mean	min	median	max	SD	skew	kurtosis	n
EQ-5D utility index	0.54	-0.21	0.70	1	0.28	-0.34	1.67	615
Count of I/ADLs with need	7.34	0.00	7.00	13	3.46	-0.14	2.09	591
Count of I/ADLs failed	5.01	0.00	5.00	13	3.35	0.49	2.43	591

Source: EXCELC INT SU AUT 2016/2017

3.7 IMMEDIATE ENVIRONMENT

Design and accessibility of the residence a person lives in becomes an important issue as people in need of care spend most of the time in their immediate environment. The immediate environment is considered an important determinant of physical and mental health and general quality of life (Garin/Olaya et al. 2014). Independence, for example, is an important factor to maintain dignity and is affected by the accessibility of a home and appropriate adaptations to the home. The home environment can help or hinder performance of daily activities and physical functions and housing barriers are of significant concern for persons with disabilities or those who are frail (National Research Council 2011; Garin/Olaya et al. 2014). Home modifications are therefore sometimes inevitable for people using a wheelchair but can be a financial challenge for those with lower incomes.

Nearly a third of the sample reported ideal accessibility of the local area by being able to get to all places they want as shown in Table 18. Close to 40%, however, reported limited access and are not able to go to all the places they want to. Concerning the design of the home, more than half of the home care service users in the sample seemed to have an adequate home environment that met their needs very well and less than 8% of the respondents appeared to have rather poor housing conditions that only met some of their needs. This does not seem to correlate with the barrier-free accessibility of the home as half of the sample lived in homes that were not barrier-free accessible (according to the interviewer ratings). The share of non-barrier-free access may be higher as the interviewers did not check accessibility for all rooms.

Table 18. Self-reported accessibility of the local area, design of home and barrier-free access of home (Interviewer-rating)

	n	%
Self-reported accessibility of the local area		
Get to all the places I want	186	29.38
At times find it difficult to get to all places	173	27.33
Unable to get to all the places	236	37.28
Do not leave the home	0	0.00
Missing	38	6.01
Self-reported design of home		
Meets my needs very well	335	52.92
Meets most of my needs	241	38.07
Meets some of my needs	47	7.42
Totally inappropriate for my needs	7	1.11
Missing	3	0.47
Barrier-free home (interviewer-rating)		
No	314	49.61
Yes	266	42.02
Missing	53	8.37
TOTAL	633	100

Source: EXCELC INT SU AUT 2016/2017

3.8 FINANCIAL AND 'SOCIAL' RESOURCES

Financial means and social relationships are two additional main resources that may influence the production of care outcomes. Sufficient financial resources enable people in need of care to make use of the adequate amount of care services they need. A good social network and family members or friends that take the role of informal carers who may substitute for or complement professional service provision. Both factors are considered as boosts to the productivity of the household (Malley 2017). Low levels of financial stress are associated with greater levels of well-being (Montpetit/Kapp et al. 2015).

3.8.1 FINANCIAL RESOURCES

The respondents were asked to estimate the net income of the household including income sources (e.g. pensions, social benefits, income on investment) and to rate their financial situation by either reporting income per month or per year. Table 19 shows the distribution along 10 percentiles revealing that close to three fifths of the sample members have quite modest economic resources, being in the three lowest percentiles and earning a maximum of EUR 28,741 per household per year. Nearly one fifth of the sample reported that their household income is less than EUR 13,677 per year and more than a fifth reported that they earn between EUR 23,554 and EUR 18,831. 10% of respondents had missing data for this variable, which is low given that people usually tend to keep a low profile regarding their financial situation.

Concerning the self-reported financial situation, a third of the sample accepts the situation as being alright but more than a third reported some financial difficulties. A difficult financial situation might

indicate a lower capacity of the household to pay for the amount of professional long term care services required.

Table 19. Distribution of household income and self-reported financial situation

	n	%
Household income per year (percentiles)		
less than 13,677 €/pa	118	18.64
13,677 – less than 18,831 €/pa	146	23.06
18,831 – less than 23,554 €/pa	105	16.59
23,554 – less than 28,741 €/pa	69	10.90
28,741 – less than 34,638 €/pa	46	7.27
34,638 – less than 40,965 €/pa	37	5.85
40,965 – less than 48,067 €/pa	14	2.21
48,067 – less than 57,910 €/pa	18	2.84
57,910 – less than 73,881 €/pa	9	1.42
73,881 €/pa or more	1	0.63
Missing	67	10.59
Self-reported financial situation		
I/we manage very well	85	4.27
I/we manage quite well	216	13.27
I/we get by alright	211	33.33
I/we have some financial difficulties	84	34.12
I/we have severe financial difficulties	27	13.43
Missing	10	1.58
TOTAL	633	100

Source: EXCELC INT SU AUT 2016/2017

3.8.2 INFORMAL HELP AND SUPPORT

The majority of the respondents indicated receiving informal help in addition to professional LTC services (see Table 20). Nearly three quarters of the sample had at least one carer or more that give regular support in the activities of daily living. These numbers are consistent with other studies on the informal care situation in Austria showing that between 75% and 80% of people in need of care receive informal help in combination with professional care services (Kügler/Sardadvar 2015; Riedel/Davoine et al. 2015). However, nearly a fifth of our sample did not receive any other help from relatives and friends.

Regarding the gender distribution of informal help (as shown in Table 21), the informal helper was more likely to be female (around 80% get support from at least one female carer), but still over half of the sample received help from at least one male carer. Over one third of the carers resided with the LTC service user, 20% of whom are a husband, wife or partner.

As shown in Table 22 the great majority (over four fifths) of the sample were supported mostly by a family member, primarily by one of their children; close to 30% of the main carers were daughters, nearly 20% were sons. More than 10% reported relying on extra-familial help from a friend or a neighbor as the main carer.

Table 20. Number of informal carers

	n	%
Number of carers		
No informal carer	111	17.54
One carer	226	35.70
Two carers	183	28.91
3 or more carers	113	17.85
TOTAL	633	100

Source: EXCELC INT SU AUT 2016/2017

Table 21. Number of informal carers by gender and residency

Total (n=522)	0		1		2 or more		TOTAL
	Freq.	%	Freq.	%	Freq.	%	%
Of those with carers...							
number of female carers	102	19.54	278	53.26	142	27.20	100
number of male carers	233	44.64	222	42.53	67	12.83	100
number of co-resident carers	329	63.03	162	31.03	31	5.94	100
number of extra-resident carers	107	20.50	195	37.36	220	42.15	100

Source: EXCELC INT SU AUT 2016/2017

Table 22. Relationship of main carer to LTC service user

	1 st Main Informal Carer		2 nd Main Informal Carer	
	n	%	n	%
Relationship to LTC service user				
husband/wife/partner	97	18.58	1	2.38
son (incl. step / adopted / in-law)	91	17.43	7	16.67
daughter (incl. step / adopted / in-law)	146	27.97	9	21.43
grandchild (incl. great grandchildren)	20	3.83	5	11.90
brother / sister (incl step / adopted)	37	7.09	4	9.52
niece / nephew	25	4.79	2	4.76
mother/father (incl. in-laws)	5	0.96	0	0.00
other family member	21	4.02	5	11.90
friend	33	6.32	3	7.14
neighbor	33	6.32	2	4.76
other	14	2.68	4	9.52
TOTAL	522	100	42	100

Source: EXCELC INT SU AUT 2016/2017

The amount of support an informal carer provided for the person in need of care is presented in Table 23. The first main carer was assisting on average more than 20 hours per week in daily activities. However, the distribution is skewed to the right with the median number of hours being 6 and the maximum being 168. The carer that was ranked second in providing help spent on average fewer

than 10 hours per week but the distribution is again positively skewed with a median of 4 hours and a maximum of 130 hours.

Table 23. Informal care time of the main carer per week (reported by the LTC service user)

Hours per week provided by...	mean	min	median	max	SD	skew	kurtosis	n
1 st main carer	21.64	0.0	6	168	40.56	2.70	9.42	522
2 nd main carer	8.57	0.5	4	130	19.79	5.69	35.41	42
All informal carers	24.48	0.0	7	410	44.53	3.26	17.30	522

Source: EXCELC INT SU AUT 2016/2017

4 DETAILS OF SURVEY DELIVERY

When looking at the collected data, it is important to consider several contextual aspects of the survey and to regard interviewing as a situation of social interaction (see De Santis 1980).

4.1 MAINTENANCE OF INTERVIEWEES' CONCENTRATION

The level of concentration and signs of fatigue might be an indicator for the interview performance and the reliability of the information given by the respondent. Nearly three fifths of the sample reported that they could maintain the concentration easily over the time of the study (see Table 24). Another fifth was capable of maintaining their concentration with some difficulties throughout the study. Around 10% of the respondents admitted that their concentration decreased and another 5% reported that they lost their concentration in the later stage of the study.

Table 24. Level of concentration throughout the survey

	n	%
Degree of fatigue shown by the respondent		
Easily maintained concentration throughout the survey	362	57.19
Maintained the concentration with some effort throughout the survey	133	21.01
Lessened concentration in the later stages	65	10.27
Maintained concentration with a deal of effort throughout the survey	38	6.00
Lost concentration in the later stages	29	4.58
Missing	6	0.95
TOTAL	633	100

Source: EXCELC INT SU AUT 2016/2017

4.2 INTERVIEWER CHARACTERISTICS

A total of 63 interviewers conducted the interviews with a higher proportion of women (about two thirds). The gender distribution among the interviewers was consistent with the gender distribution among the respondents (see section 3.1.3). We did not match female respondents with female interviewers unless it was requested by the LTC service users.

On average, an interviewer conducted 14 interviews in total. The interviewers were principally asked to conduct 5 interviews or more provided that they were doing a good job and interviewees were available in their region. This arrangement had the advantage that the interviewer could conduct interviews as long as he or she enjoyed doing so and prevented from fatigue and demotivation that might again influence the interviewer's performance. After having conducted 15 interviews many interviewers reported that this was just enough and more would lead to monotony. However, there were also a few very enthusiastic interviewers that were willing to conduct as many interviews as possible and the maximum number reached was 28 interviews. (see Table 25)

Table 25. Interviewer characteristics

	n	%	
Number of Interviewers			
Men	22	34.92	
Women	41	65.08	
TOTAL	63	100	

	min	max	average number
Interviews per Interviewer	1	28	13.76

Source: EXCELC INT SU AUT 2016/2017

5 SUMMARY & CONCLUSIONS

Data on 633 LTC service users were collected in Austria between 2016 and 2017 (May 2016 and November 2017) to enable the analysis of the efficiency and effectiveness of non-institutional LTC across Austria, England and Finland.

Data collection in Austria was challenging as there was no standardized access to LTC service users available and several approaches had to be taken. Access to LTC service users turned out to be very time- and cost-consuming, irrespective of the approach taken (postal invitation or recruitment by the care organization). In addition to the use of national HVCP-data, region-specific approaches via governments, administrative units and care organizations were applied.

On average, home care services had a positive impact on the QoL of service users. The Adult Social Care Outcomes Toolkit for LTC- Service users (ASCOT) was used to measure social care-related QoL across eight life domains. Overall descriptive results showed a positive impact of LTC service provision on home service users' QoL, improving the QoL by 0.3 points on the ASCOT-scale on average. Impact of home care services on QoL were highest for the *control over daily life* domain and for physiological needs, such as *Personal cleanliness, Food and drink, and Accommodation and comfort*. However, the Austrian home care services have a lower impact on *Social participation and Personal safety*.

Unit costs, needed for cost-effectiveness analysis, were not available in a sufficient quality – they were hardly comparable across the nine Laender. Unit costs for LTC services that are needed for economic evaluation are not available on a regular basis in Austria. Cost data quality turned out poor and hardly comparable across the nine Laender. Improvements with database is needed to allow for in-depths evaluation of LTC service provision.

Austrian home care service users reported the highest needs for instrumental tasks and generally received support where they needed it, with the exception for support related to mobility. Formal or informal support is needed the most for instrumental tasks such as *housekeeping and laundry* (87%), *shopping* (80%) and *getting out of the house* (66%). Concerning the basic tasks, most support was needed and provided for *personal hygiene* (66%) and *dressing or undressing* (58%). Overall, the Austrian home care service users received help when help was needed for most (instrumental) activities of daily living with the exception of activities related to mobility, with 24% reporting a need but not receiving help. Most frequently used home-based care services were home care (used by 62%) and home nursing (42%) with an intensity of provision of around 4 hours per week on average. 44% use a personal alarm service, 25% receive Meals on Wheels and close to 20% occasionally use a patient transport service.

A great majority of Austrian home care service users reported problems with mobility and with the accessibility of the local area. Considering the health status of the LTC service users the majority reported problems in all five health-related dimensions, whereby the most prevalent problems were reported for the mobility domain (85% indicated at least some problems). Overall, the EQ5D-score of home care service users was neither high nor low with 0.54 (where 1 is maximum health). The majority of home care service users (65%) reported limitations when it comes to the accessibility of the local area (difficulties or not able to get to all places they want to go).

Almost half of LTC service users reported some or severe financial difficulties. Concerning the financial situation, 34% of the Austrian home care service users in the sample reported some financial difficulties and 14% indicated severe financial difficulties.

Close to 20% of the Austrian home care service users did not receive informal help. The majority of home care service users had informal support, but 18% of the LTC service users did not have any informal carer as additional support to the professional home care. The average amount of support provided by the main informal carer was 6 hours per week (median).

Strengths and limitations of the data

The data collected allow to assess the impact of home care services on the quality of life outcomes of service users in Austria. ASCOT for service users was used for the first time in Austria to measure the social care-related quality of life in its multidimensionality. Another strength of the data is the large sample and its high coverage of the diversity of home care service users, including different age groups, a different mix of LTC services and geographic coverage of all Austrian provinces (including urban and rural areas). However, there is also the limitation concerning the sample characteristics. Due to the length and complexity of the questionnaire, solely home care

service users, who were mentally capable of answering questions for at least one hour, were included in the sample. Another limitation may concern the social desirability bias resulting from self-reported data through personal interview conduct. Nonetheless, the comprehensive approach of the study, focusing on many different factors that are relevant to the quality of life of LTC service users, enables a deeper analysis of the topic. Future work will be done on the assessment of ASCOT for service users, evaluating its validity, and on the relationship of LTC-induced quality of life outcomes and other factors in Austria and across the three European countries (Austria, England and Finland).

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