EUR♥FAMCARE

Services for Supporting
Family Carers of Older Dependent People
in Europe:
Characteristics, Coverage and Usage

The National Survey Report for the
United Kingdom

(Deliverable N° 18)

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1 Introduction to the study: EUROFAMCARE

1.1 Aims and structure of the EUROFAMCARE project

The main aim of the EUROFAMCARE project was to evaluate the **situation of family carers of older people in Europe** in relation to the existence, familiarity, availability, use and acceptability of **supporting services**, with the objective of formulating:

- at a **macro-level**, suggestions for the implementation of more comprehensive, carer-friendly elderly care policies in Europe;

- at a **meso-level**, suggestions for developing new partnerships between service providers, local authorities and caring families, and the implementation of innovative user-oriented services and

- at a **micro-level**, more systematic and adequately disseminated knowledge about caregiving, thus contributing to significantly reducing the risk of impairment in cared-for older people and at the same time improving caregivers' quality of life.

The main **core questions** the research aimed to address were:

- Which services are available and able to promote positive effects and to avoid negative consequences and implications in caring for elderly family members?

- Which approaches and services already exist in the different European countries?

- What are family carers' experiences in using these?

- What are the barriers that keep family carers from using support services?

- Do these services really reach the persons in need of support and do they really fit with the needs and demands of caregivers?

- What are the criteria for effective, sufficient and successful measures, where can such measures be found, and what are their deficiencies?

- How can they be implemented and disseminated?

The project intended to promote a **partnership approach in family care**, with the main focus being on the perspective of family carers and their dependent elderly relatives, rather than the currently predominant service provider-based approach. The project also aimed to fill a knowledge gap concerning the characteristics, coverage and usage of services supporting family carers in Europe at both the trans-European and the pan-European levels.

- At a **trans-European** level, a core group consisting of six countries Germany (coordination), Greece, Italy, Poland, Sweden and the UK, conducted primary research studies of family carers and the dependent older people they cared for, as well as of providers of relevant support services as follows:

  o A baseline survey of ca. 6000 family carers (1000 per country) using an agreed protocol for sample selection and implementation of the survey, a common assessment tool/questionnaire (CAT) for face-to-face interviews with the sample of family carers, data input and mainly quantitative, but some qualitative, data analysis.

  o A follow-up study of the original sample of family carers 1 year after the baseline interviews using a common questionnaire (CAT-FU)

     o   A service-provider study, consisting of interviews with key personnel providing services to family carers and/or older people, analysed using mainly qualitative methods.

After a brief background and context the following sections of this report detail the methods and findings of the UK study.

2   Policy Background and Context: Family Care in the UK

A detailed description of the situation of family carers and the legislative framework within which services for family carers are delivered was provided in the National Background Report (NABARE) for the UK (http://www.uke.uni-hamburg.de/extern/eurofamcare/presentations.html). Similarly a consideration of the literature (research, policy and practice) relating to family care more generally is available in Chapter Two of the Trans-European Survey Report (http://www.uke.uni-hamburg.de/extern/eurofamcare/presentations.html), and it is not intended to repeat this information here. Rather this section will provide a brief overview of key issues in order to set the remainder of this report in context.

The emergence of family care

> *'With its strategic importance, and the unresolved issues surrounding it, we expect that the family will continue to be centre stage for many years to come.'*
>
> (Pearlin et al 2001, p55)

The past 30 years have witnessed a remarkable growth in interest in 'family carers' as the main source of support for people who need help to remain living within their own homes. As the above quote suggests, there is no sign of this interest abating; indeed in many respects it is on the increase. Moreover, such interest spans several areas, ranging from the academic to policy and practice. From an academic perspective family, or informal care, as it was referred to, was 'hardly mentioned in the 1960's' (Brody 1995) and yet 30 years later it had become one of the most researched areas in social gerontology (Kane and Penrod 1995). The result has been a 'voluminous literature' (Schulz and Williamson 1997) and an 'explosion' in research activity (Fortinsky 2001), much of it focussing on interventions designed to support family carers in their role. Yet despite this, and the fervent hope of most researchers that their efforts will in some way 'make a difference' (Pearlin et al 2001), there is still remarkably little evidence for the effectiveness of existing interventions (Braithwaite 2000, Thompson and Briggs 2000, Cooke et al 2001, Pusey and Richards 2001). This paradox requires further exploration.

Similar considerations apply in policy and practice fields. In response to their ageing populations welfare systems throughout the world have for some time pursued a policy of community care, in which the aim is to enable older people to live for as long as possible in their environment of choice, usually their own homes (Davies 1995). As approximately 80% of any help they need is provided by the family (Walker 1995) it is hardly surprising that family care has become highly politicised (Chappell 1996). Consequently policy initiatives and services designed to support family carers have proliferated to the point where they have become one of the most 'striking developments' in the policy arena (Moriarty and Webb 2000).

In England, for example, the last decade has seen the introduction of several pieces of legislation including the Carers (Recognition and Services) Act (1995), the Carers and Disabled Chil-

dren's Act (2002), and most recently the Carers (Equal Opportunities) Act (2004), all intended to give more formal recognition to the rights and circumstances of family carers. Realisation that the 1995 Act was having a limited effect prompted the Government to launch the Carers National Strategy (DoH 1999). This introduced a range of initiatives intended both to empower carers to take greater control of their lives, and to promote a change of culture so that carers are not only recognised but also respected and admired. However, notwithstanding a considerable investment of time and money, a recent major review of support for family carers in the UK concluded that the situation remains unsatisfactory to the extent that:

> *'The Government's aspirations for carers of older people are not being realised in practice for the majority of them. A clearly articulated and coordinated approach is needed from all concerned if this is to change.'*
>
> (Audit Commission 2004)

Current difficulties can be attributed to a number of factors but two of the most compelling are the manner in which carers interact with service systems, particularly how their needs are assessed and the quality of service responses designed to address the needs identified.

Support for carers has been one of the most 'striking' policy developments in the UK in recent years (Moriarty and Webb 2000), and yet despite this many existing services are not fully utilised by carers. There are a number of potential explanations for this but two important factors are that carers either do not always see services as relevant to their needs (Pickard 1999, Braithwaite 2000), or they do not consider that the service provides care of sufficient quality (Moriarty 1999, Pickard 1999, Whitehouse 1999), with carers rejecting services that are not deemed good enough, or are not consistent with their routines and preferences.

However, in order to reject a service, carers have to be offered one in the first place, and they frequently face several barriers before even reaching this point. Often carers simply do not know what support is available, nor how to access it. In other words, they do not know how to get into the 'system'. Take, for example, obtaining an assessment of their needs. In England carers have a statutory right to such an assessment yet the majority are not aware of this (Audit Commission 2004).

Even if carers are able to access the 'system', the reaction they receive is often not welcoming. As Wuest (2000) suggests, carers' experiences of interacting with 'helping systems' largely determine whether or not they will seek further help. Assessment may be the first point of contact and therefore should provide the opportunity to engage family carers as 'real partners' (Audit Commission 2004). Yet all too often this is not the case. Firstly, assessments are not as widely promoted as they might be (Audit Commission 2004), thereby limiting access. Secondly, assessors frequently adopt a 'gate-keeping' role and see the process as a means of rationing existing resources rather than thinking creatively about a range of potential, and possibly unconventional, solutions to existing problems (Audit Commission 2004). As such assessment represents a lost opportunity to explore the issues that are of real concern to carers. Carers have a not unreasonable expectation that services and professionals will be 'connected' with their concerns (Wuest and Stern 2001), yet they are frequently disappointed.

To make matters worse, professionals' interactions with carers are not always positive, with the Audit Commission (2004) reporting that the attitudes of some care managers was *'surprising'*

and that the subsequent *'anger and frustration'* of carers was worrying. They stress the need for services in general, and individual practitioners in particular, to be far more *'carer aware'*.

Even if carers are able to navigate their way through the 'system' and obtain services they still encounter problems. Respite care is a good exemplar. The service provided is often not sufficiently flexible or responsive and frequently does not fit in with carers' routines, nor is it necessarily provided at a time or in a form that best suits carers or the person they support (Moriarty 1999). Moreover, carers have concerns about poor quality of care and the lack of continuity of paid carers that further inhibits use, not only of respite care, but of a range of support services (Pickard 1999, Brereton and Nolan 2003). Services are therefore often not seen as meaningful by carers.

Nolan et al (2003a) argue that agreement about the aims of service provision and the goals of support are major determinants of whether help is seen as meaningful by family carers and disabled people. Assessment is the main means by which agreement can be reached and therefore the way in which assessments are conducted is crucial.

Some time ago Smale et al (1993) suggested that the assessment process, during which decisions about service allocations are usually made, often follows one of three models: the questioning model; the procedural model; or, the exchange model. In the questioning model the assessor is the 'expert' who asks a series of questions to which the carer or disabled person responds, with the appropriate service being determined largely on the basis of their answers. Here the power lies essentially with the individual assessor. The procedural approach is dominated by the expectations of the service agency, based on relatively fixed eligibility criteria which determine if a carer has a 'right' to services. These usually comprise objective criteria, such as the amount and type of help that the carer has to provide. Once again the balance of power does not lie with the carer/disabled person. In contrast the exchange model assumes that all parties have knowledge and expectations that will influence the type of service that is needed, and that an 'exchange' of views is essential.

Most assessment processes currently adopt a procedural or questioning approach, and Nolan et al (2003a) suggest that this usually results in services either being 'allocated' or 'imparted'. The 'allocation' of services is based mainly on considerations such as the amount or intensity of help and support that the family carer provides. Here eligibility for services is determined mainly by the objective circumstances of carers. This is typical of the currently dominant approach to the assessment of carers' needs in the UK, in which services are targeted primarily at carers providing 'regular and substantial' care, which is generally equated with more than 20 hours of care per week (Hirst 2001). Procedural models of assessment are likely to result in services being 'allocated', with the assessor adopting the role of 'gatekeeper' (Audit Commission 2004).

The 'imparting' model is underpinned by the belief that the service provider is in possession of information or other expertise that the carer or disabled person needs. Such as model implicitly or explicitly underpins several psycho-educational interventions targeted at family carers. However, for new carers and newly disabled people the 'imparting' model may be appropriate, as there is general consensus that all carers are likely to benefit from knowledge of the disease condition, the caregiving role, the resources available, and require some training in problem-solving and related skills (Schulz et al 2002). On the other hand carers also have 'expert' knowledge of various types and it is important that such information is considered fully when

assessment takes place (Nolan et al 1996, 2003a). It is here that the exchange model is more likely to ensure that services are 'negotiated' and are agreed as the result of all parties sharing their expertise and knowledge. These models are illustrated in Figure 1. Adopting an exchange model of working is consistent with the present emphasis on developing partnerships with family carers (Audit Commission 2004), and is more likely to result in good quality support being provided to carers.

Figure 2: Models of assessment and their impact on services

Model of assessment		Role of practitioners/assessor		Services
Procedural – usually based on predetermined objective eligibility criteria		Gatekeeper		Allocated – little opportunity for innovation or flexibility
Questioning – with questions being determined largely by the assessor		Expert		Imparted – as from an expert to a novice
Exchange – based on the assumption that everyone has something to contribute		Co-expert/facilitator		Negotiated – between partners, more opportunity for agreement and innovation

(After Smale 1993)   (After Nolan et al 2003a)

Good quality support is valued and highly appreciated by carers (Lowenstein and Ogg 2003), but usage and uptake is influenced by several factors including: family culture (that is readiness to use services); family norms and their preferences for certain types of care and the availability, accessibility, quality and costs of the support available (Lowenstein and Katz 2003). In respect of usage of services for older people more generally, Bojo and Ancizu (2003) argue that this is primarily determined by knowledge, image and availability. In situations where public knowledge of services is high, such services have a positive image, and there is easy access, then uptake is likely to be good.

Whittier et al (2002) have suggested that there are five reasons why carer support may not be used. These are:

- Availability
- Accessibility
- Appropriateness
- Acceptability
- Affordability

These seem to distil the key messages from several studies and are useful in considering how better support services might be developed.

7

Availability

Clearly services cannot be used if they are not available, and even in those countries where support for carers has become a policy priority, such as the UK and Sweden, services remain largely reactive rather than proactive, and innovation is relatively limited (National Board of Health and Welfare 2003, Audit Commission 2004). Particular difficulties have been noted for several marginalised groups of carers such as those in rural areas, those from black and minority ethnic groups, and other minorities such as gay and lesbian carers (Scottish Executive 2005b).

Availability is in part an issue of resourcing, but things are unlikely to improve significantly until there is greater recognition of carers as individuals with rights of their own. Such formal recognition needs to permeate policy and practice more widely, as is characteristic of recent developments in Scotland, which are promoting a 'bold new vision' for carers (Scottish Executive/Office of Public Management 2005a).

These new proposals are based on the belief that the contribution that carers make to society must be fully recognised, the economic impact of that contribution accepted, and that carers have to be wholly included in a society that provides adequate support for their needs. Interestingly, the term 'unpaid carer' is preferred to family carers, signalling another shift in emphasis with 'unpaid carers' being seen as the major **providers** of care rather than as clients or recipients of services per se. This 'bold new vision' is underpinned by two key principles:

- greater recognition of, and respect for unpaid carers as key partners and providers of care;

- the development of a rights based policy framework to support unpaid carers who are seen as 'people first' and unpaid carers second.

The goal is to ensure that people have the opportunity to choose when, how, and if to care, and to promote unpaid caring as a 'positive life choice'. In order to achieve these aims it is argued that carers should have rights to:

- flexible employment;
- adequate financial support and planning;
- accessible information and technology;
- practical support;
- regular breaks from caring;
- adequate housing;
- training and health care;
- good transport links;
- accessible leisure and recreational opportunities.

Essentially, therefore, carers should have rights to the same opportunities as other citizens, including the right not to care, to choose an appropriate level of care, and to receive appropriate

support from agencies adequately resourced to do so. This extends the debate beyond availability to issues such as accessibility.

Accessibility

There are several dimensions to accessibility, and perhaps the most obvious relates to the physical accessibility of services. Carers are often older people themselves and services that are geographically remote or do not provide disabled access have obvious limitations. Basic infrastructure such as adequate transport and a good built environment are therefore essential (Scottish Executive 2005a). Another key factor is knowledge and awareness of services, for even if services exist, carers cannot access them if they do not know about them. Despite living in the age of the 'information superhighway' one of the biggest single complaints from carers is a lack of information about available services and how to access them. Even in countries such as the UK where carers have certain statutory rights, many remain unaware of these (Audit Commission 2004, Scottish Executive 2005b). Certainly this is one area where immediate improvements could be made, and Information and Communication Technology (ICT) could have a major role to play.

However, greater knowledge is only the first step to increasing accessibility, and most carers still have to learn how to get into the 'system' and use it to their best advantage. Most formal services are accessed via some form of 'assessment' and, as previously discussed, it is here that difficulties often arise and barriers are constructed.

Exacerbating the situation, eligibility for service is determined largely by the objective circumstances of carers. This is typical of the currently dominant approach to the assessment of carers' needs in the UK, in which services are targeted primarily at carers providing 'regular and substantial' care, which is generally equated with more than 20 hours of care per week (Hirst 2001). Several recent studies in Canada and the USA have noted that carers' needs are still not routinely considered by practitioners (Guberman 2005a, b), and even when they are the dominant focus is on burden (Guberman 2005a, b, Huyck 2005, Turner 2005). Eligibility criteria for services, usually in the form of an assessment of the activities of daily living that carers undertake for the cared for person, remain prevalent (Albert 2005, Bedford 2005). Therefore whilst assessment should provide a 'new lens' through which better to understand carers' needs (Fancey et al 2005), resulting in customised support tailored to individual needs and priorities (Zank 2005) this is rarely the case.

Guberman (2005b) has called for a move away from a service driven model towards one that provides carers with genuine choice. If such a shift is to occur it is suggested that:

> *'Regardless of the type of service required, it is critical that carers receive a service that is tailored to their individual needs. To make this happen assessment processes need to be more interactive and holistic, giving carers the opportunity to determine more fully what they need.'*

(Scottish Executive 2005a)

This is essential if services are to more appropriately address carers' needs, and be acceptable to carers.

Appropriateness and acceptability

In carers' eyes the appropriateness and acceptability of services are closely related attributes and therefore will be considered together. As noted earlier, the paradoxical situation often exists where, despite considerable need for support, carers do not always make full use of the limited help available. This is because they frequently do not see such services as appropriate to their needs, or of acceptable quality. Carers make subtle judgements about the relative 'costs and benefits' of support and reject help if the former outweigh the latter (Clarke 1999, Montgomery and Kosloski 2000). Essentially, carers want to be reassured that those providing support are 'up to the job' (Brereton and Nolan 2003, Brereton 2005), and if formal carers do not have the requisite knowledge, skills and attributes then help will be unacceptable. This is one of the key issues to be addressed in the NASURE.

3   The EUROFAMCARE Common Assessment Tool (CAT):

3.1   Item and scale development

The Common Assessment Tool (CAT) used in the EUROFAMCARE study was developed over a period of several months. It comprises a series of items and scales that were developed by the partners specifically for this project, or selected for use from among a range of standardised and validated published instruments. Development was achieved through a series of discussions, database searching for published instruments, and research evidence of validity/reliability. Formatting of the CAT took place, and the draft questionnaire was tested in two pilot studies. Following the first pilot study, substantial revision to the CAT occurred. The second pilot study indicated the need for further minor revision.   The final instrument therefore represents a third version of the original.

Items and instruments were developed by the partners or selected from the research literature with reference to a model of carer service use and quality of life as a guiding framework. Derived from the work of Aneshensel and colleagues (Aneshensel et al., 1995), the model conceptualises the relationship between constructs that are hypothesised to impact on carer and elder service use and carer quality of life. Following further development, the constructs were operationalised in the CAT via a series of variable categories: *Elder's demographic and background characteristics; Elder's disability and need; Carer's demographic and background characteristics; Carer's caregiving situation; Carer quality of life (QoL); Financial circumstances; Service use; Characteristics and quality of services*. In addition, some variables in the CAT addressed issues related to the administration of the questionnaire. The CAT also included a project consent form.

3.2   The Common Assessment Tool – Follow-Up Questionnaire (CAT-FUQ): Item and scale development.

As part of the EUROFAMCARE project, a follow-up phase of data collection occurred one year after the initial survey (see Sections X and 9). For this second wave of data collection, a follow-

up questionnaire (CAT-FUQ) was developed that drew substantially on the CAT instrument used in the first wave, so that comparison between the two waves of data would be most optimally effected.

The development of the Common Assessment Tool – Follow-up Questionnaire (CAT-FUQ) followed a similar trajectory to that of the original CAT. The first stage of development involved the selection of items and scales from the CAT that it was felt were essential for inclusion in the CAT-FUQ in order to understand the change in circumstances among our carer sample between the first and second wave of data collection. In this respect, most of the variable categories as obtained for the CAT also applied for the CAT-FUQ: *Elder's demographic and background characteristics; Elder's disability and need; Carer's demographic and background characteristics; Carer's caregiving situation; Carer quality of life (QoL); Financial circumstances; Service use.* To maximise comparability, items and scales selected from the CAT for inclusion in the CAT-FUQ were altered only if a) problems had been found in their original administration, and/or b) it was necessitated as a result of a change in mode of administration between the two waves.

In addition to the inclusion of variables in the CAT-FUQ that addressed issues related to the administration of the questionnaire, some new items were also included that the partners felt were justified on the basis of issues emerging from the first wave of data. For new items, development proceeded in the same way as for the original CAT items. Following the development of the CAT-FUQ, the draft questionnaire was tested in a pilot study. The final instrument therefore represents a second version, which incorporates minor changes to the original that followed evaluation of the pilot study results.

4   Sampling and recruitment

4.1   Creating the sampling frame

Whilst there is a legal definition of a carer in the UK, this is variously interpreted in day-to-day practice and, as such, there is no accepted shared definition of what constitutes a 'carer', and no national database of carers from which a random sample could be drawn. As such, for the purpose of the study we had to both define a 'carer' and also develop a sampling frame that would enable us to locate and recruit our sample of carers. Below are the definitions used in our study in order to create our sampling frame.

sample units: individuals who give care or support to a person who is aged $\geq$65 years, for four hours a week or more (excluding those people who only give financial support or companionship).

sampling frame: three parameters were used in order to create our sampling frame:

■ a geographical parameter, which subdivided the UK into five regions: England North, England South, Northern Ireland, Scotland, and Wales.

■ a population density parameter, which divided the regions into metropolitan, urban, and rural sub-areas.

■ a service accessibility parameter, which took account of the level of supply of support services for elderly people, in order to ensure that sub-areas with high, medium and low availability of services where included.

For four of the regions one urban and one rural location were chosen as data collection sites. In the fifth area, England South, one metropolitan area and one rural area were chosen in order to ensure the largest variability in services available. This gave a total of four urban, five rural and one metropolitan sample regions.

The combined application of the geographical and population density parameters described above ensured that the achieved sample could be considered a good representation of the socio-economic differences existing throughout the country in terms of income, level of education, kind of professional activities performed and social structure.

4.2 Locating the sample

In order to achieve satisfactory statistical power for sub-group data analysis, a figure of 1,000 respondents was derived from exploratory power calculations. A proportionate sampling in order to achieve 1,000 respondents was carried out within the five regions defined above, according to the size of the population aged 65+ living at home within in each region derived from national statistics (see Table 1).

Table 1: **Distribution of people 65 years+ living at home in the five sub areas.**

Region	Total	% of the sample
Northern Ireland	40	4%
Scotland	100	10%
Wales	60	6%
England North	275	27.5%
England South	525	52.5%
Total	1000	100%

4.2.1 The inclusion of the 'urban – rural' dimension

The definition of urban and rural areas used in this study was taken from a 2001 report from the Office of the Deputy Prime Minister (ODPM) - then the Department of Transport, Local Government & the Regions (DTLR), and based on figures from the 1991 census. The definition of Urban and Rural areas adopted by the EUROFAMCARE study in the UK was as follows:

Urban Areas in the UK study are those built up settlements with a minimum population of 1,000 and a minimum land area of 20 hectares and all settlements of over 10,000 are treated as urban areas. All smaller settlements, together with all other land, are treated as rural areas (see Table 2).

Table 2: **Urban and Rural populations in the UK**

Definition	Urban population (millions)	Rural population (millions)	Urban land area (hectares, millions)	Rural land area (hectares, millions)

Urban Settlements				
Over 1,000+ population	42.4	4.6	1.1	2.0
Over 10,000+ population	37.8	9.2	0.9	12.1

N.B. Figures taken from the United Kingdom 1991 census

Although the UK census figures had no definition of a 'metropolitan' area, there were six areas in England and Wales with populations of over 750,00. Therefore we classified these as metropolitan areas for the purposes of the EUROFAMCARE study. The number of respondents to be recruited were therefore derived from the populations living in each region , distributed between rural, urban and metropolitan areas using the proportion of people living in each type of locality as defined below in Table 3

Table 3: Number of respondents sought within each metropolitan, urban, and rural sub-area

Region	**Metropolitan**	**Urban**	**Rural**	**Total**
Northern Ireland	0	20	20	40
Scotland	0	60	40	100
Wales	0	26	34	60
England North	0	215	60	275
England South	200	147	178	525
Total		668	332	1000

4.2.2 Saturation sampling

Initially we identified 'saturation zones', i.e. one or more sites representative of the region in terms of socio-economic context and availability of some basic services. It was anticipated that all family carers of older people in that zone would be identified and invited to take part in the study. However, identification of carers was more difficult than anticipated and therefore these zones were widened considerably in order to achieve the required sample of carers who met the inclusion criteria of the study.

4.3 Recruitment procedure

All of the recruitment and interviewing, with the exception of Northern England, was undertaken by a subcontracting market research company that specialises in health related survey work. In Northern England, recruitment and interviews were carried out by interviewers employed by the University of Sheffield. All interviewers employed used a variety of strategies to recruit carers to the survey, including:

■ Contacts through volunteer, religious and private organisations, etc

■ Door-to-door census

■ Advertisement in newspapers and on local radio

■ Letters sent by mail to residents

■ Snowball through contacts reached by any of the previous methods

■ Personal contacts of interviewers

We achieved a sample of 995 respondents, very close to the desired 1,000. Approximately 90 interviewers were employed in data collection around the country. Overall 'door-to-door' was the most popular mode of recruitment in the UK (table 4.4) notably in Northern Ireland (95.8%) and Wales (70.4%). However, the North of England, for whom voluntary agencies formed the main source of respondents (44.0%) were an exception to this.

Table 4:   Mode of participant recruitment

Mode of Recruitment	(n=995) (%)
Health of social care professional	29 (2.9)
Religious organisation	8 (0.8)
Door to door	433 (43.5)
Voluntary organisations	182 (18.3)
Advertisement	56 (5.6)
Lists	38 (3.8)
Snowball	146 (14.7)
Other	103 (10.4)

5   Findings (1): Description of the sample

5.1   Basic descriptive information

5.1.1   Elder characteristics

Variables considered within this category include the age, gender, marital status and place of residence of the main older person cared for by the recruited carer. Other variables include the elder's cognitive status, problems with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and behavioural problems.

The mean age of the cared-for person was 78 (SD=8.63, range=65-102). The majority of elders in the total sample were female (69.5%), with the majority of elders not married (63.4%). The vast majority of elders in the total sample were living at home (91.4%). Overall, most elders had either no cognitive impairment (43.9%) or probable dementia (29.2%), with a significant minority of older people classified as having age associated memory impairment (14.8%).

Elder behavioural problems (measured on a scale ranging from 0-9 with high scores indicating more problems) for the sample had a mean of 1.66 and a median value of 0 (IQR 0-3). ADL problems were assessed through two derivations. Measured in terms of the number of activities with problems (range 0-11), the mean number of ADL problems was 2.31 (median 1, IQR 0-3), and measured on a 0-100 scale of ADL independence the mean was 73.9 (median 85, IQR 60-95). The sample mean for number of problems for which the carer indicated help was needed (range 0-8) was 5.52 (median=6, IQR 4-7).

The largest proportion of carers (29.4%) identified physical illness and/or disability as the main care need of their cared-for person, with substantial proportions of carers identifying mobility (20.4)%, memory problems and/or cognitive impairment (11.1%), inability to self-care (11.1%) or old-age related decline (10.7%) as the main care need.

5.1.2   Carer Characteristics

This category of variables consisted of characteristics of the carer such as age, sex, marital status, educational status, working status, the number of people in the carer's household, and the number of people in the carer's household younger than 14 years of age.

The mean age of the total carer sample was 54.5 (SD=15.0, range 15-88), the majority of carers were female (75.4%), with most married or cohabiting (69.6%). The majority of carers were of intermediate educational status (69.3%), with the largest proportions working or retired (39.7% and 36.6% respectively). The mean number of people in the carer's household for the overall sample was 2.70 (median=2, IQR 2-3), and 77.6% of households did not contain a person under the age of 14.

5.1.3   Carer-elder relationship and residence

The largest proportion of carers were the children of the elder that they cared for (31.6%), although 30.4% of carers had a relationship with the elder categorised as 'other'. The majority of carers (42.1%) lived in the same building as their elder, but perhaps as a consequence of the number of carers who were not closely related to the cared-for, as much as 34.9% of the carer sample lived outside walking distance from their elder.

5.1.4   Carer caregiving characteristics

This category of variables consisted of measures of the duration of caregiving and the number of hours per week spent in providing care for the elder. The number of elderly people cared for and the number of non-elderly people cared for was also considered, as was the number of hours of week spent in providing care for people other then the elder.

The mean duration of caregiving for the overall sample was 61.5 months (median=36, IQR 18-75). The mean number of hours per week that the carers provided care to their elder was 50.6 (median 16.5, IQR 8-72.5). The mean number of elderly people to whom carers were providing

care was 1.20 (median 1, IQR 1-1). The mean number of non-elderly people being cared for by the carers was 0.75 (median=0, IQR 0-1).

5.1.5 Observations on the 'representativeness of the sample

In our sample there is a substantial representation of carers whose relationship to their elder is categorised as 'other', matching the significant proportion of carers who live outside of walking distance from their elder. It is likely that this representation of carers in the sample who are not closely related to their cared-for is reflected in other ways. For example, the relatively lower levels of dependency in the sample would be consistent with a proportionate over-representation of non-spouse, non-child carers, as would the skewed distribution of number of carer hours per week, with a low median (reflecting a substantial group of slightly 'light' carers) and high mean (reflecting a smaller but important group of very 'heavy' carers). It is likely that the sampling techniques used by the fieldwork sub-contractor has delivered a sample in which non-family carers (neighbours for example) are over-represented relative to a 'true' picture of carers in the UK – further comparison with other available national surveys will help to clarify this point.

5.2 Further description of the sample

5.2.1 Motivating reasons for accepting care role

Carers were asked to nominate from a range of factors those that had motivated them to take on the caregiving role. Table N displays the proportion of carers endorsing each factor.

Table 5:   Motivations for accepting care role

Reason:	%
Emotional bonds	90.5
A sense of duty	79.5
Personal sense of obligation	75.6
Cared-for did not wish anyone else to care for them	62.9
Caring for cared-for would make me feel good	61.9
I found myself caring without making a decision	61.5
There was no alternative	46.0
The cost of professional care was too high	30.2
My religious beliefs	22.6
There were economic benefits for myself and cared-for	8.7

Note: Multiple selections were possible, hence percentages sum to more than 100%

Altruistic reasons were most often endorsed, including 'emotional bonds', 'a sense of duty' and 'a personal sense of obligation' (all >75%). However, a high proportion of carers took up the caring role without any clear decision-making process (61.5%), or because their elder would not

accept care from anyone else (62.9%). Indeed, an analysis of the European sample of the EUROFAMCARE data has found that the UK sample is distinguished from the other five European countries in the study by the relative proportion of carers endorsing such 'extrinisic' reasons for taking on the caregiving role as their being no alternative, having made no decision, or due to their elder refusing care from anyone else, this distinctiveness being however confined to caregiving situations where objective and subjective stresses of care are high (Mnich et al., 2006).

5.2.2 Care role flexibility

With regard to the carer's capacity for finding someone to take over their caring role, less than half of our sample reported that they could easily find someone to replace them if they were ill (45.9%) or if they needed a break (44.5%). Only just over half of our sample (53.1%) indicated that they never felt trapped in their role as a caregiver..

5.2.3 Perceptions of the caring role

Most of our sample (53.6%) felt that they always coped well with being a carer, and always found caregiving worthwhile (55.9%), although slightly less than half of our sample (47.6%) always felt appreciated in their role, with nearly half (46.4%) sometimes finding caregiving too demanding. Over half of our sample indicated that they never experienced any negative effect of their caregiving on their physical health (57.6%), on their emotional well-being (51.0%), on their financial circumstances (78.2%), or on their relationship with their friends (66.9%) or family (74.6%). A substantial majority of our sample (73.1%) reported always having a good relationship with they person they cared for.

5.2.4 Health and well-being

The substantial majority of our carers (73.4%) reported their health as being good or better than good, while the majority (66.6%) rated their quality of life as good or better than good.

5.2.5 Need for further support

Only a third of our sample (34.3%) always felt well-supported in their caring role. While nearly half of our sample (49.8%) always felt well-supported by their family, this was only true of 27.6% of our carers with regard to support from friends and neighbours, and 41.5% never felt well-supported by social and/or health care services. While the older person's physical and mental health needs may have been primary reasons for care being provided, it emerged that of those carers providing the main support with regard to each category of cared-for need, the largest proportion of carers (n=119, 40.1%) needed extra help with providing financial support. Substantial proportions of carers also required extra help with meeting the cared-for's personal care needs (n=209, 35.6%), emotional psychosocial needs (n=284, 33.5%), mobility needs (n=250, 32.1%) and domestic care needs (n=271, 31.4%).

6   Findings (2) Experiences and Preferences of Carers in the Use of Care and Support Services

This section describes the use of support services by carers of older people. The information provided indicate **what kind of services are mainly used** by carers and cared-for older per-

sons, detailing their experiences in using them, and whether they receive **care allowances** and quantifying their amount. This includes an analysis of the **frequency** of service use, whether any **costs** have to be met by carers in order to use them, and, when used, the extent and degree of general **satisfaction** with services. A further part of this section focuses on the **types of support** that carers identify as most "important", and investigates which of them are actually received. This information is integrated with data revealing the most useful **characteristics of services** as perceived by carers', and whether these are currently met. **Services' accessibility**, including their availability, is a further key factor tackled in this section, differentiating between what carers experience both as the main obstacles and as the greatest help in accessing services, reasons for not using (needed) services (at all) or for stopping using still needed services. A final issue examines **service effectiveness**, in order to understand whether the use of a service really makes a "measurable" difference for carers.

6.1   Methodology

The CAT included a section aimed at collecting detailed data on service use by the carer and the cared-for older. Carers were asked to indicate their use of, and satisfaction with, any of a number of services indicated on a list prepared by the partners especially for this study. For comparative reasons, our UK list of services (including care allowances, also based on national categories) were then re-classified into a **European classification** (see Appendices), allowing comparisons of the cross-national data. This re-classification allowed the creation of **a first level** grouping of the services based mainly on the **care needs** covered by the different services (e.g. health care needs, personal care needs etc.); this criterion was revealed to be particularly useful in categorising the several care services addressing older people, while a simple distinction between "generic" and "specific" support services was sufficient for the (far less numerous) services addressing the needs of carers.

A **second, more detailed grouping level** was created on the basis of **which and how specific care needs were addressed** by the considered services. This level is particularly relevant in distinguishing between different kinds of <u>health care</u> (i.e. hospital, medical, nursing and rehabilitation care, including temporary residential care of this kind), <u>personal care</u> (differentiating organised assistance of "formal" services from the private care provided on an individual basis – at home or even in residential settings - by single care workers) and <u>residential care</u> (subdivided into permanent, temporary - of social kind only, to differentiate it from the health-based one – and semi-residential)

With regard to **care allowances**, the primary level of distinction concerns the beneficiary (i.e. the dependent older person or the carer).

It should be noted that services used by carers were collected separately from those used by older people, and interviewers were trained to ask carers explicitly to list only those "support" services which were relevant to them in their role as caregivers. This did not prevent some carers from indicating as relevant also "generic" health and social care services (i.e. "usual" services for the general population, e.g. GPs), especially when specific support services for carers were absent (which "normal", generic services compensated for). As a result, since it was not always possible to distinguish between a "care-related" and a "health or social related" use of generic services by family carers, a possible overestimation of the carers' use of "generic services" might have occurred (since these might have been used simply for the carer's personal health, with no direct relation with the caring situation).

6.2   Main findings

6.2.1   Which services and allowances are used by family carers and by older people?

6.2.1.1   Services used by carers

Just under a half of carers (41.6%) of carers used services, although the number of services used by any given carer was relatively low, with a mean number of services used of 0.7 (Table 6). The main category of carer-specific services used is **socio-emotional support services,** which are accessed by 7.9% of carers, followed by **information services** (5.9%) and **respite services** (2.3%). In terms of generic services used by carers in relations to their caregiving role, the General Practitioner is by far the most often used service, with 25.7% of carers having seen the GP during the previous six months. However, 7.2% of carers had also been to hospital in the previous six month period.

Table 6:   Which services do carers use?

Services used by carers in previous 6 months

Total % of carers using at least one service	41,6
Mean number of services used by carers	0,7
Specific support services for carers	%
Socio-emotional support (counselling, social work, support or self help groups etc.)	7,9
Information (about disease, caring, available services and benefits, help lines, internet)	5,9
Respite care (including supervision of elder)	2,3
Assessment of caring situation	2,0
Training for caring	1,8
Other specific services for carers	1,1
Generic services used by family carers	%
General practitioner (GP)	25,7
General hospital	7,2
Specialist doctor	3,1
Other generic services used by carers	7,2

With regard to the frequency of use of carer-specific services, 63.1% of carers that use respite care use it at least weekly. In comparison, 38.2% of carers that use information services use them at least weekly, 20% of carers that use socio-emotional services use them at least weekly, and 6.7% of carers that use training services use them at least weekly.

6.2.1.2 Services used by older people

The information contained in Table 4 shows that almost all older people (90.6%) cared for by the carers in our sample have used at least one care service in the last six months. On average, this situation corresponds to a mean of 3,5 services used by each elder.

With regard to the kind of services used most by older persons, and starting with those addressing health care needs, a central role is clearly played by primary care services, i.e. medical and nursing services, with over 79% of older persons using them. Acute care provided by general hospitals is a second major category of service, which just under a third of the sample had used in the previous six months. Just under 15% of our sample had also used rehabilitation services.

Compared to the above level of service use, services addressing personal care needs are not used to the same level. Technical equipment and home environment adaptation is the category most widely used (27.3%), followed by home-based personal care services (20.3%), emotional/psychological/social services (18.7%), domestic care services (17.0%), and organisational support via social services (16.5%).

Table 7:   Which services do elder use?

Services used by cared-for older person in previous six months

Total % of elders using at least one service	90,6	
Mean number of services used by elders	3,5	
Services addressing health care needs	%	% weekly use
Medical and nursing services	79,1	19.5
General hospital	33,2	7.3
Rehabilitation services	14,9	37.6
Temporary residential health care	0,6	
Services addressing personal care needs	%	
Technical equipment/home environment adaptation	27,3	67.1
Home based personal care services	20,3	90.7
Emotional/psychological/social services	18,7	69.6
Home based (domestic) care services	17,0	83.4
Organisational support (social work)	16,5	20.6
Transport services	11,1	58.9
Day care centres health and/or social care	9,2	87.8
Temporary residential social	8,6	16.2
Permanent residential (social/nursing/medical)	5,4	90.7
Cohabiting/co-resident non-family paid care	1,3	
Other services used by elder	0,7	

The information collected with regard to the frequency of service use shows that, in those participants that use the service there is a relatively high level of weekly use of medical and nursing services (19.5%) and particularly of rehabilitation services (37.6%). However, in those participants that at all using the service, weekly use of services addressing personal care needs is found in a much high proportion of our sample, in particular home based personal care services and permanent residential care (both 90.7%), day care centres (87.8%) and domestic care services (83.4%).

6.2.1.3   Care allowances

Support to older people and their family carers can be provided not only in the form of services, but also through allowances and financial benefits aimed at better meeting care related costs. Receipt of at least one kind of care allowance was found in 56.4% of older people cared for by our sample of carers, of whom 10.1% themselves received a care allowance. On average, the cared-for older person's allowance represented a monetary value of €2742.1 and the carer allowance represented €463.6.

6.2.1.4   Cost of services

Most of our carers (87.4%) did not have to pay for the services they received, although there was considerable variation across the different categories of services. Thus, just under a third of carers using respite care had to pay for the service, and outside of the main carer-specific services, 80% of carers had to pay for other services.

6.2.2   What are family carers' experiences in using services?

6.2.2.1   General satisfaction with used support services

The carers' level of satisfaction concerning the support services used is quite high (see Table 8), which should not be a surprise as research has frequently established that service users are reluctant to express dissatisfaction about services. Nevertheless, more than a quarter of those carers receiving an assessment of need was dissatisfied with this service.

Table 8:   Proportion of carers indicating that provided service meets needs

Services used by family carers

Specific support services for carers	
Socio-emotional support (counselling, social work, support or self help groups etc.)	89,6
Information (about disease, caring, available services and benefits, help lines, internet)	94,7
Respite care (including supervision of elder)	90,5
Training for caring	100,0
Assessment of caring situation	73,7
Other specific services for carers	*
Generic services used by family carers	

GP	92,4
Specialist doctor	100,0
General hospital	94,3
Other generic services used by carers	91,0

Note: *less than 10 cases reported

6.2.2.2 Factors affecting accessibility of care services

Table 9 indicates the stated factors or resources that most often assisted carers in accessing services. By far the most significant category of assistance nominated by carers was that obtained from medical or nursing professionals or services (39% of carers), followed by social services or local authority services (16.6%). Considerably lower numbers of carers nominated friends or family (8.64%) or voluntary organisations (7.64%) as being a source of assistance.

Table 9: **Greatest Assistance in Accessing Services**

Factor	Number (%)
1. Medical or Nursing Professional/Services	388 (39.0)
2. Social Services/Local Authority	165 (16.6)
3. Family, friends, neighbours	86 (8.64)
4. Voluntary Organisations (NA)	76 (7.64)
5. Personal experience and knowledge	39 (3.91)
6. Various media (flyers, adverts etc.)	8 (0.80)
7. Religious Organisations	7 (0.70)
8 Personal savings	5 (0.50)
9. Transport quality	4 (0.40)
10. Local availability	2 (0.20)
Others	66 (6.63)

Note: respondents could indicate more than one reason – numbers indicate total number of times reason indicated.

Complementary to factors helping carers access services are the **barriers** experienced in accessing services (see Table 10). Overall it is noticeable that the presence of barriers is not reported as frequently as sources of assistance. Nevertheless, 11.4% of carers nominate a lack of information as an impediment to access, and 9.45% indicate that the poor quality of the service itself is a barrier to its use. Barriers are clearly a very idiosyncratic issue, however, as 26.5% of carers nominated specific barriers that could not easily be categorised.

The findings above can be usefully integrated with the findings concerning the reasons for not accessing care services provided by family carers who did not use any services at all (see Table 11). The majority of carers, unsurprisingly, indicate that not needing a service is the main reason why a service has not been accessed. However, a quarter of our service non-users indicate that the attitude of the cared-for person is a barrier to accessing services. Furthermore, nearly 10% indicate a lack of knowledge or information is a barrier to their use of service. Thus, a lack of information or knowledge about services is cited by a significant minority of both service-using carers and non-service using carers in our sample as a barrier to access.

Other findings can be added to this emerging pattern of barriers to using services. Carers were asked for the main reason why they had not used services that were needed. The largest proportions of carers (from a sample of 230 respondents) indicated that bureaucratic and complicated procedures (28.3%) or the cared-for's lack of co-operation (27.8%) were the main reasons for not accessing needed services. The third most commonly nominated reason was a lack of knowledge about the service (18.7%).

Table 10:   Significant Barriers to Accessing Services

Barrier	Number (%)
1. Lack of information	113 (11.4)
2. Poor quality of service	94 (9.45)
3. Financial costs	60 (6.03)
4. Bureaucracy	58 (5.83)
5. Elder's resistance	47 (4.72)
6. Availability	20 (2.01)
7. Eligibility	11 (1.11)
8 Physical barriers	8 (0.80)
9. Service scheduling inflexibility	7 (0.70)

Others   264 (26.5)

Note: respondents could indicate more than one reason – numbers indicate total number of times reason indicated.

Similarly, we asked carers to nominate the main reason why they had stopped using a service that was still needed. From a sample of 146 carers, the most commonly cited reason was that the service was no longer available (27.4%), followed by the service being of low quality (22.6%). A lack of co-operation by the cared-for once again nominated by a significant minority of carers (15.1%).

Table 11:   Non-service Users (n=192) Reasons for Not Accessing Services

Reason	Number (%)
1. Services not needed	132 (68.8)
2. Attitudes of Elder or Carer	48 (25.0)
3. Lack knowledge or information	19 (9.90)
4. Financial barriers	11 (5.73)
5. No availability	7 (3.65)
6. Poor quality	6 (3.13)
7 Physical barriers	3 (1.56)
8 Not eligible	2 (1.04)
Other reasons	29 (15.1)

Note: respondents could indicate more than one reason – numbers indicate total number of times reason indicated.

6.2.2.3 Carers preferences for types of support and characteristics of services

Carers were provided with two lists, one of types of support and one of characteristics of services. We asked carers to indicate the level of importance of each type of support and each service characteristic. The results are shown in Tables 12 and 13.

The types of support which the highest proportion of carers indicated to be very important (Table 12) related to information needs, both in terms of information on the availability of help (76.6%) and information relating to the cared-for's condition (66.5%). Next came types of support relating to the cared-for older person's needs, in terms of support for activities (62.9%) and environmental enhancement (62.5%). Over half of our carers also rated as very important sup-

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port that helps plan future care (60.2%), and support that provides opportunities, either to have a holiday or take a break from caring (59.3%), to enjoy activities outside of caring (57.9%), or to spend more time with one's family (55.0%).

The characteristics of services which the highest proportion of carers indicated to be very important (Table 13) related to their effect on the well-being of the cared-for older person, including the capacity to treat the older person with dignity and respect (91.0%) and improve the older person's quality of life (87.9). The next set of characteristics that the highest proportion of carers rated as very important concerned the timeliness of the service, both in terms of when it is needed (85.7) and its reliability (84.9). The quality of the service provider's skills was another important characteristic (81.7%), and more than three-quarter of carers rated as very important characteristics that related to the treatment of the carer by the service provider, including the characteristic of treating the carer with dignity and respect (79.2) and that of taking account of the carer's views and opinions (78.7)

6.2.2.4   Are carers' preferences for support types and service characteristics being met?

Using the same lists of types of support and service characteristics, we asked carers to indicate for those types of support and service characteristics which they rated as very important, whether this preference was being met by their current service provision.

Table 12:   Carers rating different types of support as 'very important'.

Type of support	n, (%)
Information/advice on type and accessibility of help & support	988 (76.6)
Information about the disease that the older person has	982 (66.5)
Opportunities for the older person to undertake activities they enjoy	974 (62.9)
Help to make older person's environment more suitable for caring	978 (62.5)
Help with planning future care	974 (60.2)
Opportunities to have a holiday or take a break from caring	976 (59.3)
Opportunities to enjoy activities outside of caring	979 (57.9)
Opportunities to spend more time with their family	827 (55.0)
The possibility to combine care giving with paid employment	672 (48.5)
Opportunity to talk over their problems as a carer	981 (46.9)

More money to help provide things I need to give good care	977 (39.8)
Training to help family carers develop the skills they need to care	973 (34.0)
Help to deal with family disagreements	566 (31.6)
Opportunities to attend a carer support group	976 (29.0)

Note: n refers to number of valid responses to each item

With regard to carers preferences for types of support, the highest proportion of carers indicated that their preferences were not being met for: 'more money to help provide things I need to give good care (n=272, 72.0%); 'training to help me develop the skills I need to care (n=192, 60.6%); 'opportunities to attend a carer support group' (n=164, 58.4%); 'help with planning for the future care' (n=322, 56.7%); 'help to deal with family arrangements' (n=100, 56.5%); and 'the opportunity talk over my problems as a carer (n=225, 50.0%).

Table 13: Carers rating different characteristics of services as 'very important'

Characteristic of Service	n, %
Care workers treat older person with dignity and respect	984 (91.0)
The help provided improves the quality of life of the older person	987 (87.9)
Help is available at the time they need it most	990 (85.7)
Help arrives at the time it is promised	983 (84.9)
Care workers have the skills and training they require	987 (81.7)
Care workers treat carers with dignity and respect	983 (79.2)
Carer's views and opinions are listened to	987 (78.7)
The help provided is not too expensive	982 (71.1)
The help provided improves the carers' quality of life	977 (68.9)
Help is provided by the same care worker each time	978 (65.4)
The help provided fits in with the carer's own routines	986 (64.6)

Help focuses on the carer's needs as well as those of the older person	981 (58.8)

Note: n refers to number of valid responses to each item

With regard to carers preferences for characteristics of services, the highest proportion of carers indicated that their preferences were not being met for: 'help that focuses on your needs as well as those of elder' (n=145, 37.1%); 'help provided is not too expensive' (n=140, 30.6%); 'help is provided by the same care worker each time' (n=123, 30.6%); 'help is available at the time you need it most' (n=198, 30.0%), 'care workers have the skills and training required' (n=143, 27.3%); 'help arrives at the time it is promised' (n=161, 26.9%); and 'the help provided improves your quality of life' (n=126, 25.2%).

7 Findings (3): Preliminary analysis of the Follow-Up Study

7.1 Background and Method

The Follow-Up (FU; Time 2) study was carried out approximately 12 months after the main study (MS; Time 1) plus/minus one month of tolerance, between December 2004 and July 2005 (see Section 3 for details regarding the CAT-FU instrument used in the FU study). The aim of the FU study was to resurvey all caregivers originally interviewed in the baseline study (except for those who had expressed a preference in the MS not to be contacted again.

The FU study was carried out using the CAT-FU, which distinguished "former carers" (i.e. those who had given up caring for different reasons, e.g. older person's death, etc.), from those family carers still caring for the same older relative. Former carers were asked to complete a short version of the CAT-FU. Those still caring were administered the full CAT-FU.

From our initial sample, 722 (72.6%) carers indicated a willingness to be recontacted for the follow-up study. Of these carers, 102 carers completed the short CAT-FU and 214 completed the full CAT-FU, a total of 316 (43.8% response rate). The main mode of re-survey for the FU study was by post, with 277 (87.7%) of carers receiving and completing the questionnaire at home and returning it to the project centre by post. The remaining 39 (12.3%) carers were interviewed by phone, with the researcher completing the questionnaire on the carer's behalf. Carers were re-surveyed on average 368.5 days (SD=49.1) after their initial interview.

7.2 Findings

7.2.1 Withdrawal from care role

Of the 316 carers in our FU study, 104 (32.9%) were no longer caring for the same older person as at T1. Fifty seven (18.0%) carers' cared-for older person had died since T1, 18 (5.7%) carers' cared-for had entered institutional care, while 14 (4.4%) carers' care recipient was now being cared for by another family member or professional carer (n=15, 4.8% missing data). As would be anticipated, the cared-for person's mortality was associated with greater age, higher levels of dependency, and cognitive impairment in the older person at T1. Similarly, institutionalisation of the cared for was particularly associated with higher levels of dependency and

higher levels of cognitive impairment in the older person, and with the carer being non-working, experiencing higher levels of negative impact of care, and being in better health at T1.

7.2.2 Changes in care-recipient characteristics among 'still caring' carers

There was relatively little change in the dependency level of the cared-for person in caregiving situations where the carer was still providing care. While 68 (34.7%) carers reported an increase in the number of ADLs that their cared-for was unable to perform without help or at all, this only corresponded to an average decrease of 2.9 points on the 0-100 Barthel scale. Similarly, very few cared-for older people demonstrated the emergence of memory problems (n=19, 9.1%) between T1 and T2; indeed, there were more cases reported of memory problems diminishing (n=32, 15.4%). Nevertheless, a substantial number of cared-for older people had worse behavioural problems at T2 than at T1 (n=98, 48.3%).

7.2.3 Changes in caregiving characteristics among 'still caring' carers

Those carers still providing care to the same care-recipient as in the main study were, on average, providing slightly less care than at T1 (-9.5 hours care per week), although there was considerable variation across carers. The vast majority of carers and cared-for (n=198, 95.2%) had not changed their co-habitation status since T1. Similarly, carers' occupational status was for the vast majority unchanged (189, 92.2%), although of those carers working at both T1 and T2, 11 (22.9%) had reduced their work hours between T1 and T2 due to their caregiving commitments. Proportionately fewer carers at T2 in comparison to T1 indicated that they could easily find someone to help out if they needed a break from caregiving (T1, 44.5%; T2, 23.6%), while the majority of carers recorded a higher score on the COPE Index Negative Impact scale (110, 61.8%) and a lower score on the COPE Index Positive Value scale (n=104, 53.9%) at T2 than T1. Carers' health status at T2 relative to T1 also demonstrates a decline, with 61 (29.5%) having worse health status at T2. Finally, there is also a decline in carers' willingness to maintain their caring role between T1 and T2, with 66 (36.9%) carers recording lower levels of willingness at T2.

The level of service use is unchanged for 96 (46.4%) of carers, with 99 (47.8%) indicating a greater level of service use than at T1 and only 11 (5.31%) a decrease in service level use. Initial analyses suggest that variability in level of service use between T1 and T2 is unrelated to change in carer outcomes (quality of life, health status, negative impact ad/or positive value of caregiving).

7.2.4 Comment on findings

While these absolute changes from T1 to T2 in the cared-for and carer are interesting in themselves, further analysis is needed to determine their statistical reliability. Furthermore, there are differences in the demographic characteristics between our T1 and T2 samples, meaning that comparison of the two samples on any variable is problematic unless such T1-T2 differences are also accounted for in the analyses. Further work is needed to reveal the true value of the data collected in the FU study.

8   Conclusions: Where to from here?

Notwithstanding the limitations of the sample the results of the NASURE provide a number of important insights, especially with respect to carers' use of services and the factors that help to

shape the quality and acceptability of support. These results have been fed-back to key stake-holder groups (carers, carer organisations, policy makers, practitioners) in a series of REACT (Research Action) events. Their perceptions are presently being distilled in order to produce a user friendly summary and overview of the main messages to arise from the UK EUROFA-CARE study. This is currently being developed for widespread dissemination.

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9   Appendices

9.1   Categories of care services in the EUROFAMCARE countries used by carers

SERVICES USED BY FAMILY CARERS	
1. Specific support services for family carers	1.1 Socio-emotional support (counselling, social work, family support or self help groups, crisis management)
	1.2 Respite care (including supervision of elder)
	1.3 Information (about the disease, caring, available services and benefits, Help lines, Internet services etc.)
	1.4 Training for caring
	1.5 Assessment of caring situation
	1.6 Other specific services for carers
2. Generic services used by family carers	**2.1 General hospital (acute care)**
	2.2 General Practitioner (GP)
	2.3 Specialist doctor
	2.4 Other generic services used by carers

9.2 Categories of care services in the EUROFAMCARE countries used by cared-for older person.

SERVICES USED BY ELDER (classified accordingly to the needs covered)		
3. health care needs	3.1 General hospital (acute care)	
	3.2 Temporary residential health (not acute) care (Rehabilitation, Medical, Nursing)	
	3.3. Medical and nursing services	3.3.1 <u>Ambulatory</u> services (nurse, GP, medical specialists, diagnostic tests; day hospital; integrated assessment of elderly people etc.)
		3.3.2 <u>Home based</u> services (doctor at home, medical specialists at home, nurse at home, diagnostic tests at home, chiropodist, palliative care at home etc.)
	3.4 Rehabilitation services	3.4.1 <u>Ambulatory</u> services (physiotherapy, occupational therapy)
		3.4.2 <u>Home based</u> services (physiotherapy at home, occupational therapy at home etc.)
4. physical or personal care needs	**4.1 <u>Home based</u> personal care (bathing, toileting, hairdressing, nail care etc.)**	
	4.2 Cohabiting/co-resident non-family (paid) carer	
	4.3 Privately paid non-family carer in temporary residential settings or in hospital	
5. mobility needs	5.1 Transport services	
6. emotional, psychological or social needs	6.1 Emotional, psychological or social support service	6.1.1<u>Ambulatory services</u> (counselling, psychologist, recreational social centre etc.)
		6.1.2 <u>Home based</u> services (companionship, care attendant, respite care at home, counselling, help lines etc.)
7. Organizing and managing care and support	7.1 Organizational support services	7.1.1 Ambulatory social work (help in organising care etc.)
		7.1.2. Home based social work (visits at home etc.)
8. domestic care	8.1. <u>Home based</u> services: Domestic (help with cooking, cleaning, shopping, laundry, meals on wheels etc)	
9. residential and semi-residential care	**9.1 Permanent Residential Care (nursing homes, sheltered housing, old people's home, psycho-geriatric residences, palliative care hospices etc.)**	
	9.2 Temporary residential care of social kind only (respite care etc.)	
	9.3 Day care centre with either health and social care purposes or both	
10. other kinds of care	**10.1 Technical equipment/ aids/home environment adaptation (telemedicine, stair lifts, security systems etc.)**	
	10.2 Other services used by elderly people	

9.3 Categories of care allowances in the EUROFAMCARE countries.

CARE ALLOWANCES		
11. financial support to older person	11.1 Disability-related allowance to older person	
	11.2 Care allowances to elder	11.2.1 Care allowance to older person from national state/social insurance
		11.2.2 Care allowance to older person from local authorities
	11.3 other financial (fiscal etc.) benefits to older person	
12. financial support to carer	11.4 Care allowances to carer	11.4.1 Care allowance to carer from a national, state, or social insurance scheme
		11.4.2 care allowance to carer from local authorities
	11.5. other financial (fiscal etc.) benefits to carer	