DISCUSSION PAPER

Discussion paper 29/2020

Ismo Linnosmaa, Lien Nguyen, Hanna Jokimäki

The EXCELC project in Finland

The main descriptive findings from surveys using the Adult Social Care Outcomes Toolkit (ASCOT)

Exploring Comparative Effectiveness and Efficiency in Long-term Care (EXCELC), an international research project, started in 2015 to explore the comparative effectiveness and efficiency of non-institutional long-term care in Austria, England and Finland. The EXCELC project has applied the Adult Social Care Outcomes Toolkit (ASCOT) to measure social care-related quality of life of old service users, their carers and the effectiveness of non-institutional long-term care (www.pssru.ac.uk/ascot/tools). This methodological report describes the process of translating the ASCOT quality of life measures from English into Finnish, the methods of collecting survey data in 12 Finnish regions, and the main descriptive findings from the surveys.

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Foreword

Our motivation to get involved with the EXCELC (Exploring Comparative Effectiveness and Efficiency in Long-term Care) research project was the measurement of effectiveness of long-term care. Current literature suggests that widely used health-related outcome measures may be neither sensitive nor valid to measure the effectiveness of long-term care. Literature further suggests that a valid measure to be used in the research on long-term care effectiveness is Adult Social Care Outcomes Toolkit (ASCOT) that was developed in the University of Kent, England, to measure the social care-related quality of life (SCRQoL) and effectiveness of adult social care. Our previous contacts with the developers of the ASCOT measure in England started a research collaboration, a part of which was to apply NORFACE[1] funding for comparative research on the quality of life of old long-term care clients and the (cost-)effectiveness of non-institutional long-term care. This collaboration consisted of researchers from Austria, England and Finland. A positive decision from NORFACE to our research funding application in the spring of 2015 launched the EXCELC project.

To researchers, who often work with secondary data from administrative registers, the EXCELC project has been an illuminating journey to the research using primary data. The project has revealed to us how much time and effort are needed in the ethics procedures, planning of data collection and samples, the design of questionnaires, the collection of data, data cleaning, and finally data analysis and reporting. The project was well-planned and realistic in the beginning. However, because the collection of individual data via structured interviews took longer than expected, not all the objectives of the project were achieved within the planned time frame. While the data collection was finalised within the planned time frame, the work related to reporting and publishing has continued since the official ending of the project in the fall of 2018.

This project would not have been realised without support and effort that we have received from several parties or institutions. First, with regard to financial support, we want to thank the NORFACE programme Welfare State Futures for financial support (grant nro 462-14-160) and Finnish Institute for Health and Welfare (THL) for co-funding.

Secondly, we want to express our warmest thanks to our colleagues from Austria and England. English colleagues, Julien Forder, Juliette Malley, Eirini Saloniki, Laurie Batchelder, Stacey Rand, Kamilla Razik, Peter Burge and Hui Lu, have provided important help and advice in translating ASCOT questionnaires, designing data collection, questionnaires that were used to collect data, the execution of the survey collection via structured interviews, and advise in data cleaning and analysis. Austrian colleagues of ours, Birgit Trukeschitz, Assma Hajji, Judith Kleininger, Judith Litschauer and Adiam Schoch, have provided important peer support to the Finnish research team by sharing their experiences from data collection on the ASCOT quality of life and the effectiveness of long-term care in Austria. Shared data and experiences from the project have already produced a number of joint publications. Our thanks also go to all other people at University of Kent, London School of Economics and Vienna University of Economics and Business who have been involved in the EXCELC project at various stages.

We want to thank the participating municipalities and health and social care regions for fluent cooperation in the EXCELC project. The collection of survey data via structured interviews would not have been possible without the input that the municipalities and regions and their workers put on sampling and contacting regular home care users. Reported high preference-weighted SCRQoL of the service users and carers in Sections 7 and 8 of this report also indicate that the local authorities have succeeded in improving the quality of life of old regular home care users and their informal carers via service provision.

We want to express our deepest gratitude to regular home care service users and informal carers who participated in this study as interviewees. Your willingness to participate in this study allows us for the first

[1] New Opportunities for Research Funding Agency Co-operation in EUROPE.

time to report preference-weighted SCRQoL of Finnish regular home care service users and their carers and to study the effectiveness of their service use in Finland using preference-weighted SCRQoL as an outcome measure. Similarly, our greatest thank also go to fieldworkers Iiris Pykäläinen, Miina Nikkanen, Helena Rovamo, Maarit Ojanen, Tuula Kontio and Susanna Nevalainen. We were very fortunate to find you, our well-motivated fieldworkers, to conduct the interviews. Spirit among the fieldworkers was extremely good during the period of interview data collection in August 2016–September 2017, even though the number of interviews was quite high for some fieldworkers. Many thanks to you all for collecting very important high-quality data that can be used to investigate quality of life of both study groups and the effectiveness of regular home care.

We cannot thank enough THL CHESS unit leaders Timo Seppälä and Mikko Peltola, who supportively provided us the necessary time to be effectively involved in various stages of the project. In addition, we want to extend our thanks Taru Haula and Salla Ikäheimo, who contributed to the EXCELC project in the phase of translating ASCOT measures. Our thanks also go out to THL lawyers Tanja Stormbom and Ulla Ahlblad-Bordi, who helped us to design contracts regarding the copyrights of the Finnish-translated ASCOT and data sharing in the EXCELC project. We really appreciate valuable help provided by Pirre Talponen from THL in administering the finance of the project in Finland.

Helsinki August 25, 2020

Ismo Linnosmaa Lien Nguyen Hanna Jokimäki

Abstract

Ismo Linnosmaa, Lien Nguyen, Hanna Jokimäki. The EXCELC project in Finland. The main descriptive findings from surveys using the Adult Social Care Outcomes Toolkit (ASCOT). Finnish Institute for Health and Welfare (THL). Discussion paper 29/2020. 44 pages. Helsinki, Finland 2020.
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Exploring Comparative Effectiveness and Efficiency in Long-term Care (EXCELC), an international research project, started in 2015 to explore the comparative effectiveness and efficiency of non-institutional long-term care in Austria, England and Finland. The EXCELC project has applied the Adult Social Care Outcomes Toolkit (ASCOT) to measure social care-related quality of life (SCRQoL) of old service users, their carers and the effectiveness of non-institutional long-term care. The aims of this methodological report are to describe the process of translating the ASCOT quality of life measures from English into Finnish, to describe the methods of collecting survey data in Finland, and to provide the main descriptive findings from the interview surveys.

The original ASCOT measures were translated from English into Finnish in June 2015–March 2016. The translating agency PharmaQuest (a part of Corporate Translations now) translated self-completion questionnaires for service users (SCT4 Service users) and carers (SCT4 Carers) and interview schedules for service users (INT4 Service users) and carers (INT4 Carers) from English into Finnish in cooperation with researchers from Finland and England (www.pssru.ac.uk/ascot/tools or email finascot@thl.fi). The full translation process consisted of 13 distinct steps, including forward and back translations and full cognitive debriefings to explore how difficult or easy it is to understand wording in translated questionnaires/interview schedules.

To measure the ASCOT quality of life of old service users and the effectiveness of non-institutional long-term care, we collected survey data by interviewing regular home care users over 54 years old and their carers in 10 municipalities and two health and social care regions in Finland. Structured interviews were conducted during the time period August 2016–August 2017 by six fieldworkers, who were trained to do the interviews. The final sample consists of 493 interviews with regular home care service users and 254 interviews with informal carers. The service user sample is a good representation of Finnish regular home care users over 64 years old in terms of age and gender.

Data collection with the ASCOT interview schedules allowed us to define and measure three quality of life concepts. Current SCRQoL was SCRQoL associated with services that are used in the current situation. Expected SCRQoL was SCRQoL generated in a hypothetical situation where the currently used services would not be available. Finally, SCRQoL gain measured the difference between the current and expected SCRQoL. SCRQoL gain can be used to measure the effectiveness of social care. Regular home care users' intensity of service use was measured by the total costs of services per week.

Descriptive analysis of the SCRQoL of service users and informal carers showed that both groups benefited from the provided services. This was illustrated by the fact that the average current SCRQoL exceeded the average expected SCRQoL for both regular home care users and informal carers. Secondly, we found large variation in the average intensity of the most commonly used long-term care services and the average SCRQoL across regions. Finally, descriptive analysis revealed a high positive correlation between the average service intensity and the average SCRQoL gain across regions. A more detailed analysis on the causal effects of the service intensity on the SCRQoL of regular home care users was left for future analysis.

Keywords: quality of life, effectiveness, home care, old people, informal carers, ASCOT

Tiivistelmä

Ismo Linnosmaa, Lien Nguyen, Hanna Jokimäki. EXCELC-tutkimushanke Suomessa. Tuloksia ikääntyneiden säännöllisen kotihoidon asiakkaiden ja heitä auttavien henkilöiden ASCOT elämänlaadusta ja palvelujen käytöstä. Terveyden ja hyvinvoinnin laitos (THL). Työpaperi 29/2020. 44 sivua. Helsinki 2020.
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Vuonna 2015 alkaneessa EXCELC-tutkimushankkeessa on tutkittu ikääntyneiden henkilöiden avohoidon palvelujen, kuten säännöllisen kotihoidon, tukipalvelujen ja päivätoiminnan, vaikuttavuutta, kustannuksia ja kustannusvaikuttavuutta Englannissa, Itävallassa ja Suomessa. Hankkeessa on hyödynnetty *Adult Social Care Outcomes Toolkit* (ASCOT)-mittaria palvelun käyttäjien sosiaalipalvelujen käyttöön liittyvän elämänlaadun (social care-related quality of life SCRQoL) ja palvelujen vaikuttavuuden mittaamiseen. Tässä metodologisessa raportissa kuvataan tutkimuksessa käytettyjen ASCOT-mittareiden kääntäminen englannista suomeksi, haastatteluaineiston keräämisen vaiheet sekä aineiston edustavuus suhteessa säännöllisen kotihoidon asiakkaisiin Suomessa. Lisäksi raportoimme tuloksia kotihoidon asiakkaiden ja heitä auttavien henkilöiden SCRQoL:sta ja palvelujen käytöstä käyttäen haastatteluaineistoa.

ASCOT-mittareiden suomentaminen aloitettin heinäkuussa 2015 ja käännökset valmistuivat maaliskuussa 2016. Käännöstoimisto PharmaQuest (nykyään osa Corporate Translations yritystä) suomensi nelitasoisen itse täytettävän kyselylomakkeen (SCT4) palvelun käyttäjille ja omaishoitajille sekä nelitasoisen haastattelulomakkeen (INT4) palvelun käyttäjille ja omaishoitajille (www.pssru.ac.uk/ascot/tools tai sähköposti finascot@thl.fi) yhteistyössä suomalaisten ja englantilaisten tutkijoiden kanssa. Suomennosten laadun vamistamiseksi ASCOT lomakkeet suomennettiin hyödyntäen kaksivaiheista forward-and-back menetelmää. Suomennettujen lomakkeiden sanamuotoja ja lauseiden ymmärrettävyyttä tutkittiin pilottihaastattelututkimuksessa, johon osallistui viisi omaishoidettavaa ja viisi omaishoitajaa.

Ikääntyneiden palvelun käyttäjien elämänlaadun ja heille tarjottujen palvelujen vaikuttavuuden tutkimiseksi hankkeessa haastateltiin 55 vuotta täyttäneitä säännöllisen kotihoidon asiakkaita ja heidän omaishoitajiaan (tai läheisauttajiaan) 10 Suomen kunnassa ja kahdella sosiaali- ja terveydenhuollon alueella. Kuusi tehtävään erikseen koulutettua kenttätyöntekijää haastatteli suostumuksen antaneet säännöllisen kotihoidon asiakkaat ja heidän omaishoitajat (tai läheisauttajat) ajanjaksolla elokuu 2016–syyskuu 2017. Kerätty aineisto koostuu 493 säännöllisen kotihoidon asiakkaan ja 254 omaishoitajan (tai läheisauttajan) haastatteluista. Otos säännöllisen kotihoidon asiakkaista edustaa Suomen säännöllisen kotihoidon asiakkaita sukupuolen ja iän suhteen.

INT4 mittareiden käyttö haastatteluaineiston keräämisessä teki mahdolliseksi elämänlaadun määrittelyn ja mittaamisen kolmella tavalla. Nykyinen SCRQoL mittasi säännöllisen kotihoidon asiakkaiden ja omaishoitajien (tai läheisauttajien) SCRQoL:ia nykyisten palvelujen kanssa. Odotettu SCRQoL mittasi SCRQoL:ia kuvitteellisessa tilanteessa, jossa nykyiset palvelut eivät olisi asiakkaiden ja omaishoitajien (tai läheisauttajien) käytettävissä. SCRQoL-hyötyä mitattiin nykyisen ja odotun SCRQoL:n erotuksena. SCRQoL-hyödyn avulla voidaan arvioida sosiaalipalvelujen vaikuttavuutta. Palvelujen käytön määriä mitattiin viikottaisilla palvelujen käytön kustannuksilla (euroa/viikko).

Kuvaileva analyysi säännöllisen kotihoidon asiakkaiden ja omaishoitajien (tai läheisauttajien) ASCOT-elämänlaadusta osoitti, että molemmat tutkimusryhmät hyötyvät heille tarjotuista palveluista. Tämä päätelmä perustuu tutkimustulokseen, jonka mukaan keskimääräinen nykyinen SCRQoL ylittää keskimääräisen odotetun SCRQoL:n molemmissa tutkimusryhmissä. Havaitsimme myös suurta alueellista vaihtelua yleisimmin käytössä olleiden palvelujen käytön määrissä sekä nykyisen ja odotetun SCRQoL:n ja SCRQoL-hyödyn keskiarvioissa. Alueellisten keskiarvojen vertailun perusteella havaittiin lisäksi, että suurempi palvelujen käyttö oli yhteydessä SCRQoL-hyödyn kasvuun, mikä viittaisi siihen, että palvelujen lisääntyvä käyttö kohentaa niiden vaikuttavuutta. Jätimme kuitenkin tarkemman tarkastelun palvelujen käytön määrien ja vaikuttavuuden kausaalisista suhteista tulevaan tutkimukseen.

Avainsanat: elämänlaatu, vaikuttavuus, kotihoito, ikääntyneet, omaishoito tai läheishoito, ASCOT

Abbreviations

ADL	Activity of daily living
ASCOT	Adult social care outcomes toolkit
ASCOT-SU	Adult social care outcomes toolkit for service users
ASCOT-Carer	Adult social care outcomes toolkit for carers
BWS	Best-worst scaling
EQ-5D	EuroQoL-5D, a preference-based HRQoL measure with five dimensions
EXCELC	Exploring Comparative Effectiveness and Efficiency in Long-term Care
HRQoL	Health-related quality of life
IADL	Instrumental activity of daily living
IIASC	Identifying the Impact of Adult Social Care
LTC	Long-term care
QALY	Quality-adjusted life year
QoL	Quality of life
POW	Production of welfare
SAH	Self-assessed health
SCRQoL	Social care-related quality of life
std. dev	Standard deviation
r	Pairwise correlation
BA	Bachelor of Arts
MA	Master of Arts
PhD	Doctor of Philosophy

Municipalities

Esp	Espoo
Hel	Helsinki
Häm	Hämeenlinna
Joe	Joensuu
Kuo	Kuopio
Lah	Lahti
Mik	Mikkeli
Tam	Tampere
Vaa	Vaasa
Van	Vantaa

Health and social care regions

Eks	Eksote, South Karelia Social and Health Care District
Kai	Kainuu, Kainuu Social and Health Care Authority

Contents

1 Introduction

Quality-Adjusted Life Years (QALYs) has been commonly applied in health economics studies to measure the effectiveness of health care interventions (Drummond et al. 2015). Older populations often need help and support with their (instrumental) activities of daily living (ADLs), such as personal care, being fed and keeping a clean accommodation, that may have been put at risk due to functional impairments or chronic health conditions. One of the main functions of adult social care is to compensate losses in wellbeing resulting from functional impairments (Netten et al. 2012). Health-related quality of life (HRQoL) measurement instruments (henceforth measures), e.g., EQ-5D, are often insensitive to the use of adult social care (Forder and Caiels 2011) because they miss those aspects of wellbeing that relate to one's ability to manage daily activities. Therefore, in assessments of the quality of life (QoL) of older populations or the effectiveness of long-term care, there is a need to measure aspects of QoL that are sensitive to peoples' ability to perform daily activities and hence the use of social care services (Makai et al. 2013). This is increasingly important at the time of ageing populations and increased need for long-term care for older people.

Exploring Comparative Effectiveness and Efficiency in Long-term Care (EXCELC) is a research project that started in May 2015 to explore the comparative effectiveness and efficiency of non-institutional long-term care (LTC) in Austria, England and Finland. The EXCELC project applies Adult Social Care Outcomes Toolkit (ASCOT) to measure the QoL of old service users and the effectiveness of LTC services. The ASCOT measures were developed to measure social care-related quality of life (SCRQoL) (Netten et al. 2012) and they are sensitive to the use of LTC provided for old people (e.g. Forder and Caiels 2011).

Previous work on the ASCOT measure and its applications in England are described in Netten et al. (2012) and Forder et al. (2014; 2018). The underlying idea of the EXCELC project was to add a comparative aspect to the previous work. This required both the translation of ASCOT measures and the collection of comparable data sets from the participating countries. The main objectives of the EXCELC project, each involving a working package (WP), were

1. to translate and validate ASCOT for service users (ASCOT-Service user or ASCOT-SU) and ASCOT for carers (ASCOT-Carer) instruments into Finnish and German (WP1);
2. to generate country-specific preference weights for the ASCOT-SU and ASCOT-Carer measures (WP2);
3. to compare the QoL of non-institutional LTC service users and their carers in Austria, England and Finland (WP3);
4. to examine and compare the effectiveness and cost-effectiveness of non-institutional LTC in Austria, England and Finland (WP4).

The first two WPs took the necessary steps to make ASCOT measures available in Austria and Finland by translating and validating relevant ASCOT instruments in the first place, and then by estimating country-specific preference weights for the translated instruments. In addition, WP2 provided preference weights for the English carer instrument (Batchelder et al. 2019). The last two work packages applied ASCOT together with other appropriate measures to collect survey data via structured interviews for the comparison of the QoL of old service users and carers (WP3) and for the empirical analysis of the effectiveness and cost-effectiveness of non-institutional LTC in Austria, England and Finland (WP4).

The EXCELC project was led by Professor Julien Forder from the University of Kent. The principal investigators were Birgit Trukeschitz (Austria), Juliette Malley (England) and Ismo Linnosmaa (Finland), respectively. The project was funded by the NORFACE Welfare State Futures programme. The Finnish contribution to the project was co-funded by the Finnish Institute for Health and Welfare (THL, previously the National Institute for Health and Welfare), Finland, and the Austrian contribution by the Austrian Science Fund and the Vienna Social Fund (FSW), Austria. Ismo Linnosmaa, Lien Nguyen, Hanna Jokimäki

(April 2016–August 2018), Salla Ikäheimo (June–October 2015) and Taru Haula (January–February 2016) were members of the Finnish research team in the EXCELC project.

The general aims of this report are i) to describe the process of translating the ASCOT QoL measures from English into Finnish, ii) to describe the methods of survey data collection via structured interviews in Finland, and iii) to provide the main descriptive findings from the interview surveys. After defining the relevant concepts related to the ASCOT measures in Section 2, we will describe the steps taken to translate the ASCOT-QoL measures into Finnish. We then describe the processes of applying ethics clearances (Section 4) and organising survey data collection via structured interviews in Finland (Section 5). Subsequent to that, we assess the representativeness of the collected data (Section 6) and provide descriptive findings on the SCRQoL and the use of non-institutional LTC using the survey data (Sections 7 and 8). The final section provides an assessment of the main findings and some policy recommendations.

2 Methods

2.1 Adult Social Care Outcomes Toolkit (ASCOT)

The EXCELC project applied the Adults Social Care Toolkit (ASCOT) (Netten et al. 2012) to measure the social care-related quality of life (SCRQoL) and the effectiveness of non-institutional LTC. The ASCOT contains several indicators, which have been developed to measure service users' and carers' SCRQoL.

The ASCOT measure designed for service users (ASCOT-Service user) has eight attributes (domains): (1) *control over daily life*, (2) *personal cleanliness and comfort*, (3) *food and drink*, (4) *accommodation cleanliness and comfort*, (5) *personal safety*, (6) *social participation and involvement*, (7) *occupation*, and (8) *dignity*. According to their needs for support and care, survey respondents can choose from four levels: "0 = high needs", "1 = some needs", "2 = no needs" and "3 = ideal state" in each attribute. Although the two highest levels measure the situation with no needs for care and support, they differ from each other to some extent: the better outcome ("ideal state") describes the situation with no needs but with a free choice of how the care needs are met and the lower outcome ("no needs") is the situation with no such choice. The two lowest levels measure the situations with either some needs (level 1) or high needs (level 0) for care and support.

The ASCOT-Service user measures both the basic (the *personal cleanliness and comfort, food and drink, personal safety,* and *accommodation cleanliness and comfort* domains) and the higher order (the *control over daily life, social participation and involvement,* and *occupation* domains) aspects of SCRQoL (Towers et al. 2016). The *dignity* domain differs from the other domains in its intention to capture the effects of the process of care-giving on the service user's self-esteem (Netten et al., 2012; Malley et al. 2012). *Dignity* is measured by asking service users to assess how the way they are helped and treated influences their self-esteem. As a filter question for the *dignity* domain, service users (or care recipients) are asked to evaluate how having help in doing things influences their feelings about themselves.

The ASCOT measure designed for carers (ASCOT-Carer) has seven attributes: (1) *occupation*, (2) *control over daily life*, (3) *looking after yourself* (or *self-care*), (4) *personal safety*, (5) *social participation and involvement*, (6) *space and time to be yourself*, and (7) *feeling supported and encouraged*. Similar to the ASCOT-Service user, each attribute of the ASCOT-Carer has four levels ranging from "high needs" (level 0) to "ideal state" (level 3) with "some needs" (level 1) and "no needs" (level 2) measuring the intermediate levels of ASCOT-QoL.

The ASCOT-Service user and ASCOT-Carer measures have both interview (INT4) and self-completion (SCT4) versions. The INT4 versions (interview schedules) contain questions that can be used to measure current and expected SCRQoL. The current SCRQoL is the SCRQoL associated with the services that are used in the current situation, while the expected SCRQoL is the SCRQoL generated in a hypothetical situation where the current services—services that are currently in use—would not be available. The rationale for developing both values of SCRQoL is that the difference between the current and expected SCRQoL can be used to measure the effectiveness of social care on respondents' QoL (Netten et al. 2012; Towers et al. 2016). Since it is expected that the current SCRQoL score is higher than the expected SCRQoL score, the difference between the current and expected SCRQoL is called the SCRQoL gain.

For both ASCOT-Service user and ASCOT-carer measures, individual responses to the ASCOT domain-levels can be summed over the domains to produce an unweighted (equally weighted) or preference-weighted scores of the current and expected SCRQoL. For the ASCOT-Service user measure, the unweighted current and expected SCRQoL can vary from zero (worst individual response '00000000') to 24

(best individual response '33333333').[2] The score that captures the SCRQoL gain can vary from -24 to 24, where positive (negative) values indicate a QoL gain (loss). For the ASCOT-Carer measure, the un-weighted current and expected SCRQoL scores vary from 0 (worst individual response '0000000') to 21 (best individual response '3333333'), and the range of the SCRQoL gain is from -21 to 21.

To compute the preference-weighted SCRQoL score as the sum of preference-weighted, domain-specific SCRQoL scores, one needs to apply separate preference weights to the attribute-levels. Netten et al. (2012) and Batchelder et al. (2019) have produced English preference weights for the ASCOT-Service user and ASCOT-Carer instruments. Both studies applied the best-worst scaling (BWS) method (Louviere et al. 2015) to collect preference data and multinomial logit models to estimate preference weights. With the similar methodological approach, Hajji et al. (2020) and Trukeschitz et al. (2020) have produced Austrian preference weights and Nguyen et al. (2020a; 2020b) have produced Finnish preference weights for the ASCOT-Service user and ASCOT-Carer measures.

The preference-weighed SCRQoL score for each individual is computed by summing the preference-weighted ASCOT attribute-levels that describe response options s/he chose. In total, there are 32 [28] preference-weighted attribute-levels for the ASCOT-Service user [for the ASCOT-Carer]. Netten et al. (2012) anchor the variation of the preference-weighted SCRQoL score between -0.17 and 1, where the value of one measures the highest possible QoL and the value of zero corresponds to the QoL of a dead person. Batchelder at al. (2019), Hajji et al. (2020), Trukeschitz et al. (2020) and Nguyen et al. (2020a; 2020b) adjust the estimated preference weights for the ASCOT-Service user and ASCOT-Carer measures so that the current and expected SCRQoL scores vary between 0 and 1. This adjustment implies that the range of the preference-weighted SCRQoL gain score is from -1 to 1.

2.2 Descriptive data analysis

We used the production of welfare (POW) model (Knapp 1984; Malley and Fernandez 2010) to examine the use of services and the SCRQoL outcomes in our survey data. The POW model builds on the notion that service user outcomes are affected by service-related factors, such as the number of visits and their intensity, but also by non-service-related factors, such as user (living circumstances, need for care) and carer characteristics (the quantity and quality of informal care, the attitudes of care workers). The main message of the POW model is that, when estimating the effectiveness of services, it is imperative to be able to separate the effects of service-related factors from the effects of non-service-related factors. Our aim in this report was not to test the causal relationships of the POW model but to use the model as a framework to structure our descriptive analysis.

We examined the use and intensity of services, attribute-levels describing ASCOT-QoL states and preference-weighted SCRQoL scores as well as individual characteristics by providing individual- and municipal-level descriptive analyses. Descriptive statistical methods, including histograms, sample means and standard deviations, and two-sample t-tests were applied in the data analysis.

[2] The value level "zero" indicates the lowest domain-level (high needs) and the value level "three" indicates the highest domain-level (ideal state).

3 Translating the ASCOT measures

Four original ASCOT measures were translated from English into Finnish between June 2015 and March 2016. The translation was done by the translation agency PharmaQuest (now a part of Corporate Translations) in cooperation with research teams in Finland and England. Self-completion questionniares for service users (SCT4 Service users) and for carers (SCT4 Carers) and interview schedules for service users (INT4 Service users) and for carers (INT4 Carers) were translated into Finnish (www.pssru.ac.uk/ascot/tools).

The aim of the translation process was to produce the official translations of the ASCOT measures such that the Finnish-translated ASCOT measures would be conceptually equivalent to the original ASCOT measures and culturally meaningful to target populations in Finland.

The translation process took several steps (Figure 1). After concept elaboration in June 2015, forward and backward translation techniques were applied (PharmaQuest 2016). In step 2, qualified and experienced translators produced two independent forward translations of the English ASCOT measures into Finnish. In sequence, in-country investigators working for the translation agency produced reconciliated versions of the four ASCOT measures based on forward translations (two translations for each measure) (Step 3). In step 4, two qualified and experienced translators produced backward English translations of each of the Finnish-translated ASCOT measures. These backward translations were compared with the original English ASCOT measures to highlight any notable discrepancies in the translations (Step 5).

Feedback and comments from the developer of the ASCOT measures, from the Finnish research team and from professionals working in Finnish social care were collected in steps 6, 8 and 9. Furthermore, we collected thorough feedback and comments from service users and informal carers in the pilot testing phase (Step 10).

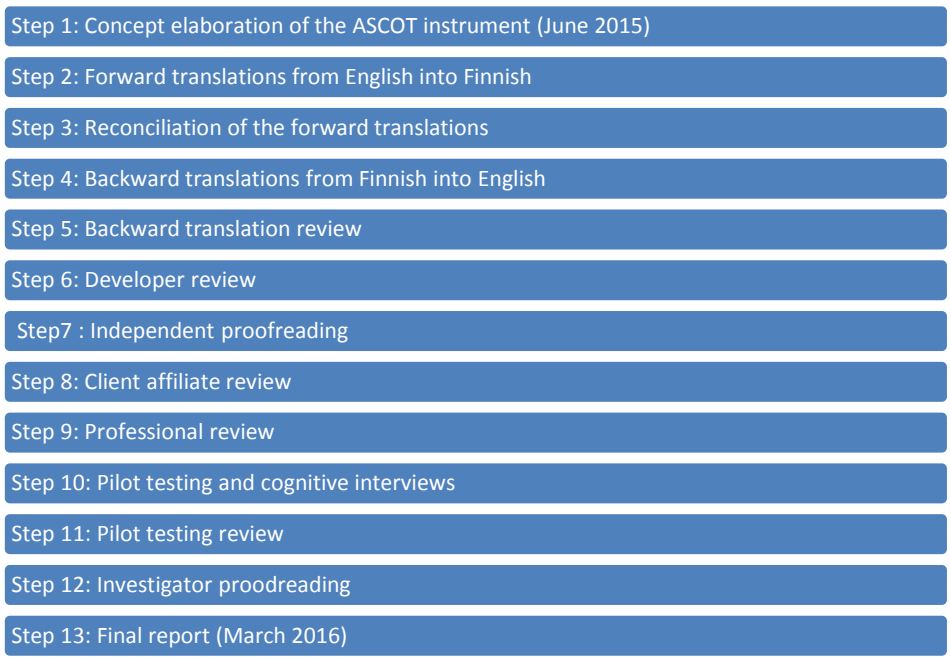

Figure 1. Translation process of the ASCOT instruments from English to Finnish.

We organised cognitive interviews to further evaluate the cross-cultural equivalence and meaningfulness of the Finnish-translated measures among Finnish target populations. Two native Finnish researchers from our team interviewed five (two female and three male) service users and five (two female and three male) informal carers during January and February 2016. All carers in the pilot study had formal contracts with the

city of Helsinki to provide informal care to service users. The average age of carers was 72 years old (a minimum of 65 and maximum of 78) and the average age of the service users was 73 years old (a minimum 65 and maximum of 79).

Full cognitive interviews were carried out on the respondent-oriented text in both the ASCOT-Service user and ASCOT-Carer measures. As the think aloud method (Willis 2015) was applied during the interviews, the participants (service users and carers) had a chance to comment on the response options and wording of the questionnaires/interview schedules and suggest alternative wording to difficult phrases or wording. Whenever deemed necessary, the translation agency and the Finnish interviewers and research team took the comments and suggestions received from the interviewed service users and carers into account in the process of producing the final versions of the ASCOT measures (Steps 12 and 13, Figure 1).

The conducted cognitive interviews were considered helpful and led to some amendments in the Finnish-translated ASCOT measures. For example, several response options in the ASCOT-Service user measures contain the word "adequate", referring to the sufficiently high QoL. Some participants thought that "adequacy" is defined by health and social care professionals, like social workers and medical doctors. To emphasise the notion that we want participants (as service users) to consider their own subjective situation, we added the sentence "Please answer the question on the basis of your current situation and personal experience" to the interview prompts.

Regarding the expected situation asked in the INT4 Service user and INT4 Carer interview schedules, the participants were required to consider a situation, in which they would not receive the services that they do receive currently and no other help stepped in to replace those services. The Finnish translation (before pilot testing) "eikä muutakaan apua olisi saatavilla" implied that the respondent should think about the situation "with no help at all". Since this may bias the self-evaluation of the counterfactual situation, we made the Finnish translation more precise by asking respondents to consider a situation in which no assistance to compensate for the current services ("niitä korvaavaa" in Finnish) was utilised. PharmaQuest (2016) provides the full report on the findings of the cognitive interviews.

4 Ethics clearances

The EXCELC research project in Finland has translated four ASCOT measures, estimated preference weights for the Finnish-translated versions of the ASCOT measures, examined the ASCOT-QoL of old service users and carers, and estimated the effectiveness and cost-effectiveness of non-institutional LTC. The research plan for cognitive interviews that took place in the pilot testing step of the translation process (Figure 1) was submitted to the THL ethics committee, who approved the cognitive interview data collection plan in August 2015 (THL/984/6.02.01/2015).

Finnish preference weights were estimated using data from two online BWS surveys. In one survey, the ASCOT-Service user measure was used, while in the other survey the ASCOT-Carer measure was used. These survey data were collected in July and August 2016. Collected samples were representative of the Finnish adult population in terms or age, sex and regional distribution.

To examine the ASCOT-QoL of old regular home care service users and carers and the effectiveness of non-institutional LTC, structured interviews were organized during the period August 2016–September 2017. Survey data collection in Finland followed the principles that were applied in England (Forder et al. 2016) to produce comparable data in all three countries participating in the project. This implied, for example, applying similar approaches to sample recruitment and using the same questionnaires in the interviews.

We submitted a research proposal, including plans for both online survey and interview data collections, to the THL ethics committee for an ethics assessment in November 2015. In their meeting in December 2015, the ethics committee asked us to both supplement the submitted material and redefine the process of fieldwork data collection in the participating Finnish municipalities and health and social care regions. We provided the necessary material and required information regarding the process of data collection for the THL ethics committee before their next meeting in January 2016. The ethics committee gave approval for our data collection plan involving both online survey and interview data on January 26, 2016 (THL/1523/6.02.01/2015).

5 Survey data collection

The target populations in the interview survey data collection (WP3 and WP4) were Finnish regular home care users over 54 years old (aged 55 years or older) and their informal carers. Our initial aim was to collect a random sample of at least 450 regular home care users and 250 of their carers from the largest Finnish municipalities or health and social care regions based on their population size. The reason for concentrating on the largest municipalities or regions in Finland was that a random sample collected from all municipalities would have led to very small municipal-level strata that cannot be applied to analyse the cost-effectiveness of home care. Instead, we aimed to utilise an equally sized strata of interviews from each participating municipality or region to guarantee sufficiently large regional samples for the estimation of cost-effectiveness.

The 21 largest municipalities or health and social care regions that were defined based on population size were: Helsinki, Espoo, Vantaa, Tampere, Oulu, Turku, Jyväskylä, Kuopio, Lahti, Kouvola, Pori, Joensuu, Hämeenlinna, Vaasa, Joensuu, Rovaniemi, Mikkeli, Kotka, Seinäjoki, Eksote and Kainuu. Among these, Eksote and Kainuu are health and social care regions and the rest of them are municipalities (hereafter *regions*).

The collection of the fieldwork data began in the spring of 2016 when we contacted the selected Finnish regions and invited them to participate in the EXCELC research project. Invitation letters to the local authorities of those 21 regions were emailed during the period February 26–March 1, 2016. By the end of June 2016, 12 regions (Helsinki, Espoo, Vantaa, Tampere, Lahti, Hämeenlinna, Vaasa, Kuopio, Joensuu, Mikkeli, Kainuu and Eksote) had decided to participate in the research project. We applied for consents to interview municipal or regional users of regular home care service and their informal carers from the participating regions and consents were granted over the course of the period April 2016–July 2016.

5.1 Getting ready for interviews

Six fieldworkers were recruited in April 2016–July 2016 to conduct face-to-face interviews with service users and informal carers. They were sought via a job advertisement in newspapers and the THL website. For these six positions, more than 300 applications were received. We interviewed the most potential applicants in May 2016–July 2016. Eventually, we chose six people on the basis of their previous experience in health and social care (through either work or studies) and their previous experience interviewing the elderly. Hence, our interviewers were Iiris Pykäläinen, Miina Nikkanen, Helena Rovamo, Maarit Ojanen, Tuula Kontio and Susanna Nevalainen.

Each interviewer was responsible for interviewing service users and carers in one or three municipalities or health and social care regions (Table 1). We organised a training day for the interviewers on August 24, 2016. Interviews were put into the practice by applying the computer-assisted personal interview (CAPI) techniques with iPads and Qualtrics software (www.qualtrics.com).

To ensure the comparability of the collected Finnish interview data with English and Austrian interview data, we used the questionnaires that were developed for the IIASC (Identifying the Impact of Adult Social Care) project in England (Forder et al. 2016). The questionnaires used in the service user interviews covered a wide range of topics, containing questions on

- care needs (e.g. ADLs and IADLS)
- the receipt of formal services (e.g. home care, meals-on-wheels)
- the receipt of informal care
- the use of instruments and aid (e.g. rollator, senior alarm)
- the ASCOT measure for service users, i.e. ASCOT-Service user (INT4 Service user, including questions on both current and expected SCRQoL)

- the quality of formal services
- overall satisfaction with formal services
- home and living environment
- general QoL
- health (e.g. self-assessed health, EuroQol-5 Dimension (EQ-5D), long-term conditions)
- control and autonomy
- social contacts
- socioeconomic and demographic characteristics of the service users (e.g. education, age and sex)
- the interviewer's personal assessment of the interview.

The questionnaires used in the carer interviews contained questions on

- the cared-for person
- the care and care tasks provided
- support and services received (e.g. respite care, care leave, carer assessment)
- the ASCOT measure for carers, i.e. ASCOT-Carer (INT4 Carer, including questions for both current and expected SCRQoL)
- the quality of formal services received by the care-recipient (service user) and the informal carer
- the receipt of formal services
- general satisfaction with services
- the general QoL
- health (e.g. self-assessed health, EQ-5D)
- control and autonomy
- social contacts
- the home and environment of the carer and the care-recipient
- socioeconomic and demographic characteristics of the informal carers
- the interviewer's personal assessment of the interview.

The English questionnaires of the IIASC study were translated into Finnish in spring and summer 2016. To pilot the Finnish-translated questionnaires, Hanna Jokimäki and Ismo Linnosmaa interviewed four home care clients and one carer at the end of August and the beginning of September 2016. Whenever considered necessary, the questionnaires were amended on the basis of these pilot interviews. In addition, Iris Pykäläinen piloted the ASCOT carer questionnaire in the first two interviews in September 2016. Since there was no need to change the wording of the carer questionnaire on the basis of these two pilot interviews, those interviews were kept as part of the analysis data set.

Interviews were conducted in the 12 participating regions over the course of the period from August 2016 to September 2017. During this period, we had monthly online meetings with the interviewers to discuss, evaluate and occasionally further develop the process of data collection. Table 1 below provides information on the number of interviews done in different regions.

5.2 Recruiting service users and carers

The participating local authorities helped us to recruit survey participants. We provided necessary materials (e.g., invitation and response letters to service users and carers) to the participating regions. The assigned contact persons in the regions then delivered invitation letters to a randomly selected sample of regular home care users over 54 years old. Most invitations were sent by regular mail, but some municipalities also delivered the letters via care workers during their regular visits to home care service users. If municipal or regional response rates turned out to be too low, reminder letters or invitation letters to new potential interviewees were sent. Some small municipalities delivered invitation letters to all regular home care users in order to ensure a sufficiently large regional stratum.

Those home care service users who were willing to participate in the study returned their consent forms to us. We then supplied contact information to the interviewers who were responsible for scheduling and conducting interviews with them. Nearly all of the interviews took place in the service users' homes. Interviewers asked participants, who had agreed to be interviewed, whether they wanted someone close to them to be present as the interview was conducted. In such cases, the interviews were scheduled such that the close person was also able to attend the interview.

As an objective, we wanted to have 450 valid interviews with service users and 250 valid interviews with informal carers. Although numerical targets were reached and even exceeded, the recruitment of home care service users turned out to be challenging due to low response rates (Table 1). In total, 8 855 invitation letters were delivered to regular home care service users. We received 592 return letters (indicating willingness to participate) from invited service users, and eventually 498 regular home care service users were interviewed. The average response rate of service users (number of interviews/number of invitations) was 5.6%. Response rates varied regionally from 1.8% (Mikkeli) to 11% (Tampere).

The guiding principle in the sampling of informal carers was that each interviewed carer should provide care for a regular home care user in the service user sample, with the aim of ending up with 250 carer-service user dyads. Varying methods were applied to recruit informal carers. The most common method was through the service user interviews. The interviewers asked interviewed service users if they had a carer who would be willing to participate in the study. If the service users had a carer, an invitation letter would be given or mailed to the carer. The easiest situation in which to recruit a carer was when s/he was present in the service user's interview. Some municipalities also mailed invitation letters directly to informal carers at the same time the invitation letters were sent to home care service users. This would be possible if municipalities had access to the contact information of informal carers who had contracted with their municipality of residence ("omaishoitajat" in Finnish). Concurrently, another similar method for recruiting carers was to put study and contact information as well as invitation letters to potential carers into the invitation letters that were mailed to home care service users. Finally, on some occasions, home care workers also delivered our invitation letters to informal carers when they paid visits to their clients, i.e. regular home care users. Because the approaches to recruit carers varied so widely (and were often decided upon by local authorities), we received no information about the response rates regarding the interviews with informal carers (Table 1).

There were some carers, who cared for a service user and wanted to participate in the study, but the service user did not want to or could not participate due to his/her health condition or for some other reasons. In such cases, we merely interviewed them. Such carers were called *solo carers*. In addition to face-to-face interviews, some carers were also provided the opportunity to respond to an online questionnaire similar to the questionnaire that was used in the face-to-face interviews.

Table 1. Service user and carer interviews by region and interviewer

Region	Interviewer	Sample of service users			Sample of carers	
		Number of face-to-face interviews	Number of invitations	Response rate (%)	Number of face-to-face interviews	Number of face-to-face and online interviews
Helsinki	Iiris Pykäläinen	58	600	9.7	22	36
Espoo	Iiris Pykäläinen	51	566	9.0	23	29
Vantaa	Iiris Pykäläinen	49	1 200	4.1	6	14
Tampere	Miina Nikkanen	48	438	11.0	21	25
Lahti	Miina Nikkanen	31	650	4.8	18	25
Hämeenlinna	Miina Nikkanen	45	1 166	3.9	18	20
Eksote	Tuula Kontio	38	365	10.4	17	18
Vaasa	Maarit Ojanen	40	830	4.8	15	25
Kuopio	Helena Rovamo	44	750	5.9	23	23
Joensuu	Helena Rovamo	26	720	3.6	6	7
Mikkeli	Helena Rovamo	20	1 120	1.8	2	3
Kainuu	Susanna Nevalainen	48	450	10.7	27	30
Total		498	8 855	5.6	198	255

Table 1 displays detailed information on the number of service user and carer interviews by the regions and response rates for the service user interviews. All conducted interviews could not be used in the analysis due to the incompleteness of some interviews. There were also a very small number of interviewed service users, who were younger than 55 years old. After the removal of these observations, the final service user sample contained 493 interviews of the regular home care users.

After deleting one carer interview because of missing information, the final carer sample included 254 interviews. The most common case in the carer data was that the carer and the service user were interviewed face-to-face (n = 179). Some “solo” carers (n = 16) were also interviewed. In addition, some carers who had a service user in the service user sample responded to an online survey questionnaire that was similar to the original questionnaire (n = 59).

6 Representativeness of the service user data

To examine how well our sample represents the population of home care users in Finland, we collected data on the characteristics of Finnish regular home care users from the Sotkanet database (www.sotkanet.fi). This database provides information on the number, age and sex of regular home care users in Finland by municipalities and health and social care regions.

According to Sotkanet, there were 73 481 regular home care clients on November 30, 2016 and 67 108 (91.3%) of them were aged 65 years old or older. Sotkanet provides no further information on the age distribution of the 6 373 regular home care service users who were younger than 65 years old. Since our data contain regular home care users over 54 years old, we will next compare the age and sex distributions of the regular home care users in our sample with the corresponding distributions of the regular home care users in Finland in two ways: firstly, we compare all home care users in Finland and in our sample and, secondly, we focus on those services users in Finland and in our sample who are over 64 years of age (aged 65 years or older). In the latter case, our sample is comparable with the Sotkanet data on regular home carer users aged 65 years old or older.

Table 2. Regular home care users' gender distributions among in the sample (n = 493) and in the Sotkanet-based data in 2016

Sex	All home care users		Home care users over 64 years old		
	Sample % (n)	Sotkanet % (N)	Sample % (n)	Sotkanet % (N)	Equality of two population proportions: p-value[a]
Female	66.3 (327)	65.5 (48 110)	67.3 (311)	67.3 (45 163)	p > 0.05
Male	33.1 (163)	34.5 (25 371)	32.0 (148)	32.7 (21 945)	p > 0.05
Missing	0.6 (3)	not applicable	0.65 (3)	not applicable	
Total	100 (493)	100 (73 481)	100 (462)	100 (67 108)	

[a] Two-sided test tests the null hypothesis there is no difference between the proportions in our sample and Sotkanet-based data.

In terms of the gender distribution, regular home care users in our sample closely resembled the whole population of Finnish regular home care users (Table 2). This holds true in particular for the sub-sample of regular home care users over 64 years of age. Regarding this group, 67.3% of the respondents in our sample were female. This was also the proportion of female service users in Finland according to Sotkanet-based data.

Table 3. Home care users' age distributions in the sample (n = 493) and in the Sotkanet-based data in 2016

Age groups	All home care users		Home care users over 64 years old		
	Sample % (n)	Sotkanet % (N)	Sample % (n)	Sotkanet % (N)	Equality of two population proportions: p-value[a]
55–64	6.3 (31)	8.7 (6 373[a])			
65–74	13.6 (67)	14.1 (10 394)	14.5 (67)	15.5 (10 394)	p > 0.05
75–84	37.9 (187)	34.6 (25 457)	40.5 (187)	37.9 (25 457)	p > 0.05
85 or older	42.2 (208)	42.6 (31 257)	45.0 (208)	46.6 (31 257)	p > 0.05
Missing	not applicable	not applicable	not applicable	not applicable	
Total	100 (493)	100 (73 481)	100 (462)	100 (67 108)	

[a] Two-sided test test the null hypothesis there is no difference between the proportions in our sample and Sotkanet-based data.

Table 3 displays the age distribution in the sample and in the Sotkanet-based data. As the findings suggest, there was a slight over-representation of the age group 75–84 in our sample in comparison to the Sotkanet-based data. It is notable, however, that the fraction of service users over 84 years old was about the same in both data sets. This is a promising feature of the sample as one would expect the likelihood of non-participation to be the highest among the oldest service users. In particular, for those service users aged 65 years old or older, two population proportions were quite similar and the difference between two population proportions was not statistically significant ($p>0.05$). Overall, in terms of gender and age, our sample represents the population of regular home care service users in the whole country reasonably well (Tables 2–3).

Comparable information presented in Table 4 below allows us to draw conclusions on whether our sample represented the population of regular home care service users in the participating regions or in the country as a whole during the year 2016 or not.

Table 4. Regional distributions of regular home care users in the sample and in Sotkanet-based data in 2016

Region	Home care users		Regionally sampled home care users / regular home care users in Finland (N = 73 481) %	Regional home care users / regular home care users in Finland (N = 73 481) %
	Sample % (n)	Sample region % (N)		
Helsinki	11.8 (58)	30.3 (6 732)	0.079	9.16
Espoo	10.3 (51)	6.6 (1 466)	0.069	1.99
Vantaa	9.9 (49)	6.1 (1 362)	0.067	1.85
Vaasa	7.5 (37)	4.4 (974)	0.050	1.32
Tampere	9.7 (48)	12.3 (2 732)	0.065	3.71
Hämeenlinna	8.9 (44)	3.8 (847)	0.060	1.15
Lahti	6.5 (32)	6.4 (1 425)	0.043	1.94
Kuopio	8.9 (44)	5.5 (1 229)	0.060	1.67
Mikkeli	4.1 (20)	4.2 (927)	0.027	1.26
Joensuu	5.1 (25)	3.8 (850)	0.034	1.15
Eksote	7.5 (37)	10.2 (2 281)	0.050	3.10
Kainuu	9.7 (48)	6.4 (1 427)	0.065	1.94
Total	100 (493)	100 (22 252)	0.67	30.28

Table 4 reveals that a regionally representative sample would have required a sampling strategy with more interviews in large municipalities, e.g., in Helsinki and Tampere, and relatively fewer interviews in smaller municipalities, e.g., Joensuu, Hämeenlinna and Vaasa. However, we decided to follow a sampling strategy that could produce a more even number of interviews in each participating region to ensure the availability of a data set with enough regional variation. The individual data incorporating varied regional characteristics would allow us to examine the cost-effectiveness of home care services with instrumental variables (Forder et al. 2014; 2018). Table A1 in the Appendix provides the same information as Table 4 but for service users over 64 years of age. To correct the regional representativeness in the sample, one can apply appropriate sampling weights before the statistical analysis. Table A2 in the Appendix illustrates the computation of sampling weights using the numbers of home care service users aged 65 years or older in both data.

7 Descriptive analysis: service user data

The following descriptive analysis is based on the production of welfare (POW) model (Knapp 1984; Malley and Fernandez 2010). Within the framework of the POW model, we next describe characteristics of the interviewed home care service users and carers, service use and service intensity as well as the SCRQoL outcomes.

7.1 Service user characteristics

The majority of respondents in our sample were over 74 years old (80.1%) and female (66.3%) (Table 5). The average age of the home care service users was 81.6 years old (median 83, std. dev 9.13). Almost 24% of the service users in our sample were married. This figure closely matches the fraction of individuals living with a spouse or a partner (21.5%). Given the high mean age of the respondents, we also found a high fraction of the service users that were widowed (44.2%) or lived alone (73.6%).

Overall, 61% of the respondents were homeowners or lived in their own dwelling and 38% were paying rent. When asked about how well their home is designed to meet their needs, more than 93% of them responded that the home environment meets their needs very well or most of their needs. Only 5.3% said the home environment only meets some of their needs or it is totally inappropriate for their needs (Table 5).

Regarding self-assessed health (SAH), 29% of the respondents reported that their health was either good or quite good, while the rest of them assessed that their health was either fair (38.3%), quite bad (21.5%) or bad (7.3%). Most of the interviewed service users (93.7%) reported that they have at least one long-term medical condition. More than 85% of the respondents received informal care (Table 5). Approximately 70% of the respondents received informal care from one or two informal carers and around 15% of them were helped by three or more carers.

Table 5. Characteristics of sample home care service users (n = 493)

Variable	Description	n	%
Sex			
	Female	327	66.33
	Male	163	33.06
	Missing	3	0.61
Age			
	55–64 years	31	6.29
	65–74 years	67	13.59
	75–84 years	187	37.93
	85+ years	208	42.19
	Missing	not applicable	
Marital status			
	Never married	60	12.17
	Married	118	23.94
	Separated	1	0.20
	Divorced	91	18.46
	Widowed	218	44.22
	Prefer not to say or missing	5	1.02
Living arrangement			
	Lives alone	363	73.63
	Lives with spouse or partner only	106	21.50
	Lives only with adults other than spouse or partner	21	4.26
	Missing	3	0.61
Tenure			
	Homeowner	301	61.05
	Renting	188	38.13
	Living rent-free/other type	1	0.20
	Missing	3	0.61
Home design			
	My home meets my needs very well	283	57.40
	My home meets most of my needs	178	36.11
	My home meets some of my needs	23	4.67
	My home is totally inappropriate for my needs	3	0.61
	Prefer not to say or missing	6	1.22
Self-assessed health (SAH)			
	Good	44	8.92
	Quite good	100	20.28
	Fair	189	38.34
	Quite bad	106	21.50
	Bad	36	7.30
	Prefer not to say or missing	18	3.65
Long-term medical condition			
	No	28	5.68
	Yes	462	93.71
	Missing	3	0.61
Receipt of informal care			
	No	73	14.81
	Yes	420	85.19

7.2 Service use and intensity

The questions concerning the service use were based on those that were used in the IIASC study (Forder et al. 2016). Whenever needed, the English questions were adjusted to better correspond to the Finnish system of health and social care services.

In Finland, *home care* refers to integrated home health care (or home nursing) and home services (or home help). We asked about the use of home care and support services (Noro et al. 2014) that occurred during the last month before the interview. We also included questions about the visits to day centres, personal assistants, voluntary helpers, and the use of short-term residential care, physiotherapy and occupational therapy as well as questions about the receipt of information and advice from social services during the month before the interview.

Most of the respondents received home care services (95.5%) (Figure 2). This was expected because regular home care users were the target population of the study. Approximately half of the respondents had used cleaning and transport services. Similarly, they were frequent users of meal services: 35% of the respondents reported the use of meal services. Almost one-fifth of the respondents had used physiotherapy. The least used services were advice and information received from social care staff (2.8%) and occupational therapy (3.3%).

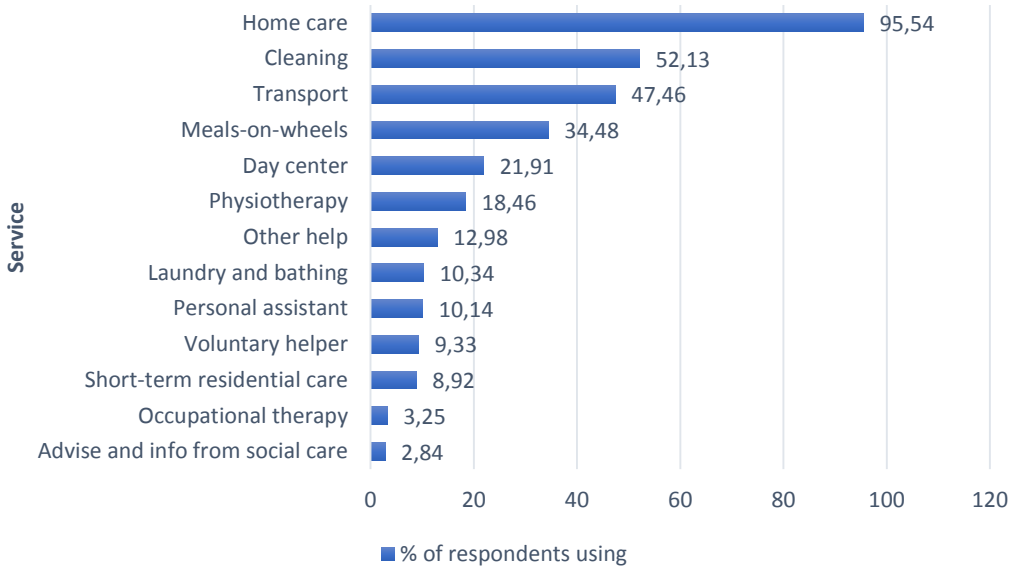

Figure 2. The use of services by service type (n = 493).

The intensity of the service use (or service intensity) is not adequately captured by simple measures describing the use of services (Figure 2). To measure the intensity of the service use, additional information on the number of visits and/or the duration of visits is needed (Forder et al, 2014; 2018).

Our questionnaire also contained questions about the intensity of service use, measured by three indicators: the number of visits, the number of services, and the duration of service use (e.g. the hours of home care received per week). To create a single-valued measure for the service intensity of each respondent, we first multiplied measures of service use intensity by respective unit costs and then added up all service-specific costs. The resulting service intensity measured the respondent's weekly total costs of service use (euros/week).

Unit costs were obtained from the existing statistics and from the reports on municipal expenditures on the LTC for old people and on national unit costs. We used the following unit costs:

- Home care: 36 €/visit (Lyly 2016)
- Meal services: 7.50 €/meal (Ilmarinen 2017)
- Transport services: 20 €/transport (Sirola and Nurmi-Koikkalainen 2014)
- Cleaning services: 15.1 €/hour (Median of the hourly salary of cleaners, Statistics Finland 2016)
- Day care: 117 €/day (Lyly 2016)
- Physiotherapy 61 € (length of the visit: 1–30 min), 123 € (length of the visit: 31–60 min), and 209 € (length of the visit: 60 min or more) (Kapiainen et al. 2014)

Two intensity measures were defined using information on the service use and unit costs. The first measure, *Intensity 1*, measures the intensity of home care use by using information on the number of home care visits and their unit costs. The second measure, *Intensity 2*, contains information on the intensity of the most commonly used services in our sample: home care, support services, day care and physiotherapy. Support services consisted of meals-on-wheels, cleaning and transport services. The use of support services was measured by the number of services (meals-on-wheels and transport) and by hours (cleaning); the use of day care by the number of days in adult day care; and the use of the physiotherapy by the number of length-adjusted visits (see the above list on unit costs). The costs of the used services were added up to obtain a single value of service intensity for each respondent in the service user sample.

Table 6 provides descriptive statistics on the service intensity for both intensity measures. The average intensity of weekly home care use per home care user was €356.4 (std. dev €325.2). Adding costs of support services, day care and physiotherapy to the costs of home care increased the average weekly intensity of the service use to €438.9 (std. dev €347.3) per respondent.

Table 6. Descriptive statistics on the service intensity by intensity measures

Intensity of service use	n	Mean (€)	Median (€)	Std. dev (€)
Intensity 1: home care	483	356.37	252.0	325.17
Intensity 2: home care, support services, day care and physiotherapy	478	438.88	359.97	347.34

Figure 3, below, describes the average service intensity per service user by the regions using the Intensity 2 measure. The average intensity was the highest in Eksote (average cost 646 €/week), followed by Kuopio (average cost 539 €/week) and Joensuu (average cost 527 €/week). On the other hand, Tampere (average cost 335 €/week) and Vantaa (average cost 343 €/week) had the lowest average intensities. In all regions, home care was the most used service. The 95% confidence intervals for the average values of service intensities by regions are presented in the Appendix, Table A3.

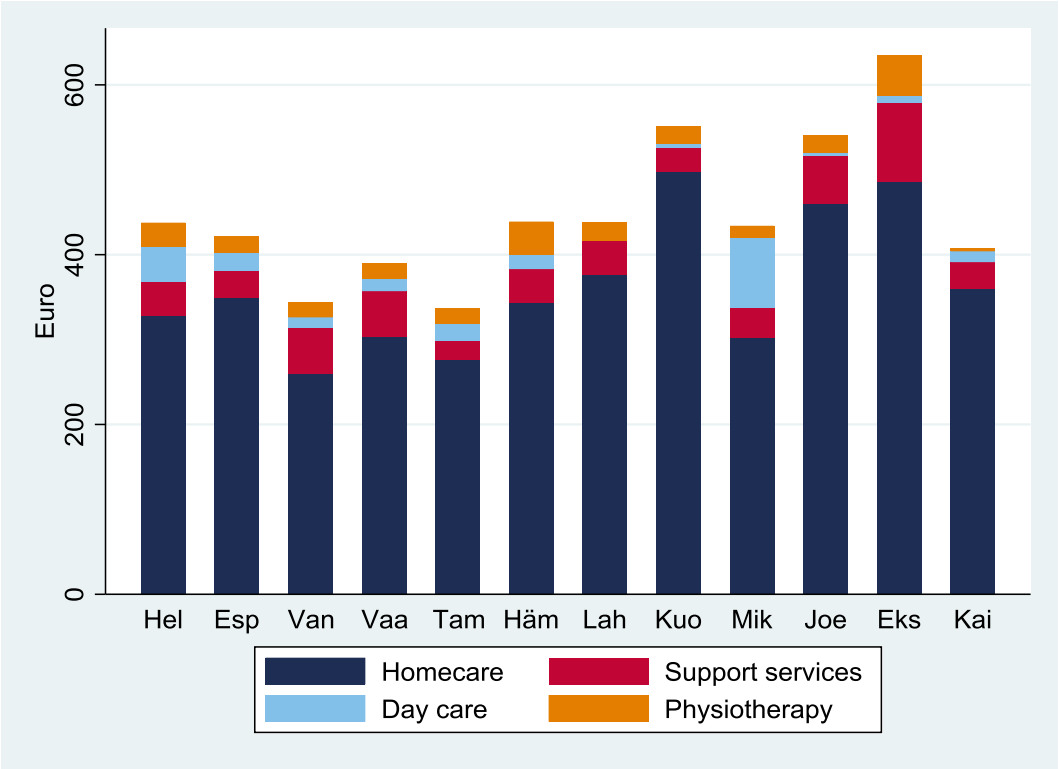

Figure 3. Average service intensity by the regions and service type.

7.3 Social care-related quality of life (SCRQoL) outcomes for service users

The ASCOT-Service user (INT4) questionnaire prompted respondents to respond to the current ASCOT-Service user questions by considering their QoL with services currently in use and to the expected ASCOT-Service user questions by considering their QoL in a hypothetical situation without currently used services. Table 7 describes the responses of the respondents to the questions regarding the current situation with currently used services (consequently, current ASCOT-QoL) and the hypothetical situation in which there would be no services that are currently used (consequently, expected ASCOT-QoL).

Regarding all domains, more than half of the responses to the current ASCOT questions indicated the two highest levels "no needs" (level 2) or "ideal state" (level 3). The situation was the most extreme in the "Food and drink" domain, where 93% of the responses to the current ASCOT questions indicated one of the two highest levels, "ideal state" (level 3) or "no needs" (level 2). A look at the responses to the expected ASCOT questions revealed the opposite situation: for all domains other than the "Food and drink" domain, more than half of the responses indicated one of the two lowest levels, "some needs" (level 1) or "high needs" (level 0). Thus, the central tendency of the *current* ASCOT-QoL distribution was located at the two top levels 2 ('no needs') and 3 ('ideal state'), while the central tendency of the *expected* ASCOT-QoL distribution focused on the two bottom levels 1 ('some needs') and 0 ('high needs'), suggesting that received regular home care services were effective. We will return to this question below with preference-weighted SCRQoL measures.

Table 7. Responses to the current and expected ASCOT-Service user questions by sample service users (n = 493)

ASCOT domain and level	Current ASCOT-QoL		Expected ASCOT-QoL	
	n	%	n	%
Control over daily life				
High needs (level 0): I (would)[a] have no control over my daily life[b]	22	4.46	187	37.93
Some needs (level 1): I (would)[a] have some control over my daily life, but not enough[b]	125	25.35	183	37.12
No needs (level 2): I (would)[a] have adequate control over my daily life[b]	196	39.76	44	8.92
Ideal state (level 3): I (would)[a] have as much control over my daily life as I want[b]	127	25.76	31	6.29
Prefer not to say or missing	23	4.66	48	9.74
Personal cleanliness and comfort				
High needs	1	0.20	103	20.89
Some needs	65	13.18	171	34.69
No needs	244	49.49	111	22.52
Ideal state	162	32.86	74	15.01
Prefer not to say or missing	21	4.26	34	6.90
Food and drink				
High needs	2	0.41	106	21.50
Some needs	16	3.25	106	21.50
No needs	188	38.13	105	21.30
Ideal state	272	55.17	146	29.61
Prefer not to say or missing	15	3.05	30	6.09
Accommodation cleanliness and comfort				
High needs	8	1.62	105	21.30
Some needs	46	9.33	167	33.87
No needs	231	46.86	109	22.11
Ideal state	190	38.54	78	15.82
Prefer not to say or missing	18	3.66	34	6.90
Personal safety				
High needs	4	0.81	100	20.28
Some needs	40	8.11	168	34.08
No needs	159	32.52	111	22.52
Ideal state	274	55.58	77	15.62
Prefer not to say or missing	16	3.25	37	7.51
Social participation and involvement				
High needs	21	4.62	100	20.28
Some needs	152	30.83	187	37.93
No needs	201	40.77	105	21.30
Ideal state	100	20.28	54	10.95
Prefer not to say or missing	19	3.86	47	9.54
Occupation				
High needs	29	5.88	84	17.04
Some needs	152	30.83	194	39.35
No needs	157	31.85	85	17.24
Ideal state	130	26.37	74	15.01
Prefer not to say or missing	25	5.08	56	11.36
Dignity – receiving care (filter question)				
High needs	8	1.62		
Some needs	62	12.58		
No needs	195	39.55		
Ideal state	192	38.95		
Prefer not to say or missing	36	7.31		

Table 7 continued. Responses to the current and expected ASCOT-Service user questions by sample service users (n = 493)

ASCOT domain and level	Current ASCOT-QoL		Expected ASCOT-QoL	
	n	%	n	%
Dignity – way of being helped				
High needs (level 0): The way I'm helped and treated completely undermines the way I think and feel about myself[b]	4	0.81		
Some needs (level 1): The way I'm helped and treated sometimes undermines the way I think and feel about myself[b]	51	10.34		
No needs (level 2): The way I'm helped and treated makes me think and feel better about myself[b]	181	36.71		
Ideal state (level 3): The way I'm helped and treated makes me think and feel better about myself[b]	216	43.81		
Prefer not to say or missing	41	8.32		

[a] Expected response options contain the word in parenthesis.
[b] The ASCOT measure is disclosed in full herein but ordinarily should not be used for any purposes without the appropriate permissions of the ASCOT team and the copyright holder, the University of Kent. Please visit www.pssru.ac.uk/ascot or email finascot@thl.fi to inquire about permissions.

The distributions of the current and expected preference-weighted SCRQoL and the preference-weighted SCRQoL gain for the ASCOT-Service user measure are displayed in Figure 4. The computation of preference-weighted SCRQoL scores was based on non-missing data. For service users, the sample average value of the current preference-weighted SCRQoL was 0.807 (n = 433; median 0.843; std. dev 0.153) and the sample average value of the expected preference-weighted SCRQoL was 0.495 (n = 392; median 0.473; std. dev 0.231). The average value of the preference-weighted SCRQoL gain was 0.315 (n = 383; median 0.299; std. dev 0.206), indicating that services used by regular home care service users were effective on average.

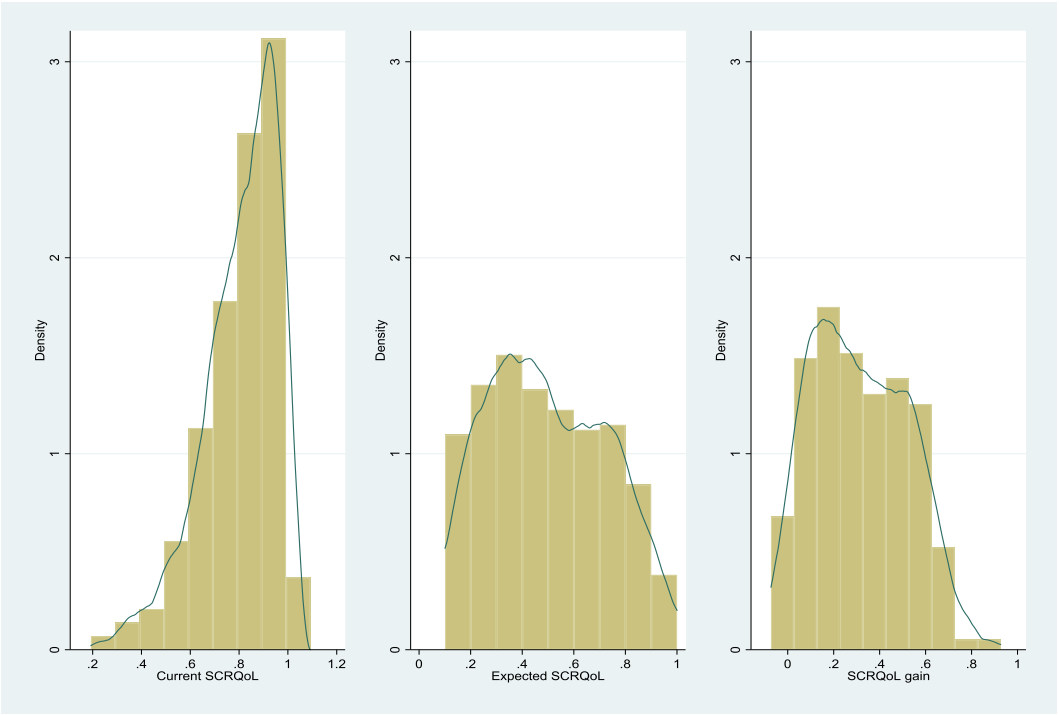

Figure 4. Current and expected preference-weighted SCRQoL and preference-weighted SCRQoL gain for sample service users.

Figure 5 displays the average values of preference-weighted SCRQoL measures by the participating regions. The highest average value of the current preference-weighted SCRQoL was found in Joensuu (average value 0.836), followed by Eksote (average value 0.833) and Vaasa (average value 0.833). Service users residing in Kainuu (average value 0.752) and Mikkeli (average value 0.758) had the lowest average values of the current preference-weighted SCRQoL.

When comparing the preference-weighted SCRQoL gain across regions, the ranking of the regions changed. Service users living in Eksote experienced the highest gain in SCRQoL (average gain 0.463), followed by those living in Joensuu (average gain 0.360) and Vantaa (average gain 0.349). Service users in Mikkeli (average gain 0.205) and Tampere (average gain 0.228) experienced the smallest gains. The 95% confidence intervals of the average values of the preference-weighted SCRQoL scores for sample service users by the regions are presented in the Appendix, Tables A4–A6.

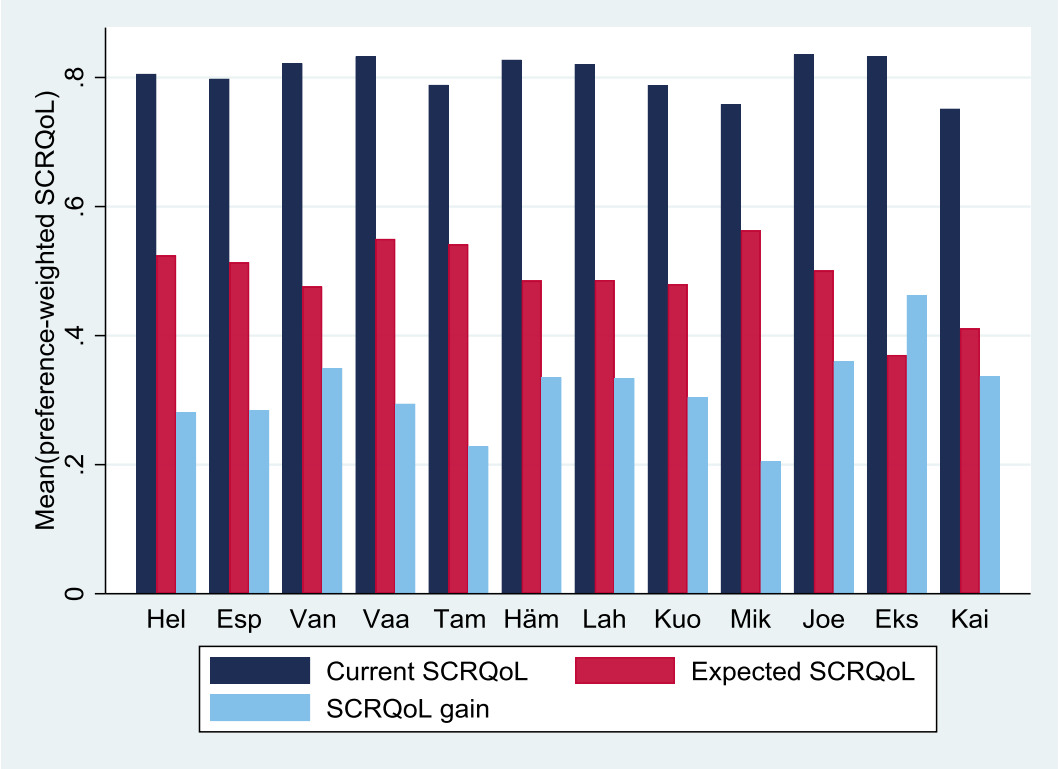

Figure 5. Current and expected preference-weighted SCRQoL and preference-weighted SCRQoL gain for service users by the regions.

The comparison of the regional service intensity and the regional preference-weighted SCRQoL gain reveals a high positive correlation (r = 0.64) between the average intensity (Figure 3) and average SCRQoL gain (Figure 5) across regions. This finding implies a high (low) effectiveness of non-institutional LTC in regions with high (low) service intensity.

8 Descriptive analysis: carer data

Although the ways of recruiting carers varied (Section 5), we primarily recruited carers who provided help and support to regular home care users in the service user sample described above. In total, there were 254 informal carers in our carer sample. For 238 carers (93.7%), there was a corresponding home care client in the service user sample. Of these carers, 179 (75.2% of 238) were interviewed by fieldworkers and 59 (24.8% of 238) responded to an online questionnaire. The remaining 16 carers (6.3%) were solo carers because they did not have any service user dyad in the service user sample. Solo carers provided information regarding the use of services by those service users who did not participate in the study and thus were not in the service user sample.

8.1 Carer characteristics

Most of the respondents in our carer sample were female (72.1%) (Table 8). Amongst them, 78.3% were between 55 and 84 years old. The carers were mostly married or lived in a partnership (65.75%). As was expected, the number of carers living with a spouse or a partner closely matched the number of married carers. While 50% of the carers had the lower or upper secondary education at most, the number of carers with the university degree was also relatively high (28.7%). More than 80% of the carers were home-owners. Almost 88.2% of the carers reported their current health (SAH) to be fair, quite good or good, even though 69.3% of them also said that they have a long-term medical condition.

Table 8. Characteristics of carers (n = 254)

Variable	Description	n	%
Sex			
	Female	183	72.05
	Male	66	25.98
	Missing	5	1.97
Age			
	18-54	34	13.39
	55-64	73	28.74
	65-74	75	29.53
	75-84	51	20.08
	85+	19	7.48
	Missing	2	0.79
Marital status			
	Never married	38	14.96
	Married	167	65.75
	Separated	1	0.39
	Divorced	31	12.20
	Widowed	9	3.54
	Prefer not to say, missing or don't know	8	3.15
Living arrangements			
	Lives alone	58	22.83
	Lives with spouse or partner only	172	67.72
	Lives only with adults other than spouse or partner	15	5.91
	Lives only with children (younger than 16 years)	4	1.57
	Missing	5	1.97
Education			
	Lower secondary school or below	40	15.75
	Upper secondary school	87	34.25
	Short-cycle tertiary and post-secondary school	44	17.32
	BA/MA/PhD or equivalent	73	28.74
	Prefer not to say or missing	10	3.94
Housing tenure			
	Homeowner	204	80.31
	Renting	44	17.32
	Other type	not applicable	not applicable
	Missing	6	2.36
Self-assessed health (SAH)			
	Good	64	25.20
	Quite good	81	31.89
	Fair	79	31.10
	Quite bad	18	7.09
	Bad	7	2.76
	Prefer not to say or missing	5	1.97
Long-term medical condition			
	No	72	28.35
	Yes	176	69.29
	Missing or prefer not to say	6	2.36

8.2 Social care-related quality of life outcomes (SCRQoL) for carers

The INT4 Carers questionnaire asked carers to answer the current ASCOT-Carer questions by considering their QoL with services received by both carers and service users (consequently, current ASCOT-QoL). On the other hand, when responding to the expected ASCOT-Carer questions, carers were asked to consider their QoL in a hypothetical situation without services that are currently used by both carers and service users (consequently, expected ASCOT-QoL).

Table 9 describes carers' responses to the current and expected ASCOT-Carer questions. More than half of the carers' responses to the current ASCOT questions indicated the two highest levels, "ideal state" (level 3) or "no needs" (level 2) for all ASCOT-Carer domains. On the other hand, more than half of the responses to the expected ASCOT questions indicated the two lowest levels, "some needs" (level 1) or "high needs" (level 0). As the central tendencies of the distributions of the current and expected SCRQoL measures are located at the high and low ends of the distributions, respectively, these observations demonstrate that, on average, carers in our sample benefited from services provided to them and service users they cared for. We will return to this issue below.

Table 9. Responses to the current and expected ASCOT-Carer questions by sample carers (n = 254)

ASCOT domain and level	Current ASCOT-QoL		Expected ASCOT-QoL	
	n	%	n	%
Occupation				
High needs (level 0): I don't (I wouldn't)[a] do anything I value and enjoy with my time[b]	9	3.54	102	40.16
Some needs (level 1): I do (would do)[a] some of the things I value and enjoy with my time, but not enough[b]	106	41.73	109	42.91
No needs (level 2): I'm (I would be)[a] able to do enough of the things I value and enjoy with my time[b]	86	33.86	24	9.45
Ideal state (level 3): I'm (I would be)[a] able to spend my time as I want, doing things I value and enjoy[b]	48	18.90	12	4.72
Prefer not to say or missing	5	1.97	7	2.75
Control over daily life				
High needs	9	3.54	92	36.22
Some needs	95	37.40	110	43.31
No needs	101	39.76	39	15.35
Ideal state	44	17.32	7	2.76
Prefer not to say or missing	5	1.97	6	2.36
Looking after yourself				
High needs	35	13.78	89	35.04
Some needs	51	20.08	73	28.74
No needs	108	42.52	66	25.98
Ideal state	56	22.05	21	8.27
Prefer not to say or missing	4	1.57	5	1.97
Personal safety				
High needs	2	0.79	60	23.62
Some needs	23	9.06	84	33.07
No needs	82	32.28	57	22.44
Ideal state	144	56.69	46	18.11
Prefer not to say or missing	3	1.18	7	2.75
Social participation and involvement				
High needs	8	3.15	46	18.11
Some needs	89	35.04	117	46.06
No needs	86	33.86	57	22.44
Ideal state	67	26.38	28	11.02
Prefer not to say or missing	4	1.57	6	2.36
Space and time and space to be yourself				
High needs	5	1.97	77	30.31
Some needs	101	39.76	114	44.88
No needs	101	39.76	41	16.14
Ideal state	44	17.32	19	7.48
Prefer not to say or missing	3	1.18	3	1.18

Table 9 continued. Responses to the current and expected ASCOT-Carer questions by sample carers (n = 254)

ASCOT domain and level	Current ASCOT-QoL		Expected ASCOT-QoL	
	n	%	n	%
Feeling supported and encouraged				
High needs (level 0): I feel (would feel)[a] I have no encouragement and support[b]	29	11.42	93	36.61
Some needs (level 1): I feel (would feel)[a] I have some encouragement and support, but not enough[b]	87	34.25	80	31.50
No needs (level 2): I feel (would feel)[a] I have adequate encouragement and support[b]	94	37.01	47	18.50
Ideal state (level 3): I feel (would feel)[a] I have the encouragement and support I want[b]	37	14.57	20	7.87
Prefer not to say or missing	7	2.75	14	5.51

[a] Expected response options contain the word(s) in parenthesis.
[b] The ASCOT measure is disclosed in full herein but ordinarily should not be used for any purposes without the appropriate permissions of the ASCOT team and the copyright holder, the University of Kent. Please visit www.pssru.ac.uk/ascot or email finascot@thl.fi to inquire about permissions.

Figure 6 below displays the distributions of the current and expected preference-weighted SCRQoL and that of the preference-weighted SCRQoL gain using the ASCOT-Carer measure. For carers, the sample average of the current preference-weighted SCRQoL was 0.719 (n = 244; median 0.7655; std. dev 0.223) and the sample average of the expected preference-weighted SCRQoL was 0.396 (n = 235; median 0.36; std. dev 0.267). The estimated average preference-weighted SCRQoL gain, i.e., the average value of the difference between the current and expected SCRQoL scores in the sample, was 0.325 (n = 233; median 0.332; std. dev 0.222). A positive-valued prerence-weighted SCRQoL gain indicates that carers benefited from the current services that were provided for carers and their cared-for persons.

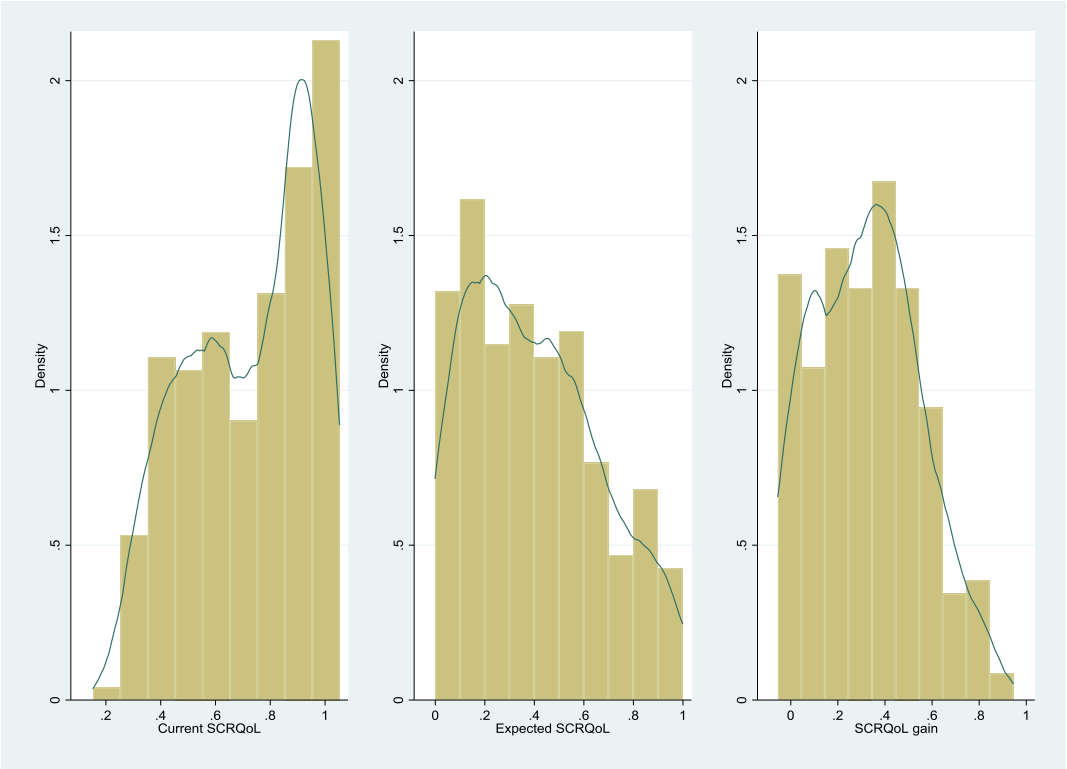

Figure 6. Current and expected preference-weighted SCRQoL scores and preference-weighted SCRQoL gain for sample carers.

The regional average values of the current and expected preference-weighted SCRQoL and those of the preference-weighted SCRQoL gain using the ASCOT-Carer measure are displayed in Figure 7. Due to the low number of observations, we do not present average values of the ASCOT-Carer measures for Mikkeli in Figure 7 or in Tables A7–A9 in the Appendix. The average value of the current preference-weighted SCRQoL-Carer score was the highest in Eksote (average value 0.794), followed by Vantaa (average value 0.768). The average value was also high in Joensuu, but the low number of observations in Joensuu (n = 7) do not allow us to compare Joensuu reliably with the other regions. The current preference-weighted SCRQoL for carers was the lowest in Helsinki (average value 0.662) and Tampere (average value 0.666).

The preference-weighted SCRQoL gain for carers was also the highest in Eksote (average gain 0.458). The lowest average gain in the preference-weighted SCRQoL for carers was found in Tampere (average gain 0.203). The 95% confidence intervals of the average values of the preference-weighted SCRQoL scores for carers by the participating regions are presented in the Appendix, Tables A7–A9.

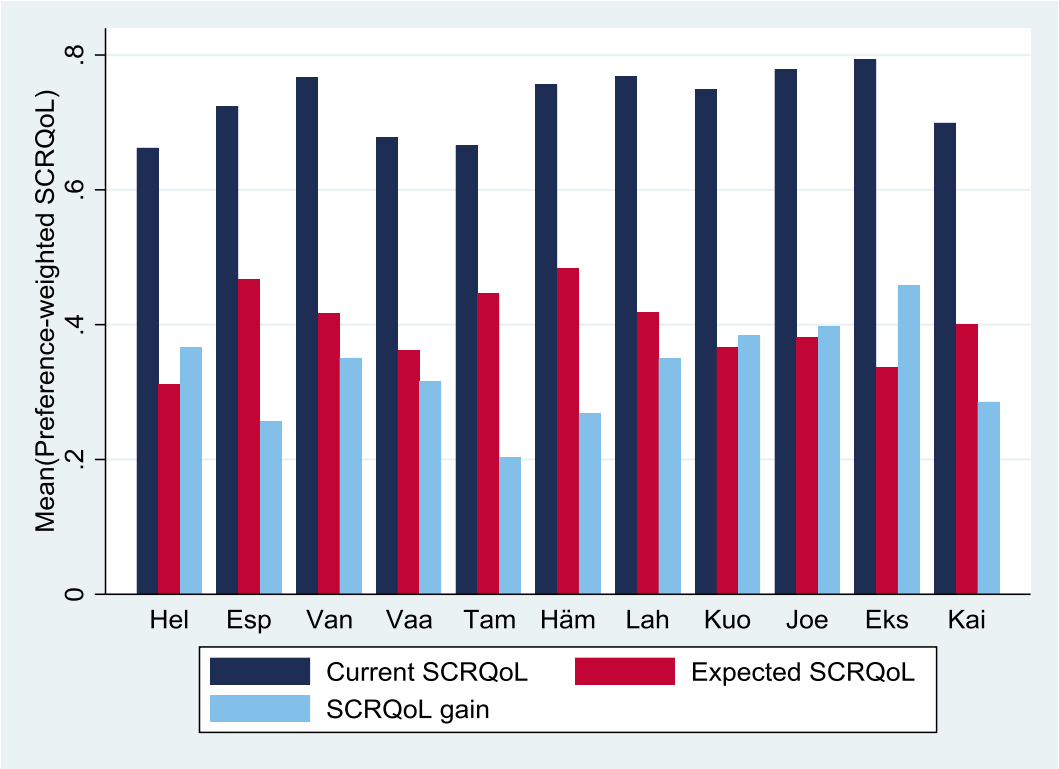

Figure 7. Current and expected preference-weighted SCRQoL and preference-weighted SCRQoL gain for sample carers by the regions.

9 Conclusions

In this methodological report, we described the translation process of the service user-specific and carer-specific ASCOT instruments from English to Finnish and gave insights into the process of survey data collection that was applied in the EXCELC project. We also provided the main descriptive findings on both service users' and their carers' SCRQoL and the use of non-institutional LTC services consumed by regular home care users in the participating regions in Finland.

Several interesting findings arise from this Finland-based descriptive EXCELC study. First, the data collection was challenged by a high non-response rate among regular home care service users who were invited to participate in the study. However, the comparison of the collected regular home care user sample with the Finnish population of regular home care users based on Sotkanet revealed that our sample resembles very much of the national data in terms of the age and sex of service users. Secondly, the descriptive analysis on the SCRQoL of service users and carers showed that both groups benefit from the services provided for them. This is illustrated by the fact that the average value of the current preference-weighted SCRQoL score exceeds that of the expected preference-weighted SCRQoL score, which implies a positive average gain in SCRQoL for both study populations and thus effectiveness of used services. Thirdly, we found large regional variation of the preference-weighted SCRQoL scores for sampled service users and in the intensity of non-institutional LTC services.

We also found a positive and high correlation between the average service intensity and the SCRQoL gain measures across the participating regions. The average SCRQoL gain is found to be high in those regions where the intensity of services, measured by the weekly costs of service use, is high (Figures 3 and 5). However, these observations do not give a final answer to the question whether there is an association or a causal relationship between the service intensity and service user outcomes. Hence, we leave the interesting question of whether service intensity has an impact on service users' SCRQoL for future work. As the last observation, we note that, even though the SCRQoL of carers may not be fully comparable with that of service users, the average current preference-weighted SCRQoL of carers is lower than the average current preference-weighted SCRQoL of servicer users. Answering the question why this might be the case is also left for future research.

One should also mention a study limitation that is commonly applicable to interview studies. Although our aim was to make structured interviews as comparable and controlled as possible e.g. via interviewer training, it is possible that the circumstances in interviews might have influenced interviewees' responses. We can explore this question further in the future work because we also collected data on interviewers' assessments of the interview situations. These data contain information on whether interviewees responded alone or were helped by someone else and whether they stayed focused throughout the interview session. Interviewers' assessments provide valuable information on the quality of responses received during the interview sessions.

The Finnish-translated ASCOT measures provide new tools for local Finnish decision-makers responsible for organising statutory LTC services for elderly people to measure the effectiveness of care services or interventions and the QoL of service users (see www.pssru.ac.uk/ascot/translations or e-mail to finascot@thl.fi). In addition, our descriptive findings provide important information for the local decision-makers in the regions participating in this study about the effectiveness and costs of non-institutional LTC services and how they are related.

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Appendix

Table A1. Regional distribution of the sample for regular home care service users over 64 years old (65+) in 2016

Region	65+ home care users		Regionally sampled 65+ home care users / 65+ home care users in the whole country (N = 67 108) %	65+ home care users in the sample regions / 65+ home care users in the whole country (N = 67 108) %
	Sample % (n)	Sample region % (N)		
Helsinki	11.5 (53)	30.5 (6 228)	0.079	9.28
Espoo	10.4 (48)	6.2 (1 268)	0.071	1.89
Vantaa	10.4 (48)	6.1 (1 249)	0.071	1.86
Vaasa	6.9 (32)	4.2 (853)	0.048	1.27
Tampere	10.4 (48)	12.5 (2 555)	0.071	3.81
Hämeenlinna	9.3 (43)	3.9 (806)	0.064	1.20
Lahti	6.1 (28)	6.2 (1 262)	0.041	1.88
Kuopio	8.7 (40)	5.5 (1 128)	0.060	1.68
Mikkeli	4.1 (19)	4.2 (849)	0.028	1.26
Joensuu	5.0 (23)	3.8 (778)	0.034	1.16
Eksote	7.1 (33)	10.2 (2 091)	0.049	3.11
Kainuu	10.2 (47)	6.7 (1 364)	0.070	2.03
Total	100 (462)	100 (20 431)	0.69	30.44

Table A2. Sampling weights for service users over 64 years old

Region	Service users over 64 years old		Sampling weight (= 1/(A/B))
	(A) Sample	(B) Sample region (in 2016)	
Helsinki	53	6 228	117.5
Espoo	48	1 268	26.4
Vantaa	48	1 249	26.0
Vaasa	32	853	22.7
Tampere	48	2 555	53.2
Hämeenlinna	43	806	18.7
Lahti	28	1 262	45.1
Kuopio	40	1 128	28.2
Mikkeli	19	849	44.7
Joensuu	23	778	33.8
Eksote	33	2 091	63.4
Kainuu	47	1 364	29.0

Table A3. Average intensity of service use by the regions

Region	n	Average	95% confidence interval	
			Lower bound	Upper bound
Helsinki	57	439.07	342.12	536.01
Espoo	51	421.42	316.00	526.85
Vantaa	49	343.74	276.69	410.79
Vaasa	36	391.43	298.33	484.53
Tampere	46	335.54	238.97	432.10
Hämeenlinna	42	442.09	342.47	541.72
Lahti	32	438.34	337.12	539.56
Kuopio	43	539.25	441.88	636.61
Mikkeli	19	434.75	283.30	586.19
Joensuu	21	527.14	349.18	705.10
Eksote	35	646.74	514.62	778.85
Kainuu	47	407.37	300.99	513.75

Table A4. Average current preference-weighted SCRQoL for service users by the regions

Region	n	Average	95% confidence interval	
			Lower bound	Upper bound
Helsinki	56	0.81	0.76	0.85
Espoo	51	0.80	0.75	0.84
Vantaa	48	0.82	0.78	0.86
Vaasa	36	0.83	0.79	0.87
Tampere	41	0.79	0.74	0.83
Hämeenlinna	38	0.83	0.78	0.87
Lahti	29	0.82	0.76	0.88
Kuopio	33	0.79	0.74	0.83
Mikkeli	19	0.76	0.67	0.85
Joensuu	21	0.84	0.78	0.89
Eksote	35	0.83	0.79	0.88
Kainuu	26	0.75	0.68	0.82

Table A5. Average expected preference-weighted SCRQoL for service users by the regions

Region	n	Average	95% confidence interval	
			Lower bound	Upper bound
Helsinki	55	0.52	0.46	0.58
Espoo	51	0.51	0.45	0.58
Vantaa	49	0.48	0.41	0.54
Vaasa	34	0.55	0.49	0.61
Tampere	35	0.54	0.47	0.61
Hämeenlinna	34	0.48	0.41	0.56
Lahti	26	0.49	0.38	0.59
Kuopio	26	0.48	0.38	0.58
Mikkeli	17	0.56	0.47	0.66
Joensuu	16	0.50	0.39	0.61
Eksote	35	0.37	0.30	0.43
Kainuu	14	0.41	0.28	0.54

Table A6. Average preference-weighted SCRQoL gain for service users by the regions

Region	n	Average	95% confidence interval	
			Lower bound	Upper bound
Helsinki	53	0.28	0.23	0.33
Espoo	51	0.28	0.24	0.33
Vantaa	48	0.35	0.29	0.41
Vaasa	34	0.29	0.23	0.36
Tampere	33	0.23	0.17	0.28
Hämeenlinna	33	0.33	0.27	0.40
Lahti	26	0.33	0.24	0.43
Kuopio	24	0.30	0.22	0.39
Mikkeli	17	0.20	0.11	0.30
Joensuu	16	0.36	0.26	0.46
Eksote	35	0.46	0.39	0.53
Kainuu	13	0.34	0.21	0.47

Table A7. Average current preference-weighted SCRQoL for carers by the regions

Region	n	Average	95% confidence intervals	
			Lower bound	Upper bound
Helsinki	36	0.66	0.59	0.73
Espoo	28	0.72	0.65	0.80
Vantaa	13	0.77	0.65	0.88
Vaasa	24	0.68	0.57	0.79
Tampere	24	0.67	0.57	0.76
Hämeenlinna	16	0.76	0.66	0.85
Lahti	25	0.77	0.68	0.85
Kuopio	22	0.75	0.64	0.85
Mikkeli	not reported	not reported		
Joensuu	7	0.78	0.61	0.94
Eksote	17	0.79	0.70	0.89
Kainuu	29	0.70	0.62	0.78

Table A8. Average expected preference-weighted SCRQoL for carers by the regions

Region	n	Average	95% confidence interval	
			Lower bound	Upper bound
Helsinki	34	0.31	0.23	0.39
Espoo	28	0.47	0.35	0.58
Vantaa	13	0.42	0.27	0.56
Vaasa	24	0.36	0.26	0.46
Tampere	20	0.45	0.33	0.57
Hämeenlinna	15	0.48	0.41	0.56
Lahti	25	0.42	0.31	0.53
Kuopio	23	0.37	0.24	0.49
Mikkeli	not reported	not reported		
Joensuu	7	0.38	0.13	0.63
Eksote	17	0.34	0.23	0.44
Kainuu	26	0.40	0.30	0.50

Table A9. Average preference-weighted SCRQoL gain for carers by the regions

Region	n	Average	95% confidence interval	
			Lower bound	Upper bound
Helsinki	34	0.37	0.31	0.42
Espoo	28	0.26	0.19	0.32
Vantaa	13	0.35	0.21	0.49
Vaasa	24	0.32	0.21	0.42
Tampere	20	0.20	0.12	0.29
Hämeenlinna	15	0.27	0.17	0.37
Lahti	25	0.35	0.25	0.45
Kuopio	23	0.38	0.28	0.49
Mikkeli	not reported	not reported		
Joensuu	7	0.40	0.23	0.56
Eksote	17	0.46	0.36	0.55
Kainuu	26	0.28	0.20	0.37