

# RemoAge: remote support for aged people

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D.T2.2.2: Summative evaluation report

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This report summarises the evaluation of the RemoAge project across the test sites. It examines the activities and services developed in the test sites and their impacts for the organisations, the local communities and the people using the services.

## Contents

|  |    |
|--|----|
| 1. Introduction: the RemoAge project .....                           | 5  |
| 1.1 Aims and objectives .....  | 5  |
| 1.2 The RemoAge concept .....  | 5  |
| 1.3 Outputs from RemoAge .....                                       | 6  |
| 1.4 The tests .....  | 8  |
| 1.5 The report .....   | 9  |
| 2. Methods used in the evaluation .....                              | 10 |
| 2.1 Baseline data – ‘what we have’ .....                             | 10 |
| 2.2 Quantitative evaluation data .....                               | 11 |
| 2.3 Key informant interviews .....                                   | 12 |
| 2.4 Local evaluation data .....                                      | 12 |
| 2.5 Ethical approval .....   | 12 |
| 3. Baseline information .....  | 13 |
| 3.1 Baseline data .....  | 13 |
| 3.1.1. Population aged 60+ in areas involved in RemoAge .....        | 13 |
| 3.2 Existing services and aspirations .....                          | 16 |
| 3.3 The starting points for RemoAge .....                            | 26 |
| 4. Services developed and issues encountered .....                   | 27 |
| 4.1 Services developed: the RemoAge approach in each test site ..... | 27 |
| 4.1.1 Norrbotten .....   | 27 |
| 4.1.2 Shetland .....   | 29 |
| 4.1.3 Tromsø .....   | 30 |
| 4.1.4 Western Isles .....  | 33 |
| 4.2 Issues encountered and lessons learned .....                     | 34 |
| 4.2.1 Challenges for individuals .....                               | 35 |
| 4.2.2 Challenges for organisations .....                             | 36 |
| 4.2.3 Challenges for communities .....                               | 36 |
| 5. Service user data .....   | 38 |
| 5.1 Challenges in project-specific data collection .....             | 38 |
| 5.2 Swedish frail older service users and their main carers .....    | 38 |
| 5.2.1 Demographic characteristics .....                              | 39 |

|  |    |
|--|----|
| 5.2.2 Health characteristics.....  | 40 |
| 5.2.3 Difficulties with everyday activities .....  | 41 |
| 5.2.4 Psychological wellbeing .....  | 43 |
| 5.2.5 Carers of service users .....  | 48 |
| 5.3 Norwegian service users and frail older people receiving services during RemoAge .....                         | 50 |
| 5.4 Shetland Islands service users.....  | 51 |
| 5.5 Service users in the Western Isles .....   | 52 |
| 6. Conclusion and implications .....   | 54 |
| 6.1 Evaluation processes and questions .....   | 54 |
| 6.2 Real world issues.....   | 54 |
| 6.3 Technology use in services for frail older people .....  | 56 |
| 6.4 Benefits of international collaboration.....   | 56 |
| 7. Appendix .....  | 57 |
| 7.1 Evaluation of services delivered (service users and carers) .....  | 57 |
| Section 1: Background questions.....   | 57 |
| Q1 – Q4: complete from records/interaction with the person .....   | 57 |
| Q5 onwards ask the person themselves or the carer: complete the answers as they apply to the<br>older person ..... | 57 |
| Section 2: questions for the main carer of the person receiving the service .....                                  | 64 |

## Tables

|   |    |
|---|----|
| Table 1 RemoAge ‘core’ modules .....  | 7  |
| Table 2 Population aged 60 and over in the test sites.....  | 13 |
| Table 3 Older population in the test sites as a proportion of the total population .....  | 14 |
| Table 4: Locations of older people according to rurality and remoteness .....   | 14 |
| Table 5 Diagnosis and estimated prevalence of dementia in the test sites .....  | 15 |
| Table 6 'What we have' and 'what we want' in the test sites .....   | 17 |
| Table 7: Model of a patient-centred service via communication tools.....  | 31 |
| Table 8: Demographic characteristics of RemoAge service user sample from Swedish test sites .....   | 39 |
| Table 9: Mental wellbeing: responses of Swedish RemoAge service users and Swedish respondents to<br>the 2016 European Quality of Life Survey aged 65+ compared .....      | 46 |
| Table 10: Subjective wellbeing: responses of Swedish RemoAge service users and Swedish respondents<br>to the 2016 European Quality of Life Survey aged 65+ compared ..... | 48 |
| Table 11: Swedish service users’ main carers’ scores on Brief COPE subscales (n=12).....  | 49 |

|  |    |
|--|----|
| Table 12: Characteristics of the first patients to be treated by the Patient-Centred Healthcare Team (n=98) (from Bergmo et al 2016) ..... | 50 |
|--|----|

## Figures

|   |    |
|---|----|
| Figure 1 The RemoAge conceptual model .....   | 6  |
| Figure 2 Example of the service development flow envisaged by the RemoAge project .....   | 8  |
| Figure 3: Services developed in Norrbotten .....  | 27 |
| Figure 4: Frequency of identification of selected chronic health problems in Swedish RemoAge service users (n=41, multiple problems identified in 30 cases) .....   | 40 |
| Figure 5: Profile of service users by difficulties experienced with Activities of Daily Living (ADLs) (n=53 service users) and Instrumental Activities of Daily Living (IADLs) (n=52 service users) .....   | 41 |
| Figure 6: Swedish RemoAge service users' difficulties with selected ADLs (n=53 service users) .....   | 42 |
| Figure 7: Swedish RemoAge service users' difficulties with selected IADLs (n=52 service users) .....  | 43 |
| Figure 8: Swedish RemoAge service user scores on the Geriatric Depression Scale (Short Form) (Sheikh and Yesavage 1986) (n=52 service users) (Maximum score 15, scores 6-10 warrant further investigation, scores >10 indicate probable depression) ..... | 44 |
| Figure 9: Service users' ratings of mood in the two weeks prior to being interviewed .....  | 45 |
| Figure 10: Swedish RemoAge service users' responses to selected statements relating to subjective wellbeing (n=51 service users) .....  | 47 |

## 1. Introduction: the RemoAge project

'RemoAge' is the acronym for a project titled 'Remote support of aged people' which has been funded through the European Union's Northern Periphery and Arctic Programme (NPA).

The project, which is led by The County Council of Norrbotten, Luleå, Sweden, is a collaborative venture between academic institutions and local health and social care providers located in three different countries: Norway, Scotland and Sweden. There are seven full partners and two associate partners. Full partners are: in Norway The Norwegian Center for Integrated Care and Telemedicine; in Scotland, the University of Stirling; NHS Western Isles; The Shetland Council, Shetland Isles; and in Sweden, the County Council of Norrbotten, the Society of Local Authorities in Norrbotten and Luleå University of Technology. The associate partners are the National Association of Municipalities in the Faroe Islands and Ulster University Science Research Institute, Smart Environments Research Group.

RemoAge is a 3-year project, which commenced 1 May 2015. The total value of the project is around €1.9 million, of which approximately €1.2m is funded by the NPA with the remainder coming from partner contributions.

### 1.1 Aims and objectives

The overall aim of the project was to improve services for frail older people, including people with dementia, living in remote rural communities which allow and support them to continue living in their current homes and prevent/postpone their placement in institutional care.

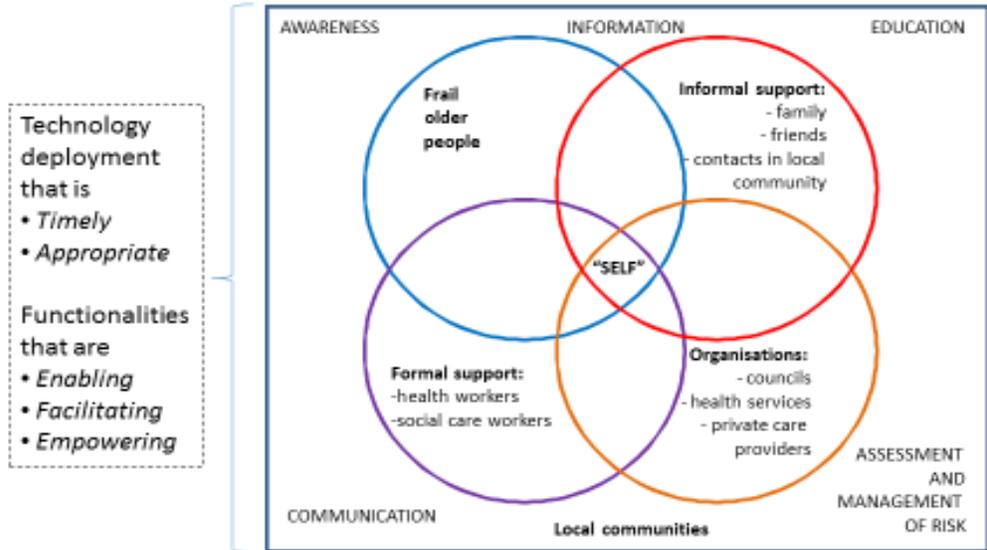
The specific objectives of the project were to:

- develop, test and disseminate new solutions for services that improve the quality of support to frail older people in remote communities
- develop, test and disseminate services that include aspects of remote support
- develop, test and disseminate innovative technology-driven public services
- develop, test and disseminate new services for awareness raising and training of the family, community members and professionals.
- develop, test and disseminate models for support of frail older people built on a transnational learning process

### 1.2 The RemoAge concept

The RemoAge project builds on the work of the RemoDem project (2013-2015), which was built around a conceptual model of dementia support which has been extended for the RemoAge project to include frail older people experiencing a range of impairment. The model places the "self" of an individual frail older person at the centre of a series of intersecting 'circles of support', bounded by the community in which they live, as represented in Figure 1. Peer support, formal and informal sources of support, relevant organisations and local communities all have parts to play in helping a frail older person to preserve, maintain and nurture their independence and "self".

Figure 1 The RemoAge conceptual model



The appropriate and timely use of technology can enable and facilitate the support of frail older people, for example by providing: novel means of providing education for people, their supporters, and the wider public; access to detailed information; more joined-up communication between supporting organisations; remote access to specialist services. It can also empower both frail older people and their supporters, for example through on-line peer support, devices to support safe walking, memory aids, and so on.

Many technologies have been developed. Some have been designed specifically to enable the support of frail older people, others have been developed in other contexts but can be usefully ‘repurposed’ to assist frail older people and people with dementia and their supporters. Many service providers would like to deploy appropriate technologies but are faced with a situation in which they often do not have the resources to gather and to remain abreast of the evidence of efficacy and acceptability of different technologies which could be used to support frail older people and their carers. The RemoAge project sought to address this by supporting the deployment of technologies in services in remote areas.

### 1.3 Outputs from RemoAge

RemoAge has further developed the RemoDem decision support tool for use in planning the provision of services for frail older people in remote rural areas. The tool (Deliverable 6.3) provides access to technical data and to information on the available evidence on acceptability and efficacy of deployment

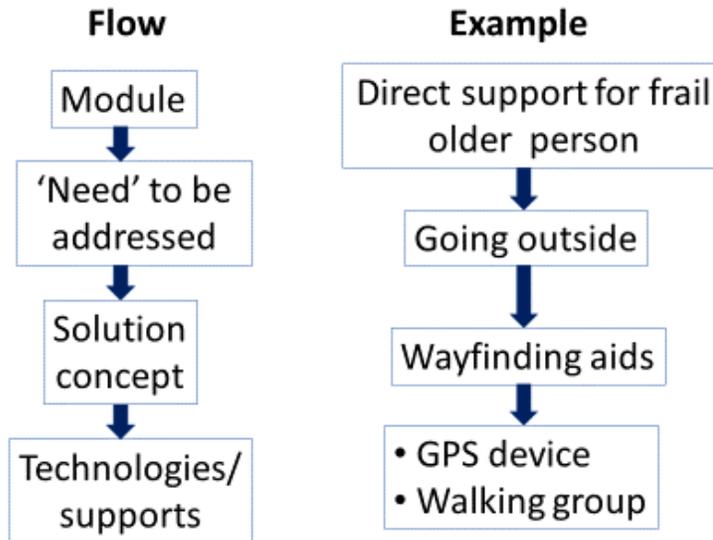
of different technologies. The services include: the direct support of frail older people; services for informal supporters; professional support services; and services aimed at communities and community members. As well as using findings from an extensive literature review, which included a review of evidence supporting technology use, the RemoAge decision support tool (Deliverable D6.3) incorporates findings from the evaluation.

The RemoAge tool provides structured access to both summarised and detailed information. The RemoAge tool presents information in ‘modules’ which focus on different areas of service provision. Within each module users can browse ‘solution concepts’ for identified needs and access data on specific technologies delivering each solution concept. Table 1 introduces the RemoAge ‘core’ modules and provides examples, and Figure 2 illustrates and provides an example of the service development flow envisaged by the RemoAge project.

**Table 1 RemoAge ‘core’ modules**

| <b>Module:</b>  | <b>Could include:</b>  |
|---|--|
| <i>Direct support of the frail older person</i>               | Activity supports such as navigation aids and way finding devices, communication aids  |
| <i>Support of family and other informal carers</i>            | Help-lines for family members; community supported respite services  |
| <i>Support for professionals</i>                              | relevant educational resources, facilities for remote consultation   |
| <i>Support for community members</i>                          | Specially tailored programs to engage young people; other community support  |
| <i>Support for information exchange between organisations</i> | Web-based local, national and transnational networks for knowledge exchange  |
| <i>Support for community awareness</i>                        | Publicly available information and education resources about ageing generally; resources detailing and promoting community-based support |
| <i>Support for service integration</i>                        | Technology-enabled ways of tailoring the service package to the individual needs of frail older people                                   |

Figure 2 Example of the service development flow envisaged by the RemoAge project



The RemoAge tool does not make decisions – it is designed to be a tool to aid decision-making which draws on published literature and transnational learning to help inform decisions by summarising the evidence base and detailing technical requirements for implementation of tried and tested potential solutions.

Through the tool RemoAge aims to support organisations in planning the implementation of national and local elder care strategies. RemoAge tool modules are arranged so that users can access information on different areas of service provision in line with local priorities.

The RemoAge tool also allows users to browse available data by ‘solution concept’. In this way decision-makers can access evidence of acceptance and efficacy of the solution concept and existing technologies delivering that solution which will assist them in evaluating new product offerings.

### 1.4 The tests

The seven test sites involved in developing RemoAge services are Gällivare, Haparanda, Luleå and Övertorneå in Sweden; Shetland and the Western Isles in Scotland; and Tromsø in Norway. During the course of the project, other sites became interested and also started to develop services and engage with RemoAge. The test sites were invited to use the RemoAge tool to facilitate decisions about what service innovations were most appropriate to their local circumstances, and implemented new services for frail older people. The sites took part in the evaluation described in this report to varying degrees.

## **1.5 The report**

This report covers the evaluation of the project. It describes the innovations that were put into place and comments on the challenges and facilitators that the sites encountered. In addition, the report explores the users of services in each locality and considers the impact of the innovations for them. As they faced very different local circumstances, each of the sites provided data for the evaluation to the best of their abilities and according to their local experience. As will be clear, the data are patchy.

## 2. Methods used in the evaluation

Evaluation of the programme was intended to be both summative and formative, i.e. producing an overview of the results of the service implementations and also informing the services as they proceeded, facilitating sharing of experience and shared learning across sites. Our approach drew on guidelines for domains of focus and recommended ways of collecting data in the MAST (*Model for Assessment of Telemedicine*) manual (<http://www.epractice.eu/en/library/315610>) (of which NST and Stirling are co-authors). MAST is specifically designed for assessing the effectiveness of telemedicine and telecare interventions. For RemoAge, we added the element of formative evaluation and the focus on complex conditions (the many dimensions of frailty) and complex services.

The evaluation aimed to produce information about how well the services worked, what differences services made, and impacts for the stakeholders identified in the template of support i.e. frail older people, informal supporters, formal supporters and organisations. The evaluation set out to compare experiences across the service sites and to generate cross national learning to inform future deployment of the services.

The sites were requested to provide data relating to existing services and the services they intended to develop during RemoAge. The sites were provided with templates to facilitate collection of evaluation data during the implementation period. The data were centrally collated and analysed by the WP lead (Stirling) and reported back to the project group at project meetings, during which progress and experiences across sites were compared and discussed.

The following outlines each element of the evaluation.

### 2.1 Baseline data – ‘what we have’

The baseline was provided by each of the sites at the start of the project. The data collected included

- details of the structure of the local population aged 60 and over;
- available information about income and wealth;
- details of the distribution of the population across more urban and more rural areas;
- available information about how many people were diagnosed with dementia, and how many were expected to have dementia given the population;
- an account of local services for frail older people including public, private and third sector provision;
- an account of the financing of care;
- information about national and local strategies for frail older people and people with dementia;
- information about national and local standards for care;
- information about national and local plans for care;
- any local service evaluations or needs assessments;
- information about any particular local issues.

The information was collated into a database providing an overview of the test sites and their current standing in relation to services provision. The data were not complete, reflecting local difficulties. In

addition, the test sites were asked to provide information about their current services for frail older people, and their aspirations for developing new services. These are discussed in section 3 (below).

## 2.2 Quantitative evaluation data

The service sites were asked to provide regular updates on developments in their services through interviews with a designated local representative. These updates are discussed below (2.3).

To collect data from people who were using the services, a questionnaire was translated into local languages where needed and administered by local staff. The questionnaire included the following elements:

- Background demographic information regarding severity of dementia, gender and age, household living arrangements, educational level;
- Questions about activities of daily living and whether these were affected by health, physical or mental difficulties. These questions used standard SHARE (Survey of Health, Ageing and Retirement in Europe at <http://www.share-project.org/>) formats, and standard translation was available into Swedish.
- To assess aspects of quality of life, we used selected questions from the European Quality of Life Survey Swedish translation (<http://www.eurofound.europa.eu/eqls-2012-questionnaire-translation>) and the Geriatric Depression Scale Swedish translation (<http://web.stanford.edu/~yesavage/GDS.html>)
- Questions for the family/other informal caregiver to assess how they were managing with the support they were giving to the person. These used the Brief COPE inventory (<http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>) which was translated by the project teams for local use.

The sites encountered some difficulties in collecting the data as envisaged, and the dataset is therefore rather incomplete. Difficulties primarily related to local considerations about whether the service provided lent itself to the collection of service user perspectives, or to services which had very small numbers of users. In some cases, the services provided did not lend themselves readily to evaluation over time, as they were one off services. In others, the services took many months to establish and there was insufficient time to collect meaningful data on service users' experiences. However, we obtained some data from the Swedish sites. Where possible, local evaluations were also reviewed to provide further information about service delivery and its impacts. These were obtained from all of the Swedish sites and are described in aggregate below. The Norwegian site has, at the time of writing, published a protocol and conference paper concerning a controlled before and after study of their service (Bergmo et al 2015, 2016<sup>1</sup>).

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<sup>1</sup> Bergmo TS, Berntsen GK, Dalbakk M, Rumpsfeld M.(2015) The effectiveness and cost effectiveness of the Patient-Centred Team (PACT) model: study protocol of a prospective matched control before-and-after study BMC Geriatr. 15:133. doi: 10.1186/s12877-015-0133-x.

## **2.3 Key informant interviews**

Interviews with site representatives were designed to capture the experience of developing and delivering the services in the test sites, focusing on the organisations and individuals involved in each location. The key informants were staff with overviews of the service delivery process, who had interacted with other stakeholders including other professionals, frail older people and informal carers. Data were collected partly through interviews, through the discussions at the regular team meetings, when sites provided updates of their progress, and through discussion at the annual face to face meetings of the full project team. Topics included experiences of delivering services, perceived challenges faced, and facilitators to effective service development.

The data provided accounts of the experience of delivering the services and the challenges faced and overcome along the way. The focus was primarily on the benefits and challenges specifically for organisations, but also captured the key informants' perspectives on how the test was progressing for frail older people and informal carers.

The discussions among the project team provided opportunities for cross-site learning, comparing notes, suggesting new ideas and mutual support. In-country meetings were also held in Scotland and Sweden, and these provided further opportunities for cross site learning between the Swedish, and the two Scottish sites respectively.

## **2.4 Local evaluation data**

The Swedish sites conducted local evaluations: these were supplied to the evaluation team, and have been used to inform the report.

## **2.5 Ethical approval**

Each test site followed procedures to gain ethical approval for data collection that applied locally. Principles of informed consent and confidentiality of data were followed throughout. Data were provided to the University of Stirling team without any identifying material. The University of Stirling team received ethical approval from the School of Applied Social Science Ethics Committee to analyse the data provided by the sites.

### 3. Baseline information

#### 3.1 Baseline data

At the start of the project each of the test sites was asked to provide a range of data about their locality. This included baseline data on the numbers of people with dementia living in their area and characteristics of their locality. In addition test sites were asked to provide information about current services and support provided to frail older people and their families. This information was collected under seven headings, relating to the seven modules of support identified in the RemoDem project proposal. Test sites also provided information about current gaps in services and areas for development; this was included under the headings ‘what we have’ and ‘what we need.’

##### 3.1.1. Population aged 60+ in areas involved in RemoAge

All sites were able to provide data about the numbers of older people in their areas. Table 2 gives the population aged 60 and over, and shows the breakdown between men and women.

Table 2 Population aged 60 and over in the test sites

|                     | Tromsø -<br>Norway | Gällivare<br>-<br>Sweden | Haparanda<br>– Sweden | Luleå -<br>Sweden | Övertorneå<br>- Sweden | Shetland<br>Islands | Western<br>Isles |
|---------------------|--------------------|--------------------------|-----------------------|-------------------|------------------------|---------------------|------------------|
| <b>Older people</b> |                    |                          |                       |                   |                        |                     |                  |
| 60-64               | 3835               | 1310                     | 835                   | 4616              | 426                    | 1592                | 2004             |
| 65-69               | 3767               | 1244                     | 860                   | 4612              | 425                    | 1251                | 1965             |
| 70-74               | 2246               | 1058                     | 596                   | 3680              | 340                    | 925                 | 1541             |
| 75-79               | 1422               | 987                      | 442                   | 2824              | 261                    | 693                 | 1213             |
| 80-84               | 963                | 691                      | 318                   | 1998              | 208                    | 497                 | 858              |
| 85-89               | 624                | 404                      | 174                   | 1186              | 106                    | 315                 | 562              |
| 90+                 | 324                | 198                      | 69                    | 560               | 64                     | 174                 | 307              |
| <b>Total</b>        | <b>12681</b>       | <b>5892</b>              | <b>3294</b>           | <b>19476</b>      | <b>1830</b>            | <b>5447</b>         | <b>8450</b>      |
| <b>Older men</b>    |                    |                          |                       |                   |                        |                     |                  |
| 60-64               | 1942               | 673                      | 417                   | 2307              | 248                    | 857                 | 1012             |
| 65-69               | 1627               | 685                      | 452                   | 2228              | 246                    | 621                 | 1010             |
| 70-74               | 1121               | 546                      | 294                   | 1777              | 178                    | 457                 | 722              |
| 75-79               | 646                | 453                      | 196                   | 1282              | 132                    | 313                 | 560              |
| 80-84               | 414                | 328                      | 142                   | 838               | 95                     | 209                 | 325              |
| 85-89               | 212                | 165                      | 63                    | 450               | 39                     | 112                 | 215              |
| 90+                 | 80                 | 70                       | 16                    | 182               | 24                     | 58                  | 70               |
| <b>Total</b>        | <b>6042</b>        | <b>2920</b>              | <b>1580</b>           | <b>9064</b>       | <b>962</b>             | <b>2627</b>         | <b>3914</b>      |
| <b>Older women</b>  |                    |                          |                       |                   |                        |                     |                  |
| 60-64               | 1893               | 637                      | 418                   | 2309              | 178                    | 735                 | 992              |
| 65-69               | 1640               | 559                      | 408                   | 2384              | 179                    | 630                 | 955              |
| 70-74               | 1125               | 512                      | 302                   | 1903              | 162                    | 468                 | 819              |
| 75-79               | 776                | 534                      | 246                   | 1542              | 129                    | 380                 | 653              |

|              |             |             |             |              |            |             |             |
|--------------|-------------|-------------|-------------|--------------|------------|-------------|-------------|
| 80-84        | 549         | 363         | 176         | 1160         | 113        | 288         | 533         |
| 85-89        | 412         | 239         | 111         | 736          | 67         | 203         | 347         |
| 90+          | 244         | 128         | 53          | 378          | 40         | 116         | 237         |
| <b>Total</b> | <b>6639</b> | <b>2972</b> | <b>1714</b> | <b>10412</b> | <b>868</b> | <b>2820</b> | <b>4536</b> |

In all the areas, men tend to be more numerous in the younger old age groups, with women represented in larger numbers amongst the oldest old. This pattern may reflect more out-migration by women at younger ages. In the oldest groups, women significantly outnumber men, representing patterns common across Europe.

The areas include varied populations of older people in relation to the whole population. Table 3 shows the proportion of older people in the populations of each area.

**Table 3 Older population in the test sites as a proportion of the total population**

|   | <b>Tromsø - Norway</b> | <b>Gällivare - Sweden</b> | <b>Haparanda - Sweden</b> | <b>Luleå - Sweden</b> | <b>Övertorneå - Sweden</b> | <b>Shetland Islands</b> | <b>Western Isles</b> |
|---|------------------------|---------------------------|---------------------------|-----------------------|----------------------------|-------------------------|----------------------|
| <b>Population aged 60 and over</b>      | 12681                  | 5892                      | 3294                      | 19476                 | 1830                       | 5447                    | 7748                 |
| <b>Total population</b>                 | *                      | 18252                     | 9789                      | 75911                 | 4719                       | 22210                   | 26502                |
| <b>% of population aged 60 and over</b> | *                      | 32%                       | 34%                       | 26%                   | 39%                        | 25%                     | 29%                  |
| <b>Life expectancy - men</b>            | *                      | 76.26                     | 75.39                     | 79.38                 | 79.24                      | 77.6                    | 76.7                 |
| <b>Life expectancy - women</b>          | *                      | 83.33                     | 81.89                     | 83.91                 | 83.31                      | 81.9                    | 82.9                 |

\*figure not provided

The high proportions of older people in these areas, most notably in rural Sweden, reflect historical out-migration of young people and have particularly significant implications for workforce availability.

Figures were also provided indicating the type of area in which people lived, whether very remote small towns or very remote and rural. The format of the data varied a little between the sites, but we include the figures here to alert readers to the potential variation in frail older peoples' circumstances in respect of their likelihood of having neighbours close by, and their variable distance from the service providers.

**Table 4: Locations of older people according to rurality and remoteness**

|  | <b>Tromsø - Norway</b> | <b>Gällivare - Sweden</b> | <b>Haparanda - Sweden</b> | <b>Övertorneå - Sweden</b> | <b>Shetland Islands</b> | <b>Western Isles</b> |
|--|------------------------|---------------------------|---------------------------|----------------------------|-------------------------|----------------------|
|--|------------------------|---------------------------|---------------------------|----------------------------|-------------------------|----------------------|

|                                |       |      |      |      |            |      |
|--------------------------------|-------|------|------|------|------------|------|
| <b>Very remote small towns</b> |       |      |      |      |            |      |
| 60-64                          | 6309  | 1022 | 683  | 151  | No figures | 487  |
| 65-69                          |       | 931  | 694  | 158  | 1498       | 449  |
| 70-74                          | 3106  | 763  | 470  | 129  |            | 383  |
| 75-79                          |       | 722  | 349  | 111  | 757        | 327  |
| 80-84                          | 1660  | 510  | 254  | 65   |            | 255  |
| 85-89                          |       | 315  | 143  | 46   | 299        | 166  |
| 90+                            |       | 149  | 62   | 16   |            | 108  |
| <b>Total</b>                   | 11075 | 1022 | 2655 | 676  | 2554       | 2175 |
| <b>Very remote rural areas</b> |       |      |      |      |            |      |
| 60-64                          | 898   | 276  | 152  | 282  |            | 1575 |
| 65-69                          |       | 306  | 166  | 276  | 1022       | 1445 |
| 70-74                          | 534   | 285  | 126  | 216  |            | 1136 |
| 75-79                          |       | 252  | 93   | 172  | 543        | 869  |
| 80-84                          | 255   | 158  | 64   | 124  |            | 602  |
| 85-89                          |       | 76   | 31   | 76   | 182        | 356  |
| 90+                            |       | 37   | 7    | 41   |            | 170  |
| <b>Total</b>                   | 1687  | 1390 | 639  | 1187 | 1747       | 6153 |

A further potential source of variation in circumstances and experiences derives from socioeconomic factors. The sites differed in circumstances in several ways.

An important difference between RemoDem and RemoAge is that RemoAge focuses on all frail older people, whereas RemoDem concentrated only on people with dementia. This restricted potential activities, because only people with a diagnosis of dementia could be included, and it was known that rates of dementia diagnosis were low in the participating sites. We investigated the rates of dementia diagnosis in the RemoAge test sites to support this change of focus.

It is difficult to obtain figures for prevalence of dementia in many countries, as rates of diagnosis are often low, and dementia is often hidden. The test sites varied in the knowledge they had about diagnosis, and we used Eurocode<sup>2</sup> estimates to suggest how many people in their areas might actually have dementia. As Table 4 demonstrates, in every case the figures suggest that many people had not received a diagnosis. Thus it is likely that people who would have been excluded from RemoDem were able to be included in RemoAge.

**Table 5 Diagnosis and estimated prevalence of dementia in the test sites**

<sup>2</sup> <http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/>

|  | <b>Tromsø - Norway</b> | <b>Gällivare - Sweden</b> | <b>Haparanda – Sweden</b> | <b>Övertorneå - Sweden</b> | <b>Shetland Islands</b> | <b>Western Isles</b> |
|--|------------------------|---------------------------|---------------------------|----------------------------|-------------------------|----------------------|
| Diagnosed with dementia                    | No figures available   | 144                       | 203                       | 77                         | 183                     | 313                  |
| Estimated numbers with dementia (Eurocode) | 667                    | 669                       | 344                       | 223                        | 307                     | 608                  |

In all areas, informal care provided by family, friends and neighbours was recognised as an important aspect of support for frail older people, but test sites did not hold data about numbers of informal carers locally. Much care and support was provided at the expense of the public purse, with individuals receiving care being required to pay a portion of the costs on a means tested basis.

### **3.2 Existing services and aspirations**

In this section, we consider the information from the test sites regarding ‘what we have’ in terms of service provision and ‘what we want’ in terms of the aspirations to develop new services under the RemoAge project. The information is summarised in Table 5.

Table 6 'What we have' and 'what we want' in the test sites

| <b>Country/region</b>              | <b>What we have</b>   | <b>What we want</b>  |
|------------------------------------|---|--|
| <b>Norway</b>                      | People who cannot leave hospital after treatment due to lack of support at home, and others who do not recover so well at home.   | To work with our multidisciplinary team that will support older people leaving hospital after treatment such as hip surgery, to support recovery at home using communications technology   |
| <b>Scotland - Shetland Islands</b> | <p>Shetland Islands Council (SIC) provides 7 residential Care Centres throughout Shetland and there is one on each of the islands of Unst and Yell. Both provide a range of services including respite, day support and home care. They also support home care workers on the neighbouring island of Fetlar which does not have a Care Centre. There is also 1 Care Centre run by Crossreach (this is funded through the Church of Scotland) in the town of Scalloway on the main island.</p> <p>There are 10 GP practices throughout Shetland and Yell and Unst both have GP practices with 2 GPs in each. They also have a range of associated health care professionals attached to the practices, including practice and Community Nurses, access to OT and physiotherapy and more specialist services visiting regularly. Fetlar only has a Community Nurse based there full time.</p> <p>There are some specially designed and adapted supported accommodation complexes both in Lerwick and on the island of Unst for people deemed as being frail elderly and/or living with dementia.</p> <p>There is a Positive Dementia group in Lerwick providing peer support to people living with dementia.</p> <p>Alzheimer Scotland provides a range of activities and support for people living with dementia, mainly in Lerwick. There are</p> | <p>A local network for sharing information, support and ideas<br/>Greater access to activities for people living with dementia and frail older people in the more rural parts of Shetland.</p> <p>More support for adaptations to people’s own homes and more accommodation designed to allow people who are frail elderly and/or living with dementia to remain independent in their own homes or more homely environments.</p> <p>Training for carers of people living with dementia.</p> <p>A wider range of training opportunities available locally as many of the National training programmes are held in the central belt of Scotland and are financially prohibitive for people in Shetland to attend.</p> <p>More use of videoconferencing for support, supervision and access to training.</p> <p>Need to organise local awareness events in different parts of Shetland would be useful and would be worth developing</p> <p>Full managerial and budgetary integration will allow for services to be developed that reduce duplication of care and improve care provided</p> |

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|  | <p>Dementia cafes held in 3 more rural areas.</p> <p>There is a good level of provision and use of telecare and telehealth equipment.</p> <p>Demonstrations of telecare and aids and adaptation are available at the Independent Living Centre.<br/>The third sector provides support to older people through a Befriending service.</p> <p>There is a range of generic Carer Support groups in Shetland and there is one serving the population of Unst and Yell.</p> <p>There is a Carers Support group for partners of people living with dementia and a separate one for adult children of this group. Both are based in Lerwick.</p> <p>Voluntary Action Shetland (VAS) offers a range of training for informal carers.</p> <p>Respite for carers can be arranged by VAS through accessing a Short Breaks fund.</p> <p>Respite is also available in the council or Crossreach run care centres for the person deemed frail elderly and/or living with dementia to allow the carer to have a break.</p> <p>Promoting Excellence is a stepped framework for training health and social services staff in dementia. This is a National programme developed jointly by NHS Education Scotland and the Scottish Social Services Council. It has been rolled out locally.</p> | <p>Local Dementia and Older Person's Strategies are currently in draft form and out for consultation</p> |
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|  | <p>There is a National Dementia Nurse Consultant group with participation from our Nurse Consultant.</p> <p>There are online Communities of Practice that professionals can access in a range of topics.</p> <p>The local Dementia Assessment Service receives Consultant Psychiatrist support by means of a video link clinic.</p> <p>Alzheimer Scotland provides Dementia Friends training to a range of individuals and groups throughout Shetland including school children.</p> <p>There have been a number of instances of media engagement including interviews and articles in the local newspaper, interviews with the local radio station as well as a feature programme dealing with dementia on the local radio station.</p> <p>There were a number of public consultation meetings to provide information and gather opinions when developing the local Dementia Strategy and the Older Person’s Strategy.</p> <p>There is a “Playlist For Life” project about to commence involving young volunteers from one of the secondary schools and people living with advanced dementia in one of the care centres.</p> <p>There is an online Knowledge Network dealing with a range of topics including dementia. This is provided through NHS Education Scotland and available to professionals in health and social care.</p> <p>Dementia services are integrated through a local Dementia Services Partnership.</p> |  |
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|  | <p>All health and social care services are currently becoming integrated through the Scottish Government Integration agenda.</p> <p>National Dementia and Older Person's Strategies are in place.<br/>National Dementia Standards are in place.</p>   |   |
| <p><b>Scotland -<br/>Western Isles</b></p> | <p>National Health Service Western Isles (NHS WI) provides:<br/> Acute hospital services<br/> Out- patient clinics<br/> Community Health services (nursing, occupational therapy, physiotherapy, speech &amp; language therapy, podiatry, dietetics)<br/> Specialist Long Term Condition (LTC)nurses/service provision<br/> Community Mental Health service</p> <p>Local Authority(LA) provides:<br/> Home Care Service<br/> Day Care Services<br/> Residential Care<br/> Respite Care– public and independent sector care homes – specialist and integrated units</p> <p>FAIRE - Community Careline Service is a 24 Careline service and covers the whole of the Western Isles. The service is designed to:<br/> · Provide support and reassurance for people living on their own<br/> · Provide an immediate response in an emergency<br/> · Provide reassurance and support for family carers</p> <p>Integrated Care (Partnership working NHS WI &amp; LA) provides:</p> | <p>Further work around assistive technologies to enable people to stay at home for longer.</p> <p>To examine further use of befriending schemes.</p> <p>Carer education programmes.</p> <p>To continue work around DFC with roll out across all islands.</p> <p>Community roadshow type events</p> <p>Transnational networking for knowledge exchange</p> |

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|  | <p>Assessment, treatment and care including the provision of a range of equipment and home adaptations including assistive technologies – from Podiatry, Community Nursing, Occupational Therapy etc.</p> <p>Third Sector (Voluntary Sector) provides:</p> <p>Alzheimer Scotland - Day care centre provided &amp; Home support service + Dementia Cafes/Lewis and Harris</p> <p>Tagsa Uibhist – range of activities and services to support older people including those with dementia and their carers/Uist and Benbecula</p> <p>Cobhair Bharraigh – range of activities and services to support older people including those with dementia and their carers/Barra and Vatersay</p> <p>Village and township Community groups/Older people groups/Dementia Cafes</p> <p>Catch 23 - a service user led drop – in facility operated 6 days a week by the Western Isles Association for Mental Health (WIAMH) and is available to those who have experienced difficulties with mental illness.</p> <p>Carer Strategy</p> <p>Western Isles Carer and User Support Network</p> <p>Crossroads : offer a Core Service to carers and service users which is delivered by team of fully-trained and paid Care Attendants. Commissioned by the Social Work Department (LA)to organise respite care. Also provides some daytime or overnight palliative care service to those with a terminal illness.</p> <p>Western Isles Community Care Forum (brings together all the major voluntary sector groups)</p> <p>Promoting excellence resource</p> <p>Dementia Friendly Communities Initiative</p> <p>Dementia Champions</p> |  |
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|  | <p>Community Clinics<br/> Dementia Awareness Week<br/> Wide ranging campaigns around many long-term conditions e.g. cancer, stroke, coronary heart disease, diabetes, respiratory conditions.</p> <p>Partnership in Practice Agreement (learning disabilities)</p> <ul style="list-style-type: none"> <li>•Delayed Discharge Plan</li> <li>•Carers’ Information Strategy</li> <li>•Carers’ Strategy</li> <li>•Joint Mental Health Services Plans</li> <li>•Dementia Services Strategy</li> <li>•Advocacy Plan</li> <li>•Alcohol and Drugs Partnership (ADP) Action Plan</li> <li>•Housing Strategy</li> <li>•Health Improvement Plan</li> <li>•‘Protecting Vulnerable Adults in the Western Isles’</li> <li>•Social Work Department (Community Care) Business Plan</li> </ul> <p>Dementia Steering Group<br/> Older Peoples Partnership<br/> Community Care Forum<br/> Managed Clinical Networks(MCNs) for all LTC<br/> Dementia Champions</p> <p>Change Plan 2011/12 and 2012/13<br/> Single Outcome Agreement (LA)<br/> Alcohol and Drugs Partnership Strategy<br/> All our Futures: Planning for a Scotland with an Ageing Population<br/> Carers strategies<br/> CnES(LA) Corporate Strategy 2007-2011 and 2012-17<br/> Draft Re-ablement Strategy for the Outer Hebrides.<br/> Falls Policy</p> |  |
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|---------------------------------------|---|---|
|                                       | <p>Health and Homelessness Plan<br/> HEAT Targets<br/> Housing Strategy 2011-2016<br/> Joint Hospital Discharge Policy<br/> Joint Futures and Better Outcomes for Older People<br/> Long Term Care Plan<br/> National Minimum Information Standards<br/> NHS WI Local Health Plan 2009-2013<br/> Tele Health and Tele Care Plan</p>   |   |
| <p><b>Sweden –<br/> Gällivare</b></p> | <p>We provide actual contact from the home care service.</p> <p>People have a community alarm for security.</p> <p>Today the doctor from the Heath Centre can do physical home visits to those patients who cannot come to the Health Care Centre.</p> <p>In Norrbotten we have guidelines which say that people who have receive care from both organizations, municipality and health care, should have a personal plan which describes what kind of needs they have and who is going to provide support.</p> <p>Delivery of the care plans takes place at the Health Centre and the patient’s home. Today few plans are made, so we need to work differently to get more individual plans for the patients.</p> <p>Currently it is problematic to exchange information about patients between the organization because we use a different recording system in the municipality and the county council.</p> <p>Today we have physical meetings between the organizations.</p> | <p>We would like to have time-controlled medicine dosage units, remote supervision for security and GPS alarm and navigation support.</p> <p>We want to use Ipads so that the nurse and doctor can do home visits with the technology.</p> <p>We would like to use the technology Skype for planning with different professionals, family and the patients.</p> <p>Using Ipads could enable the staff to document in the recording system whilst they are in the patient’s home.</p> <p>We would like to use Smartphones for keyless home care.</p> <p>We would like the municipality staff to see and use a patient’s overview electronically so they can read what the doctor has done with the patient.</p> <p>We would like to hold virtual meetings between the organizations using Skype.</p> |

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| <p><b>Sweden - Haparanda</b></p> | <p>GPS alarm alerts when help is needed.</p> <p>Today the doctor from the Health Centre can do physical home visits to those patients who cannot come to the Health Care Centre.</p> <p>In Norrbotten we have guidelines which say that people who have receive care from both organizations, municipality and health care, should have a personal plan which describes what kind of needs they have and who is going to provide support.</p> <p>Delivery of the care plans takes place at the Health Centre and the patient's home. Today few plans are made, so we need to work differently to get more individual plans for the patients.</p> <p>Currently it is problematic to exchange information about patients between the organization because we use a different recording system in the municipality and the county council.</p> <p>Today we have physical meetings between the organizations.</p> | <p>We would like to introduce time-controlled medicine dosage units and remote night supervision.</p> <p>We would like to provide Ipads for the frail older people that the personnel from the municipality and Health Centre can use to support care giving.</p> <p>We would like the nurses in the municipality to use a care bag to do more professionals assessments of the patients.</p> <p>We would like the nurses and doctors to do home visits with the technology.</p> <p>We would like to use Skype technology for planning with different professionals, family and the patients.</p> <p>We would like the municipality staff to see and use a patient's overview electronically so they can read what the doctor has done with the patient.</p> |
| <p><b>Sweden Luleå</b></p>       | <p>Nurses put medication into a dosette box and the home care staff give the patient the medicine.</p>  | <p>We would like time-controlled medicine dosage units.</p>  |

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| <p><b>Sweden - Overtorneå</b></p> | <p>Frail older people get actual visits from the home care staff. They have community alarms for security.</p> <p>Today the doctor from the Health Centre can do physical home visits to those patients who cannot come to the Health Care Centre.</p> <p>In Norrbotten we have guidelines which say that people who have receive care from both organizations, municipality and health care, should have a personal plan which describes what kind of needs they have and who is going to provide support.</p> <p>Delivery of the care plans takes place at the Health Centre and the patient's home. Today few plans are made, so we need to work differently to get more individual plans for the patients.</p> <p>We provide Web-based education in dementia; we have conducted a day with activity and information for the older people; a local newspaper acts as a channel for information to the communities members.</p> <p>Physical training from a physiotherapist is provided on the local TV channel</p> <p>Currently it is problematic to exchange information about patients between the organization because we use a different recording system in the municipality and the county council.</p> <p>Today we have physical meetings between the organizations.</p> | <p>We would like to introduce navigation support with GPS and remote support for the family.</p> <p>We would like to provide professional remote support from the nurse and doctor in the Health Centre to the patients in the nursing home.</p> <p>We want to use Skype technology for planning care involving different professionals, family and the patients.</p> <p>We want staff to use iPads to document records whilst in people's homes.</p> <p>We would like to introduce the use of Smartphones for keyless home care.</p> <p>We would like to provide virtual activity for old people.</p> <p>The problem in the municipality is that the internet technology is bad and does not have coverage in all villages. They need a better internet service to use the technologies.</p> <p>We would like the municipality staff to see and use a patient's overview electronically so they can read what the doctor has done with the patient.</p> <p>We would like to hold virtual meetings between the organizations using Skype.</p> |
|-----------------------------------|--|---|

The table demonstrates the different starting points of each of the test sites in terms of the services they were currently delivering, and their needs for the future. The different starting points emphasised the need for the decision tool to include comprehensive information about a wide range of possibilities and allow sites to identify the information most appropriate for them. In particular, the characterisations of the sites and their aspirations supported the organisation of the decision tool according to the modules of support previously outlined.

The test sites each produced an extensive list of aspirations: inevitably, as we will describe, it was not possible for them to achieve all they aspired to, and they each chose a number of particular aspects on which to concentrate their efforts.

### **3.3 The starting points for RemoAge**

The baseline data and the existing services and aspirations show that there were some shared issues and aspirations across the sites, as well as some clear plans for particular developments. A frequent concern was the quality of connectivity, which was not always optimum in the test sites, notably Shetland, the Western Isles and Overtorneå. There was a widespread felt need to communicate about the project in the test sites, both to communities and to staff teams. Examples of particular aspirations included Norway's clear plan for the patient-centred team and the references to iPads, navigation support and medication devices in the Swedish sites. Each of the test sites developed their own approach within the broad framework of the RemoAge project to address their specific concerns and these are described in the next section.

## 4. Services developed and issues encountered

### 4.1 Services developed: the RemoAge approach in each test site

Each of the test sites has taken a different approach within the broad framework of the RemoAge project. This section of the report provides a brief outline for each test site, detailing the key elements of their approach.

#### 4.1.1 Norrbotten

The Norrbotten County covers 14 municipalities in Northern Sweden, of which 11 eventually joined the RemoAge project, building on the four which were involved at the start. The County Council reported that RemoAge was seen as very important in the region because it provided opportunities to test new ways of working with the help of digital technology; helped staff to develop new routines and train themselves to use the new technology in everyday life; and improved cooperation between the municipality and County. The project was seen as helping to develop new ways of providing care and support to an increasingly older population. Figure 3 shows the services that were developed, with the yellow ones being worked on collaboratively between the County and the Municipalities, and the green, projects that municipalities alone were developing.

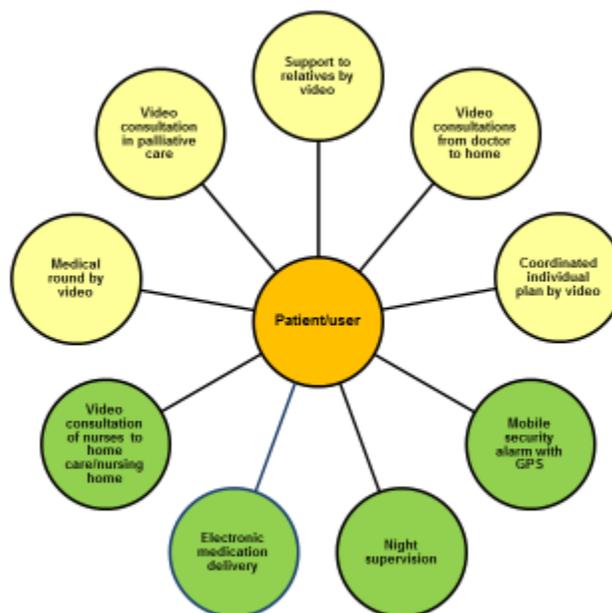


Figure 3: Services developed in Norrbotten

The target group for the services were people who needed support from both social and health care, including primary care services and hospital. A range of consultation services were included, which used video links, often through tablet computers. These included medical rounds for frail older people living in nursing homes; palliative care consultations both at home and in nursing homes; nurse consultations with people at home and in nursing homes; and support for relatives of people with dementia. In these cases, a member of social services staff would be with the person in their home, and would help with using the IT equipment. Other staff would be based in their workplace. The consultations would involve a wide range of matters, including assessment, treatment, consulting and monitoring. Other services included night supervision: previously, staff had driven long distances, let themselves into people's houses to check on them, then departed, often waking the person in the process. With the video equipment, which could be checked from an office or from a car, people were not disturbed, and staff travelled only in cases where help was needed. Mobile security alarms were used for people with cognitive impairment living in their own homes or in nursing homes, with the purpose of knowing their location. The alarms enabled people to go out and be found if they became lost, and could also alert staff to people leaving premises, if needed. They helped support physical activity and thus provided increased participation and inclusion, and also ensured safety. The electronic medicine delivery was particularly used for people with cognitive impairment, increasing their independence and supporting safer medication.

In Norrbotten, a local evaluation involved a survey of service users and their relatives (n=100), a survey of staff (n=90), a series of focus groups and a log schedule of the work involved.

The evaluation demonstrated that the innovations had brought increased security, participation and independence for the service users. People were receiving care in their own home, and spending less time travelling to appointments. Similarly, staff travel was reduced, therefore ensuring their time was spent more efficiently. The Region and the municipalities had been cooperating more through the programme, and routines were increasingly shared across staff groups. Staff felt more secure in their work, with less lone travel and more collaboration with others. In particular, where case meetings took place, it was possible for more professionals to join in the meetings. A large majority (85%) of service users wanted to continue using the technology. Most staff (90%) found the technology easy to use and 97% viewed it positively.

A number of challenges were identified, including the need to mainstream the new methods of working across all the services; the need for staff training; some technical issues including the difficulties of linking up different digital solutions that did not necessarily communicate with one another and unstable internet provision in some areas. Recruitment of users for the pilots had not always been easy, and there had been some complex discussions between healthcare providers about divisions of responsibility.

Identified successes included the clear organisation of the projects the cooperation between regional and local services at management level in particular and the joint decision-making and procedures that were in place. There had been useful learning between the activities across Norrbotten; there had been increased use of IT in the service provision; knowledge of digital technologies had increased; technology

had been used in new areas; and overall, it was felt that the digital technology complemented and supported the services that were being delivered.

#### 4.1.2 Shetland

The RemoAge activities in Shetland had three main workstreams.

Workstream 1 involved enhancing service delivery with technology, using a tablet-like system called My Ethel ([myethel.co.uk](http://myethel.co.uk)) and working with a care centre on Yell, the largest of the Northern Isles of Shetland. Four people with dementia were recruited, two died, one moved away, one progressed beyond being able to use technology. So the project moved into a second recruitment phase, for which two men with dementia seemed likely to be recruited. Both were receiving services of two weeks' respite followed by two weeks at home, continuously. 'My Ethel' was used by carers (wives) while the men were receiving respite care and by care staff while the men were at home to ensure consistency in care and support. One challenge of this workstream was catching the right time to recruit clients.

Workstream 2a linked to an existing drop in service run by Voluntary Action Shetland called 'Stepping Out' run on a fortnightly basis, also on the Island of Yell. RemoAge joined with the service to provide IT workshops at the end of every meeting to teach skills using iPads, including online safety, how to take a 'selfie' for your grandchildren, and how to order medication online. Around 10-15 people attended each meeting, including carers, older people and people with dementia. This activity was reported as progressing well, and to be promoting peer support, enabling men to use Skype together to stay in closer contact. This group set up its own Facebook page.

Workstream 2b entailed individual support using the iPads, working out with individuals something they would like to do, and then planning steps to get there. One example is that of a woman learning a new language. She was the longest standing client and had been part of the project for 3 months. Towards the end of the RemoAge test period, four clients were engaged, with two more due to join in the near future. For this part of the work, all clients would get an initial assessment and then a support/review/assess cycle following, to ensure work was followed through. Data was collected using a matrix to track progress and types of activity chosen for each client.

Workstream 3 connected day care groups of older people in Unst with those in Lerwick for reminiscence and other activities using iPads and Skype. This project started later on in the test period, and ran weekly sessions. This project experienced some technical issues due to broadband problems.

The Shetland team noted that they had been committed from the start to the RemoAge activities, that they already had some of the necessary skills from the outset, and that they had found the work enjoyable and rewarding. They felt the work had enabled vulnerable people to live independently with a degree of safety and security in very remote locations. People had been enabled to link with services outside their own community, including professionals, family and friends. They had been enabled to access resources that would otherwise have been difficult or impossible to access without support. Feedback from participants in 'Stepping out' was particularly positive: the peer support seemed to be a

crucial part of this. Although there was some training and guidance from staff, the main positive feedback concerned the peer support within the group. Staff commented that they were starting to see the emergence of a community web, which enabled service users to see friends more often using Skype supported by the Stepping Out work. The other two workstreams were also seen positively, by carers and customers alike. It was noteworthy that the users' perceptions was that the services were not really 'care', reflecting the very light emphasis on care. It appeared that if the work had been strongly promoted as 'care' it would have been less positively received.

For the staff involved, trusting working relationships had developed, probably more quickly than when using conventional methods of care delivery.

There were some particular challenges in the work on Shetland. Staffing was problematic – and the team reported that recruitment and retention of staff is an on-going issue in this region. The funding for the project they felt might have been better used to fund 3-4 project workers, or even one person full time, rather than being spread across several different people.

Key issues for the project related to funding and procurement, due to the division of responsibilities between health and social care services. The money came into the NHS (responsible for health) but most of it was used by local authority projects (social care). That created delays and problems with procurement of technology and other equipment, which led to further delays, meaning that the project was around 12 months behind where the team would have liked it to be. Additional problems arose from the need to buy apps for clients to use on their iPads. This could not be done easily: the only way to do it was for a staff member to drive to the nearest large supermarket (a 60 mile round trip) to buy a voucher.

The team reported that there had been some negativity towards the project in the early stages, especially among managers: however, once they were clearer about what the project entailed, attitudes softened. The staff directly involved in the work had to do significant work persuading managers of the benefits of the work.

#### **4.1.3 Tromsø**

The test site in Norway was the Patient-centered Healthcare Teams that offered services to frail patients with multiple and/or chronic diseases after their discharge from hospital. The teams consisted of health care professionals from the University Hospital of Northern-Norway and the Municipality of Tromsø.

These multi-disciplinary teams offer integrated and coordinated health care to patients over 60 with complex long-term needs. The patients referred to the teams have one or more chronic conditions; more than one hospital stay the previous year; and risk of readmission to hospital. All patients receive homecare services. The teams follow patients through the system and help them to receive appropriate, patient-centred and timely care at the most appropriate location, with a particular focus on providing support at home to minimise hospital admissions. Patients are followed up for a limited time until all necessary services are in place.

The teams involve collaboration between primary and secondary health care and are at present established at two different geographic locations of the University Hospital of North Norway. They include nurses, physiotherapists and occupational therapists from both the municipality and the hospital. One of the teams includes a pharmacist and a doctor. PACTs are also established in the rural municipalities of Balsfjord and Karlsøy, which both border Tromsø. These teams consist of home care staff and rely on close collaboration with the Tromsø team. Several further teams will be established in rural municipalities in the region in 2018.

ICT/digital solutions and mobile devices are used and tested by team members to support patient treatment and follow-up of patients outside of the hospital. The goal is to improve communication and facilitate information exchange between team members, with external health care professionals and with patients and their family.

Based on discussions and user case scenarios organized by NST together with the Patient centered team, a model of a service was developed, including technologies, actors and organization. Table 1 provides an overview of the service and the deployment of resources.

**Table 7: Model of a patient-centred service via communication tools**

|                                | Patients  | Healthcare professionals  | Others   |
|--------------------------------|---|---|--|
| Technologies                   | Tablet computer, head phone, stand, sim card.   | PC, videoconference screen, tablets   | A unit at the University hospital: 6 tablets, head phones, stands, sim cards |
| Communication                  | Communication via WiFi and the mobile network (if the patient doesn't have internet in his or her home) | Internet  |  |
| Software                       | WebRCT: Program for video conference with health care professionals                                     | WebRCT: Program for video conference with patients, next of kin and other health care professionals |  |
| Service 1:<br>Video conference | Patients can see and talk with the health carers  | The carers can see and talk with the patients, carers from the municipality and next of kin         | Next of kin and/or carers from the municipality can join the sessions        |

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| Service 2:<br>Video films            | Watching short films showing exercises to be performed. Together with health carers and/or next of kin | Making short, instructional films on how perform exercises   | Personnel at NST guide the health carers on how to make the films. Next of kin and/or carers from the municipality can be helping the patients at home   |
| Recruitment                          | Frail, older people  | The Patient centered team recruits patients when the patients are at the hospital  |  |
| Instructions on how to use the tools |  | Hands-on training sessions while the patients visit the hospital. Hand out paper manuals.  |  |
| Organization                         | The patients have the communication tools in their homes for 14 days, sometimes more than 14 days      | A member of the Patient-centered team calls the patients. This can be done based on a schedule, or ad hoc.<br><br>Further time schedule for the use of the service will be prepared. | A unit at the University Hospital takes care of the tools, hands them out, gathers the tools back, cleans them and removes data related to the patients. The unit is supported by personnel at NST |
| Support                              |  | Some support to the patients on how to use the tools   | Support to the patients can be offered via phone or internet by a unit at the University Hospital  |

The service started in Tromsø, and two further municipalities later joined the pilot. The use of the technology evolved as the project progressed. A particular issue was that the older people themselves found the tablet computers difficult to use, and therefore they were mostly being used by staff and relatives. Reasons for difficulties were cited as lack of familiarity, difficulties with touch-screen technology, and issues of cognitive impairment. Most of the older people were unaware that the tablets were being used by staff.

Over the test period, the service was used by 1-2 people every week: this did not include everyone who had used the main service, and tended to be those who lived further away from the hospital. The service was normally used for between two weeks and a month before people were signed off. Training had been delivered to 21 staff by NST by March 2017 on how to use the tablet, and 'superusers' locally

based had subsequently cascaded the knowledge. It was noted that the staff were relatively confident using the tablets, with a minority needing additional support.

The local informants reported that the main benefits of the RemoAge project had been for the staff rather than the older people themselves. Staff were saving significant travel time, and when they were in an older person's home, were readily able to make contact with other staff. They were generally positive about the technology, once they had got over the initial notion that this was 'just one more thing' they had to contend with. Once they started to use the technology, they tended to continue. Then, the main challenge was that in some areas, the Wi-Fi service was very poor. Even where that was so however, the staff found the technology useful to take photos.

In Tromsø, feedback from the service users was not collected: the clients were considered to be too frail to respond.

#### **4.1.4 Western Isles**

The RemoAge projects in the Western Isles had several elements: an intergenerational project focused on linking schools and older people, with the purpose of reminiscence; Technology Demonstrator Centres opening in Uist and Barra, two of the more remote islands and one on the mainland; a project on social prescribing to prevent loneliness located in the Uists and Benbecula; and a continuation of the activity around dementia friendly communities which had been started under the RemoDem project.

The intergenerational project which aimed to link older people in care homes and schools, encountered issues of connectivity, necessitating complicated 'workarounds' using VC links or iPads. The main outcome of the project was to successfully make the links and get the older people and the children talking with each other. About twenty children, two or three care staff and three care home residents had taken part. The experience of the project however for all concerned was very positive, leading to connections and relationships being established across the generations. The schools concerned reported that the children had gained important knowledge and understanding from the work, having understood very little about ageing and particularly about dementia beforehand. The schools also became more confident about using the technology once they understood its simplicity. The connectivity issues were eventually solved when, with the help of the local IT staff, the project linked up with a local company which was able to provide improved satellite coverage: however, there was still concern at this dependency on one provider. The availability of local IT assistance related to the existence of other e-health work in the locality, illustrating the benefits of being able to communicate between projects, possible in a small, local context.

Use of the Technology Centres increased over the course of the RemoAge project, and also benefitted from the wider portfolio of projects in progress. Issues with broadband provision also affected these, especially on the more remote islands, leading to delays in developing the facilities. Further challenges arose from issues with some of the technologies being demonstrated not being fit for purpose. In retrospect, project staff felt more attention should have been paid to guidance on technology, pointing out that it was easy to be attracted to technological 'fixes' without full knowledge of their operation and effectiveness. Over time, it became clear that the simpler technologies were more effective, and that

the initial approach had been too 'hi-tech'. The Centres had been relaunched, to provide 'drop-in' sessions with staff present, and to ensure that there were links to other services nearby: technology alone was not what people needed and the importance of integrating technology into the pattern of support that clients received was eventually acknowledged. The staff enthusiasm grew, as they became more confident with the technologies, and they were more inclined to experiment and find 'another way round' or a new way of bringing technology in to support service provision. A further development over time was an increasing orientation towards and acceptance of health and social care staff and services working together. Interest among local people had grown over time, and a series of open days had proven very popular. There had been significant local media coverage which was reported to have been positive. As in Shetland however, there had been problems of staff turnover, making delivery of the services more difficult.

The social prescribing project was intended for older people who were socially isolated or lonely where this was affecting their health or ability to self-manage conditions. Once identified, people were referred to a 'Social Navigator' who assessed their support needs, and agreed a 'social prescription' that could involve a range of items according to individual need. Examples of prescriptions could include linking to relevant clubs or societies; linking to local befrienders or mentors; learning to use social media and ICT support to keep in touch with friends or family. The Social Navigator held a list of local community resources that could be brought in to play, depending on individual needs. Receipt of clients into the service was slow to begin with, as much time was spent in developing community and stakeholder engagement that was considered crucial to the success of such a scheme. Engagement meetings were held with participating GP Practices, Community Nurses, Social Workers and Community Groups to raise the profile of the service, while programme promotional materials were distributed across media channels and community locations. By the end of the project, small numbers of clients were beginning to be referred and the work was considered locally to have important potential, with a plan being produced to continue the scheme beyond the RemoAge project and extend it beyond social support to wider wellbeing support.

The Western Isles team was building links with Shetland, for example to support an open day, in which the Western Isles had provided a session advising on use of GPS location systems. Western Isles staff had also visited a sheltered housing development in Shetland which operated with a housing with care model. The Western Isles team reported that they were keen to learn from other remote places about innovative ways of delivering services, on the basis that issues were faced in common.

## **4.2 Issues encountered and lessons learned**

In this section, we refer to the preceding discussion and incorporate material from three focus group discussions that were held in Norrbotten during January 2018 towards the end of the project. In these focus groups, representatives from all the field sites shared experiences of developing their new services and identified the challenges and solutions they had encountered in relation to their individual, organisational and community learning, examining the impacts of RemoAge at different levels. The

discussions aimed to develop insights from the comparison of experiences in the different test sites. The transnational learning aspect is written up separately as Deliverable 6.5.

For the focus groups, three areas for discussion were identified through review of early data, each with a set of specific emerging issues for discussion. These were as follows:

*Group one – individual learning*

Please consider your own personal learning as an individual and answer the following questions:

- What have been the key lessons you have learnt from the RemoAge project?
- Who have been the key people that have supported your learning?
- What activities have been most important in supporting your learning?
- What networks are you involved in that have supported your learning on the RemoAge project?

*Group two – organisational learning*

Please consider how your organisation has developed through involvement in the RemoAge project and answer the following questions:

- What key lessons has your organisation taken on board through its involvement in the RemoAge project?
- What people or other organisations have supported your organisation during the project?
- What activities have been most important for your organisation to support its development within RemoAge?
- What are the most important networks that your organisation links with?

*Group three – community learning*

Please consider how your community has developed through involvement in the RemoAge project and answer the following questions:

- What key changes have taken place within your community as a result of the RemoAge project?
- What people or organisations have been most influential on these changes?
- What activities have been most important for promoting change within your community?
- What networks have been important in supporting change in your community?

Whilst we present the issues under the three headings, in reality, the levels interact, and an issue at one level is linked to wider or narrower challenges as will be readily apparent.

#### **4.2.1 Challenges for individuals**

Those directly involved in RemoAge became champions for the project in their local areas. They faced challenges of involving other parts of their organisations, and the ease of doing this varied between sites. It was reported that this proved easier where the organisations had a strategic overview of developments and more difficult where projects were perceived as more ad hoc. Those involved in the

project needed to get involved in communication activities to publicise the work, and to promote evidence of its successes. They found important support from their local team members, and several reported having gained additional support and confidence from exchanging experiences with other sites.

Staff, it was noted, will of course think for themselves, and this could be an asset for projects. In many of the sites, there were examples of inventive and useful ways of using the tablet computers in particular, for example where staff took opportunities to stay in touch with each other. Project teams were responsive to these ideas, which became part of the RemoAge work.

Staff would also need training in the new ideas and technologies, and the importance of leaders having dedicated time to deliver training was noted. Acquiring technological knowledge was considered especially important, as the 'IT department' was often rather separate from the rest of the organisation and much less focused than front line staff on the needs of service users.

#### **4.2.2 Challenges for organisations**

Where organisations had a view of the work as mainstream, the benefits appeared to be greater, whereas in cases in which projects were small and perceived as peripheral, the benefit was more difficult to realise. It was also reported that some of the local statutory organisations had rather rigid procedures (such as for procurement of equipment) that were difficult to negotiate and could hold developments up, especially if the RemoAge work was not widely understood. Partners agreed there was a need for organisations to be flexible and open to innovation. In the Scottish sites, working with the third sector had proven easier, as the sector was found to have these necessary attributes.

To engage organisations in the project, sites had used a range of tactics. For some, personal networking and winning over key managers with evidence of the success of initiatives had been important. Others had held dissemination events involving both organisational and community stakeholders.

The engagement of the organisation, and especially managers, was considered important in reflections at the end of the project. Discussing whether the work would continue after the funding was finished, it was felt that stronger engagement and evidence of the positive impact of the work made its continuation more likely.

#### **4.2.3 Challenges for communities**

There was some debate about the impetus for RemoAge work, which in some cases had come from the service provider organisations, and in some, from consultation with community members and users and potential users of services. It appeared that either could work, but that the close alignment between needs and provision was crucial to the success or otherwise of projects.

In the case of some services and activities, there was a need to win over public concerns about the work. For example, the night cameras in Sweden had worried some third sector organisations, who were concerned about surveillance. This was remedied by public education, explaining the benefits of the camera to the individual, who would not be awoken or disturbed during the night by a visiting care worker.

RemoAge could have wider community benefits, beyond the initial service users and staff groups. In Sweden, the Norrbotten project had become nationally celebrated as an example of good practice, not only for use in remote areas but also in more populated ones: a government review of healthcare for the ageing population had made a fact-finding visit. In Shetland, the demonstrated benefits of the RemoAge work were used as part of the evidence for improved broadband access.

The particular community context made a difference across sites in how the projects operated. For example, in Sweden, there was an emphasis on planning from the start, whereas the development of services in the Scottish sites was more organic. The Scottish sites worked from the start with the voluntary sector, and for them, this was a natural way of working, less familiar in Norway and Sweden.

Across sites, there were concerns about the need for services to benefit users, to take users along with the service developments, and to collect evidence about their views and experiences. It proved difficult however for sites to collect such data, and the service delivery work consumed attention.

## 5. Service user data

### 5.1 Challenges in project-specific data collection

Tensions arise in data collection for evaluation purposes where simultaneous local and project-wide evaluations are taking place. There is inevitably an overlap in data requirements for local and project-wide evaluations, but differences in the aims of each mean that the requirements are not identical. Local evaluations aim to inform local service development and delivery, so the priority is for collected data to be sufficient to address specific local concerns. By contrast, project evaluation aims to enable comparison, both across test sites and with other populations. The use of standardised questions is critical where wider comparisons are sought, but these can sometimes be regarded as unnecessary, excessive, inflexible, or otherwise not fit for local purposes. Repeated requests for similar data duplicate work for staff and repeatedly answering questions can easily become tiring for frail older respondents, so it is important to try and minimise the levels of duplication between local and project data collection. RemoAge partners sought to do this where possible.

For example, the Swedish RemoAge partners developed separate local questionnaires at the start of the project for capturing baseline data and for exploring RemoAge service users' experiences of the services as part of their local evaluation plans. The RemoAge evaluation team were invited to comment on early drafts of these amid concerns of the potential for duplication of effort and additional work for staff at test sites. In addition to providing methodological guidance in relation to some questions, the feedback which was provided included encouraging the use of standardised questions in the baseline data collection instrument to enable comparison with other populations.

Challenges were also posed by the range of different services being developed and tested by the RemoAge partner test sites and the different sets of potential direct users and indirect beneficiaries for each service

### 5.2 Swedish frail older service users and their main carers

Using the project evaluation team's service user questionnaire, data for a number of Swedish test sites were collected by local project leaders. The data describe baseline characteristics of a sample of 55 users of RemoAge services from four different test sites, i.e. characteristics as at the start of their respective service test periods. This represents approximately one quarter of the overall population of service users across the Swedish test sites. It was intended that for the purposes of the project evaluation, data would be collected about/from each service user at the start and end of the test period for the service that they were receiving. However, data from second interviews is only available for six of the 55 service users. Additional data were collected as part of the local evaluation: partners report that approximately 100 service users and relatives have completed local evaluation questionnaires. The RemoAge evaluation team does not have access to these data, and the local evaluation report was not available at the time of writing.

The Swedish test sites' designated data collection contacts identified a number of issues which limited the gathering of data using the questionnaire provided by the RemoAge project evaluation team. First, the questionnaire was perceived by those administering it to be too long and too complicated. Second,

it was seen as unsuitable for use with especially frail service users, e.g. people recently discharged from hospital or receiving palliative care services.

### 5.2.1 Demographic characteristics

Selected demographic characteristics of the service user sample are described in Table 8. Thirty-two of the described service users (58%) were female, with an average age of 78.9 years (range 51-93 years). Twenty-two service users (42%) were male, with an average age of 77.8 years (range 50-96 years). Eleven service users had not been born in Sweden, but had lived in Sweden since 1970 or earlier. Of those not born in Sweden, nine were born in Finland, one in Norway, and no country of birth was provided for one person.

58% of the RemoAge service users had been educated to primary school or less, 30% had received upper secondary school educations, and 12% had attended higher education (university or college).

Twenty-six female service users (81% of females) were either never married, or were separated, divorced or widowed and 6 were either married or had a partner. Nine male service users (41% of males) were either never married or were separated, divorced or widowed, and 13 were either married or had a partner.

Twenty-five service users (45%) lived alone, with 18 people (33%) living sharing accommodation with only a spouse or partner, three sharing accommodation with offspring (two with a son, and one with a daughter). Nine service users (16% of the sample; 5 female, 4 male) lived in group residences, special housing or a nursing home.

Table 8: Demographic characteristics of RemoAge service user sample from Swedish test sites

| Service user characteristic                                 |                                |                                      |
|---|--------------------------------|--------------------------------------|
| <b>Sex (n=55)</b>   | <b>Number of service users</b> | <b>Percentage of sample</b>          |
| Female  | 32                             | 58                                   |
| Male  | 23                             | 42                                   |
| <b>Age (years)</b>  | <b>Mean</b>                    | <b>Range</b>                         |
| Females (n=31)  | 78.9                           | 51-93                                |
| Males (n=23)  | 77.8                           | 50-96                                |
| <b>Education (n=53)</b>                                     | <b>Number of service users</b> | <b>Percentage of service users</b>   |
| Elementary school or less                                   | 31                             | 58                                   |
| Upper secondary school                                      | 16                             | 30                                   |
| Higher education (University / college)                     | 6                              | 11                                   |
| <b>Marital status (n=55)</b>                                | <b>Number of service users</b> | <b>Percentage of service users</b>   |
| Either never married, or now separated, divorced or widowed | 35<br>(26 females, 9 males)    | 64<br>(81% of females, 41% of males) |
| Married or have partner                                     | 20<br>(6 females, 13 males)    | 36                                   |

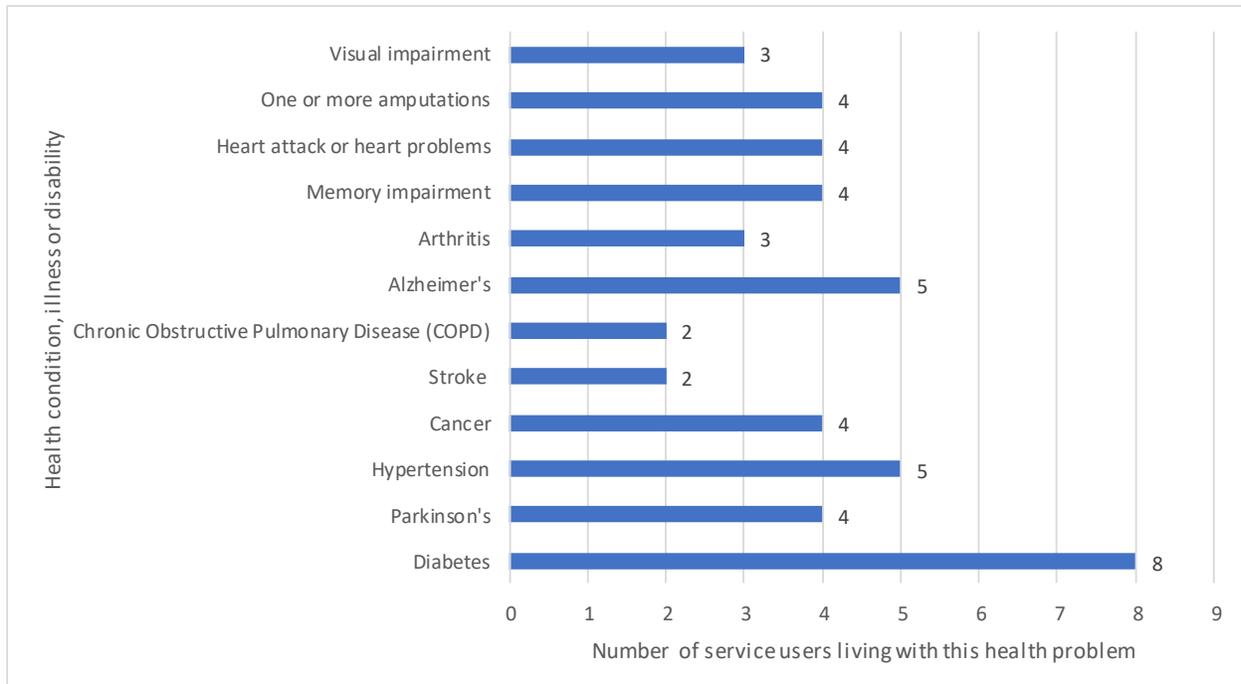
|  |                                | (19% of females, 59% of males)     |
|--|--------------------------------|------------------------------------|
| <b>Living arrangements (n=55)</b>                            | <b>Number of service users</b> | <b>Percentage of service users</b> |
| Lives alone  | 25                             | 45                                 |
| Lives with spouse or partner                                 | 18                             | 33                                 |
| Lives with son or daughter                                   | 3                              | 5                                  |
| Lives in group residence, special housing, or a nursing home | 9                              | 16                                 |

(NB percentages may not add to 100% due to rounding errors)

**5.2.2 Health characteristics**

Although 62% of Swedish service users rated their health as ‘Good’ or better (33 of 53 who provided this data) and only two people rated their health as ‘Poor’, significant proportions of the sample were living with cognitive impairment and many service users reported living with one or more chronic health conditions. A third of service users (17) had diagnoses of dementia, but local health and care staff who conducted the interviews suspected that as many as 30 service users (57% of those for whom data was provided) had some level of cognitive impairment. Of 47 who answered this question, 41 people (87%) indicated suffering from chronic or long-term health problems, illness, disability or infirmity. Thirty people (64% of those providing data on this question) identified two or more chronic health problems. The frequencies of the most commonly identified health issues are illustrated in Figure 1. Where people identified only a single chronic health problem, in most cases this related to different dementias or to ‘cognitive impairment’.

**Figure 4: Frequency of identification of selected chronic health problems in Swedish RemoAge service users (n=41, multiple problems identified in 30 cases)**



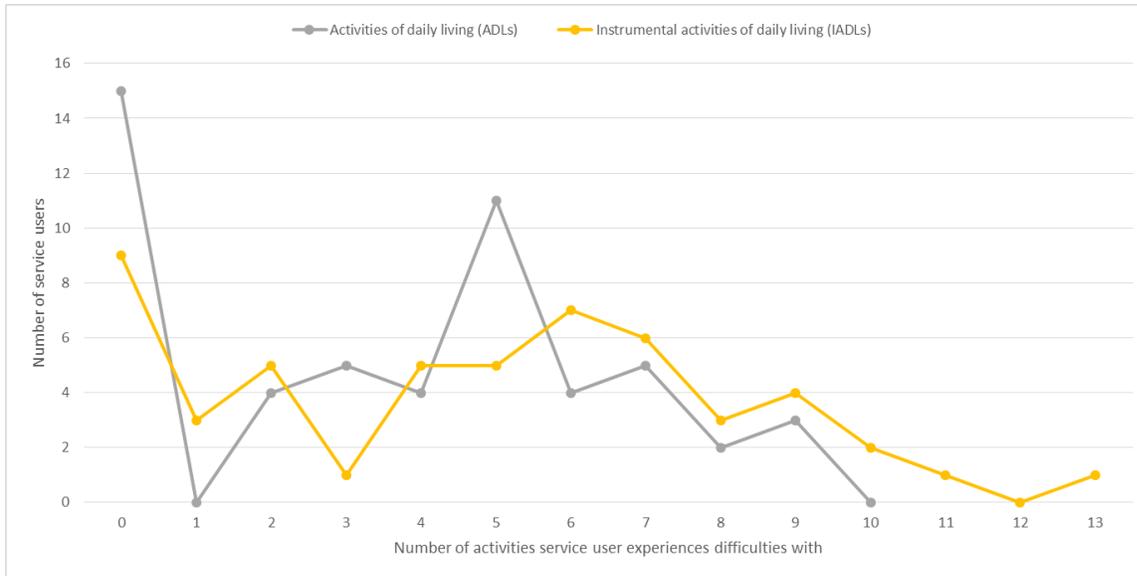
Sensory impairment can be an issue in later life. One in five service users (11 of 52 answering this question) reported wearing a hearing aid. Several eye conditions that can cause visual impairment are more prevalent with age, but despite this 36 of 50 service users providing data (72%) reported having 'Good' or better than good distance vision when wearing glasses if necessary, with one in five reporting 'Excellent' distance vision. Service users' rating of their near vision followed a similar pattern with 39 of the 52 who answered (75%) rating their near vision as 'Good' or better.

### 5.2.3 Difficulties with everyday activities

Whether performed independently or with appropriate supports, frail older people need to be able to complete a wide range of 'everyday' activities if they are to live safely in their own homes and communities. The service user questionnaire asked RemoAge service users to identify activities with which they experienced difficulties from standardised lists of activities classified as 'Activities of daily living' (ADLs) and 'Instrumental Activities of Daily Living' (IADLs) respectively. The more activities individuals experience difficulties with, the higher the levels of support that may be needed to allow them to live safely and comfortably in their own home.

Figure 5 gives a 'baseline' profile of service users in terms of the numbers of activities with which they experience difficulties at the start of the RemoAge service test period and figures 6 and 7 show the percentages of service users experiencing difficulties with each of the activities in the lists.

Figure 5: Profile of service users by difficulties experienced with Activities of Daily Living (ADLs) (n=53 service users) and Instrumental Activities of Daily Living (IADLs) (n=52 service users)



These data help to demonstrate the frailty of the population of service users who received RemoAge services. As Figure 6 shows, 38 service users (72%) reported experiencing difficulties with one or more of the ADLs presented, with 43 individuals (83%) reporting difficulties with one or more of the IADLs presented. Service users reporting difficulties with one or more ADLs experienced problems with a mean of 5.2 and median of 5 ADLs. Those reporting difficulties with one or more IADLs experienced problems with a mean of 5.8 and median of 6 IADLs.

Figure 6: Swedish RemoAge service users' difficulties with selected ADLs (n=53 service users)

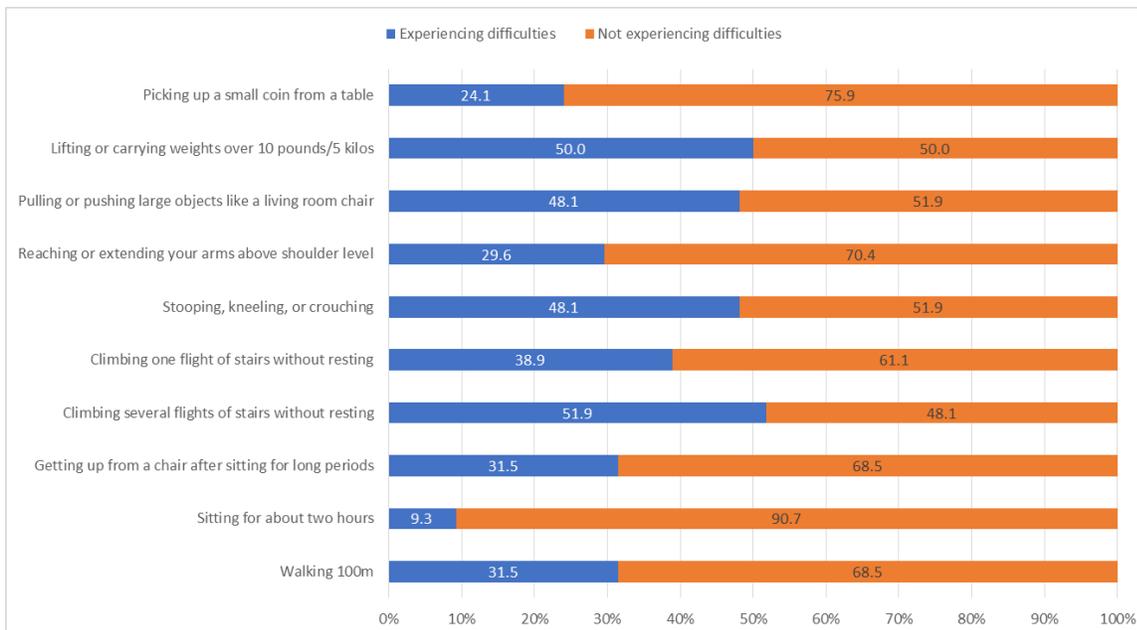
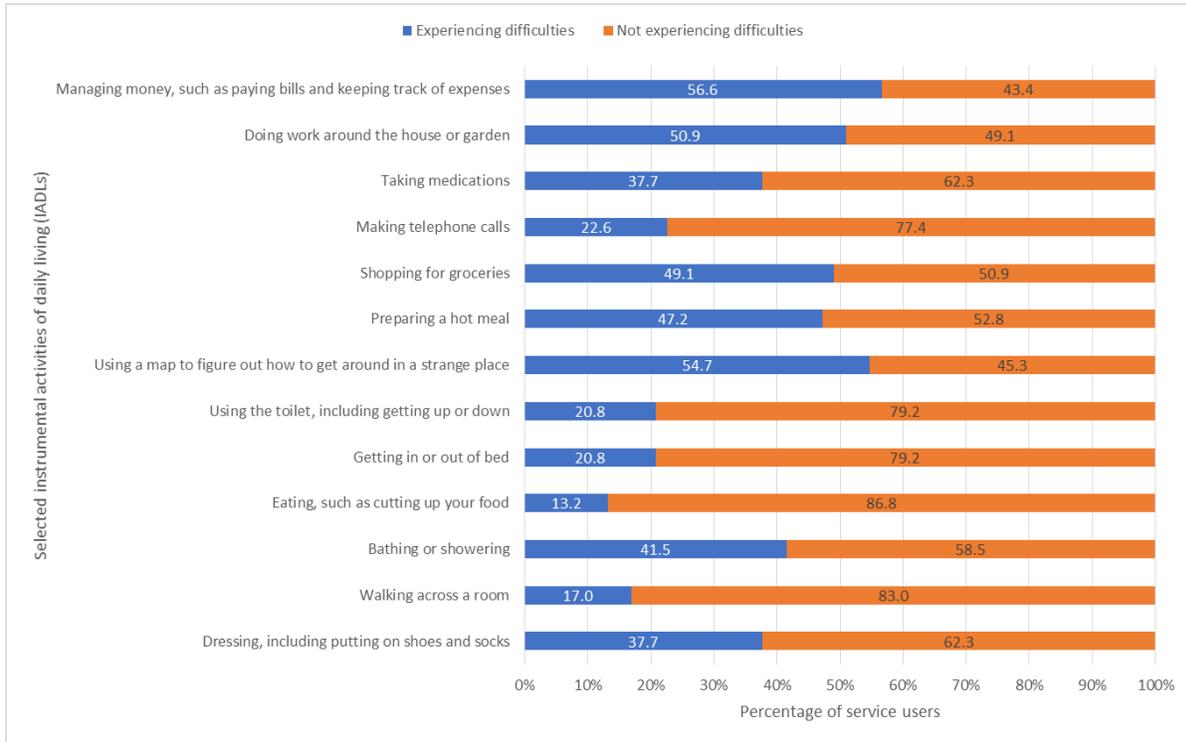


Figure 7: Swedish RemoAge service users' difficulties with selected IADLs (n=52 service users)



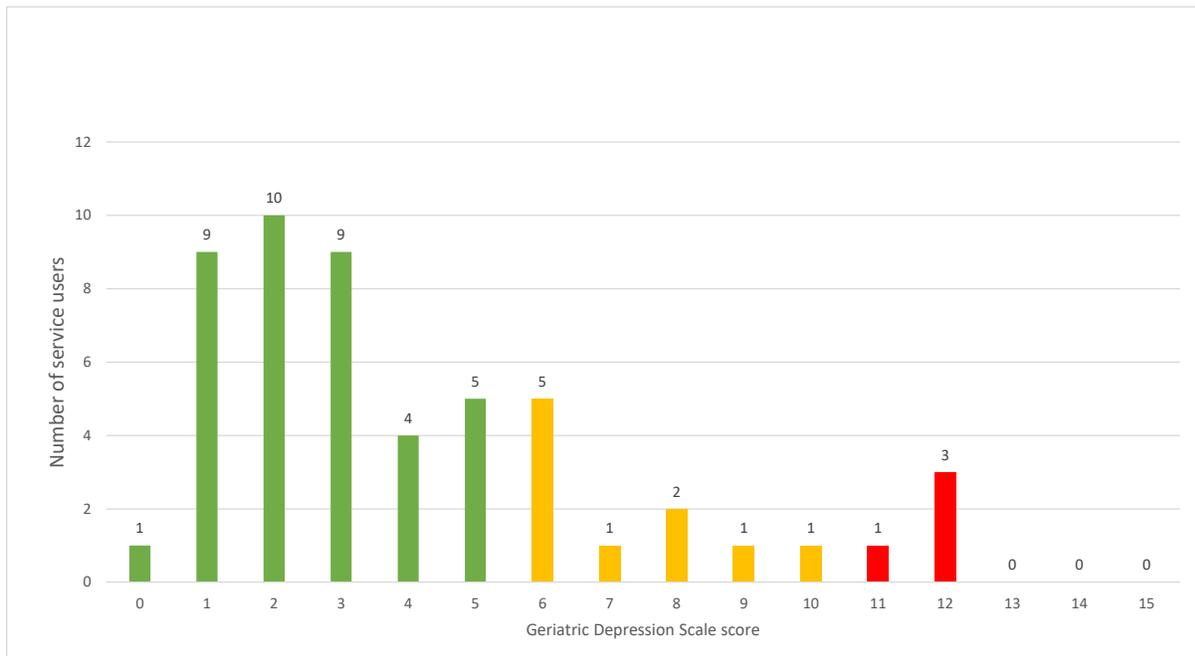
As Figure 6 illustrates, the ADLs that RemoAge service users most frequently experienced difficulties with were activities requiring musculoskeletal strength: climbing multiple flights of stairs, carrying or moving heavier objects, and activities such as stooping or crouching which require core body strength. This underlines the physical frailty of this population. It is perhaps unsurprising then that RemoAge service users most frequently reported experiencing difficulties with IADLs which call for physical strength, such as doing house work or gardening or shopping for groceries. However, as Figure 7 shows, the IADLs that were most frequently reported as difficult by this population are ones that call for high levels of cognitive functioning: managing finances and using a map. This suggests a population characterised by both physical and cognitive impairment.

### 5.2.4 Psychological wellbeing

The RemoAge service user questionnaire sought to provide insight into the psychological wellbeing of service users through use of an established screening tool for depression in later life, the 15-item Geriatric Depression Scale (Short Form) ('GDS') (Sheikh and Yesavage 1986), and standardised questions on mood and outlook from the 2011 European Quality of Life Survey.

Those completing the GDS are asked to answer ‘Yes’ or ‘No’ to a series of questions which seek to establish their state of mind over the previous seven days. The scoring scheme allocates 1 point for each answer that indicates depression. The scale has a maximum score of 15 points. Scores of 6-10 are deemed indicative of possible depression and warrant follow-up interviewing, and scores higher than 10 indicate probable depression. Figure 8 summarises the GDS score of the 52 service users who completed this part of the questionnaire. Of those service users, 27% had GDS scores that would indicate potential issues with depression. Four had GDS scores of more than 10, normally indicative of depression, and a further ten individuals (19% of those completing the GDS) had scores of 6-10, which would generally warrant further investigation.

**Figure 8: Swedish RemoAge service user scores on the Geriatric Depression Scale (Short Form) (Sheikh and Yesavage 1986) (n=52 service users) (Maximum score 15, scores 6-10 warrant further investigation, scores >10 indicate probable depression)**

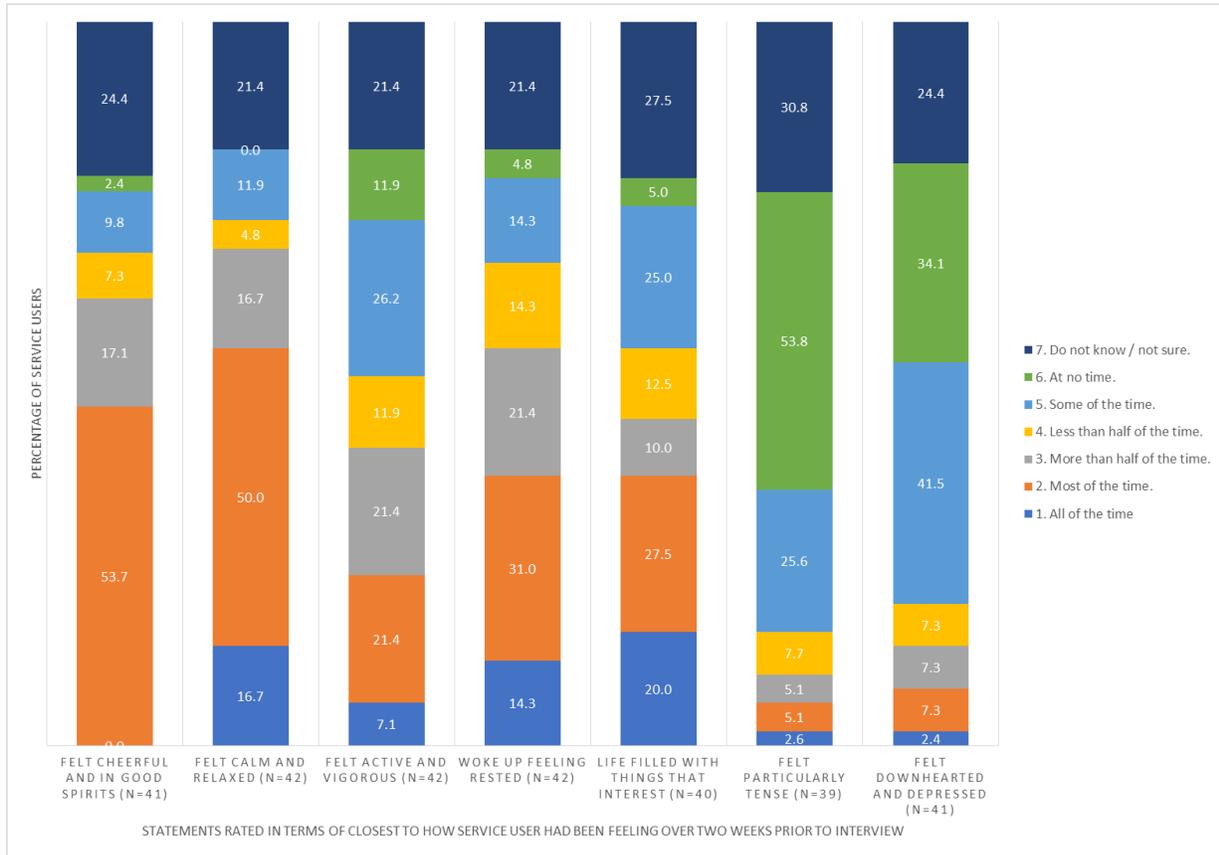


The first set of questions from the 2011 EQLS included in the service use questionnaire combine the seven items required for computing both the ‘WHO-5 Mental Well-Being Index’, designed to measure positive psychological wellbeing, and the ‘Hedonic Wellbeing Index’, a measure which incorporates all possible combinations of affect-arousal (Eurofound 2013). The items ask respondents to indicate the extent to which they have been experiencing selected feelings over the previous two weeks, with answers on a six-point scale from ‘All of the time’ to ‘At no time’ plus a ‘Don’t know’ option.

The data indicate that this part of the questionnaire was not experienced as straightforward: approximately one fifth of service users in the sample provided no data at all, with the number of responses varying by item between 39 and 42). Of those that did provide data, for each item around a

quarter of respondents selected 'Don't know / not sure'. This proportion varied between 21.4% and 30.8%, depending on the question item, as illustrated in Figure 9. No further data is available to explain why this percentage should be so high, but more than half of the service users were thought by their interviewers to have cognitive impairment and it might be that recollection of feelings over the previous two weeks is challenging for people with memory problems.

Figure 9: Service users' ratings of mood in the two weeks prior to being interviewed



To contextualise the findings, Table 9 compares the responses of Swedish RemoAge service users to the wellbeing questions from EQLS to those of Swedish respondents to the 2016 EQLS aged 65+, in which the same questions were asked. EQLS uses face-to-face questionnaire administration methods and surveys a multi-stage, stratified, random sample of 1,000-2,000 people aged 18+ living in the community in each country. The 2016 EQLS gathered data from 1,053 Swedish respondents. More detailed data is not yet available, but EQLS 2016 data visualisations provide information on the numbers of respondents by age category answering ‘Most of the time’ or ‘All of the time’ to this set of questions.

Table 9 shows that a higher proportion of RemoAge service users experience frequent feelings of negativity and a lower proportion experience frequent feelings of cheerfulness and good spirits than in a random sample of Swedish adults aged 65+ years old.

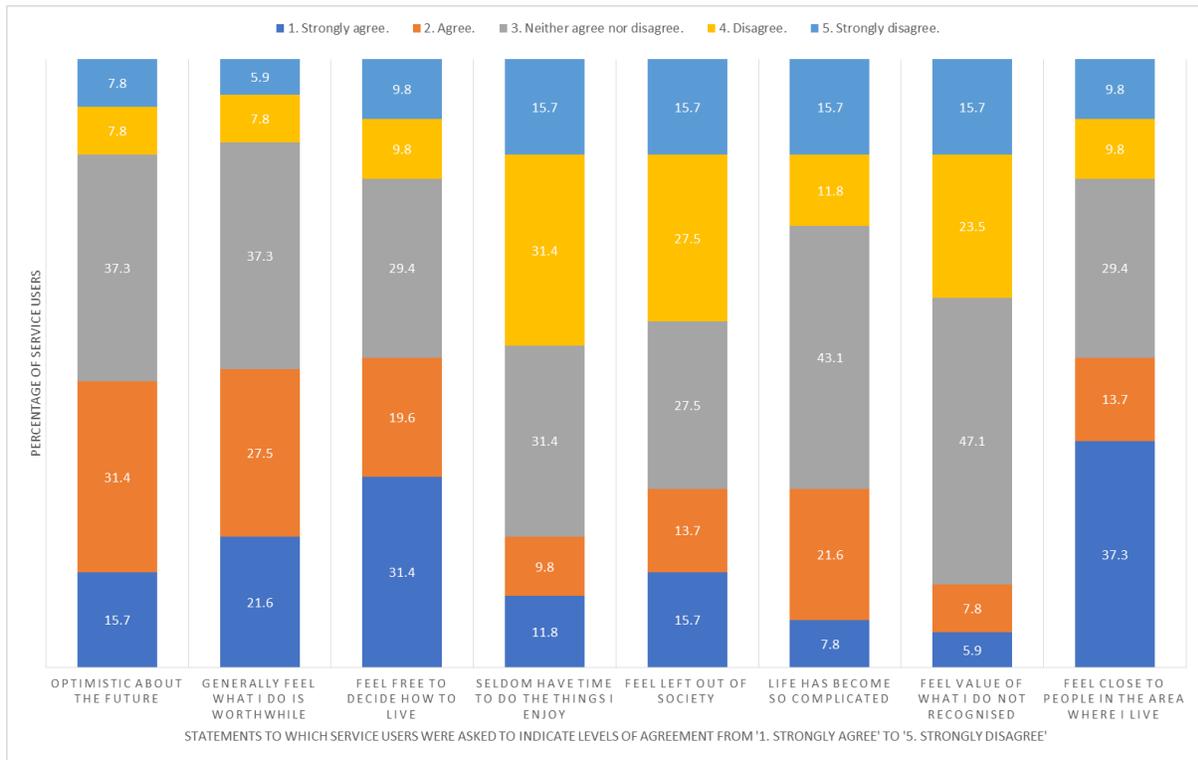
**Table 9: Mental wellbeing: responses of Swedish RemoAge service users and Swedish respondents to the 2016 European Quality of Life Survey aged 65+ compared**

| Wellbeing questions asked in each questionnaire            | Percentage of individuals answering ‘Most of the time’ or ‘All of the time’ |   |
|--|---|---|
|  | Swedish RemoAge service users   | Swedish respondents to European Quality of Life Survey 2016 aged 65+* |
| I have felt cheerful and in good spirits                   | 53.7  | 76  |
| I have felt calm and relaxed                               | 66.7  | 76  |
| I have felt active and vigorous                            | 28.5  | 50  |
| I woke up feeling fresh and rested                         | 45.3  | 53  |
| My daily life has been filled with things that interest me | 47.5  | 65  |
| I have felt particularly tense                             | 7.7   | 5   |
| I have felt downhearted or depressed                       | 9.7   | 2   |

\*From ‘European Quality of Life Survey – Data Visualisation (Health and wellbeing’ questions), <https://www.eurofound.europa.eu/data/european-quality-of-life-survey>

The second set of questions drawn from the 2011 EQLS includes eight items, four of which relate to respondents’ subjective wellbeing and four to respondents’ sense of social inclusion. Figure 10 illustrates RemoAge service users’ responses. Less than half agreed or strongly agreed that they were optimistic about the future (47.1%) or that they generally felt that what they do is worthwhile (49.1%). Almost one in five (19.6%) disagreed or strongly disagreed with the statement ‘I feel I am free to decide how to live my life’, a figure which may reflect the difficulties with ADLs and IADLs which many experience. This contrasts with the finding that almost half felt that they had time to do the things that they enjoy, with 47.1% disagreeing or strongly disagreeing with the statement ‘In my daily life, I seldom have time to do the things I really enjoy’.

**Figure 10: Swedish RemoAge service users' responses to selected statements relating to subjective wellbeing (n=51 service users)**



Again, the responses of Swedish RemoAge service users can be compared to those of Swedish respondents to the 2016 EQLS aged 65+, in which the same questions were asked. The available data visualisations for these questions identify percentages of respondents who ‘Agree’ or ‘Strongly agree’ with each statement. Table 10 summarises this data.

Direct comparison of responses to the statement ‘I am optimistic about the future’ are not possible, because the 2016 EQLS asks respondents to rate their agreement to separate statements regarding optimism about their own future and optimism about their children or grandchildren’s futures, however the percentage of RemoAge service users agreeing to the more general statement around optimism for the future is considerable lower than that of the randomly selected Swedish respondents aged 65 years or older agreeing to either of the statements regarding optimism about the future included in EQLS 2016. This could reflect the greater age or poorer health of the RemoAge service users.

The two populations had a similar response to the statement ‘In my daily life, I seldom have time to do the things I really enjoy’, but a far smaller percentage of the RemoAge service users felt that they were free to decide how to live their life or that what they did in life was worthwhile. Again, this could relate to differences in abilities to engage in ADLs and IADLs, but it might also be in part explained by the

constraints imposed by the rural location of RemoAge service users which may act to constrain life choices even where RemoAge service users enjoy relatively good health.

Rurality may also help to explain differences between the proportions of people who agree or strongly agree with the statements ‘I feel left out of society’ and ‘I feel close to people in the area where I live’. Whilst rurality is often popularly associated with greater community cohesion and closer ties within communities, a number of the municipalities in the Norrbotten region are experiencing simultaneously ageing and shrinking populations as a result of demographic change and migration of younger people to more urban areas. The effect of such trends may be to deplete RemoAge service users’ social circles and wider potential networks of support

**Table 10: Subjective wellbeing: responses of Swedish RemoAge service users and Swedish respondents to the 2016 European Quality of Life Survey aged 65+ compared**

| Wellbeing questions asked in each questionnaire                      | Percentage of individuals who ‘Agree’ or ‘Strongly agree’ |   |
|--|---|---|
|  | Swedish RemoAge service users                             | Swedish respondents to European Quality of Life Survey 2016 aged 65+* |
| I am optimistic about the future                                     | 47.1  | Own: 71<br>Children/grandchildren’s: 79                               |
| I generally feel that what I do in life is worthwhile                | 49.1  | 87  |
| I feel I am free to decide how to live my life                       | 51.0  | 94  |
| In my daily life, I seldom have time to do the things I really enjoy | 21.6  | 23  |
| I feel left out of society   | 29.4  | 4   |
| Life has become so complicated today that I almost can’t find my way | 29.4  | 11  |
| I feel that the value of what I do is not recognised by others       | 13.7  | 8   |
| I feel close to people in the area where I live                      | 51.0  | 81  |

\*From ‘European Quality of Life Survey – Data Visualisation (‘Subjective wellbeing’ and ‘Social exclusion and support’ questions’, <https://www.eurofound.europa.eu/data/european-quality-of-life-survey>

### 5.2.5 Carers of service users

The RemoAge service user questionnaire asked whether service users had a ‘main carer’, and if so whether the carer was present at the time of the interview. Ten out of 45 service users who answered this question had main family carers, of whom nine were present at the time of the baseline interview. Whilst not answering the question regarding presence of a main carer, Brief COPE was completed on a

further three service user questionnaires, in each case a service user living alone. Since this section was clearly marked as being for the family carer these data have been included in our analysis on the assumption that they were provided by a family carer who did not self-identify as a 'main carer'. We did not ask for the relationship between the main carer and the RemoAge service user, but in six out of ten cases where a main carer was identified the service user was living with a spouse or partner, and this person is likely to be the main carer.

Where the carer was present, they were invited to complete 'Brief COPE' (Carver 1997), a 28-item measure consisting of 14 subscales relating to conceptually differentiable coping strategies. Each subscale consists of two items, and each item presents a description of a potential coping strategy and the person completing the measure is asked to choose one of four responses which best describes the frequency with which they have been doing the thing described: 'Not at all', 'A little', 'Quite a bit', or 'Very much'. These are scored from 0-3, to give a potential score for each subscale of 0-6. Carver observed that 'Some of these reactions are known to be generally adaptive: others are known to be problematic' and suggested that Brief COPE provided 'a way to assess potentially important coping responses quickly' (1997: 98). Table 11 shows the mean scores and ranges for each of the 14 subscales.

**Table 11: Swedish service users' main carers' scores on Brief COPE subscales (n=12)**

| <b>Brief COPE subscale</b> | <b>Mean score</b> | <b>Range</b> |
|----------------------------|-------------------|--------------|
| Active coping              | 2.3               | 0-6          |
| Planning                   | 3.2               | 0-6          |
| Positive reframing         | 3.5               | 0-6          |
| Acceptance                 | 0.7               | 0-2          |
| Humour                     | 4.8               | 1-6          |
| Religion                   | 5.4               | 2-6          |
| Using emotional support    | 1.9               | 0-5          |
| Using instrumental support | 2.0               | 0-4          |
| Self-distraction           | 4.3               | 1-6          |
| Denial                     | 4.1               | 2-6          |
| Venting                    | 4.0               | 2-6          |
| Substance Use              | 5.9               | 5-6          |
| Behavioural disengagement  | 5.7               | 4-6          |
| Self-blame                 | 4.3               | 2-6          |

The results as summarised in Table 11 suggest that the carers of RemoAge service users tended to use coping strategies that have been broadly classified variously as 'problematic' (Carver 1997), 'maladaptive' (Meyer 2001) or 'dysfunctional' (Cooper et al 2006) and which are associated with negative outcomes more frequently than those strategies regarded as more positive. In particular, there are universally high scores for substance use and behavioural disengagement subscales, universally low scores on the acceptance subscale, and low mean scores on using emotional support, using instrumental support, and active coping subscales, although with greater variation in individual responses. Further investigation is needed to understand the factors which may lead to this pattern of coping strategy use and the extent to which it is reflective of that of the wider population of carers of frail older people.

### 5.3 Norwegian service users and frail older people receiving services during RemoAge

In the Norwegian test site, members of the Patient-Centred Healthcare Teams were the ‘service users’, with the frail older people supported by the teams benefiting from the changes in working practices made possible by the introduction and use of tablet-based technology by the teams.

The initial healthcare teams were established jointly by the University Hospital of North Norway and the Community Nursing Service in Tromsø Municipality in pursuit of an integrated patient-centred care model to improve the continuity and quality of care for multimorbid older patients living in the region. Further teams have since been established for different hospital-municipality dyads in the region.

The teams consist of healthcare personnel from the Community Nursing Service and the hospital. The main aim is to help the patients get the needed hospital care, ensure safe discharge, provide support in the home environment, and prevent unnecessary hospital admissions (Bergmo et al 2016).

The original Patient-centred Healthcare Team consisted of a team leader plus one geriatric nurse from each partner organisation who act as full-time team coordinators and a further ten healthcare and allied healthcare professionals, including a geriatric consultant, nurses, district nurses, physiotherapists, occupational therapists and a pharmacist, drawn from hospital and community staff.

Due to data privacy concerns specific data are not available from the Norwegian RemoAge partner to describe the frail older people who received support from the Patient-Centred Healthcare Teams. However, Bergmo et al (2016) describe the characteristics of the first 98 patients to be treated by the healthcare team, and this description is reproduced here to provide a general indication of the population likely to have received services from the healthcare team during the RemoAge test period.

**Table 12: Characteristics of the first patients to be treated by the Patient-Centred Healthcare Team (n=98) (from Bergmo et al 2016)**

| Characteristic                                      | Patient sample   |
|---|--|
| Sex   | female = 57, male = 41   |
| Age   | Mean age 80 years (range 54 to 95)   |
| Number of diagnosed health conditions at referral   | Mean 3.5 diagnoses (range 0-7 per patient)   |
| Hospitalisations in the 12 months prior to referral | Mean 2.5 hospitalisations (range 0-9 times)  |
| Referral routes                                     | Hospital staff: 62% of referrals<br>GPs and healthcare personnel in the municipality: 38% of referrals |
| Patient location at time of referral                | Hospital: 63.3%<br>Home: 26.5%<br>Nursing home: 8.2%<br>Rehabilitation centre: 2.0%                    |

As Table 12 shows, the first patients initially referred to the Patient-Centred Healthcare Teams were typically older people (mean 80 years), living with multi-morbidities (mean 3.5 diagnosed health conditions) and in poor health (hospitalised a mean of 2.5 times in the 12 months prior to referral and

63.3% in hospital at time of referral). It might be anticipated that those receiving support from the healthcare teams during the RemoAge test period had broadly similar characteristics.

## 5.4 Shetland Islands service users

The Shetland Islands developed and tested three different services for older people during the RemoAge project. Each service targeted a different service user population. The first service, working with Shetland Islands Council's Isleshavn and Nordalea Services team based on Unst, aimed to support older service users living on the islands via 'ETHEL', 'An 'always-on' large touch screen device designed specifically for the elderly, allowing them to stay in touch with family and carers' (<http://myethel.co.uk/#>). The second service, delivered in partnership with Voluntary Action Shetland, sought to build community resilience by providing older people with opportunities to increase familiarity and competence with using tablet-based technologies for communication via the provision of supported group activity in which attendees learn how to use iPads. The final service, was aimed at reducing social isolation through the provision of support to enable frail older people to use iPads to access groups and activities beyond their local communities via readily available applications such as Skype. The services are described in more detail elsewhere (4.1.2).

Detailed demographic data are not available to the project evaluation team for RemoAge service users in Shetland, but this may be included in local evaluation reports when available.

The services were developed and tested with service users living on Yell, Fetlar and Unst, the most northerly inhabited Islands of Shetland. In all three islands the total population has been in decline. Scottish census data indicates that between 1991 and 2011 the total population of Yell fell from 1,075 to 966, the population of Fetlar from 90 to 61, and the population of Unst from 1,055 to 632 (Shetland Island Council 2017). Out-migration has been primarily by younger people, with older people making up an increasing proportion of those that remain. Figures provided by the Shetland Islands RemoAge partner suggest that of a total population on Yell and Fetlar of 1053, 272 (26%) are aged 65 years or over and of the 613 inhabitants of Unst, 196 (32%) are aged 65 years or over (Murdoch 2018).

During the RemoAge project a total of six service users from the Shetland Islands received the service based on using the ETHEL device. The system was used for different purposes for different service users, including: supporting a service user receiving community care; supporting a male service user with Parkinson's disease living on Fetlar to live as independently as possible and to comply with a complex medication regime; enabling a service user with dementia living in residential care to maintain communication with family living on the Scottish mainland; and providing additional support to service users when they were using existing short stay services.

A total of twelve people undertook the familiarisation and training to use iPads provided in the second Shetland RemoAge service. These service users were part of a mixed sex group of people aged over 60 and carers of older people who were already attending meetings of the 'Stepping Out Together' group, a lunch and activities group run by Voluntary Action Shetland which meets fortnightly on Yell.

The third service tested in the Shetland Islands involved six older female service users who are in receipt of regular day support services at the Nordalea Care Centre on Unst. The service users in this group experience a high degree of social isolation due to a combination of household circumstances, remoteness and low population density on Unst.

## 5.5 Service users in the Western Isles

The Western Isles RemoAge partner developed services for the RemoAge project aimed at using digital solutions and addressing social isolation. The digital solutions strand of their RemoAge work encompassed three areas: establishing a technology centre and developing services at the centre including twice-weekly open 'drop-in' sessions offering help and advice in understanding what technology is available, open days with different health and care professionals, 'Tea and technology' familiarisation and education sessions for potential users, and training sessions for health and care staff; developing and testing a multi-faceted 'intergenerational project' which included a service using iPads, satellite broadband services and Skype to link frail older residents of care home in South Uist with primary school children located 20 miles away at the other end of South Uist for activities themed around the use of Scottish Gaelic language, dementia awareness raising sessions with pre-school and primary school children, and supporting placements for health and social care college students; and continuing support for a 'dementia friendly communities' scheme established as part of the RemoDem project. For the social isolation strand, they developed 'Connecting Uists', a social prescribing and social navigation service aimed at addressing social isolation and its negative impacts. The services are described in detail elsewhere (4.1.4).

Detailed demographic data are not available to the project evaluation team for RemoAge service users in the Western Isles but this may be included in local evaluation reports when available.

Approximately ten care home residents took part in the Skype sessions organised as part of the intergenerational project, in addition to formal and informal carers for some activities. The group included both male and female participants. The care home on South Uist provides residential accommodation for up to 16 frail older permanent residents, including up to seven permanent residents in a specialist dementia unit, with two further places for short respite stays and day care services provided for a further three people, so those using this RemoAge service can be assumed to be living with age-related frailty and/or ill-health. Residents who participated in the intergenerational project sessions were aged up to 103. The primary school participating in the Skype session has approximately 60 pupils. An estimated 20 pupils took part in the Skype sessions with care home residents, but more may have participated in activities such as live streaming of Gaelic songs included in the school's Christmas concert.

The 'Connecting Uists' social prescribing service provided support to ten service users living on the islands of North and South Uist or Benbecula in the period from March 2017 to January 2018, with those supported receiving up to ten follow-up visits following referral. All three GP Practices in the deployment area and over 50 community nursing, community psychiatric nurses and social work care professionals were engaged with around the service. The service operates multiple routes for referral, including by primary care staff and community nurses in addition to self-referrals. The referral criterion is risk of social isolation and/or loneliness. Technology was a key aspect of the service both in providing clients with access to digital tools for socially connecting but also as enablers for the service. Hence, an online referral form was created and integrated into community health systems in order for the referral process to be as straightforward as possible. An online social prescribing database was created for holding the client Social Support Plans with paper copies available for clients. Feedback was electronically provided to original referrers on progress with plan. The plan included a number of

validated scales for assessing social isolation, loneliness and health and wellbeing impacts so that these could be measured across the duration of the social prescribing service interaction with the client. These digital tools have provided the basis for future plans around development of the service beyond the initial pilot in RemoAge.

The Dementia Friends Work has continued through the provision of Dementia Friends training and the Dementia Friendly Business Scheme and plaque recognition. Examples of this work are training that has been undertaken with local acute hospital setting all staff and student nurses. There are also weekly ceilidh in the ward for all patients on a delayed discharge to offer stimulation, company and interaction. Local Airport staff are working with the local Alzheimer's Scotland group looking to improving local transport links for people with dementia. Similarly there is partnership working with local fire departments in Barra and the Uists to improve fire safety for individuals living at home.

This has engaged a wide range of participants with 364 individuals signed up as Dementia Friends in the Western Isles. Similarly 49 school children have engaged in separate awareness raising sessions.

There has been widespread engagement with shops, businesses, community groups, public and private sector services from libraries, banks, post offices to taxi and public transport bus drivers, who have expressed an interest in supporting the work around making our communities more dementia friendly and accessible.

## 6. Conclusion and implications

The RemoAge evaluation offers a number of conclusions and implications.

### 6.1 Evaluation processes and questions

Concerning the evaluation itself, there were significant challenges in obtaining data from the test sites, as we have described. These are at least partly due to the different demands of local evaluation and its purposes as compared with the need to provide an overall evaluation which can compare findings across the whole project.

Our recommendation would be that there is a need for pragmatism and recognition of competing priorities. At the same time, the important learning that comes from cross national work needs to be captured and considered.

The evaluation approach that was most helpful involved and learned from the team discussions and focus groups, in which test site representatives compared experiences and challenges and provided specific examples from their own experiences. These discussions not only informed the evaluation, but also provided formative feedback for the sites. In RemoAge, as compared with RemoDem, delivery partners had better data on their local populations, though there were still some difficulties with assembling it, and in some case data protection issues made the use of existing data problematic: this appears to be an under-reported issue. The collection of data from receivers of services was more challenging for some sites than others. As we have seen, the populations involved were similar across sites in their levels of impairment, and yet between sites, there were differing perspectives on the possibilities or otherwise of collecting the views of service users. As evaluators, who have worked extensively with frail older people, we would recommend further work to support service providers to be able to collect the views of the people whom they serve: this will certainly involve further training and some changes in thinking. Assumptions that frail older people cannot provide opinions run the risk of silencing people because they have difficulties. It is important to note in this connection that none of the partners in RemoAge would disregard or devalue the views of frail older people: our recommendations relate to better ways of hearing such views.

### 6.2 Real world issues

It was not possible to treat the tests as controlled experimental situations. All the sites had different starting points, and it was not intended that the provision developed would be standardised across the sites. From the start, each site was encouraged to assess local conditions and needs and to develop provision most appropriate to these. Furthermore, as RemoAge proceeded, the service provision developed and adapted further to the local circumstances, sometimes with unforeseen results. There were significant elements of experimentation, trial and error in the development of services, aspects which, from the points of view of the service providers were frequently part of processes of change and service development. Overall, the principle of RemoAge was to see general improvements in services for older people in remote areas, and it is not surprising that with such a large and general aim, there was much scope for movement as time went on. One striking example was the ways in which tablet computers were used in very different ways over time: in several cases, they were introduced to be useful for clients, with the potential benefits for staff communication and support not having been

considered, yet communication between staff emerged as a very significant issue which the computers could help them address.

The lack of standardisation and the dynamics of service development support the argument we made in RemoDem for the needs for flexible and responsive research designs that can respond to and try to understand these dynamics in real time. We used a mixed methods approach with formative and summative evaluation components and an emphasis on the qualitative understanding of processes as well as the collection of quantitative indicators that could inform our conclusions. The attempt to collect systematic data on the perspectives of service users was only partly successful, for reasons we have explained, but the limited data that were available were helpful in providing systematic comparisons of the populations targeted and involved between the different sites.

RemoAge targeted frail older people following on from some issues identified in the RemoDem project. In RemoDem, only people who had a diagnosis of dementia could be supported by the services developed. The team learned that the low rates of dementia diagnosis in all the partner areas meant that people who could benefit from the services, many of whom had significant cognitive impairment and probable though undiagnosed dementia, were being excluded. The data we have reported on those who received RemoAge services bear this out, and RemoAge has been able to work with a wider and very frail older population. There is a general lesson here for research and service development that seeks to work with frail older people, that measures to ensure inclusion of those who need services require careful planning and particularly that people with dementia can be included.

A very strong real-world theme that emerged from the evaluation was that of connection and communication. This appeared in relation to all the stakeholders and throughout the service provision systems. The importance of improved staff communication was a strong theme, and this was seen as improving the work experience for staff – who can feel very isolated when working in remote areas – as well as the effectiveness of their work. Involving families in discussions with service users and staff was also indicated, and clients communicating with each other was also promoted in some areas (especially in Scotland). In terms of communication, ICT was seen to provide means that had not previously existed, and once people realised the possibilities, they began to take on the technology and use it in new ways. Importantly, the specific focus on introducing the use of tablets was needed to realise these benefits: people's personal awareness of technology had not automatically led them to use it in their work.

A well-rehearsed issue in temporarily funded projects in health and social care is that of how to roll out successful innovations to be mainstreamed. The more developed services within RemoAge were facing questions of this kind towards the end of the project, and had started to effect more widespread change. In Sweden, it was notable that RemoAge had achieved significant growth during the lifetime of the project, spreading to many more municipalities than those originally involved, and there had also been similar spread in Tromsø. These expansions had been facilitated by proactive communication, collective working and the leadership of the core teams. The need for clear local leadership and management and local political support was noted in all the areas as critical for ensuring that work would be fully mainstreamed after the end of the project. In Sweden, mainstreaming had already begun, and signs for the future were promising.

### **6.3 Technology use in services for frail older people**

Like RemoDem, the RemoAge project aimed to consider how technology could be used to improve support for its client group, and considerable effort was expended identifying appropriate technologies that could be used. In RemoAge, the most successful technologies used turned out to be the most commonplace, with only minor inclusion of specialist care technologies or specialist devices targeted at frail older people. Tablet computers and video communication technology were the most widely used technologies, and were agreed to be useful in the service delivery. Some specialist softwares were used (such as myEthel), delivered using the tablets.

For service providers, such 'off the shelf' technologies can, as we have demonstrated, be useful and popular, and they are of course relatively reasonably priced. They are of their nature very flexible and adaptable, are easy to use and widely familiar, and permit experimentation and trial and error to suit the aims and nature of the services being delivered. From the experience of the project, these seem to be advantages as compared with specialist devices, whose use presents much greater complexity.

There continue to be issues for these remote and rural areas concerning access to broadband, and broadband speed. Arguably, these facilities are needed more in these areas than they are elsewhere, in order to improve service provision. The RemoAge findings suggest that investment in broadband access in remote and rural areas can pay dividends in terms of improving service and the quality of life of frail older people.

### **6.4 Benefits of international collaboration**

The evaluation of RemoAge service delivery across the wide range of areas and projects has enabled us to identify some underlying and shared issues, whose address could inform the better development and delivery of services for frail older people in remote and rural areas. During the course of the project, several transnational meetings were held, and, as we report elsewhere (Deliverable 6.5), these enabled comparison of experiences, and mutual learning and reflection. They also promoted collective working between groups of sites (in Sweden and in Scotland). All the sites reported that the international dimension of their work was beneficial for themselves and for their clients.

## 7. Appendix

### 7.1 Evaluation of services delivered (service users and carers)

#### Section 1: Background questions

##### Q1 – Q4: complete from records/interaction with the person

1. Identifying number of the older person receiving the service.
2. Date and place of interview
3. (If the person has dementia) Severity of dementia: please include the result of the most recent test done, note what test it was, and give the date when it was done.
4. Please provide your own classification of the severity of dementia. Is it<sup>3</sup>:

Mild: a person might have difficulty making decisions, coping with complexities in their work or hobbies, and may have problems remembering to pay bills or attend appointments

Moderate: the person with dementia may have increasing difficulty recognising family, friends or familiar places, may need more help with everyday activities such as reading or dressing, and their behaviour may change.

Severe: the disease affects more functions of the brain, and problems of memory and everyday activity become more severe. Communication can become very challenging, and the illness is likely to increasingly affect the person's physical abilities.

##### Q5 onwards ask the person themselves or the carer: complete the answers as they apply to the older person<sup>4</sup>

5. Male or female (note from observation – ask if unsure)
6. In which month and year were you born?

Month:

Year:

7. Are you

Living with a spouse?

Living with a partner?

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<sup>3</sup> Classifications from Alzheimer Scotland <http://www.alzscot.org/pages/info/dementiafacts.htm>

<sup>4</sup> Q5-Q15 (not Q13 – see below) use the SHARE (Survey of Health, Ageing and Retirement in Europe) questionnaire available at <http://www.share-project.org/data-access-documentation/questionnaires/questionnaire-wave-1.html>. Translations into Danish and Swedish are available on the website (look under the columns 'CAPI coverscreen' and 'CAPI main questionnaire').

Living as a single?

8. [If there is a partner] In which month and year was your partner born?

Month:            Year:

9. Does anyone else live in this household<sup>5</sup>

[if yes] Who else? (specify relationship to respondent)

In which month and year were they born?

Month:            Year

10. Were you born in [this country – name country]?

11. [If not] In which country were you born? (please name the country your birthplace belonged to at the time of your birth)

12. [if not born in this country] In which year did you come to live in this country?

13. What is the highest level of education you have received?<sup>6</sup>

Primary or less?

Secondary?

Post secondary, non-tertiary?

Tertiary?

14. Would you say that your health is.....<sup>7</sup>

Excellent

Very good

Good

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<sup>5</sup> A household consists of all persons who live in the same dwelling (using the same entrance door) and who have a common house-keeping budget or usually have their meals together. Lodgers (people who sublet) are not included. If parents and children are living in the same dwelling, they are considered the same household, whether or not they have a common housekeeping budget.

<sup>6</sup> International Standard Classification of Education

<sup>7</sup> Questions 14-21 come from the Survey of Health, Ageing and Retirement in Europe (SHARE) wave 5 questionnaire, refs: PH003\_HealthGen2; PH004\_LStill; PH006\_DocCond; PH007\_OthCond; PH043\_EyeSightDist; PH044\_EyeSightPap; PH045\_UseHearingAid; PH046\_Hearing. Translations are available in Danish and Swedish from <http://www.share-project.org/data-access-documentation/questionnaires/questionnaire-wave-5.html> - 'CAPI main questionnaire' and 'Showcards'.

Fair

Poor

15. Some people suffer from chronic or long-term health problems. By chronic or long-term we mean it has troubled you over a period of time or is likely to affect you over a period of time. Do you have any such health problems, illness, disability or infirmity? (Including mental health problems)

Yes

No

16. Please look at this card [show the card CARD 1 with list of health conditions]

[Has a doctor ever told you that you had/Do you currently have] any of the conditions on this card? [With this we mean that a doctor has told you that you have this condition, and that you are either currently being treated for or bothered by this condition.] Please tell me the number or numbers of the conditions.

[Interviewer to record all that apply]

1. A heart attack including myocardial infarction or coronary thrombosis or any other heart problem including congestive heart failure

2. High blood pressure or hypertension

3. High blood cholesterol

4. A stroke or cerebral vascular disease

5. Diabetes or high blood sugar

6. Chronic lung disease such as chronic bronchitis or emphysema

10. Cancer or malignant tumour, including leukaemia or lymphoma, but excluding minor skin cancers

11. Stomach or duodenal ulcer, peptic ulcer

12. Parkinson disease

13. Cataracts

14. Hip fracture

15. Other fractures

16. Alzheimer's disease, dementia, organic brain syndrome, senility or any other serious memory impairment

18. Other affective or emotional disorders, including anxiety, nervous or psychiatric problems

19. Rheumatoid Arthritis

20. Osteoarthritis, or other rheumatism

96. None

97. Other conditions, not yet mentioned

17. What other conditions have you had?

18. How good is your eyesight for seeing things at a distance, like recognising a friend across the street [using glasses or contact lenses as usual]? Would you say it is...

Excellent

Very good

Good

Fair

Poor

19. How good is your eyesight for seeing things up close, like reading ordinary newspaper print [using glasses or contact lenses as usual]? Would you say it is...

Excellent

Very good

Good

Fair

Poor

20. Are you usually wearing a hearing aid?

Yes

No

21. Is your hearing [using a hearing aid as usual]...

Excellent

Very good

Good

Fair

Poor

22. We need to understand difficulties people may have with various activities because of a health or physical problem. Please tell me whether you have any difficulty doing each of the everyday activities on this card [show the card CARD 2 with the list of activities]. Exclude any difficulties that you expect to last less than three months.

Because of a health problem, do you have difficulty doing any of the activities on this card? TICK ALL THAT APPLY

1. Walking 100 metres
2. Sitting for about two hours
3. Getting up from a chair after sitting for long periods
4. Climbing several flights of stairs without resting
5. Climbing one flight of stairs without resting
6. Stooping, kneeling, or crouching
7. Reaching or extending your arms above shoulder level
8. Pulling or pushing large objects like a living room chair
9. Lifting or carrying weights over 10 pounds/5 kilos, like a heavy bag of groceries
10. Picking up a small coin from a table
96. None of these

23. [show the card CARD 3 with the list of activities] Please look at this card. Here are a few more everyday activities. Please tell me if you have any difficulty with these because of a physical, mental, emotional or memory problem. Again exclude any difficulties you expect to last less than three months.

Because of a health or memory problem, do you have difficulty doing any of the activities on this card? TICK ALL THAT APPLY

1. Dressing, including putting on shoes and socks
2. Walking across a room
3. Bathing or showering
4. Eating, such as cutting up your food
5. Getting in or out of bed
6. Using the toilet, including getting up or down
7. Using a map to figure out how to get around in a strange place
8. Preparing a hot meal
9. Shopping for groceries
10. Making telephone calls
11. Taking medications
12. Doing work around the house or garden
13. Managing money, such as paying bills and keeping track of expenses
96. None of these

24. For these questions, please choose the best answer for how you have felt over the past week.  
ANSWER YES OR NO<sup>8</sup>

1. Are you basically satisfied with your life? YES / NO
2. Have you dropped many of your activities and interests? YES / NO
3. Do you feel that your life is empty? YES / NO
4. Do you often get bored? YES / NO
5. Are you in good spirits most of the time? YES / NO
6. Are you afraid that something bad is going to happen to you? YES / NO
7. Do you feel happy most of the time? YES / NO
8. Do you often feel helpless? YES / NO

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<sup>8</sup> These questions are the Geriatric Depression Scale <http://web.stanford.edu/~yesavage/GDS.html> The website provides translations into Norwegian and Swedish.

9. Do you prefer to stay at home, rather than going out and doing new things? YES / NO

10. Do you feel you have more problems with memory than most? YES / NO

11. Do you think it is wonderful to be alive now? YES / NO

12. Do you feel pretty worthless the way you are now? YES / NO

13. Do you feel full of energy? YES / NO

14. Do you feel that your situation is hopeless? YES / NO

15. Do you think that most people are better off than you are? YES / NO

25. Please indicate for each of the statements which is closest to how you have been feeling over the last two weeks. SHOW CARD 4<sup>9</sup>

1. I have felt cheerful and in good spirits.

2. I have felt calm and relaxed

3. I have felt active and vigorous

4. I woke up feeling fresh and rested

5. My daily life has been filled with things that interest me.

6. I have felt particularly tense.

7. I have felt downhearted and depressed.

26. Please tell me whether you strongly agree, agree, neither agree nor disagree, disagree or strongly disagree with each statement SHOW CARD 5<sup>10</sup>

1. I am optimistic about the future.

2. I generally feel that what I do in life is worthwhile.

3. I feel I am free to decide how to live my life.

4. In my daily life, I seldom have time to do the things I really enjoy.

5. I feel left out of society.

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<sup>9</sup> These questions are from the European Quality of Life Survey, Q45a-e, Q46a and Q46c. A Swedish translation is available at <http://www.eurofound.europa.eu/eqls-2012-questionnaire-translation>

<sup>10</sup> These questions are from the European Quality of Life Survey, Q29a,b,c,d,e,f,g,l (not Q29h because it relates to employment). A Swedish translation is available at <http://www.eurofound.europa.eu/eqls-2012-questionnaire-translation>

6. Life has become so complicated today that I almost can't find my way.
7. I feel that the value of what I do is not recognised by others.
8. I feel close to people in the area where I live.

## Section 2: questions for the main carer of the person receiving the service<sup>11</sup>

READ OUT: You are the main carer for your relative. Caring for others can be stressful. These items ask about how you have been coping with stress in your life since becoming a carer. There are many ways to try to deal with problems. These items ask what you've been doing to cope with any stresses. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

### SHOW CARD 6

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.

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<sup>11</sup> These questions are the BriefCOPE scale <http://www.psy.miami.edu/faculty/ccarver/sclBrCOPE.html>. This has been widely used and is sensitive to change. Stefan provided a Swedish translation for RemoDem which can be re-used once the introduction text has been replaced with this version which is specific to RemoAge.

16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.