HOME CARE IN WALES · VIEWS AND EXPERIENCES OF OLDER PEOPLE

Report of Findings

for Older People's Commissioner for Wales

Welsh Institute for Health and Social Care · University of Glamorgan

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Sefydliad Iechyd a Gofal Cymdeithasol

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We should like to acknowledge the contribution of older people across Wales (and their carers, families and care workers who supported them) who took the opportunity to provide us with their views and experiences, without which this project would not have been possible. Thanks are also due to the local authorities who offered to take part in the study and to facilitate the distribution of questionnaires.

The report uses a range of analytical techniques – both quantitative and qualitative – to comprehend the different sources of data gathered during the course of the study. These findings are based on our understanding of the evidence presented to us by respondents and any errors of interpretation are solely due to the authors. We trust that this independent analysis will help the OPCW with its ongoing work programme.

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1 · INTRODUCTION

The Welsh Institute for Health and Social Care (WIHSC), University of Glamorgan was commissioned by the Older People's Commissioner for Wales (OPCW) to undertake a study to gather data on what to date has been a somewhat under-researched group. There were essentially three key objectives, namely to:

1. Review the academic literature on home care and older people in the UK;
2. Analyse returns from an 'open call' for information, which was issued by OPCW in the Summer of 2011; and
3. Design, issue and analyse a postal questionnaire (distributed in January 2012) to older people in receipt of home care across four sample local authorities in Wales.

This report is an account of the experiences of older people in Wales who gave their views to us. The structure of the following sections mirrors that of the approach as described above. There are, therefore, three substantive chapters, each of which reports evidence from different sources of data.

It should be noted that in the sections that follow, older people have given us their views about their care workers as they were asked to. However the terminology they have used to describe them has not been consistent. For example instead of describing the professionals who support them at home as 'care workers' at times they have called them 'carers', a term typically reserved for unpaid carers, normally partners, family or friends. As such, and following convention, when people have used the term 'carer' to mean 'care worker', the designation [*sic*][1] follows it. This way we have deliberately preserved the integrity of the words they have used, but denoted where the term has been used incorrectly.

1.1 KEY FACTS ABOUT HOME CARE IN WALES[2]

1.1.1 Service users in Wales

The National Statistics First Release (Statistics for Wales, 2010; see also Statistics for Wales, 2011) summarises information on assessments and social services provided to people aged 18 and over by Welsh local authorities or on their behalf by commissioned

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[1] The Latin adverb *sic* added immediately after a quoted word or phrase, indicates that the quoted words have been transcribed exactly as spelled or presented in the original source, complete with any erroneous spelling or other presentation. The usual purpose is to inform the reader that any errors or apparent errors in the transcribed material do not arise from transcription errors, and the errors have been repeated intentionally, i.e. that they are reproduced exactly as set-down by the original writer.

[2] Much greater detail on some of these data can be found in Tables A.1-A.3 in Appendix I.

independent (private and/or third sector) agencies. The latest release presented key results for Wales for the period 1st April 2009 to 31st March 2010:[3]

- During a sample week in September 2009, 22,900 people received home care. This is a fall of 3 per cent compared to the previous year, with the largest decrease in the number of people receiving less than 5 hours of care.
- During the whole of 2009-10, 25,253 people received home care;
- The total amount of home care commissioned by local authorities in 2009-10 was 11.2 million hours, a decrease of 3% when compared with 2008-09;
- The proportion provided by independent providers under contract to local authorities increased from 61% in 2009-10 to 68% in 2010-11 – the remaining 32% was directly provided by the public sector; and
- The proportion of local authority direct provision and independent sector provision varies tremendously – the largest proportion of local authority direct provision is 80% in Anglesey, with the lowest at 10% in Cardiff.

1.1.2 Home care providers

On 31st March 2009 there were a total of 354 domiciliary care agencies registered with the Care and Social Services Inspectorate Wales (CSSIW) compared to 340 in the previous year which represents a 4% increase in agencies (CSSIW, 2009). There has been an increase in the number of domiciliary care agencies providing in excess of 200 hours personal care per week. Overall, CSSIW believes there is evidence that the regulations and national minimum standards are firmly embedded in practice.

1.1.3 Local authority employed workers

There is quite a lot of data available on the local authority home care workforce. Key data at 31st March 2010 include the following:

- The total whole-time equivalent (WTE) number of staff directly employed by social services departments was 20,125, a slight decrease from the previous year;
- Home care staff represented 21% of the WTE of the social services workforce. The largest number of part-time staff work in the provision of home care, where there were 7,003 staff of whom 5,841 were part-time;
- The overall number of home care staff holding a required or recommended qualification was 4,210 (60%) compared to 4,026 (55%) in the previous year; and
- 18% of home care staff are reported as Welsh speakers, and able to conduct their work through the medium of Welsh – but this figure varies considerably by location.

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[3] The one exception to this is the figure for the total number of hours of care provided which has been taken from the 2010-11 data set which is available on StatsWales: http://statswales.org.uk

1.1.4 Independent sector employed workers

The United Kingdom Home Care Association (UKHCA) is the representative association for organisations that provide domiciliary care, home nursing and allied services. In its recent 'Overview of the Domiciliary Care Sector' (UKHCA, 2012) it notes that 'in 2001 there were an estimated 6,000 homecare workers in the independent sector' and that 'since then very little information has been collected on the independent sector homecare workforce in Wales'.[4] Based on this data, on the change in the proportion of care delivered by the independent sector since 2001, and on the proportion of staff to hours of care delivered it is possible to extrapolate the numbers of workers in the independent sector to around 9,000 – giving an estimated total of c.16,000 home care workers in Wales, across independent and public sector agencies.[5]

1.1.5 Unpaid carers

The 2001 Census collected information regarding the numbers of carers in the UK and the amount of caring they do for the first time. Based on returns, Carers UK recorded that there are nearly 6 million carers in the UK, with 340,745 in Wales – equivalent to 11% of the Welsh population. It is possible to analyse these figures and make an evidence-based judgement about the proportion of care in Wales that is paid for, and the amount that is unpaid provided by carers. Subject to a number of caveats but based on these data and using the most conservative estimates (i.e. the minimum values in the range) the analysis[6] shows that at least 288.5 million hours of care were provided by unpaid carers in Wales in 2001. When compared with the most recent data that 11.2 million annual hours were provided by local authorities (including services commissioned and delivered by others), this demonstrates that a hugely significant minimum of 96% of annual care hours in Wales are provided by unpaid carers, with the remainder provided by local authorities and independent providers. This is a much greater proportion than reported in 'Fulfilled Lives, Supportive Communities' which states that 'at least seventy per cent of the care for vulnerable people is provided by family, friends and neighbours'.

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[4] They cite the following report as evidence of the estimate figure, but note that the document is not available to download: UKHCA, CCETWS and TOPSS (2001) *Next steps: non-statutory domiciliary care providers in Wales, main findings*

[5] This figure needs to treated with extreme caution as we cannot be at all certain about the assumptions on which it is based.

[6] For details of the calculation see Tables A5.7, A5.8 and A5.9 in Llewellyn et al (2010).

2 · LITERATURE REVIEW

2.1 PREAMBLE

In order to inform the project, a review of the academic literature on older people and home care in the UK was proposed. This literature review retrieved published literature from a number of electronic bibliographic databases including CINAHL PLUS, Applied Social Sciences Index and Abstracts (ASSIA), and Science Direct.[7] Each published research database was searched using a range of key terms, such as," homecare"; "personal care"; "home help"; "domiciliary care"; "in-home care"; "home support". The search output was screened for studies of home care service provision for older people in the UK, and from an initial 81 papers (see Appendix II), 46 were selected for detailed review (see Appendix III for references).

2.2 ROLE, PURPOSE AND IMPACT OF HOME CARE

Home care encompasses activities which represent the whole spectrum of care provision from primary prevention to end-of-life palliative care (Thome et al. 2003). There are a range of home care activities which might be referred to as 'mainstream' home care services – these provide practical assistance with personal care (i.e. help with washing, dressing, etc) and essential domestic tasks. Primary prevention home care activities could involve home visits by general practice based teams or psycho-educative interventions aimed at risk prevention and self-care activities (Elkan, 2001; Hallberg and Kristensson, 2004). Home care re-ablement services are increasingly being implemented as part of a preventative and rehabilitation strategy for older people's services (Rabiee and Glendinning 2011). There is a growing body of UK research on the role of the home care worker in palliative home care provision and on the policy and practical challenges of care provision in this setting (Gott et al. 2004; Devlin and McIlfatrick, 2009; Devlin and McIlfatrick, 2010; Rolls et al. 2011; Ingleton et al. 2004; Ingleton et al. 2011). There are also specialist home care services for client groups with particular health needs, such as those with dementia (Whitby et al. 1990; Venables et al. 2006; Rothera al. 2008).

Home is a place of great significance for older people as it has emotional and physical ties from which comfort and pleasure may be derived (Genet, 2011). Thus, 'ageing in place' strategies support the preferences of many older clients with health and social care needs who wish to remain at home rather than be admitted to institutional care. The goal of home care is viewed positively for the perceived physical, emotional and psychological benefits accruing to clients in terms of maximising independence and functional health status, maintaining social and cognitive abilities and optimising quality

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[7] There is an extensive grey literature on these issues – for example see Llewellyn et al (2010) and SSIA (2011). These documents were not formally searched as part of this review.

of life. However, Godfrey et al (2001) examined the impact of home care services on several outcomes including client physical functioning and psychological well-being and found inconclusive evidence to substantiate the proposition that such positive outcomes accrue to recipients of home care services (cited in Venables et al. 2006). Several studies attest to the fact that home care facilitates older people to remain in the community for longer postponing or reducing permanent institutionalisation (Pickard, 2004). A meta analysis conducted by Jensen (1997) found that home care service provision had a positive effect through reduction in mortality rates, hospital admission rates, length of stay in hospital and admission to nursing homes (cited in Thome et al. 2003).

There has been substantial growth in the provision of home care by the independent sector in the past decade. However, there is little evidence to substantiate the theoretical proposition that the quasi-marketisation of home care in the UK offers more consumer choice or delivers more flexible, individualised care (Scourfield, 2006). A feature of home care provision in the UK is a poorly regulated private market (Genet, 2011). There is some evidence of less satisfaction among home care clients in receipt of independently provided home care. A national survey conducted in 2003 found lower levels of satisfaction and perceptions of quality of home care amongst older users of independent providers compared with in-house providers (Netten et al. 2007). Netten et al's study (2007) of 121 homecare service providers in England found that characteristics significantly associated with positive perceptions of service quality were more prevalent in in-house providers; these related to an older, more experienced workforce, no perceived difficulty with staff turnover and allowance of 10 or more minutes travel time between visits. However, an evaluation of home care services provided to older residents in Luton found that there was no perceptible difference in clients' satisfaction between in-house and private agency care (Durand and Jowett, 2001). Contracting arrangements and the recruitment and retention of staff have implications for the stability and sustainability of independent care agencies in the market and impacts on their ability to provide flexible, quality care. A single provider with a larger pool of resources has more capacity than multiple smaller providers with limited resources to offer a range of choice to consumers but the potential to deliver a less 'personal' service (Scourfield, 2006).

There is some evidence to suggest that care provision for older people in the home falls short of quality standards. Bos et al. (2007) investigated variations in the quality of home care provision between sites across Europe, including England, as measured by Home Care Quality Indicators (HCQIs). The 16 quality indicators measured the prevalence of unwanted home care practices or outcomes[8]. On eight HCQIs, England performed average or better than average, however, overall, English home care organisations

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[8] Prevalence of neglect or abuse, inadequate meals, social isolation, no assistive device among clients with difficult locomotion, inadequate control among those with pain, ADL/rehabilitation potential and no therapies, weight loss, not receiving flu vaccine in last 2 years, hospitalisation, injuries, delirium, negative mood, disruptive or intense daily pain, no medication review by at least one physician, and falls.

together with the home care providers in the Czech Republic, Italy and Germany, ranked among the top four countries for the highest prevalence of unwanted outcomes. The ranking calculation is, however, somewhat crude and none of the countries surveyed performed consistently best or worst.

Deficiencies in home care provision can mean that alternative care options can actually facilitate a greater level of independence. A study by Boyle (2004, cited in Thetford and Robinson, 2006) found that older people living in institutional care reported perceiving greater autonomy in their everyday lives compared to older people in receipt of home care services. Lack of home care provision for people requiring 24 hour care or overnight care and feeling socially isolated or unsafe in one's home were some of the decisive factors that older people in Flintshire cited as reasons for considering alternative long-term care provision options (Thetford and Robinson, 2006).

Outcomes-focused services are at an embryonic stage in adult social care and currently largely absent from mainstream home care services (Glendinning et al. 2008). There is mixed evidence about the beneficial outcomes of home care to older people's well-being and mixed satisfaction with how the service is implemented in practice. So while home care is a potentially advantageous long-term care option, evidence about how the best outcomes might be produced is still lacking (Venables et al. 2006).

2.3 HOME CARE FOR THOSE WITH CHALLENGING NEEDS

The specific needs of a growing number of older people in Wales who have dementia present significant challenges to commissioners of adult social care. Current provision for this client group in Wales is strongly reliant on specialist residential care but new models of community-based care practice include dementia care as part of re-ablement services and specialist dementia home care teams. Some studies have evaluated the effectiveness of specialist home care provision for older clients with dementia compared to standard home care services. Service users, family carers, care workers and other professionals in Nottingham perceived that the specialist service was more adept at providing person-centred, flexible and responsive care compared to the standard service. Factors identified as instrumental to its success included the prevailing philosophy of care, specialist dementia training for staff, tasks not being bound by time constraints, regular reviews, close multiagency working, capacity to develop long-term relationships with clients and caseworker continuity and autonomy (Rothera et al. 2008).

For older people living in rural or remote areas, provision of community-based health and social care services is challenged by diseconomies of scale, travel costs and a lack of provider options and staff (King and Farmer, 2009). Lack of public transport hinders not only older people themselves but also their families and friends, making it difficult to maintain social networks and supports, exposing them to a greater risk of social isolation (Thetford and Robinson, 2006). Conversely, they may benefit from some of the features believed to be associated with rural areas, including support networks, family support and a culture of reciprocity (King and Farmer, 2009).

Research with older people from ethnic minority communities shows that there is a lack of awareness among some communities about home care services and a reliance on family rather than social services to provide home support (Temple et al. 2002; Raynes et al. 2001). In a study involving independent agency care workers in Wales, the lack of culturally appropriate information was cited as a problem for providing home care to ethnic minority groups (Cooper and Urquhart, 2008).

For older lesbian, gay, bisexual, and transgender (LGBT) clients who may fear experiencing isolation and discrimination, and may feel unable to be open in heteronormative care systems, there is an imperative that they be included as stakeholders in the commissioning and planning of long term care services, standards and procedures in order to ensure that their preferences are promoted and respected. Direct payments may be a desirable means for older LGBT clients to access home care services as they could seek home care support from care workers within their own community (Concannon, 2009).

2.4 WHAT OUTCOMES/PROCESSES ARE IMPORTANT TO OLDER HOME CARE SERVICE USERS?

Performance indicators should reflect key dimensions of quality services from the user perspective (Francis and Netten, 2004). Perceptions of quality of life, meanings of concepts relating to ‘choice’, ‘independence’ and ‘control’ and what constitutes satisfactory care outcomes vary enormously among older clients (Thetford and Robinson, 2006). For example, the views of older people who are ‘homebound’ on the most important attributes of the quality of home care services may differ from other homecare recipients (Raynes et al. 2004). For older people who are located in remote, rural areas, traditional, local models of service provision that emphasise the personal, social and local aspects of care provision are generally preferred (King and Farmer, 2009). The need to include a variety of client groups with diverse circumstances and needs in the consultation and planning processes about home care services has been highlighted in the literature. These groups include those with dementia, BME older people, LGBT older people, rural-dwelling older people as well as those with learning difficulties, sensory deprivation, and the oldest old (Durand and Jowett, 2001). Because the vagaries of individual circumstances and preferences need to be taken into account, an individual centred approach to quality may be preferable to a common set of quality standards as it may promote more flexible and responsive care and greater choice and relevance for the service user (Patmore, 2001).

There are also many important aspects of quality in home care services that older recipients have repeatedly identified. These relate to the reliability, competence and attitudes of the staff and the importance of getting on well with staff (Francis and Netten, 2004; Raynes et al. 2004). King and Farmer's study (2009) highlighted the importance of having intimate care provided by those who are perceived to have the appropriate professional qualifications and statuses. However, Francis and Netten's study (2004) showed that older service users did not evaluate staff in terms of their professional training and skills but rather rated them based on their motivation and experience. Older service users in Ryan et al's study (2009) identified what they perceived to be positive and negative attributes of home care workers. The attributes of a 'good care assistant' included someone who was friendly and talkative, willing to do anything, flexible, experienced, skilled, reliable, hard working, spends time and also is someone with whom they were familiar.

Older service users in receipt of home care elsewhere generally gave a positive evaluation of their home care workers and organisational aspects of the service. However, concerns were expressed regarding the perceived unreliability of some care workers, of some seeming rushed and of a lack of information provision. A significant number of clients experienced care workers not arriving on time, not being informed if care workers were going to be late, if they could not come or if they were going to be replaced by other staff. A minority of participants refrained from complaining about a service and reasons cited were not wanting to 'take the blame' or feeling that their complaints were not worth bothering about (Durand and Jowett, 2001).

Other valued attributes of home care services relate to the continuity of care, the flexibility of the service, the provision of clear information and communication about changes, service users' preferences being understood so that they retain control over the services they receive and also help with miscellaneous household problems like house-cleaning (Francis and Netten, 2004; Raynes et al. 2004, Patmore, 2004). Although older people from BME communities share many of the same perspectives as older people generally on important aspects of quality home care services, they also identify community specific concerns relating to the provision of appropriate food, access to services and the provision of ethnic specific services and staff, the latter being particularly important among older Chinese people (Temple et al. 2002; Raynes et al. 2001).

Home care services tend to overlook social and quality of life outcomes that are often highly desirable to older people in favour of physical maintenance goals (Glendinning et al. 2008). In contrast to holistic services commissioned for younger clients, care management commissioned services for older people tend to aim to facilitate survival rather than enhance quality of life or boost morale (Patmore, 2004). The perspective adopted by older people on quality of home care services tends to be more holistic than the professional perspective in that evaluations of the quality of services is determined on the basis of not only the services received within the home but the extent to which they enable them in their lives outside of the home (Raynes et al. 2004). The holistic approach supports clients not only with their physical needs and survival but also with their emotional and mental well-being as the two are inextricably linked (Patmore, 2006).

In interviews with older home care clients, aspects of daily living which elicited the greatest dissatisfaction were 'getting out of the house', 'social life', and 'sources of interest in everyday life' (Patmore, 2002a). A study by Clark et al (1998) showed that many older women's morale was affected by the appearance of their home (cited in Patmore, 2002a). Valued interactions and relationships is an important dimension of quality of life for older people. The need for company and the need to be occupied have also been identified by older home care clients as part of quality home care provision (Temple et al. 2002). For example, an evaluation of a pilot hospital aftercare social rehabilitation project delivered by the voluntary sector to older clients in their homes found that clients valued the friendships they developed with care workers (McLeod et al. 2008).

Service provision strategies for improving older people's independence should aim to adopt a more rounded concept of independence that extends beyond non-reliance on others to include self-esteem, autonomy, self-identity and social roles (Thetford and Robinson, 2006). A potentially relevant framework for best practice care for older people has been conceived by Nolan et al. (2006). The 'senses framework' is founded on the belief that older people should derive a sense of security, belonging, continuity, purpose, achievement and significance from their care environment.

Further, home care service interventions should address some of the factors that contribute to low morale and depression among older frail community-dwelling adults and also aim to treat depression (Patmore, 2002a). From the studies that Patmore (2006) has conducted with both older home care clients and home care providers, he identifies four overarching principles needed to inform the delivery of holistic, person-centred care. These are: flexibility to use care time as a customer chooses; time commissioned for excursions and companionship for selected customers; provision of assistance to older people to buy valued services privately and enthusiasm for older people's well-being.

2.5 VOICE

Increasingly, service user voice, being listened to, having a say, and self-determination are considered fundamental elements in the organisation and delivery of services in Europe (Tarricone and Tsouros, 2008). A systematic review of the literature on home care in Europe identified individualised care and consumer choice as cornerstones of policy development in the UK (Genet et al, 2011). However, service user input into the design, delivery and evaluation of health and social care services has often been secondary to the perspectives and priorities identified by professionals (Raynes et al. 2004; Thetford and Robinson, 2006).

In respect of home care, it is increasingly being recognised that for service provision to be responsive to the needs and desires of older people who utilise them, older people must actively participate in shaping the evaluation of processes and outcomes as they relate to the quality of services and also be involved in informing the delivery and monitoring of home care services (Raynes et al. 2004). Disparities exist between what older service users desire from services and what service providers think they desire (King and Farmer, 2009). Inadequate care decision-making processes mean that professional perspectives are afforded greater precedence due to their perceived specialist knowledge about care needs and risks, while clients have limited knowledge of the processes by which decisions regarding their care are made (Thetford and Robinson, 2006). Professional priorities often relate to the safety and survival of older services users while quality of life, which is of paramount importance to older people may be afforded a cursory consideration (Patmore, 2002b). The prioritisation of risk minimisation, particularly among health service providers rather than social service providers, leads to a paternalistic decision-making approach. It has been found that service users are actually more willing to accept risk if it means having the services that they desire (Thetford and Robinson, 2006). Thus, older people's insights into their own care needs during the assessment period is essential to avoid inappropriate care plans being devised and to avoid older users' perspectives being displaced in favour of professional determinations of what constitutes 'need' (Thetford and Robinson, 2006). The absence of a permissible and manageable level of risk within the home and inflexible care provision arrangements can be barriers to choice for community dwelling older adults.

One of the most important aspects of service delivery for older people within their homes is that they determine what services they need (McLeod, 2008). A study by Patmore (2001) found that clients' preferences and priorities for home care were highly individualised and that there were also a significant number who did not identify any specific preference or priority. Low decision-making autonomy has been found in a study of home care clients in Belfast (Boyle, 2004).

While assessment procedures should give due regard to individuals' preferences and values, what these are may be contested and revised in light of what is practical and achievable (Patmore, 2002b). Thetford and Robinson (2006) suggest that the financial and resource constraints that operate within adult social care, effectively serve to limit choice, making it notional and unattainable in practice. Hardy et al. (1999) examined the extent to which choice over a range of services was offered to home care clients during the assessment and care management process in four local authority areas in England. The authors conclude that while the home care market has an increased choice of providers and an increasingly wider range of services on offer, budgetary restrictions stifle choice at an operational level as decisions are made to restrict care to those in the highest level of need category and to reduce the overall cost of care packages. Irrespective of resource constraints, the authors believe that there are a number of improvements to user and unpaid carer choice that can be implemented. These include the provision of better quality and more timely information, pro-active monitoring and review procedures which anticipate changing needs and choices, and better coordination between agencies and professionals so that procedures are more transparent to those being assessed.

2.6 COMMUNICATION

Information seeking, exchange and provision are vital, time-consuming and continuous tasks in home care provision. In order for home care clients to experience continuity and quality in the services they receive, frontline staff must coordinate their provision of care by liaising with other health professionals and management personnel (Cooper and Urquhart, 2005).

Record-keeping is an important mechanism in ensuring good practice in individual centred approaches to quality home care and coordination of care. This includes recording individual preferences for care, briefing staff on the implementation of requests and monitoring their implementation in home records. Patmore suggests that it is good practice to record all requests, irrespective of whether requests are outside the remit of the provider's practices as it could inform service development or could be referred to care management for further consideration (Patmore, 2001).

A study of independent agency home care workers, care managers and unpaid carers in a home care setting in Wales examined both formal and informal processes of information collection and exchange and identified a number of barriers to formal record keeping. Care workers were found to divulge information selectively, and in a piecemeal and untimely fashion using informal information exchange mechanisms (e.g. post-its, 'scraps', chance meetings outside of work). Also, because client needs are in a state of constant flux and because knowledge about clients is dynamic, and relies on interpretation and familiarity, they found that information cannot be easily articulated or recorded (Cooper and Urquhart, 2008).

Home care clients, particularly those without proactive family members, are often dependent on care workers for assistance with accessing and processing information (Cooper and Urquhart, 2005). Thus, care workers have a pivotal role to play in providing information to home care clients about useful services and entitlements, especially for isolated older people without family and friends around them for whom daily visits from a care worker represents their main contact with the 'outside world'. Unpaid carers also require informational support from home care workers to negotiate the care management process (Ryan et al. 2009). Home care workers often require information on health conditions, the side effects of drugs, health and social care issues, financial support, burial customs for ethnic minority members and specialist food suppliers. Most common sources of information sought by home care workers were from trusted colleagues, leaflets from their agencies, GP surgeries, post offices or hospitals, the yellow pages, personal directories, or care-services directories while few homecare workers used public libraries, NHS Direct or the internet to source information (Cooper and Urquhart, 2005). The extent to which care workers can provide information on services to clients depends on the provider's rules about doing so and whether they allow their staff any flexibility in this matter (Patmore, 2004).

2.7 CONCLUSION

The review of the literature highlights the need for a greater evidence base on the experience of home care and its outcomes for older service users. The limited evidence on such outcomes available to date suggests that an inadequate standard of care is all too often provided to older people living in their own homes.

The literature also underlines outcomes of care which are especially important to older people and which are sometimes overlooked by purchasers and providers of home care services. While physical functioning goals are recognised as important in home care provision, of equal if not greater importance to older people are those things which support them in maintaining their lives and relationships at home, and enhance their emotional and psychological wellbeing. Thus, home care services should place a greater emphasis on meeting service users' expectations of their quality of life.

A person-centred approach to home care has been advocated as one of the principal means to ensure both choice and quality care are delivered to service users, while care assessment and review processes which consult with service users and respect their voice are seen as the most effective way to place individuals at the heart of their care in practice. This approach to care management depends on a range of factors, including commissioning practice and provider arrangements, and a willingness and ability to include service users in decision-making processes thereby offering real choices about the services they can receive.

Older users of home care services desire a service that functions flexibly, reliably and responsively and they demand that care workers are imbued with qualities that include the right skills, knowledge and training combined with a compassionate and friendly approach to providing care. The interplay of these factors influences older people's satisfaction with the care they receive and the literature has highlighted that there is room for improvement in how these processes currently operate.

3 · RESEARCH FINDINGS - OPEN CALL FOR INFORMATION

3.1 INTRODUCTION

In the summer of 2011, OPCW afforded older people in Wales the opportunity to comment on the quality of care that they receive in their own homes in order to establish and encourage good practice in providing such care. Whilst ostensibly an 'open call' for information and experiences, there were five questions specifically asked on the proforma issued:

1. Who provides your care?
2. How would you rate the quality of the care you receive?
3. How are your choices and preferences included in the care that you receive?
4. What is it about your care arrangements that you are happy with?
5. What could be improved?

3.2 INTERPRETING THE FINDINGS

The following sections in this chapter provide a thematic analysis of the data supplied to OPCW. 113 valid responses were received by the Commission and on the basis of the content of responses emergent, the thematic framework was developed. The purpose of the framework was to provide a structure onto which the individual responses could be mapped in order to see how frequently individual themes arose. Without wishing to provide too many methodological details, it is worth noting that the research team read every response and made determinations about what people were saying – as such the framework represents the types of things that people told us.

Broadly speaking the information supplied by older people was either supportive or critical of the home care service received (or was a combination of the two). When feelings were mixed, the more positive comments were coded in that part of the framework, and the negative phrases coded likewise. Some people also pointed to a series of improvements that they identified. There were more negative comments (n=252) coded than positive comments (n=179), although to uncritically accept a raw 'count' of the times that good or less good statements were made would be to misinterpret the data. It would be inappropriate to judge such evidence solely on the numbers of times that individual themes were presented – much more important is to allow the data to 'speak' in terms of the depth of the issues that older people are experiencing and how their quality of life is being supported or otherwise by the home care service provided to them. That said, and in order to see this information in the appropriate context, it is worth considering the data presented in Table 1 below.

Table 1 · Differences in length of positive and negative responses to the ‘open call’

Category	Total number of words coded[9]	Total number of references[9]	Mean number of words per reference
Positively coded data	34,576	179	193.2
Negatively coded data	54,590	252	216.6
TOTAL	**89,166**	**431**	**204.9**

This shows the relationships between how people reported positively and negatively, and demonstrates that when people had something more critical to say, they wrote more about their experiences. Importantly, it does not necessarily imply that people more typically have negative rather than positive (or indeed positive rather than negative) experiences of home care in Wales. What this data does is represent in considerable detail some of the real highs and lows associated with being an older person who has home care services delivered to them. These voices are seldom heard, and the opportunity to provide an insight was taken up freely by more than 100 individuals.

The quotations and comments reproduced in the following pages mirror the structure identified through the coding process which is represented in the thematic framework (Figure 1 below). There are six substantive sections which report the views of older people on: being listened to; knowledge, skills and training; time pressures; continuity of care; quality of care; and assessment and signposting. The data has been deliberately reproduced without further comment, inference or interpretation, so that the reader can see for themselves the range of issues identified with as little by way of interpretation as possible. Further, whilst a count of the number of times that positive and negative comments were made about these topics is produced for context, the numbers of quotations are not balanced in a slavish way, for this would be to misunderstand the purpose and quality of such data. The overall aim is to provide a space within which the voices of older people can be heard.

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[9] A ‘reference’ in this context essentially means the number of passages that have been coded. For example, let’s take a fictional statement, typical of many received: “I get a good quality service overall, but I wish the care workers had a bit more time to spend with me”. In this instance two ‘sources’, and 19 words would be coded. The first source – “I get a good quality service overall…” – has seven words in it, and the second ‘source’ – “…I wish the care workers had more time to spend with me” has 12 words in it. This explains the difference between the total number of words coded, and the total number of ‘references’ coded. It should also be noted that the total number of words coded is different to the total number of words written. Going back to the example, total number of coded words is 19, but the total number of words is 20.

Figure 1 · Thematic framework from ‘open call’ and frequency of codes (n=113 responses)

Thematic Codes	Number
TOTAL	**431**
NEGATIVE	**252** (58.5%)
1. Not being listened to	**56**
Unable to communicate with managers and others	32
Choices not incorporated	24
2. Implications of poorly trained care workers	**56**
Pressure on informal carers	29
Lack of skills, knowledge and training	21
Quality depends on care worker	6
3. Time pressures	**38**
Time pressures	15
Would like more time - turning up late	9
Not enough resource available	8
No allocation for travel time	6
4. Problems with continuity	**29**
Lack of continuity of worker or provider	24
Recruitment and retention problems	5
5. Poor quality care and support	**47**
Poor quality care	35
Risks to service users	12
6. Inadequate assessment and signposting	**26**
Poor assessment	18
Poor signposting	8
POSITIVE	**179** (41.5%)
1. Good quality care and support	**91**
Good quality care	80
Maintaining independence	11
2. Listening to service users	**34**
Choices incorporated	20
Meeting service user needs	14
3. Benefits of professional care workers	**31**
4. Good continuity of care	**23**
Good care worker continuity	14
Reliability and punctuality	9

3.3 BEING LISTENED TO[10]

Respondents expressed their views around the importance of their needs and choices in their home care provision being listened to. There were many positive experiences:

> *Even though they are time limited they always do their utmost to care and provide what I need or request*
>
> *I was asked for choice and preference and all was considered in my package of care.*
>
> *On the whole she finds the carers [sic] to be quite flexible, for instance they are happy to work their visits around her needs relating to her diabetes.*[11]
>
> *The care they provide is really wonderful, we have set carers [sic] all the time where possible, the manager comes to visit to make sure we are happy with all the care and if there is a problem it is sorted out on the same day, even if it just a case of your not keen on a carer [sic] it's the same.*
>
> *Every time I spoke to someone at the office I always got treated with dignity and respect.*
>
> *Every consideration was given. I couldn't find anything to say other than excellent.*
>
> *Our choices received thoughtfully and included as best as can be.*

3.3.1 Meeting service user needs

Service users shared many positive experiences of care workers and organisations listening to them in an attempt to incorporate their choices and meet their needs:

> *They always ask if there is anything else they can do for me.*
>
> *It is valued that most of the staff are Welsh speaking, which means my mother is comfortable in her own home.*
>
> *The people who visit go beyond what is required of them.*
>
> *As [she] receives a grant to arrange her care, she feels that she has full oversight of the process, from the interview stages onwards, and can ensure that her care is 100% tailored to her needs.*

There were however several respondents that felt they had not been listened to and as a result there was a failure to incorporate their choices and meet their needs:

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[10] Overall, there were 34 positive comments about being listened to, and 56 negative comments about not being listened to.

[11] It should be noted that in the section below, the user of the term 'carer' – typically reserved for unpaid carers – is used to mean paid care workers. These have not been corrected but, where this occurs, the designation [*sic*] follows. For more detail, see Footnote 1 above.

> *Emergency care was arranged for 30 minutes a day to prepare a hot meal while we were at the hospital. We cancelled this after only 1 week as the carer [sic] was not prepared to carry out our instructions regarding his meals; she insisted on a ready cooked meal to just pop into a microwave oven (which was not in situ) to make life very easy for her. Her attitude was completely wrong and my father did not like her and eventually refused to let her into the house.*
>
> *[She] feels as though there was a 'box-ticking' mentality in place at the local authority, and that common sense was not applied. She feels that her father was not listened to, and that his human rights weren't taken into account.*
>
> *[He] is unhappy with the care that his wife receives because he says that the carers [sic] either come at 7am or 7pm which are times that he finds inconvenient. To have his wife ready for the 7am call he has to get up at 6:30am which he finds difficult when he is 88 and his wife is 89. He says that he has tried to have the time of the visits changed and was informed by the care company that this was not possible as a lot of people want a later time. He feels that this is not acceptable as the care company are supposed to be providing a service to him, and therefore it should be up to him when they call.*
>
> *The only criticism is I wake early and normally have my breakfast by 8.30 – I am diabetic, because the care workers are so busy at times it could be like yesterday 1.45 before they come to do my lunch by then I am very hungry and feeling dizzy.*

Some service users and their families put their dissatisfaction with their home care provision down to the inability of the care worker to relate to the person they were caring for. Maturity and the failure to empathise with the service user were cited as reducing the quality of the service users care experience: *He has some carers [sic] who are nearly 70 years younger than him and with the best will in the world they are unable to understand his world and vice versa.*

3.3.2 Being less risk averse

Comments were received around the restrictions that health and safety legislation or the rules around care packages placed on the provision of good quality care and meeting service user choices and needs:

> *The [agency name] people who call every day are excellent people but are somewhat hamstrung by the rules they have to operate under e.g. saying 'no' means they must not do anything.*
>
> *I would emphasise that I have no problem with the care workers who come to try to keep [service user] clean [agency name]. The rules need to be changed, particularly for mentally impaired people, to ensure that the patients' needs are the most important, over and above the carers [sic].*

> *She would like it if the carers [sic] took her out occasionally when the weather is good; and so that she can visit the community centre and interact with other people. She has been told that the carers [sic] are unable to take her out due to reasons relating to health and safety legislation.*
>
> *Occupational therapists are trapped in a web of health and safety regulations and seem to have left any common sense they possess at home.*

3.3.3 Responsiveness of decision makers

Experiences were shared with regard to communicating with decision makers and home care management and their ability to respond to service user need. Some respondents expressed satisfaction and spoke of positive experience in making contact with decision makers:

> *The care manager is 100% sympathetic to my care and does what she can with the staff she has available.*
>
> *The agency which supplies my care are very approachable and always listen to my concerns or request.*
>
> *The organisation is so professional, accommodating and pleasant to talk to.*
>
> *Communication is excellent. Nana is 100 years old and we have had good communication since she first had care.*

On the other hand there were some respondents who were less positive about their experiences and attributed their failure to resolve issues on communication problems: *Unfortunately we experienced a number of problems, all related to a lack of communication and organisation.* Some respondents would like to see improvements in communication between home care provision colleagues and other organisations involved in the provision of home care as they felt issues around communication were barriers to good quality service:

> *Better communication between grass route level carers [sic] and office staff (left hand/right hand) and more communication needed between care providers (not office staff) and family members so any queries or concerns can be resolved.*
>
> *She would like better communication between organisations that provide equipment and would like to her mother (who is registered blind) to be supported more.*
>
> *Basically, there is little joined up thinking and the service is delivered in a task orientated way rather than being person centred.*

There was also concern about the lack of consultation and failure of decision makers to inform service users and their families of changes to care packages:

> *I cannot understand why she could not be spared this upheaval and added worry. In order to better understand I asked, when first told of the change, for a copy of any*

> *criteria or procedure which the Council used in deciding who will be moved and who will stay. This request was ignored…no explanation has been given as to why my mother has been picked to move wholly to a contract service provider.*
>
> *No one informed me whose decision it was to change the carers [sic].*
>
> *I was told of the change less than three weeks before it was to be implemented.*

Several respondents felt that the home care application process was difficult for the average elderly and/or vulnerable person to successfully embark on. One respondent attributed their ability to secure a satisfactory service to their knowledge of the social care system:

> *On the whole I am delighted but if I had not worked in Social Care until five years ago I honestly don't think we would be in this situation. Whilst in theory everything an older person needs to stay at home is available, the various departments and individuals one has to deal with to insure a successful outcome is well beyond the ability of the average older person, (say over 80). Unfortunately I would suggest that if Mum had been the only person there to deal with the problems then it would not have worked, mainly because she would have been ignored by officialdom, her home would have been changed against her wishes and I feel sure her health would have suffered.*

3.3.4 Fear of withdrawal of service

There were incidents when service users or their families were fearful of complaining as they thought it might result in a reduced quality or complete withdrawal of the service they were reliant on: *He did not want to go to the police about his carer [sic], and nor did he want to report her to the care company's management. He felt that he was so dependent on this care that he couldn't afford to do anything about it. His worry was that the care would be taken from him if he complained, and that he would then have no option other than to go into a care home.*

3.4 KNOWLEDGE, SKILLS AND TRAINING OF THE WORKFORCE[12]

Confidence in care workers' knowledge, skills and training were of great importance to respondents. Many expressed a high level of satisfaction with the level of ability shown by their care workers:

> *This helps me and the carers [sic] as we know each other well and they are familiar with equipment that I need to use.*

---

[12] There were 56 negative comments about care workers' lack of knowledge, skills and training, with 31 positive comments reflecting on well skilled, trained and knowledgeable workers.

> *A few of the carers [sic] are far more knowledgeable and well trained – they want to learn.*
>
> *The care workers are more trained than before.*
>
> *She praised the carers [sic] who visit her mother for being kind, caring, and understanding.*
>
> *After nine weeks in hospital, he came home and was looked after by [local authority's] rehabilitation team in whom we had every confidence for their professionalism and their ability to find the positive areas of his ability to deal with his condition and live his life as fully possible.*
>
> *The [local authority] carers [sic] visiting my mother know her well having called upon her for many years. They know my mother and can spot very quickly if anything is wrong. This happened recently when one of the carers [sic] was able to spot a problem very quickly and have the doctor contacted. Without her experience and her knowledge of my mother this would not have been so quickly spotted and it is likely that my mother would have required hospital treatment.*
>
> *I had misgivings being a newly formed company after nine years of county council first class carers [sic], but most of these women had previous experience from working for other care firms or old people's homes, the new girls were taught by the experienced ones, plus they attended courses, they have provided first class service, very meticulous and respectful in manner so I have been totally satisfied day to day living.*

When care workers displayed an insufficient degree of skills, knowledge and training service users and their families felt very concerned, particularly with regard to the impact this could have on the service user in receipt of care:

> *Most times, after one day's shadowing the other carers [sic], they get thrown in the deep end i.e. they start with more of less no training of an individual clients care needs.*
>
> *However there were many times the carers [sic] would forget to do some of the tasks for example put the cup under the kettle spout and ensure the tea bag was in the cup. My father was not able to have a drink until the next call or until I visited*
>
> *Due to my father's diagnosis carers [sic] did not appear to have a clear understanding of the difficulties people have or their conditions.*
>
> *At the time of writing, my mother has had her first morning visit from the contract carers [sic]. On this first visit [agency name] trainer was present but of the two carers [sic] visiting my mother one had a week's actual care experience and the second no actual experience. For a ninety nine year old with my mother's circumstances this is not acceptable.*

> *The main problem is their lack of training, total lack of supervision and not enough time to care for people properly. Their conditions of employment as far as I can gather also leave something to be desired.*

3.4.1 Pressures on unpaid carers

It is evident that a great deal of care is provided by family members and is being supplemented by varying degrees of formal home care provision. Unpaid carers, often elderly with health issues themselves, shared their views and experiences of situations when they have felt pressured by the responsibility of caring for a loved one or the circumstances they were in – at times exacerbated by the lack of knowledge, skills and training of the care workers:

> *His wife is his full time carer. She has been caring for him for quite some time and does everything for him, said that he would be lost without her. He is currently housebound and is waiting to have a knee replacement. He has been told that he can't bathe properly until after he has had this operation and this won't be until May next year. He is also worried for his wife as she is also 79 and that she is doing too much but unfortunately there is nothing he can do to help her as he is in so much physical pain. He'd be grateful for some extra support for both him and his wife.*
>
> *His main concern is that he ends up needing to go into hospital. He does not know who will look after his wife if this happens.*
>
> *If my mother was unable to receive home care, my situation would be particularly difficult. She would have to either be in a home, which neither of us want, or I would have to give up my job to care for her, or pay privately and at great expense for her care. I find the support of the carers [sic] invaluable.*
>
> *Providing there is plenty of family support the system works.*

3.4.2 Dementia care

Several respondents commented on the specific training required for care workers who are providing a service to those with dementia. It was generally felt that training in dementia care could be much improved, although good practice was also identified:

> *Every care organisation needs to realise that caring for someone with dementia is totally different from any other sort of caring, and in the last 10 years 'person centred care' has been proved to be the best way to care for someone with dementia - yet most carers [sic] and medical professionals have never heard of it! Dementia sufferers need people who come into their homes to be properly trained, not just in 'Person Centred Care' but in how to teach the principal carer [sic] how to learn and use the techniques.*
>
> *Apparently they specialise in dementia. You wouldn't know it. They each write in the record book that is left at mums' comments like "[Name] had made herself a cup of*

> *tea and some toast and marmalade before I arrived”. No she hadn't - she has dementia – she has no idea how to make toast. Or "[Name] didn't want lunch today she has a sandwich in the fridge for later". No - had they opened the fridge they would see that there was no sandwich. Or "[Name]'s daughter/son/friend is bringing her a meal later”. Not true. Mum will say anything not to be a nuisance.*
>
> *Every care organisation needs to realise that caring for someone with dementia is totally different from any other sort of caring*
>
> *One respondent however had found her relative’s care workers to be very good in spite of not having had training in caring for people with dementia.*
>
> *The carer [sic] from [local authority] is brilliant despite never being trained in dementia care. The organisation didn't understand the unique requirements of dementia care. They are getting better since I undertook to teach them instead of complaining! The carer [sic] from [voluntary sector agency] is also brilliant; she also has never being trained in dementia care.*

3.5 TIME PRESSURES[13]

There were a range of issues reported here – from not having enough time and resource available, through to dealing with care workers in a rush to complete their visits.

3.5.1 Available resources

Some respondents expressed concern over what they perceived to be dwindling resources and as a result inadequate provision for the level of support or inclusion of need that some service users or their families thought necessary:

> *He has requested additional care, but has had this request turned down due to funding costs. He has also had a request for ‘Meals on Wheels’ turned down.*
>
> *[He] is happy with the care he does receive, but he feels that he needs more help especially with the cooking and cleaning and that he would like the carers [sic] to spend more time with him.*
>
> *Happy with all of her care arrangements but added that she’d like them to be able to provide a little more time but understands that they work to a busy work schedule.*

Respondents had observed that their care workers were often under unrealistic time pressures and there was a level of sympathy expressed for what some felt were the unrealistic demands placed upon them. Some felt that the time pressures that care workers were placed under inevitably had an effect on the quality of care:

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[13] Unlike previous codes, there were only negative comments in relation to this issue (n=38) – hence the wording of the section. Had there been positive comments received, the title would have been balanced to reflect this.

> *I deliver dignity in care training for social care staff four times per year for one local authority. Some of the attendees on each course deliver home care and all report the same problems, namely: 5 minute calls to deliver medication and 15 minute calls during which they are meant to get the person up, wash and dress them and provide breakfast. The 15 minutes also includes travel time to the next call. Many older people forgo the washing and ask the staff to prepare their breakfast. 5 minute calls for medication are also inadequate. The length of time for the care packages are critical and worthy of investigation.*
>
> *However they are given such a short time (usually 10 mins) with you that are not able to do a lot.*
>
> *The girls were under pressure to do too many calls. One girl or rather woman had about 15 "wake up" calls to cover in a morning.*
>
> *He also said that they only stay for half an hour which usually is not enough time for them to assist his wife sufficiently.*

Some service users felt that time pressure on care worker(s) prevented them from having conversations with them, which was an important part of the care and support package: *The time allowed does not allow the people to talk which is very important to me.* In addition, one person reflected on the impact that the processes care workers had to go through on their time to care:

> *I don't agree with the carers [sic] having to ring in and out of the office when attending to me. To me it is as if you mistrust them as to whether they are at where they're working and the fact that if they have over the 1 hour slot they have to ring back at hourly intervals which I again sometimes find inconvenient.*

Several service users were also concerned that visits were sometimes shorter than their allocated time:

> *Fee paid for ½ hour; carer [sic] here often for 10 – 15 mins, and always in a hurry. But they do turn up.*
>
> *She said that the carers [sic] stayed for less time than they were supposed to, provided sloppy and minimal care and that different carers [sic] called at inconsistent times.*

One respondent observed that agency service provision in his opinion seemed more time pressured than the service he received from the local authority home care team:

> *Initially care was provided by [agency name] until July 2010 when it was taken over by [local authority]. Whilst there was not a lot to separate the service from these organisations it soon became clear that the carers [sic] from [local authority] were under less pressure. They had more time, and were just that bit more professional.*

3.5.2 Timing of calls and travel issues

The timing of calls presented issues for some respondents creating problems ranging from the inability to plan their day around their care to the impact of receiving the care they need much late than they would want it:

> *If only I knew when to expect the care workers in the mornings. On Monday, Wednesday and Fridays I have the same care worker for bathing at around 7.15 am or I am informed otherwise. On the other days they can come from 9.00am to 11.00am but I seldom know when so I am in my dressing gown all that time.*
>
> *Whilst we recognise that a carer cannot keep exactly to time, we do not see the point of being asked our time preferences if there is not some effort to keep to the arrangement.*
>
> *He was being cared for by [agency name] but they were very haphazard in their arrival times and even failed to appear on a few occasions. Care was then transferred to [agency name] who, with no warning, in fact the Social Worker only heard from us, decided that 4 miles out of central [urban area] was "rural" and they were stopping rural care. We have now changed to [agency name], and they seem to be willing and helpful.*

Respondents put many of the issues around timing down to badly managed and unrealistic schedules for the care workers and specifically the lack of travel time allowed between calls:

> *Care worker does not have time to give full time allotted to me. They make her appointment times from one client to another and no time for travel in between. Consequently she cannot always give my husband his full half hour or myself the full time allotted.*
>
> *Another example was that the carers' [sic] appointments would often run back to back, but had no consideration for travel time and would not factor in the distances between appointments. This would then impact on the timing of each appointment.*
>
> *The rota has been changed up to three times in one week. I think this could be because the compiler has no real idea of the area and roads. They do not allow enough time for travel and therefore changes need to be made.*
>
> *There seems to be a big difference between agencies on how they treat their workers, ours seem to be expected to be in three places at once and finance their own travel on top of being poorly paid.*

3.6 CONTINUITY[14]

Continuity of care was commented on in some detail by respondents. Many felt that a recognised person or team was of great importance for a number of reasons ranging from the importance of service user and care worker building a relationship; being familiar with the service users care plan and needs and able to carry out tasks with skills with the knowledge a relationship and experience brings. When this happens, people are very happy. However service users and families do not appear to like the discomfort of not knowing which care worker is providing care until they walk through the door. Also some expressed discomfort at receiving personal care from a care worker that was unfamiliar to them:

> *What could be improved? Regular carers [sic] and not 17 different carers [sic] in two weeks.*
>
> *From September to the November we had over 80 carers [sic] calling, the time-keeping was dreadful, anything from 30 minutes to an hour early or late. We never knew when they would turn up.*
>
> *A young carer [sic] turned up and said I haven't been here before what do I do?*
>
> *I get perfect care from my regular carer [sic] but not so good on her days off when I get different people.*
>
> *I am least happy about the resilience of the service. [Agency name] are strapped for cash but [local authority] just don't seem to grasp how important for the carer [sic] to be a familiar face with an established and personal relationship.*
>
> *The carers [sic] that did arrive were not familiar with our location, or what service they needed to provide. Both of these facts resulted in delays which I feel sure would also have affected other people being cared for by [local authority reablement team].*
>
> *The final stress was when we had five different men in five mornings. My husband was very upset and distressed at all these different people coming to the house. One of the men was not very clean, left the water in the basin and the towels on the bathroom floor.*
>
> *[His] mother requires strip washes as she cannot be showered. She is very nervous and likes to know which members of the carers [sic] team will be visiting her on certain days so that she can fit in her washing schedule with the staff with whom she is most comfortable. Usually the staff are accommodating, but on one occasion the manager told his mother that she was too busy to answer her questions, and went*

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[14] The positive (n=23) and negative (n=29) coded comments were much more closely in balance in against continuity than they were elsewhere.

> *on to state that she was taking up the time of "people in hospital who are waiting to die"*

3.6.1 Reliability and punctuality

The timing of visits appeared to be of great importance to service users with many people expressing their satisfaction at the reliability and punctuality of their care worker(s):

> *[T]hey are always on time whatever the weather.*
>
> *Very reliable.*
>
> *[She] stated that her current carers [sic] were very reliable and punctual in their time keeping.*
>
> *They go out of their way to help his mother – sometimes calling in outside of scheduled hours if they are in the area for instance.*

Service users understood that on occasion circumstances might arise in the care workers day that prevents them from having their call at their allotted time. However this didn't seem to present too much concern providing that the service user was kept informed:

> *Sometimes they will be running late, but the better members of staff will phone and inform her of when they are expecting to arrive and whether this is a convenient time.*
>
> *By contrast in both winters [local authority] care staff have not missed a single call to my mother and, given the conditions, there have only been small time delays.*

3.6.2 Recruitment and retention

Some service users and their families believe that the pay, working conditions and lack of recognition and value associated with the role of care workers add to the recruitment and retention difficulties experienced by home care providers:

> *[Agency name] seem to struggle to get enough good quality carers [sic] to work for them and prevent those carers [sic] from leaving.*
>
> *I spoke to the owner/manager regarding this incident and other matters and he told me they employ staff once new clients are in place but they do not always wait while CRB checks are carried out and find alternative employment leaving the employer with a staffing problem.*
>
> *Every week in the local newspapers new care agencies appear advertising for staff, with or without experience. It would seem not enough care and consideration is given to the client as long as someone turns up, or not as the case may be, at the client's home. I feel independent back checkers should be employed by the local*

> *authority to undertake spot checks on care agencies who seem to run their businesses more for profit than out of genuine care for the elderly and infirm.*

Several of the respondents recognised the importance of the role of the care worker for service users and their families and expressed a sympathetic view to what they perceived to be the care workers' conditions of employment:

> *To improve home care or even to keep it at the present level the difficult issue of carers' [sic] pay has to be addressed. In financially tough times it is too easy to rely on the goodwill of a desperate workforce but this is not good enough. Somehow money has to be found to pay better wages to some of the most deserving people in our society.*
>
> *There is a desperate need for the government to recognise that thousands of families entrust their loved ones, often society's most vulnerable, to care workers. We trust them to carry out vital duties. Surely this trust and responsibility should in some way be acknowledged by their pay and conditions?*
>
> *However what became evident speaking with staff from both companies is the total lack of job satisfaction a lot of these care workers have. They feel devalued, demotivated and are not happy with their working conditions. I should stress that this is not the situation with the local council carers [sic], who as public sector employees, enjoy a higher standard of conditions and pay.*
>
> *I find it both very sad and alarming to hear about the dissatisfaction most of the home care workers experience in their job. For example, the pay is not very good; some companies pay their workers by the number of calls they make not the hours they work. They do not get paid double time for bank holidays, have to supply their own uniforms, no petrol allowance and some work 15 hour shifts.*
>
> *I feel that if so many home care workers continue to experience low pay etc, they will seek employment elsewhere, which means a workforce losing dedicated, experienced staff. This, in turn could mean there is going to be the situation where the industry will be attracting, shall we say, the least capable type of personnel. Agencies already experience a very high turn-over of staff, which considering the contracts many of their staff work to, is hardly surprising.*

3.7 QUALITY OF CARE AND SUPPORT[15]

Many of the views and experiences received centred around the general quality of care and support provided to service users to meet their needs. Many service users expressed their satisfaction at the service they received:

> *A very good service, which we rely on.*

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[15] Overall, there were 91 positive comments about quality of care, and 47 negative comments.

> *The strengths of the current home care model are the extraordinary qualities of devotion, kindness, good humour, and professionalism of the carers [sic]. It is a minor miracle how cheerfully they rise above all conditions and circumstances.*
>
> *The [local authority] social services reablement team were outstanding.*
>
> *As a family we have nothing but praise for the carers [sic] and we were especially pleased that in spite of the very difficult conditions they managed to get to our father.*
>
> *The quality of the care my husband receives is "second to none" and we are very grateful for their help.*
>
> *Really I think the work that people do is really fantastic. I also think that if all carers [sic] are the same they should all get a medal for the work they do*
>
> *The carers [sic] themselves although obviously under pressure to cover all their calls were generally extremely diligent.*
>
> *The carers [sic] are always punctual, cheerful, polite, properly dressed, and carry out their duties efficiently.*

However contrary to the experiences shared above, a number of issues arose around poor quality care in general.

> *Not all the carers [sic] do as I ask properly*
>
> *Some carers [sic] don't have time to give me a proper wash in the morning and has twice happened when I've needed to go into hospital for a procedure in theatre. They've sent me back home because I have fungal infections of groin/breasts etc. I am a big lady and bed bound for three years and cannot have a shower in my newly fitted out bathroom as need two carers [sic] on duty which doesn't happen.*
>
> *My uncle and aunt received 'care' via [local authority] from May 2010 until April 2011. The level of care was appalling. In June we had to empty the house when they were both taken to a care home.*
>
> *It is difficult to understand how they were left to wallow in such dirt.*
>
> *Medication was missed regularly and we had to administer it no show for 1.5 weeks. Very, very poor.*

3.7.1 Quality of care and support depends on the care worker(s)

Numerous respondents related their positive experience to their particular care worker or team. This could be seen to support the importance on the care worker and service user relationship with regard to satisfactory home care provision for both parties:

> *I get perfect care from my regular carer [sic]*
>
> *He adored his carers [sic] and they adored him*

> *I found that while taking in care by [voluntary sector organisation] respite services department the care that I got was excellent. [Name] was our main carer [sic] and I do admire that her whole attitude for care work was excellent*
>
> *….despite her excessive weakness she told me repeatedly how marvellous the young women were who came to her. She was overwhelmed by their attention and kindness and, having been some unwell, I understand that both the ladies served the food in a way which tempted her to begin eating again. An inspired service*

Again though, on occasion some service users and their families experienced less satisfactory care and also attributed this as being dependent on individual care workers or teams:

> *….in this time he has found that the care varies depending on the person calling, the times of their visits vary and the whole arrangement is not even close to meeting their needs*
>
> *The quality varies depending on which carer is visiting. Whilst [he] felt that some could not be praised highly enough, and that they go out of their way to help his mother – sometimes calling in outside of scheduled hours if they are in the area for instance. Others are less accommodating, and [he] feels that they see their work as only a job, and don't have any interest in providing care. He also feels that some of them have difficulty in carrying out the simplest tasks – such as making toast, or boiling an egg*

3.7.2 Maintaining independence

Service users and their families did not underestimate the vital role that the care worker played in maintaining people in their homes:

> *This service was amazing. Whilst I was ill, I needed care more than medical attention so I was able to be cared for at home releasing a hospital bed for a more urgent medical patient. Please keep it going!!!*
>
> *However much carers [sic] are criticised people like me could not live without them, and on the whole, I can't praise them enough.*
>
> *I am emphatic in my belief that remaining in one's own home in one's old age is vital to quality of life, to comfort and well-being and to physical and mental health.*
>
> *Furthermore, with appropriate assistance where such help is needed, I believe that remaining in one's own home constitutes the most economically viable of all options for the care of elderly people.*

3.7.3 Nothing to improve

Some respondents were so satisfied with their service provision that they felt there was no room for improvement:

> *Unable to fault the excellent service we are getting. Please do not change a thing.*
>
> *As far as my wife and I are concerned the arrangements and the care that we receive, also the service and advice cannot be faulted, or improved on.*
>
> *We are very happy with the care and support and can't think of any improvements that are needed.*

3.7.4 Risks to service users

On the downside, there were several incidents reported when poor quality care resulted in the service user being in a situation where they could be considered at risk:

> *[He] said things have improved but said there have been numerous instances in the past where he says the standard of care wasn't up to scratch. One incident [he] described is where one carer [sic] left his wife leaning against a doorway whilst the carer [sic] was watching TV.*
>
> *The social worker was bullying and intimidating towards [her]. The social worker recommended that until [local authority] could arrange for night carers [sic] for [her] husband, she might like to pay for the services of a private company, [agency name]. [She] took the her advice, but observed that her husband was being treated very roughly by people she considered elderly themselves (approx. 55+) who had not received proper training, but had been instructed by their employer to 'look professional'. [He] received injuries, cuts, wrenches and bruises as a result of mistreatment by them. The social worker blamed [her] for her husband's injuries.*
>
> *The woman received no help whatsoever and described a horrendous situation where she was reduced to tying plastic carrier bags around her mother in an attempt to contain the situation.*
>
> *The one day my wife was left for nine hours unattended. She was able to reach the sandwiches that my daughter had left for her but had to make do with the water that was left over from taking her tablets as a drink.*

3.8 ASSESSMENT AND SIGNPOSTING[16]

3.8.1 Assessment

Several issues arose around assessment. Some respondents spoke of difficulty in arranging an assessment whilst others raised concern of delays in responding to the needs identified by an assessment:

> *Her experiences of care in the community have been 'dreadful' with neither of her parents receiving a needs assessment despite her asking for this from social services*

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[16] There were only negative comments (n=26) made in relation to assessment and signposting, hence the tenor of the quotations in this section.

> *for the past two years. She feels she and her parents have been 'fobbed off' because they have their own money and that they have been 'abandoned by all the necessary services'.*
>
> *I have 23 pages of carers' [sic] notes with approx 20 visits each page which have never been seen by the management to assess my wife's condition.*
>
> *Contact with a social worker seems no longer possible. One has to ring and only if it's urgent do you get a new assessment.*
>
> *She was told her mother would need an incontinence assessment which could take six weeks.*
>
> *At the other end of the scale some organisations were a dismal failure. The worst was [local authority] social services team. They sent an OT to examine my wife in October 2009 and assessed her needs as 'substantial' and put her name on a waiting list. We are still waiting!*

Some respondents, particularly those caring for elderly relatives, expressed the opinion that the outcomes of assessment were not always considerate of the needs and choices of the service user and/or their family:

> *The professionals took the view that because mum was old she could/should not cope and therefore dad should have gone into a care home. I am left with the clear impression that they thought they knew best even when dad was adamant that he was going home.*
>
> *The OTs insisted that dad could not use these facilities and that he would have to live downstairs, this was at the time when dad was transferring between his wheelchair and my car using a turntable, so transfer to the stair lift was straightforward. We converted the dining room. This conversion only taking place after much argument about its size. Too small they said, rubbish we said, and so we prevailed. Just imagine the outcome if mum had had to fight that battle. The result of this decision by the authorities was unnecessary disruption to the home and, vital for dad, no possibility of a shower or bath.*

3.8.2 Signposting

Several respondents expressed some difficulties in easily identifying sources of assistance and information. It appears that few organisations were able to signpost sufficiently thus creating barriers to the possibility of advice, service provision or information for service users:

> *The little booklet 'caring in [location]' lists over 60 societies and organisations offering help in one way or another so it would appear I have no shortage. In practice things are rather different and I'm reminded of the saying 'every possible*

assistance short of actual help.' There is certainly no shortage of 'experts' and advice.

She has approached [organisation name], [organisation name] and local social services to seek assistance and was told on multiple occasions that because she and her parents have money they are on their own. She was then sent a list of private care agencies to choose from and simply pay for herself.

He said that he was passed from one organisation to another, and feels that there is no assistance available.

What is needed and urgently are care advisors - employed by the council who can help the families make these difficult decisions for the benefit of the service user.

For months I was buying incontinence pads and panties (approx £20 per month) until a friend told me they should be supplied free. It was only with the help of our then Assembly Member that I eventually received the most suitable pads. This considerably reduced the amount of washing every week.

4 · RESEARCH FINDINGS - QUESTIONNAIRE

This chapter reports the findings to date from the questionnaire across four sample local authority areas. After an introductory section on the design, sampling and representativeness of the questionnaire, the chapter considers the two– quantitative (section 4.2) and qualitative (section 4.3) – substantial data sets that resulted from returns from older people.

4.1 DESIGN, SAMPLING AND REPRESENTATIVENESS

The structure and content of the questionnaire (see Appendix IV) was explicitly based on the issues emerging from the literature review and the open call for information. A postal survey was determined as the only real option for engaging with older people in receipt of home care. Each local authority in Wales was approached to participate in the study and 20 of the 22 responded positively. On this basis, four sample local authorities (SLAs) were chosen based on offering a mix of the following three criteria:

- **Geography** – ensuring that the authorities were drawn from across Wales, and that they represented a mix of the urban, rural and valleys communities that make up the Welsh population;
- **Language spoken** – allowing the sample to be drawn from areas which gave the opportunity to hear from Welsh speakers, alongside a range of other languages; and
- **Proportion of home care in-house and out-sourced** – offering the opportunity to hear from those in receipt of care from directly employed local authority staff and those providing home care in the independent or voluntary sectors under contract to the local authority.

Prior to the distribution of the questionnaire, officers from each of the SLAs were engaged and offered the opportunity to contribute to the design and content of the questionnaire. In each pack sent to older people were four documents – a covering letter written by the Older People's Commissioner (in English and Welsh) and a questionnaire (in English and Welsh) – and a freepost return envelope. No identifiable information was asked for from the respondents, and all the mailing was dealt with by the SLAs in order to preserve the anonymity of respondents from the researchers.

It is possible to be statistically confident that the views of those who participated in the survey are representative of the views of other older people in receipt of home care throughout the rest of Wales, subject to two important caveats. Firstly, this representativeness only applies when the sample is taken as a whole, and secondly this is subject to a confidence interval of +/-3%. In practice what this means is that, for example, if we had asked a simple 'yes or no' question and our sample of respondents was split

50%:50%, we could be certain that if the whole of the population of Welsh older people in receipt of home care (25,253 on the basis of the 2009-10 figures) were asked the same question, their response would be in the range of 47% to 53% for either option.

4.2 QUANTITATIVE FINDINGS

4.2.1 Who filled in the questionnaire?[17]

Just over one thousand (n=1029) older people took the opportunity to fill in a questionnaire, an overall sample response rate of 26.7%. This rate has varied across the four SLAs as described in Table 2. For example, the highest proportion of responses – over one in three – came from SLA.1, which had the lowest population of older people in receipt of homecare.

Table 2 · Numbers of responses and response rate

Sample Local Authority (SLA)	Number received	Number sent	Response rate (%)
SLA.1	110	310	35.5
SLA.2	158	620	25.5
SLA.3	426	1567	27.1
SLA.4	335	1360	24.6
TOTAL	**1029**	**3857**	**26.7**

Similarly there was variation in our sample between those who are in receipt of in-house (local authority delivered) and out-sourced (independent sector provided) home care in Table 3 (below). This also varied by SLA. It is clear from this data that in our sample we have a slight over-representation of local authority-provided care (42%) when compared to the Welsh average (38% - see Table A.1 in Appendix I).

In terms of the gender of respondents, 692 women (69%) and 310 men (31%) filled in the questionnaire, the vast majority of whom (99.3%) described their ethnicity as ‘white’. Indeed only five people who told us of their ethnicity described themselves in anything other than these terms.

Table 4 describes the age profile of respondents. It is notable that more than two-thirds of respondents were aged over 80 years. It is worth reading this table in conjunction with

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[17] The data tables that follow are based on the 1029 responses that had been received as at 29.2.12, and on which the complete data analysis has been undertaken. Since then (and to 14.3.2012), a further 86 questionnaires have been received – unfortunately due to the constraints of the project timings these questionnaires have not been included in the figures reported here. Therefore the actual total of questionnaires returned (to 14.3.12) is 1105.

Table 3 · Numbers of responses by provider and SLA[18]

Sample Local Authority (SLA)	Local Authority	Independ't sector agency	Voluntary sector agency	Mixed provision[19]	Not sure who provides care	**TOTAL**
SLA.1	48 (42.5%)	46 (40.7%)	2 (1.8%)	15 (13.3%)	2 (1.8%)	113 (11.3%)
SLA.2	18 (12%)	106 (70.7%)	4 (2.7%)	16 (10.7%)	6 (4%)	150 (14.9%)
SLA.3	282 (68%)	93 (22.4%)	4 (1%)	28 (6.7%)	8 (1.9%)	415 (41.4%)
SLA.4	71 (21.8%)	216 (66.5%)	4 (1.2%)	30 (9.2%)	4 (1.2%)	325 (32.4%)
TOTAL	**418 (41.8%)**	**461 (46%)**	**14 (1.4%)**	**89 (8.9%)**	**20 (2%)**	**1003**

Table 4 · Age profile of respondents

Age	**Frequency**	**Percent**	**Valid percent**
60-69	91	8.8	9.0
70-79	240	23.3	23.9
80-89	443	43.1	44.0
90 or above	231	22.4	23.0
Do not want to say	1	0.1	0.1
No valid data[20]	23	2.2	-
TOTAL	**1029**	**100.0**	

Table 5 which provides a count of the number of people who were able to fill the questionnaire in on their own (about one in three respondents), and those who needed some support to do so. Taken together, these data point to the fact that the questionnaire was accessible to people of all ages, and that it is likely that there will have been some who wanted to fill it in but did not have the support to do so; there were many able to do this for themselves.

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[18] Table 3 only includes people who gave a valid answer to where they live and who provides their care. As such the total number of respondents (n=1003) is lower than the overall total (n=1029).

[19] This refers to whether people have a combination of local authority and/or independent sector, and/or voluntary sector care.

[20] This category (for this and other tables) includes a count of these who did not provide an answer or those who provided invalid data (i.e. they may have ticked two of the boxes).

Table 5 · Did you need help to fill in the questionnaire?

Who is filling this in?	Frequency	Percent	Valid percent
I am doing it on my own	329	32.0	33.1
I'm having some help from my care worker	50	4.9	5.0
I'm having some help from someone else	615	59.8	61.9
No valid data	35	3.4	-
TOTAL	**1029**	**100.0**	

It could be fairly stated that the sample had considerable experience of home care. Over half (54%) had been in receipt of home care for more than two years, a proportion that extends to nearly three-quarters (73.3%) when combined with those who have received home care for more than 12 months. The older people in the sample are also extensive users of home care. On average, respondents received just over 14 visits per week, or two per day (n=14.1 visits), totalling almost 6½ hours of care per week (n=388.04 minutes). These figures reveal that the average length of a visit across the sample is just under half an hour (n=27.64 minutes), but there is considerable variation around this figure.

Finally, respondents were asked about their language of choice (Table 6) and how frequently they are able to receive care in this language.[21]

Table 6 · Preferred language

Language	Frequency	Percent	Valid percent
Cymraeg/Welsh	74	7.2	7.4
English	918	89.2	92.2
Other	3	0.3	0.3
Do not want to say	1	0.1	0.1
No valid data	33	3.2	-
TOTAL	**1029**	**100.0**	

A very small proportion (0.3%) reported that their preferred language was other than Welsh or English, with more than nine in ten people (92.2%) stating that English was their

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[21] It should be noted that we received nine questionnaires in the medium of Welsh.

preferred language. Interestingly though, when seen alongside the data on how frequently they are able to use their preferred language, just over two-fifths (n=31) of the 74 Welsh speakers are 'always' or 'often' able to use this language with their care workers.

In addition to these profiling data, in the questionnaire older people were asked questions about three substantive areas of their service:

1. How frequently do they receive good care from their care workers?
2. What is the impact on them when things go wrong? and
3. What do they think about the management of their care?

The questionnaire asked them about six issues in each of these three areas – each of which had featured strongly as issues in the literature review and the 'open call' for information:

1. Being listened to about important things;
2. Having the right, skills, knowledge and training;
3. Having enough time to do all that is needed;
4. Receiving visits from as few different workers as possible;
5. Receiving the best quality care possible; and
6. Being signposted effectively to other relevant sources of information.

The following sections report findings against the three substantive areas and across each of the six issues.

4.2.2 How frequently do people receive good care?

When asked about how frequently they receive the six different aspects of good care, (Table 7) older people in our sample very positively reported that on average over half (50.5%), *always* receive the very best care they possibly can.[22] Clearly, stating that they 'always' receive the very best care is a significant compliment to those providing their care for this is very difficult to achieve, and as such speaks to a sample who are very content with their home care service. The two most positive aspects are the 59.5% of people who report that their care worker always listens to them about important things, and the 57.1% of older people who note that they always receive good quality care. On average, and taking the 'always' and 'often' categories together, just over four in every five (80.4%) older people in our sample reported positively that they receive good care.

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[22] Because of the outlying nature of the data on 'information' we feel that it can be excluded from the calculation of a meaningful average score. It is reproduced here for completeness, but the figures we will be using are those in bold in Table 7 below. This holds true for Tables 8 and 9 below also.

Table 7 · How frequently do you receive good care from your care workers?

My care workers…	Valid percent[23]					n=
	Always	Often	Sometimes	Rarely	Never	
…listen to me about important things	59.5	21.9	14.8	2.7	1.0	971
…have the right skills, knowledge and training	52.2	26.6	16.2	3.4	1.6	974
…give me as much time as I need	48.7	25.4	17.0	6.4	2.5	989
…are familiar to me	34.9	47.0	13.8	2.9	1.3	985
…provide good quality care	57.1	28.7	12.2	1.4	0.6	997
…give me useful information about other services	15.9	21.0	24.9	14.6	23.6	958
AVERAGE (incl. information)	44.7	28.4	16.5	5.2	5.1	979
AVERAGE (excl. information)	**50.5**	**29.9**	**14.8**	**3.4**	**1.4**	

Equally pertinent then is the finding that at the other end of the scale, on average 5% of recipients of home care in Wales 'rarely' or 'never' receive care that could be described in any positive way. This masks some variation across the different indicators. There are nearly one in ten older people who rarely or never have enough time with their care workers. It is difficult at this stage to draw many inferences about the middle category of 'sometimes', and depending upon a range of factors, this could be seen as more or less

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[23] Excluded from these valid percentages are missing data and invalid data, for example where someone may have ticked more than one option. Also excluded are the very small proportion of people who answered 'don't know' to these questions.

positive. What is more unequivocal is the fact that this is a benchmark that has not been identified in such a robust way in Wales before and it is rather difficult to interpret these findings overall as either 'very good' or 'not quite good enough' without a previous measurement.

4.2.3 What is the impact on older people when things go wrong?

The questionnaire was deliberately designed to allow older people to identify good practice and the things that work well, but also to let us know about the impact that problems have on them. As such the six dimensions of good home care were repeated in this set of questions, but instead of asking about how frequently they experience good care, the questionnaire instructed them to tell us how they feel when things go wrong (Table 8 below).

It is important to recognise that on average more than one in three of the older people who responded stated that they had never experienced any of the problems that were identified. This ranged from nearly half of the sample (47.5%) noting that they had never been faced with care workers who didn't listen to them about important things, through to just less than one-fifth (19.2%) who had never been faced with the problem of having home care provided by carer workers with whom they were not familiar.

That said, it is clear that for the two-thirds of older people who had experienced some problems with their home care provision, when things go wrong it can have a significant impact on them. Across the six dimensions of home care, just over two in five older people on average (40.2%) reported that when problems occur, 'it matters to them a lot'. This is most acute when it comes to issues around the quality of care, when 44.1% report that this matters a lot.

Interestingly, the problem that occurs most frequently – more than 80% of people reported that they've had to receive care from unfamiliar care workers – is the second most significant issue by way of impact, with two-fifths (43.7%) of people noting that when this happens, it matters to them a lot. However, it is this issue of dealing with unfamiliar workers that one in eight older people report as not mattering to them at all. So, it happens more often than any other problem, and almost without exception[24] is simultaneously the issue that matters most and matters least to most people.

4.2.4 What do older people think about the management of their care?

Table 9 (below) reports the findings of the responses of older people about managers and those that organise home care. The reason for asking these questions (other than to follow through the six dimensions) was to see if older people report differences in their perceptions of frontline and managerial staff. It is clear that the results need to be carefully interpreted – the larger proportion of 'don't knows' on this question indicates a

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[24] The exception is, as noted above, problems around the quality of care.

Table 8 · What is the impact on you when things go wrong?

When my care workers…	Valid percent[25]				n=
	It matters to me a lot	It matters to me a bit	It doesn’t matter to me at all	This has never happened	
…do not listen to me about important things	32.8	10.1	2.8	47.5	960
…don’t have right skills, knowledge and training	38.0	9.4	2.6	43.3	971
…are under time pressure when they visit	42.5	17.1	6.9	28.2	974
…are not familiar to me	43.7	19.2	12.2	19.2	972
…provide lower quality care than I’d hope for	44.1	8.7	1.7	39.8	971
…don’t give me useful info. about other services	26.3	15.7	9.3	35.6	895
AVERAGE (incl. information)	37.9	13.4	5.9	35.6	957.2
AVERAGE (excl. information)	**40.2**	**12.9**	**5.2**	**35.6**	

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[25] For this analysis, the valid percentage values will not total 100%. The disparity between the totals and 100% is explained by missing or invalid data, or ‘don’t knows’.

Table 9 · What do you think about those that manage and organise your care?

Those that manage and organise my care…	**Valid percent**[26]					**n=**
	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	
…are available to me and provide me with answers	33.7	39.6	14.2	7.5	5.1	890
…ensure my care workers have the right skills, knowledge and training	37.8	36.4	14.7	8.4	2.7	880
…provide me with as much time as I need	30.8	32.8	14.6	15.0	6.8	912
…ensure that I have to deal with as few different workers as possible	31.2	35.4	15.3	10.7	7.4	889
…ensure I receive good quality care	39.4	37.8	10.9	8.0	3.8	923
…provide useful information about other services	24.7	28.5	21.2	16.3	9.3	863
AVERAGE (incl. information)	32.9	35.1	15.2	11.0	5.9	892.8
AVERAGE (excl. information)	**34.6**	**36.4**	**13.9**	**9.9**	**5.2**	

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[26] Excluded from these valid percentages are missing data and invalid data, for example where someone may have ticked more than one option. Also excluded are the very small proportion of people who answered 'don't know' to these questions.

possible lack of awareness about the specific role and function of managerial staff.

Having made that observation, it is clear that across the six dimensions, older people report that they are less satisfied with the management and organisation of their care than they are with the direct delivery of their services. Overall, more than seven in ten (71.0%) older people either strongly or tend to agree that managers are doing all they can to ensure they are receiving a good service, with just over one in seven (15.1%) at the opposite end of this scale.

Consistent with other findings, older people report that they are most happy with the role of managers in respect of ensuring that they receive good quality care, and other than the outlier of the issue of information and signposting, they are least content with managers regarding the discontinuity of care workers that they are faced with. That said, when the two negative options (tend to disagree and strongly disagree) are amalgamated it is evident that the biggest issue for management concerns the allocation of enough time for the care workers to provide necessary services. More than one in five (21.8%) of older people 'tend to disagree' or 'strongly disagree' that managers are doing all they can, consistent with the one in ten older people who negatively rated the care workers on this dimension ('rarely' or 'never' in Table 5 above).

4.2.5 Overall comments and summary

Bringing all of this together, the questionnaire closed with two questions asking about people's experiences over the last 12 months.[27] The first (reported in Table 10) asked about overall satisfaction with their home care service in the past 12 months.

Table 10 · Overall satisfaction with the service in the last year

Overall I am…	Frequency	Percent	**Valid percent**
…very satisfied	449	43.6	**44.9**
…satisfied	392	38.1	**39.2**
…neither satisfied nor dissatisfied	85	8.3	**8.5**
…dissatisfied	58	5.6	**5.8**
…very dissatisfied	16	1.6	**1.6**
Don't know	5	0.5	-
No valid data	24	2.3	
TOTAL	**1029**	**100.0**	

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[27] It is worth remembering that nearly three-quarters (73.4%) of the sample had been in receipt of home care for more than 12 months, and so were well placed to offer an informed view.

Nearly half of the older people in our sample (44.9%) reported that they were ‘very satisfied’, with their care, the highest rating they could give. When combined with those who also reported that they were ‘satisfied’, this equates to just under six in every seven older people in our sample (84.1%) and subject to the confidence interval of +/-3%, by extension to the whole of Wales – it is fair therefore to suggest that between 20,500 and 22,000 older people in receipt of home care fall into this category. By definition therefore, just over 7% or between 1,000 and 2,500 older people are dissatisfied or very dissatisfied with their care in the last 12 months.

In terms of whether the service has got better, stayed the same, or got worse during the same 12 month period (Table 11), just over a quarter of people (27.0%) think that their care has improved, and more than one in seven think it has got ‘much better’. Over three in five (62.8%) people report that the care provided to them has ‘stayed the same’, with just over one in ten (10.2%) believing the service to have got worse in the same period. Extrapolated to the population of older people in receipt of home care in Wales, this equates to between 3,500 and 4,750 reporting considerable improvements in care, with between 500 and 1,000 people commenting on a significant downturn.

Table 11 · Direction of travel of the service in the last year

The service has…	Frequency	Percent	**Valid percent**
…got much better	157	15.3	**16.2**
…got a little better	105	10.2	**10.8**
…stayed about the same	609	59.2	**62.8**
…got a little worse	73	7.1	**7.5**
…got much worse	26	2.5	**2.7**
Don’t know	17	1.7	-
No valid data	42	4.1	
TOTAL	**1029**	**100.0**	

4.2.6 What relationships exist between the different variables?

The data reported above are, of course, very interesting in their own right. However in order to see whether there existed any statistically significant relationships between the different variables described above, a range of statistical techniques were employed.[28] The following sections provide an account of where such relationships were found and what the data showed. Tests were carried out to establish whether similarities and differences could be established in relation to the three substantive areas of their home

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[28] For an explanation of the different statistical tests used in this analysis see Appendix V.

care service: how frequently they receive good care, what the impact is on them when things go wrong, and what they think about the management of their care.

4.2.6.1 Differences between those who completed the questionnaire

In order to secure as large a sample as possible, those in receipt of the questionnaire were offered three options for completion. About one in three of the respondents were able to fill the questionnaire in on their own – the remainder needed some support to do so either from their care worker (5%) or someone else (62%).

Table 12 indicates the P values for the relationships between those filling in the questionnaire and care received. It is worth remembering that a P-value of less than 0.05 indicates that a statistically significant relationship exists between the variables. To help interpret the Table, cells shaded green indicate a significant relationship, and those in red have no associations – those on the borderline are left blank.

Table 12 · Relationships between who filled in questionnaire and care received (P values)

	Being listened to	Knowledge, skills and training	Time pressures	Continuity of care	Quality of care	Assessment and signposting
Frequency of receiving good care	<0.001	0.002	<0.001	<0.001	0.001	<0.001
Impact on me when things go wrong	0.243	0.008	0.045	<0.001	0.045	0.622
Views on managers of my care	0.380	0.558	0.106	0.165	0.157	0.006

In order to explain these findings, the following statements provide an indication of what is causing the relationships seen above.

Frequency of receiving good care and…

…being listened to · those filling it in themselves are more likely to 'always' be listened to, those needing help from other only 'sometimes' get listened to;

…knowledge, skills and training · this is due to lots of little effects, where those with help from someone else are less likely to 'always' have care workers with the right skills;

…time pressures · those filling it in themselves ‘always’ get enough time, those with help from someone else ‘rarely’ get enough time;

…continuity of care · those getting help from someone else do not ‘always’ get familiar care workers;

…quality of care · those getting help from someone else are less likely to ‘always’ have good care, although they ‘often’ do; and

…assessment and signposting · those getting help from someone else are less likely to ‘always’ get information; self completers are more likely to ‘always’ get information.

Impact on me when things go wrong and…

…knowledge, skills and training · those needing help from someone else are less likely to think the right skills don’t matter;

…continuity of care · self completers are less likely to think familiar care workers matter, the opposite of those having help from someone else; and

…quality of care · those completing it themselves are more likely to think quality of care doesn’t matter as much as those who getting help from someone else.

Views on managers of my care and…

…assessment and signposting · self completers are more likely to strongly agree that managers provide them with information.

Finally, in relation to the last two scaled questions, there were two other significant relationships. In terms of their satisfaction or otherwise with their care overall (P=0.008), those having help from someone else were less likely to be very satisfied and more likely to be dissatisfied. When considering whether their care had improved in the last 12 months (P=0.037) self completers were less likely to think things are ‘a little worse’, and those getting help from someone else were more likely to think they are ‘a little worse’.

4.2.6.2 Differences between Sample Local Authorities (SLAs)

On the face of the numbers, there is variation between the different SLAs in the sample. However, it is not possible at this stage to determine the type and form of any relationships and associations that appear to exist. Further work is needed to determine the exact ways in which these variables relate to one another, and the difference that geography may exert on the sample.

4.2.6.3 Differences between respondents of different ages

It would be fair to hypothesise that respondents of different ages may hold different views about the three substantive areas of their home care service: how frequently they receive good care, what the impact is on them when things go wrong, and what they think about the management of their care. Analysis demonstrably shows that this is not the case and there are no statistically significant associations between age and any of the dimensions of quality tested in the questionnaire. The age of people in our sample has not had an effect upon feelings about the home care service they receive. The only relationship exists between age and the likelihood of their needing help to fill in the questionnaire. The older people were the more likely they were to need support to complete the document, but this only really takes effect for those over 90 (P = <0.001).

4.2.6.4 Differences between recipients of in-house or out-sourced care

It is commonly thought that there are a range of differences between home care provided by local authorities (in-house) and that provided by the independent sector (out-sourced). Whilst some patterns exist, and as is the case for the potential differences between SLAs, it has not been possible at this stage to determine the precise nature of relationships and associations here due to the difficulties in isolating and testing for a range of confounding variables.

4.3 QUALITATIVE FINDINGS

In addition to the closed and scaled questions, the questionnaire contained four ‘open text’ questions. Three of these were deliberately structured to shed further light on the closed questions. There was one such question at the end of the section asking about the frequency of good care, there was another after the questions about the impact on older people when things go wrong, and a third after the overall assessments of satisfaction. The fourth open text question asked right at the end of the questionnaire was a space into which respondents could place ‘anything else’ that they thought was of relevance. Across the 1,029 responses to the survey, 1,359 valid ‘open text’ answers were received.

Given that the questionnaire was structured around the issues emanating from the ‘open call’, it was appropriate to code responses to the thematic framework. Interestingly, almost the same ratio of positive to negative comments (three negative for every two positive) was seen for both the open call and the questionnaire. Whilst there were more negative (n=1,140) than positive comments (n=739), unlike before there were shorter negative responses in the questionnaire than positive comments – see Table 13 below.

The quotations and comments reproduced in the following pages again mirror the structure identified through the coding process which is represented in the thematic framework (Figure 2 below). Data in the six substantive sections has been deliberately reproduced without further comment, inference or interpretation, so that the reader can see for themselves the range of issues identified with as little by way of interpretation as possible. Again, whilst a count of the number of times that positive and negative comments were made about these topics is produced for context, the numbers of quotations are not balanced in a slavish way, for this would be to misunderstand the

Table 13 · Differences in length of positive and negative responses in the questionnaire

Category	Total number of words coded	Total number of references[29]	Mean number of words per reference
Positively coded data	41,792	739	56.6
Negatively coded data	61,806	1140	54.2
TOTAL	**103,598**	**1,879**	**55.4**

purpose and quality of such data. As far as possible the comments reproduced below build on what had already been gathered as part of the 'open call' – an attempt has been made to avoid repeating what has already been heard.

As with the 'open call' for information, the data that follows needs to be seen in context. Two things are important here. Firstly, the data needs to seen for what it does tell us, rather than for what it doesn't. The numbers of positive and negative comments in Figure 2 does not suggest that people more typically have negative rather than positive (or indeed positive rather than negative) experiences of home care. What this data does, as before, is represent in considerable detail some of the real highs and lows associated with being an older person who has home care services delivered to them. In particular, secondly, it needs to be read in the light of the findings of the scaled questions reported above. So for example the ratio of 3:2 negative to positive comments needs to be understood in its appropriate context – i.e. one of broad satisfaction with the services received, even though there is room for improvement.

4.3.1 BEING LISTENED TO[30]

As before, respondents noted how important it is for their needs and choices in their home care provision being listened to. There were many positive experiences:

> *I now attend a day centre and every effort is made to accommodate my time change to get me ready for my transport.*
>
> *My care workers ask what I want them to do when they come.*
>
> *Carers [sic] tend to come at the time that suits the client, so she is not worrying who is calling and when.*
>
> *As well caring, they spend time with mum chatting about the past which she likes.*

---

[29] As before, a 'reference' in this context essentially means the number of passages that have been coded. For a full explanation of this see Footnote 9 above.

[30] There were 276 positive comments coded about being listened to, and 157 negative comments about not being listened to, a similar proportion to the 'open call' in Chapter 3 above.

Figure 2 · Thematic framework from questionnaire and frequency of codes (n=1029)

Thematic Codes	Number
TOTAL	**1879**
NEGATIVE	**1140** (60.7%)
1. Not being listened to	**157**
Unable to communicate with managers and others	38
Choices not incorporated	119
2. Implications of poorly trained care workers	**257**
Pressure on informal carers	36
Lack of skills, knowledge and training	137
Quality depends on care worker	84
3. Time pressures	**296**
Time pressures	122
Would like more time - turning up late	122
Not enough resource available	27
No allocation for travel time	25
4. Problems with continuity	**278**
Lack of continuity of worker or provider	250
Recruitment and retention problems	28
5. Poor quality care and support	**107**
Poor quality care	83
Risks to service users	24
6. Inadequate assessment and signposting	**45**
Poor assessment	19
Poor signposting	26
POSITIVE	**739** (39.3%)
1. Good quality care and support	**236**
Good quality care	197
Maintaining independence	39
2. Listening to service users	**276**
Choices incorporated	20
Positive relationship with care worker	122
Meeting service user needs	134
3. Benefits of professional care workers	**94**
4. Good continuity of care	**98**
Good care worker continuity	87
Reliability and punctuality	11
5. Adequate assessment and signposting	**35**
Acceptable or good assessment	17
Acceptable or good signposting	18

4.3.1.1 Positive relationship with care worker

Respondents remarked that much of this was focused on having a good relationship with their care workers. In part this focused on building trust and friendship:

> *The carers [sic] have become my mother's 'friends'*
>
> *One becomes used to the team of six and it is a sad time when one has to say goodbye, in fact quite emotional. We hasten to say however that each and every carer wishes to give of her best and for that we are eternally grateful.*
>
> *We have become attached to our main carer, trusting her and feeling secure.*
>
> *My regular team have become like family to me. I feel safe with them.*
>
> *Our team of carers [sic] are wonderful. Carers [sic] are the unsung heroes of the community and we truly appreciate all the help they give to us.*
>
> *I have nothing but admiration for my carers [sic].*
>
> *They are a brilliant group, always cheerful regardless of time and weather.*
>
> *Excellent girls. Everyone that comes to me are so pleasant and helpful. Can't praise them enough.*
>
> *Generally through the years I have been afforded kindness, courtesy and cooperation from the home care workers and management.*

This positive relationship had any number of identified benefits for older people:

> *They are always friendly and pleasant to me and I feel that I can tell them any concerns I have.*
>
> *The girls are very jolly and keep my spirits up*
>
> *As a lonely man living on my own, the girls company is a wonderful thing, they know older people watch the door to see them coming in cheerful smile and asking if you're alright – wonderful.*
>
> *I have found the carers [sic] very kind and useful. I rely on them for a chat as I do not see many folk.*
>
> *They are always cheerful and chatty.*

4.3.1.2 Meeting service user needs

Ensuring that their needs are met is clearly of central importance in any successful relationship. Older people commented on several ways in which their care workers met their needs. Firstly, they described how they met their emotional and physical needs:

> *One of my regular carers [sic] completed a day course in Parkinson's by a training official.*
>
> *Whatever my needs they see to me without hesitation.*

> *I feel the care and attention paid not only to my mother's physical needs but also her emotional well being is absolutely first class.*
>
> *My regular care workers (my team) know me well enough to see to all my needs which is considerable and cannot be faulted.*
>
> *At various times I have had care workers and I have found them very helpful. I have found that living on my own at 93 years of age, I welcome the care workers for their help and company. If only maybe to post a letter or take lids off tins etc., or even keep in touch with everything going on in the village.*
>
> *Every detail regarding my sister is written in an open book during each visit. If there is anything that the care workers are concerned about, and feel it is not in their scope, they always advise me to tell the nursing sisters or doctors at the nearby surgery. Later the care workers will check to see this has been carried out.*

For some this had the affect of improving their overall sense of wellbeing and quality of life: *'My sister looks forward to their visits and feels so much better in many ways afterwards'*. Another person commented that '*they have made my mum and my life a lot better*'. The attitude that many people reported of care workers always being ready to help was greatly appreciated:

> *I'll always ask if I need any other help, and always get it.*
>
> *I rely on them and they try very hard not to disappoint me.*
>
> *On the rare occasion when a crisis arises they can be relied upon to give me all the help I ask for.*
>
> *The care workers that visit this house are very helpful and listen to what my wife has to say, and they tell her if they notice or think if something is wrong.*
>
> *The carers [sic] do jobs that are not really their responsibility eg change beds, empty chemical bags and generally help in small ways.*
>
> *I have the utmost admiration in the way that my carers [sic] carry out their duties and feel that they go out of their way to help in every way.*

These comments extended to the fact that changes had been made in order to meet their particular needs: *The night mobile call has been a welcome addition to my care plan. I feel reassured that someone is calling between the time I am put to bed (9.30pm) and when I get up which is often 10.20am (due to the call rota) If I am unwell or need attention I know the night mobile will be around.*

4.3.1.3 Not being involved in/informed of decisions that affect service users' care

Things were not universally positive however. Older people reported that they had either been left out of decisions that they felt affected the care that they received, or had not been informed of changes that impacted upon them:

> *How can anyone change the system not knowing his needs. To them he is just a number not a human being who is severely disabled.*
>
> *I was not notified of any changes being made.*
>
> *I don't feel that I get respect from the service provider or the majority of carers [sic]. I don't like the way they operate the service. I find it very disrespectful to clients as the carers [sic] seem to think that they can come when it suits them whether or not it suits you. They operate what they call "closing the gap" which means that if a client cancels my call automatically becomes earlier whether that suits me or not. I really don't think that total strangers should be making changes in my life that I am not happy with. Why are the carers [sic] unable to keep to their timetable? I really don't understand.*
>
> *I am not happy with the system and the way it is operated but I feel that I have been forced into accepting a very low standard of care and I have been shown disrespect by the providers and carers [sic]. My opinion counts for nothing. I feel that I have given in to bullies because they only want their own way with everything and the clients view really doesn't matter at all they are not willing to change anything to suit the client.*
>
> *I don't like it when they change the team without consultation with me.*

For a number of respondents, these difficulties were a function of the relatively poor communication they had from those who are in charge of the management of the home care services:

> *Answers based on my reliance on my daughter to speak for me. I am not sure I could express my views if there was a problem because I don't like fuss.*
>
> *But we can see that if you are not forceful or articulate you are provided with the easiest option for the care agency and not the best for the client.*
>
> *I don't really know who to tell when I feel the quality of care is not so good. It feels as if I would be complaining about someone and getting them into trouble with their manager.*
>
> *I have had no contact at all with the manager.*
>
> *Also they change my regular times without letting me know. The top manageress is not very helpful. In fact I have never met her.*
>
> *If I ring the company concerned and ask to speak to a certain member of their staff I am always told they are either in a meeting or otherwise not there. Even though I have asked I have been told they will get back to me they never do.*
>
> *Managers do not listen about what we say.*

4.3.2 SKILLS, KNOWLEDGE AND TRAINING[31]

A large number of older people were satisfied with the levels of knowledge, skills and training that they saw their care workers demonstrate. However, considerably more expressed critical comments about this issue.

4.3.2.1 ‘Professional’ care workers

Respondents detected that many workers were ‘professional’ in their approach to their work, and that many were also very experienced in their role:

> *All the carers [sic] who have visited me have been helpful professional and polite.*
>
> *Care workers are sufficiently professionally not to be or show stress under pressure*
>
> *I have found the care workers from the agency do an excellent job in a cheerful professional manner.*
>
> *I feel fortunate that I have an excellent team who are well trained and keep my family informed about my care.*
>
> *The skills knowledge and training seem to be in place.*
>
> *In the latter month I have had very experienced ladies and I feel much happier. Hopefully it will continue. If I don’t feel well they are very kind and caring.*
>
> *We are very satisfied with the skill of the carers [sic] and the manner with which they perform their duties.*
>
> *Every carer [sic] wishes to give of her best and for that we are eternally grateful.*
>
> *When it is a new worker they always address themselves and show their badge through the letter box.*

Having the right kind of professionals caring for them meant that a number of older people felt more confident that their dignity was being kept intact, and that their workers were respectful of them as individuals:

> *My mother feels home care is potentially intrusive, because of the intimate nature of the work. However she says that she has been able to keep her dignity and is always treated respectfully and with genuine kindness.*
>
> *The care workers allocated to my husband have been friendly, courteous and respectful at all times. No problems whatsoever.*
>
> *Carers [sic] very good and treat me with respect and dignity.*

---

[31] On 257 occasions, negative comments about care workers’ knowledge, skills and training were coded, compared to 94 positive statements. Again this is broadly in line with the proportion of positive and negative comments seen in the ‘open call’.

4.3.2.2 Lack of knowledge, skills and training

However, as indicated, considerably more people who gave an answer to these questions, expressed concern and criticism of what they perceived to be a lack of knowledge, skills and training. This was an especial concern in relation to new and relatively inexperienced staff:

> *I feel that the carers [sic] need more training they are left to fend for themselves after only a week's "shadowing" another carer [sic] who has not had any training themselves.*
>
> *New and younger carers [sic] in my opinion do not get the correct training when it comes to people like myself.*
>
> *Only trouble is, if my husband falls (which happened yesterday with a more mature care worker), the young carers [sic] would panic and have little experience to deal with an emergency.*
>
> *She hadn't even had an induction! I had to instruct her on everything. I wasn't familiar with her.*
>
> *Carers [sic] are employed too young and made supervisors with very little practical experience - they're young for the job.*

Thinking about improvements, respondents helpfully identified a number of specific areas where they perceived changes could be made. These centred on hygiene and washing, medications and equipment, listening skills, and food preparation. The following quotations are indicative of many others:

> *In my opinion, all of the rest of them need to go back into training and be shown how to do a full body wash properly, such as rinsing soap of the body before drying. Making sure a person is dried properly and washing all of the body and not just the parts that are easy to get to. I have parts of my body that never see water with the majority of my carers [sic], and I very rarely feel clean.*
>
> *I feel that recently my care workers have not had training about cooking and presentation of food, or folding and putting away clothes neatly.*
>
> *I don't think all the carers [sic] are properly trained to understand the requirements of the drugs. They give them out in a mechanical way.*
>
> *Had a case where staff were not sure how to manage hoist properly. This meant spent all day in bed, only because they pulled the wrong rope.*
>
> *The new carers [sic] need training to work with elderly with memory problems. Half of the staff haven't got a clue!*
>
> *Hygiene standards are quite poor. We have found carers [sic] emptying a commode and the next minute handling food.*

> *When people don't listen to what I have to say, the wrong answer is given to me, that isn't any use because they haven't got the skills to listen properly to what I ask them, and to act on them.*
>
> *2 out of 6 of my carers [sic] don't have the interpersonal skills that come with maturity.*
>
> *Individuals must have good people skills and be reflective listeners so we know they have heard and understood what we are trying to say.*
>
> *Sometimes we have new staff – very young – who don't seem to necessarily see what needs doing without being told.*

4.3.2.3 Pressure on informal carers

Respondents noted that poor care leaves gaps in their services, which means that their needs are not fully met. For those who had unpaid carers – typically partners, family or friends – this put an additional burden on them. This was especially problematic in those situations where those carers had needs of their own, or were struggling to afford all the care they needed:

> *Help is most important for the people being cared for, but just as important is the help that should be given to the 24/7 full time carers who look after them. Sadly I find that after 2 years of caring for my wife this is not so. I am 89 years of age and would not have it any different looking after my lovely wife (marries 70 years) but 2 hours shopping time per week?*
>
> *Caring for a loved one becomes a way of life with very little room for anything and years pass by not without notice or very easily but pass they do.*
>
> *Have had to pay toward care and could no longer afford to pay so I do all the work myself without any help at all. Sometimes I get respite, but gain I have to try to save as I have to pay towards it.*
>
> *When people are disabled and at home they need a lot of care my wife does everything for me 24/7. By looking after me at home she saves the government thousands a year but when she needs a rest she has to pay for it, it is a disgrace when we both worked.*
>
> *I am worried that I won't be able to stay at home because my daughter isn't well and her husband takes time off work to help out and I won't be able to pay for the extra private help I need as they help out financially with this and they are under pressure at the moment too.*
>
> *I have been told that it will cost £13 a time for someone to supervise my mother's medication. I think this is rather excessive and reduces the likelihood of me going on holiday.*

> *I am lucky I have good neighbours and family that help with household chores. My husband who is also frail and partially sighted, manages to help me dress.*
>
> *My mum pays over £200 a month for ½ visits every morning. This is an essential service for us and I have thought about leaving my job to take care of her, but unfortunately my husband's job hangs in the balance. I just wish they would leave things as they are.*

4.3.3 TIME PRESSURES[32]

Much of what follows is similar to those issues raised by respondents to the 'open call' for information. Similarly there were only negatives comments raised in relation to this theme, hence the negatively-slanted title of this section.

4.3.3.1 Not enough resource available

Overall, older people again felt that the care workers were not allocated enough time to provide the care that they needed – much of this was almost identical to the complaints raised in Chapter 2 (above), but one person, representative of many others, remarked that they felt inhibited to ask for additional resource: *Care workers fill time allotted but I feel I should not ask for more time as it is expensive*. What emerged as a new theme here, was that a range of people pointed to staff shortages as part of the problem:

> *Shortage of staff and staff cuts mean there are situations one has to put up with and there is always the worry the care might change or be withdrawn.*
>
> *They send office staff if they are short staffed who haven't got a clue what to do.*
>
> *It is sad to note that within this time, how this service has dwindled down from around 20-25 carers [sic] to only six carers [sic] working this whole area now.*
>
> *They could do with more carers [sic] but at the moment government cuts mean less people being employed.*
>
> *This is usually because of staff shortage or unavailability and invariably I have the same problem both in the morning and the evening visits.*

Again as before, many respondents identified that the time pressures described above have a consequence for the quality of care that service users experience. Short of repeating much of what has already been heard, there was a degree of sympathy that this is not down to the care workers themselves – *the care workers do not have the time to sit and listen, which is not their fault* – and that they are perceived by service users to be constrained in terms of speaking out – *the carers [sic] are restricted by the Office. They are not allowed the time they need to care for me. They are afraid to lose their jobs.*

---

[32] As with the 'open call' data, there were only negative comments in relation to this issue (n=296). This was the largest number of negative comments for any theme.

That is why they do not say anything. These problems are exacerbated when dealing with increasingly complex care situations:

> *What is obvious though is that they are often pushed for time with which to deal with her – the dementia and arthritis make her reactions much slower than normal and this often eats into their time with her.*

All of this said, older people who responded did acknowledge that care workers are often doing their best in the time allocated and the difficult circumstances they are facing:

> *I have no complaint about the staff themselves, I just think too much is expected of them.*
>
> *The care workers have very limited time in my house and therefore are not able to spend time talking to me. They generally have good communication skills but are not able to use them to the fullest extent due to time constraints.*
>
> *They do what they are booked to do with no time for discussions. The office doesn't realise and give enough time for the Carer [sic] to do what is required for some jobs. Any blame is not with the Carers [sic].*

4.3.3.2 Timing of calls, and time spent on calls

Again, building on what was reported in the open call, service users expressed dissatisfaction with missed calls or the irregular call time pattern that they were frequently faced with. This was, by frequency, the biggest problem in relation to time pressures. Typical of many, many others was the following sense of frustration expressed by this person: *The dissatisfaction lies in the time of arrival of the carer [sic]. While the care plan states 8.30am-9am I may have a carer [sic] arriving anything between 7.15am-10am.*

In addition to noting the fact that call patterns are often irregular, respondents gave an indication of the kinds of impacts that these practices can have for them:

> *Unreliable time keeping is a cause of stress sometimes – seem to spend time waiting for toileting or perhaps visits too close together e.g. last call 7pm in evening – morning call 9am in morning, or morning 9.30am then lunch 12 noon.*
>
> *My mum relies on the carers [sic] to come at a certain time in the morning. This time can vary between 7am-9am. This is a long wait for my mum and she is unable to wait, so sometimes attempts to make herself breakfast. This worries me as she is very unsteady on her feet and relies on a zimmer frame.*
>
> *I am diabetic. Sometimes lunch can be at 11.45 and tea call at 5.30pm – this is far too long for my condition. I don't expect it can always suit me, but it's a kind of "you get what you get situation".*

> *The girls do not always call to a regular time, which is understandable, but if they call for breakfast at 10.30 and 12.00 for dinner that is unfair.*
>
> *I become fretful and nervous when the temporary or replacement carers [sic] do not arrive at the allotted time.*

Similarly, older people expressed a range of concerns that they were often in receipt of much less direct care than they could have expected to receive based on allocations in their care plans:

> *Care paid for – 30 mins AM, 30 mins PM. Care given – 10 -15 mins AM, none PM.*
>
> *These visits are timed for 30 minutes – 15 would be about average. Carers [sic] have very much a 'snakes and ladders' care route which of course takes time.*
>
> *The majority of carers [sic] do not adhere to the contracted hours set in the care plan*
>
> *Care plan allows for 20 min visits twice a day. However, visit last only approx 10 min on average.*
>
> *Rarely do staff stay the allocated time. They 'get away' as quickly as they can*
>
> *The care is supposed to be 45 minutes (that's all we can have) for personal care and a light snack and drink. Some days we are lucky to get 20-25 minutes. The carers [sic] are always saying they have not got enough time, because they are covering other calls.*

4.3.3.3 No allocation for travel time

Compounding this issue was the fact that older people were acutely aware that care workers are under pressure due to the fact that either little or no allocation is made for the need to travel between clients, which has an additional impact on the length of visits to them:

> *Care worker does not have time to give full time allotted to me. They make her appointment times from one client to another and no time for travel in between. Consequently she cannot always give my husband his full half hour or myself the full time allotted.*
>
> *In regards to the time allocated as the care worker is not given travelling time between calls obviously someone loses some time or all calls are shortened especially when the care worker travels to different towns.*
>
> *I am supposed to have 30 minutes of care in each session. Sometimes it is les that that. I think that the carers [sic] travelling time between clients comes out of my care time.*
>
> *The service is chaotic. Part of the problem seem to be that carers [sic] cover huge areas and take time to travel between calls and are subject to traffic hold ups. (It's not very efficient and certainly not green!)*

There was considerable empathy expressed for the difficult situation that this places care workers in, and respondents advocated that the mode of travel, time needed to get from place to place and the geography of an area needs to be taken into consideration when planning services:

> *That they all drive to do their work, pressure with time is a concern although none of my business – their rotas seem to have a "beam me up Scottie" set up involved.*
>
> *[Agency] do not give the carers [sic] enough time between addresses to get to me. You can hardly travel 7 miles in 1 to 2 minutes. Not the carers [sic] fault it's their office.*
>
> *Carers [sic] do not get paid when travelling and receive no travelling expenses. The office give out calls to opposite ends of town as they do not lose money. The carers [sic] are run ragged for little money as they get paid for the time of the call and are cutting calls short to make their list.*
>
> *Sometimes management are very inconsiderate and need to work out none realistic timetables. The times between some calls are impossible - distance and heavy traffic is not allowed for.*
>
> *One of my care workers seems to be rushing a lot. She says she has a lot of walking to do after finishing with me.*

4.3.4 CONTINUITY OF CARE[33]

There were a mixture of responses here, but for those who took the opportunity to comment, there was more to criticise than praise in terms of the continuity of care that they receive.

4.3.4.1 Good continuity

On the positive side there were a considerable amount of comments relating to the fact that older people feel that when they are in receipt of care form the 'regular'[34] care workers, their needs are understood and the familiarity that continuity affords is helpful in delivering good care. It is important to note that older people recognised that this can help both the service user, and the care worker:

> *Because the same small numbers of carers [sic] come everyday I have been able to get to know them and they have been able to get to know my husband and ways to deal with him.*

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[33] Unlike the 'open call' when the numbers of positive and negative comments were almost the same, in response to the questionnaire, there were almost three times as many negative (n=296) than positive (n=98) coded comments.

[34] It should be noted that we deliberately provided no definition of what this might mean in practice.

> *I find it helpful to have the same carers [sic] regularly, it builds up a feeling of continuity and is very helpful for them and me – they know what to do, where things are. It is important to me to build up a rapport. It makes me feel more secure*
>
> *Having the same carers [sic] helps as they know my needs and they are all very helpful and friendly.*
>
> *Some long serving carers [sic] know me well and my needs.*
>
> *The service providers are quite good in the continuity of their care workers. My mother has vascular dementia, and I have found that a routine works well for her, as it allows her to remain in her comfort zone. She gets used to the familiar faces and it also allows the carers [sic] to build up a rapport with my mother. They get to know her likes and dislikes which is very important as unfortunately, she cannot always articulate what she wants.*
>
> *A regular carer [sic] knows what food is required*
>
> *When I get my regular care worker, everything is fine.*
>
> *My regular care workers are wonderful.*
>
> *I was most happy when I had a team of 3 carers [sic] who were with me most of the time.*
>
> *For once – familiarity does not breed contempt – the first and best carer has been excellent and his holiday replacement is as good.*

Respondents noted that there were a range of potential benefits that could be derived from a long-standing relationship with care workers. These included establishing relationships, overall reliability, and punctuality:

> *As they get to know me more, we have more to chat about and I look forward to their calls.*
>
> *Is important to keep same carers [sic], as you build a good rapport with them plus a bond and trust*
>
> *I feel it's important for mum to have continuity of care worker, so that she can form a relationship with her and feel confident of the care she gets when she comes. She has!!*
>
> *Over the months, he has accepted female carers [sic] especially they are the regular carers [sic] and with whom he has built up a kind of rapport.*
>
> *My care worker calls every morning without fail no matter the adverse weather.*
>
> *They never let me down.*
>
> *We find our carers [sic] are very pleasant, punctual, efficient and helpful.*

4.3.4.2 Poor continuity

There were significant numbers of ‘open text’ comments about the problems of continuity. Indeed of all of the themes, it is the one which attracted the highest number of negative comments. Much of what was reported in the questionnaire mirrors that from the ‘open call’. One specific area that came in for criticism was the observation that because ‘regular’ care workers are more aware of service users’ needs and routine, when there is discontinuity of care, older people can suffer:

> *I find it very difficult that as soon as a carer [sic] gets to know me and how I like things done, they are taken away and I get someone else.*
>
> *I accept that sickness cover or holiday cover means this has to happen. It is unsettling and I have to explain things over and over again. Also as with any people services, sound working relationships are important and this is enhanced by being cared for by people who have got to know me and who I have got to know. We all have different strengths and you adjust to it. However, there seems to be a deliberate policy in this area to ‘shuffle the pack’ at regular intervals and disturb relationships because someone has decreed that constantly unsettling teams and partnerships is a good thing. They don’t know as much about managing people services as they think they do.*
>
> *Some members of the care team are excellent but do not visit often enough. Some are weak. When I first was receipt of this service it was excellent and I had a team that was and efficient and became “good friends”. I was very comfortable and happy with the service. I feel there has been a major deterioration since December 2011 due to the fact that the carers [sic] are swapped very often and I do not really have a “regular team”*
>
> *Due to the nature of my father’s condition I cannot stress enough about the continuity of care. To send my father new carers [sic] without warning to him is stressful and confusing.*
>
> *I don’t like having strange carers [sic] because I have a bath every day.*
>
> *I don’t like it when you send girls I have never seen and don’t know what to do and I have got to show her. It is not helping me at all or my husband.*
>
> *Having a regular care worker who knows how to approach this user is vital. She will not eat regular ‘hot meals’ and will fill up on bread and jam – as she is a diabetic it is vital she eats a proper meal to keep her sugar levels stable. Trying to explain this to different care workers with little knowledge or understanding can lead to catastrophic consequences.*

Of particular concern for older was the sense of insecurity that accompanied the sensation of not knowing the person who is coming into their house:

> *It matters to me that sometimes the care worker who turns up at my door is somebody I have not met before.*
>
> *At the start carers [sic] were constant; now they are changing (often daily). I find this distressing. Also I don't receive the letters notifying me on time who is coming.*
>
> *I feel what is most important is the number of strange carers [sic] that are allowed my key safe number to gain entrance to my home. This needs to be looked into, it is very worrying as I don't [want to] see quite [such] a number of stand in carers [sic] again.*
>
> *The service I have has been better because my husband was getting the girls he knew and you don't think of how he feels when you are sending strangers to our house.*
>
> *I think service users should be informed more often of changes being made. Then it would not be such a shock when strangers walk in.*
>
> *We used to have a list of the workers we could expect. It doesn't happen now. It is very unsettling and especially in the morning when you don't know who to expect.*
>
> *It causes us great distress to keep having strangers in the house and it breaches dignity and respect.*
>
> *I never know who is coming. I'm hard of hearing and cannot see faces clearly.*

Compounding these issues was the frequency with which older people reported that their care workers were being changed. For some the very high numbers of different care workers that they would typically expect to have to deal with was troubling:

> *In the seven months my husband has been receiving care we have met at least 17 different carers [sic] and have an average of 10 different ones per week.*
>
> *With 70 different workers coming in every week I realise it's hard to have a regular team, at the moment it varies between 12-16 different workers every week. What upsets me is when two new workers who don't know my husband's circumstances are put on the rota together. I insist that new workers must always work with someone which knows the situations.*
>
> *Lately carers [sic] are changing daily.*
>
> *The continuity I had has completely gone. I have had so many different girls that I have lost count.*
>
> *I can only say that nothing is usual or typical. It seems to me that I am continually being tended by one team and then another, I don't think even the carers [sic] themselves know where they will be from one week to the next.*
>
> *I have the impression that managers are doing their best to ensure that I meet every care worker in the whole of South Wales.*

4.3.4.3 Recruitment and retention problems

Older people suggested that the poor continuity of care that they had to face was a symptom of broader recruitment and retention problems with the workforce, a theme which also emerged in the ‘open call’.

> *At least four of dad’s regular carers [sic] left to go to another company which pays more money and petrol money.*
>
> *The resultant lack of moral is losing the better carers [sic].*
>
> *The five great carers [sic] I have lost in the last six months, said the same thing, they loved the job but management let them down, because [sic] they have gone on to the same job somewhere else. This is supposed to be CARE IN THE COMMUNITY.*
>
> *The saying “you pay peanuts, you get monkeys” comes to mind (even local manager bailed out).*
>
> *It seems that seems that girls leave quickly because of the pay, hours and job expectations.*

They suggested that in order to improve the situation, recruitment policies need to be reviewed and improved:

> *Most worrying concern is recruiting staff straight from school (18) who have had no life experience at all. For this reason I refuse this age group. We all need our dignity where personal care is concerned.*
>
> *The reason the service has got worse is that the company employed many new carers [sic]. That meant less work for the regular carers [sic], they then had to train people up who then left.*
>
> *I feel that the caring profession is a job you do because you want to help people not because of how much money you earn or you do it because you can’t get anything else. So people should be chosen more carefully to do the job.*
>
> *A lot of carers [sic] are not suitable for the job but it seems that anyone will do. One of the carers [sic] had previously worked in a pet store and very young. Hardly commendable to work for elderly clients.*

4.3.5 QUALITY OF CARE[35]

Respondents recorded almost double the amount of positive than negative comments about the overall quality of care that they receive – but it was the case that some of the negative examples of care were very poor.

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[35] There were 236 positive comments recorded about the quality of care received, and 107 negative comments. These are a very similar proportion to the 91 positive and 47 negative comments from the ‘open call’.

4.3.5.1 Good quality care

Most positively, a number of older people noted that their care workers consistently provide good quality care:

> *I have been receiving six years of excellent care from my local homecare services.*
>
> *The service has been good and settled.*
>
> *The care I get has been good and continues to stay good.*
>
> *The service is always brilliant.*
>
> *I am extremely satisfied with the level of service that I receive by the care workers. The care that I receive is always excellent and is continually improving.*
>
> *The company has grown from strength to strength. We have also recommended them to others. We have never had any serious problems and are more than happy with them.*
>
> *We've always been very satisfied with our care company.*
>
> *They perform an excellent daily service for me everyday*
>
> *Simply put the quality of the service has remained high.*
>
> *I have always been very satisfied with the service I receive. It always has been very good.*
>
> *The team of carers [sic] who look after my father every day is excellent.*
>
> *The service I receive is the same whoever calls. I am very satisfied.*

Some suggested in their answers that the care that is provided to them not only meets, but often exceeds their hopes and expectations, which results in them being able to maintain their independence as they wish:

> *I cannot speak highly enough about the quality of their care.*
>
> *The senior management and care workers have provided the quality of care I expect.*
>
> *I can only state that the care and attention I have received from social and care workers have beyond reproach. I could not have wished for better.*
>
> *The care and service today is unbelievable and we are so grateful.*
>
> *This service in the home is marvellous because it means I can stay in my own home surrounded by my own "Everything" which gives me a great degree of independence, satisfaction and happiness, means I don't have to go into a home.*
>
> *I could not remain in my own home without them. To have to give up my house where I have lived for 50 years would be terribly upsetting for me.*

> *Things have become a little harder over the last twelve months and have relied on the care workers for more support, this they gave gladly so I could continue to keep Dad in his home happy and content.*

4.3.5.2 Poor quality care

There were a number of different aspects to the poor quality care that respondents identified. The first of these focused on the fact that some service users feel that financial constraints affect the quality of their care:

> *In my view the level of care from [agency] has more to do with financial considerations than the patients needs.*
>
> *Private sector companies have driven the "care" out of caring.*
>
> *Sometimes expense overrides the care to human life.*
>
> *This is inhuman and social services have put vulnerable people's lives at risk all for saving money.*
>
> *My dad is only a client or number to management with the £ sign being the main. The management do not think of the person.*

The next issue raised was that of the emotional and physical impact that poor quality care can have on service users:

> *Sometimes when things aren't done properly it makes me anxious.*
>
> *Some workers barely recognise I am even there, using the minimum of conversation. A little common courtesy goes a long way.*
>
> *All carers [sic] must be aware that elderly people are frail and their skin is like paper. They should not be scrubbed but washed gently, patted dry not rubbed dry with a stiff towel! Pads must not be pulled up tight so that the person can sit comfortably.*
>
> *I am not happy with the system and the way it is operated but I feel that I have been forced into accepting a very low standard of care.*

Shortcomings in the quality of care received were occasionally only identified when a carer or other family member picked up on the fact that something had go wrong – they were unable to rely on the care workers to do this, which they felt was their job:

> *I, the daughter, need to check all the time that carers [sic] are doing what they should according to the care plan. I have needed to check the personal care plan (within the accommodation) and needed to point out many mistakes including vital mistakes like medication and risk assessments. I cannot trust them to get on with things – this is difficult when you live a long way away.*
>
> *Without the constant monitoring by my family when the care was contracted out to the private sector I wonder if I still would be here.*

> *I am on hand to monitor the care provided I would be concerned for elderly people who do not have this back up. I feel that I have to supervise on a daily basis to ensure satisfactory standard is maintained.*

Following this theme there were a number of specific comments made about the fact that care workers were not routinely following the instructions as laid out in the care plan, which is exacerbated on the occasions when care workers have a lack of information or knowledge about service users' needs:

> *Unfortunately the plan is not implemented very thoroughly by home care supervisor and home care team.*
>
> *One carer [sic] has written in the book that she took me shopping one day – but she didn't. That day she said she had no time to take me!*
>
> *If supervisors visit the client after a carer has been (not when they are there) they will see for themselves, the 'care plan' has not been carried out.*
>
> *The carers [sic] do the bare minimum, sometimes nothing.*
>
> *The agency does not even inform them that I am deaf...*
>
> *Where is my mother's file/care plan? Each member of staff appears more concerned with phone/logging in and out than actually performing the necessary tasks.*

At its most extreme, the poor quality care described could result in significant shortcomings for a small number of older people. Whilst comments like those below are by no means typical, there are nevertheless instructive of the magnitude of problems that can arise:

> *On three occasions the home carer [sic] has left my gas switched on in my kitchen stove. Once the gas was not even alight. I could have been killed!*
>
> *Something DID HAPPEN – DANGEROUS and more than ONCE! I was given my flask of boiling water WITHOUT the lid on but the CUPS ON so you could not see. It is very important that care workers LISTEN to me!*

4.3.5.3 Quality of care depends on the individual care worker

Respondents identified through their answers some of the factors that influence whether good or poor care is delivered. One of the most crucial aspects is the attitude and approach of the care worker. Not all care workers seemingly display the key characteristics implied by their job title:

> *Some are "carers" some are really "don't carers".*
>
> *Well it depends on the care worker that is sent to you. Some are better than others. You have care workers who care, then there are others it's just a job and that's all it is.*

> *Most carers [sic] really care, there are a few to whom I feel I'm just "a job to be done".*
>
> *There is a wide range of carers [sic] from incompetent to competent. Caring to uncaring. Patient to impatient.*
>
> *I was unhappy for some time about the care worker, who was awkward to me. She made my time with her an unhappy one. She was not always kind to me; and would sometimes avoid speaking to me, too. My son knew I was unhappy.*

Many of these views centred around the attitude taken by the individual care worker to the person they were caring for, and the job that they were there to do:

> *The evening carer is very quick (in and out) has an attitude (thinks she knows everything.) Does her job in half the allocated time. Makes statements e.g. "you don't pay for your care" without knowing any facts – I do pay for care. Causes unnecessary stress occasionally.*
>
> *Some of the care workers who visit me are not as dedicated to their job as others and can be sloppy sometimes uncaring in their approach.*
>
> *Some carers [sic] rush even when they have enough time given. Some of them can be very moody and abrut [sic]*
>
> *The quality of care varies depending on the carer – some are very conscientious; others are always in a rush and can't wait to get out.*
>
> *Not all carers [sic] are as helpful and understanding of elderly peoples needs*
>
> *Some care workers demonstrate that they can deal with persons with Alzheimer's, others don't.*
>
> *The quality of care received depends again on the individual attending; some do, some don't; some will, some won't.*

4.3.6 ASSESSMENT AND SIGNPOSTING[36]

There was a balance of both positive and negative comments in relation to assessment and signposting. In terms of assessment, older people reported that they had experienced good relationships with social workers that resulted in their needs being properly understood and met:

> *My social worker has always ensured I get the care I need*
>
> *My sister is the one in touch with the social worker who is my Home Care Plan Manager. He keeps in touch and makes sure we have everything we need.*

---

[36] Unlike for the 'open call' (when older people only reported criticism) there were both positive (n=35) and negative (n=45) comments coded in relation to assessment and signposting

> *The social worker who looks after my mother's case is particularly good. She calls me regularly before every review to see if there are any outstanding questions or issues.*
>
> *We had all the help needed in setting up the care package for my mother. The senior staff did this all for us.*
>
> *Although I received a visit to see if the time I receive could be reduced they could see that my body is worse and the services have remained the same.*
>
> *I am extremely happy with the current assessment team, and hope that when I transfer to a private sector agency their standards will be as high.*

In addition, a number of older people also reported that they had received support in finding out about other services that might help them. This signposting was undertaken by a range of people:

> *As stated above I have never had to search and apply for help, services etc. These have always in the first instance been, suggested, arranged etc. By other doctors/ district nurses / local authority and others who show concern for my wife and me also.*
>
> *I feel that the help and advice and care provided by the [location] social services is very good.*
>
> *Information on any problem always available from carers' [sic] co-ordinator.*
>
> *Information about various services is always provided to me.*
>
> *Some carers [sic] offer information. Other carers [sic] give information when it is asked for.*
>
> *I am not sure that the carers [sic] have the obligation to do so. If I asked, and they did not know, I am confident that they would refer to the managers.*
>
> *We are now told any new information regarding other services that would benefit mam.*

This good practice was not reported by all respondents. In terms of making contact with social workers and issues to do with the frequency of reviews, older people noted a number of frustrations:

> *It is always difficult to get in touch with social services to change any of the services provided.*
>
> *I have no idea who my social worker is! I have not seen or heard from a social worker for over a year, I feel that they should call on their service users regularly to do reviews as they would if I was in a care home.*

> *Getting to speak to the social service person who is supposed to be your care worker is very difficult.*
>
> *Having recently been in hospital and wanting to come home, I feel that process with social workers/panels to assess [home] care needs takes far too long.*
>
> *The carer [sic] service is limited to actual care programmes most of the time which is issued by social workers or managers who have no actual idea of what is needed. Needs change daily.*

Similarly, older people reported problems in being informed of other useful services, and generally that they lacked relevant information:

> *I need help as I am registered blind as well as terminally ill with cancer and it would help a lot if carers [sic] would or could let me have more information.*
>
> *Need to ask about other services rather than any information provided.*
>
> *Carers [sic] rarely give any information about other services on offer.*
>
> *My mother had toothache. We needed to contact [service]. [Agency] didn't have a telephone number and told us we had to find out about this service on our own. Luckily a member of the family worked in dentistry and my mother had the care she needed. What happens to these old people who have no family support? This is very worrying!*
>
> *When I have asked any care workers for useful information, they refer me to my social worker who also doesn't know the answers to some of my questions.*
>
> *I wish I knew what help I am entitled to from Care and Repair or other help where I only have to pay lower than repair people who work at a private company. I get no information at all.*
>
> *They certainly are unaware about other services available to me.*

5 · CONCLUSIONS

Thank you for allowing me after so many years to express my feelings.

Home care is not a well understood part of our social services – as the quotation above suggests. This study of home care has produced a first – a detailed and unique synopsis of the views of recipients of these services in Wales. We believe the open call for evidence, coupled with targeted questions to users of services in four local authority areas, has produced an unprecedented depth of information about the nature, extent and quality of services regardless of whether the service provider is part of the statutory, voluntary or independent sector. Moreover, the volume of participants in the survey sample allows conclusions to be reached which are representative of all of Wales, which is new, exciting and at the same time challenging.

Drawing conclusions from such a large and detailed data set is very difficult. Our research confirms that home care is a cornerstone of maintaining people's independence within their communities. It is a personal, individualised service and as such it is difficult to generalise different opinions of its efficacy. How, for example, should the total satisfaction of one service user be compared with the dissatisfaction of another? Should the fact that nearly 85% of service users are 'very satisfied' or 'satisfied' with the overall service they are receiving lead to a conclusion that, more or less, all is well with the service as a whole when we know that those who are very dissatisfied represent up to 2,500 actual service users across Wales? In this respect, satisfaction ratings, based on percentages, have to be balanced with the knowledge that an inadequate service to some individuals may represent a significant negative impact on their quality of life.

Nevertheless, there is clearly much that is right with home care services in Wales, much that is working very well, and much that is having a very positive bearing on the quality of life of older people. We also found there is inconsistency of provision within and between different sub-groups of our sample and this presents a challenge in terms of rectifying wrongs. However, it also presents an opportunity for mutual learning leading to improvement. By differentiating between attitudes about front line workers and their managers, we have identified that the agenda is about the whole home care system, not just a part of it. Whilst there is a case for celebration, there is also a case for concern. There is certainly no case for complacency.

The objective of this study was to build up an evidence-based picture of what was happening across Wales to highlight common problems and concerns as well as identifying the services people valued so that the Older People's Commissioner could continue to promote older people's interests and encourage good practice in home care service provision. We are confident that our work will now enable this to happen. There is much to praise about the provision of home care services in Wales here, but equally there is considerable room for improvement.

APPENDIX I · Welsh Government data on home care (as of 31.3.2011)

Table A.1 · Numbers of service users in receipt of homecare, 2005-2010

	2005-06			2006-07			2007-08			2008-09			2009-10		
Age	18-64	65+	**Total**	18-64	65+	**Total**	18-64	65+	**Total**	18-64	65+	**Total**	18-64	65+	**Total**
Wales	**5850**	**21077**	**26927**	**5631**	**20584**	**26215**	**5479**	**19946**	**25425**	**5530**	**20155**	**25685**	**5563**	**19690**	**25253**
Isle of Anglesey	119	641	760	118	576	694	129	684	813	134	749	883	129	627	756
Gwynedd	264	1106	1370	255	1052	1307	259	1044	1303	290	1040	1330	343	1009	1352
Conwy	409	1226	1635	433	1189	1622	423	1005	1428	166	897	1063	279	891	1170
Denbighshire	218	709	927	193	693	886	209	641	850	357	1161	1518	247	758	1005
Flintshire	283	839	1122	309	830	1139	337	820	1157	346	831	1177	323	914	1237
Wrexham	353	659	1012	314	644	958	300	676	976	249	659	908	211	673	884
Powys	191	1040	1231	170	1174	1344	188	1156	1344	178	1082	1260	191	1111	1302
Ceredigion	32	416	448	40	401	441	36	347	383	34	332	366	33	321	354
Pembrokeshire	89	983	1072	74	853	927	62	816	878	64	885	949	77	896	973
Carmarthenshire	171	1106	1277	140	1061	1201	160	1091	1251	143	1052	1195	136	981	1117
Swansea	244	1214	1458	238	1463	1701	262	1491	1753	277	1454	1731	273	1701	1974
Neath Port Talbot	275	1095	1370	287	1044	1331	271	978	1249	265	930	1195	272	882	1154
Bridgend	305	892	1197	292	882	1174	210	871	1081	207	836	1043	210	835	1045
Vale of Glamorgan	258	748	1006	237	642	879	197	596	793	188	561	749	199	474	673
Cardiff	914	1733	2647	884	1474	2358	901	1371	2272	971	1506	2477	1059	1748	2807
Rhondda Cynon Taf	506	1937	2443	512	1973	2485	512	1978	2490	524	1914	2438	520	1719	2239
Merthyr Tydfil	151	463	614	121	407	528	123	374	497	120	363	483	117	349	466
Caerphilly	262	1344	1606	215	1213	1428	190	1068	1258	174	952	1126	167	922	1089
Blaenau Gwent	235	615	850	240	593	833	177	533	710	254	622	876	198	477	675
Torfaen	112	596	708	125	704	829	117	642	759	120	621	741	119	621	740
Monmouthshire	219	869	1088	245	865	1110	229	909	1138	259	847	1106	269	892	1161
Newport	240	846	1086	189	851	1040	187	855	1042	210	861	1071	191	889	1080

Table A.2 · Proportions of home care by sector over time (millions of hours commissioned)

	Local authority provision	%	Independent sector provision	%	**Total**
2001/02	7.9	62.20	4.8	37.80	**12.7**
2002/03	7.4	62.18	4.5	37.82	**11.9**
2003/04	7.3	57.03	5.5	42.97	**12.8**
2004/05	6.8	54.40	5.7	45.60	**12.5**
2005/06	6.4	50.00	6.4	50.00	**12.8**
2006/07	6.2	46.62	7.1	53.38	**13.3**
2007/08	5.8	47.54	6.4	52.46	**12.2**
2008/09	5.2	44.07	6.6	55.93	**11.8**
2009/10	4.5	39.47	6.9	60.53	**11.4**
2010/11	3.6	32.14	7.6	67.86	**11.2**

Table A.3 · Proportions of home care by sector by local authority area, 2010-11 (millions of hours commissioned)

	Local authority provision	%	Independent sector provision	%	**Total**
Wales	**3621515.16**	**32.40**	**7555306.16**	**67.60**	**11176821.32**
Isle of Anglesey	245756	78.60	66915	21.40	312671
Bridgend	302324	74.72	102296	25.28	404620
Wrexham	456940.5	59.72	308202.5	40.28	765143
Gwynedd	360619	57.93	261939	42.07	622558
Rhondda Cynon Taf	498672	56.37	385945	43.63	884617
Neath Port Talbot	197068	45.54	235656	54.46	432724
Blaenau Gwent	138357	45.29	167127	54.71	305484
Powys	225983.32	41.62	316927.4	58.38	542910.72
Flintshire	168707	39.01	263768	60.99	432475
Newport	137862	30.99	306979	69.01	444841
Merthyr Tydfil	66520	29.89	156027	70.11	222547
Caerphilly	122750.87	25.61	356625	74.39	479375.87
Swansea	157223.7	20.97	592540	79.03	749763.7
Ceredigion	23430.83	18.32	104475.25	81.68	127906.08
Conwy	149822	17.36	713339	82.64	863161
Pembrokeshire	58991	17.09	286172	82.91	345163
Monmouthshire	97566	12.76	667168	87.24	764734
Vale of Glamorgan	41048	10.75	340821	89.25	381869
Torfaen	35715.78	10.43	306834.01	89.57	342549.79
Cardiff	136158.16	10.06	1216922	89.94	1353080.16
Denbighshire	..		..		
Carmarthenshire	..		398628		

APPENDIX II · Published academic literature - UK home care including systematic reviews (n=81)

Theme/ Heading	No. of papers	Key areas covered
Home care use	N=2 Stoddart, 2002; Bowling, 1991;	Factors predicting home care use among community dwelling older people
Quality of home care	N=8 Bos et al. 2007, Netten and Francis, 2004; Jones et al. 2007; Netten et al. 2007; Patmore, 2004, Patmore, 2006; Raynes et al. 2004; Temple et al. 2002.	Measuring quality of home care-performance indicators Aspects of quality of home care of importance to older people, both user and provider perspectives Provider and care workforce influences on quality Reasons for variation in home care services provision Ethnic minority perspective on quality home care.
Quality of life/ Satisfaction	N=3 Biker and Thompson, 2006; Boyle, 2004; Patmore, 2002;	Patient satisfaction with services including domiciliary care-factors that contribute most to patient satisfaction. Impact of choice, control and autonomy for older home care clients and clients in institutional care on QOL. Morale and quality of life among older home care clients
Service user input	N=6 Coulthard, 2001; Durand and S. Jowett, 2001; Hardy, 1999; Patmore, 2001; Raynes et al. 2004; Raynes, 2002;	Involving older home care clients in designing services Informed consultation with older home care clients User and carer involvement in assessment and care management decision-making processes User involvement in commissioning of services and service monitoring Person-centred home care services

Theme/ Heading	No. of papers	Key areas covered
Information in home care	N=2 Cooper and Urquhart, 2005; Cooper and Urquhart, 2008	Info needs and info seeking behaviours in home care Informal information exchange and implications for electronic records
Care Assessment	N=1 Carpenter et al. 2005	Comparison of assessment instruments in community care of older clients
Care Management	N=1 Challis et al. 2001	Examines the evidence for intensive care-management at home in older peoples services
Care Outcomes	N=1 Glendinning et al. 2008	Report on the progress of developing outcomes focused social care services, including homecare services, for older people.
Health issues/conditions	N=4 Finne-Soveri et al. 2008; Gilmour, 2004; Venables et al. 2004; Edwards and Jones, 2001; Walker, 1994	Faecal Incontinence-Prevalence and associated factors-implications for home care Home care for people with dementia living alone Comparison of generic and specialist services for older people with dementia Pain and psychosocial care for the elderly in the community
Specialist or integrated care teams in the home	N=2 Beech et al, 2004; Rothera et al. 2008	Evaluation of multidisciplinary Rapid Response Team in Hereford providing services to older adults with health and social care needs in their homes. An evaluation of a specialist multiagency home support service for older people with dementia compared to standard care.

Theme/ Heading	No. of papers	Key areas covered
Long term care of older people/community care	N=6 Comas-Herrera et al. 2010; Low et al. 2011; Ryan et al. 2009; Ware et al. 2003; King and Farmer, 2009	Long term-care financing in England Systematic review to evaluate the outcomes of case managed, integrated or consumer directed home and community care services for older persons, including those with dementia. Exploration of the impact of community care policies in enabling older people with complex needs to remain at home Implications of commissioning community care services for older people Rural dwelling older populations- health and social care preferences
Home care market	N=9 Curtice and Fraser, 2000; Kendall et al. 2003; Ware et al. 2001; Wistow and Hardy, 1999; Leece, 2003; Scourfield, 2006; Hindle et al. 2009; Leason, 2002; Bowes et al. 2007)	Composition of the domiciliary care market in Scotland Motivations of Domiciliary Care Providers in England-typologies Development and changes in the domiciliary care market Policy directions Population dispersion and travel costs Free personal care in Scotland
Home care workforce issues	N=3 Fleming and Taylor, 2007; Taylor and. Donnelly, 2006; Green, 2000	Staff retention Health and safety issues Care boundaries
Preventive health care at home	N=3 Rabiee and Glendinning, 2011; Elkan et al. 2001; Hallberg andKristensson, 2004	Home care reablement services Systematic review of the effectiveness of home visiting programmes offering health promotion and preventative care to older people. Evidence of preventative health care practice in case management interventions for older frail adults in the community.

Theme/ Heading	No. of papers	Key areas covered
Palliative or End of Life Home Care	N=6 Devlin and McIlfatrick, 2009; Devlin and McIlfatrick, 2010; Gott et al. 2004; Rolls et al. 2011; Ingleton et al. 2011; Ingleton et al. 2004;	Role of the home-care worker Challenges of providing care at home in this context Challenges to older people living alone remaining in their own homes and the influences of physical, material and social factors. Policy challenges Attitudes of older people towards home as a place of care when dying Carer satisfaction with end-of-life care services in Powys, Wales
Home care technology/ Dwelling Quality	N=6 Clark and McGee-Lennon, 2011; Lansley et al. 2004; Sainty et al. 2009; Windle et al, 2006; Hanson et al. 2003	Barriers to uptake in the UK Feasibility of adapting properties to meet the dwellers needs Community equipment-meeting health and social care needs and facilitating choice, control, autonomy etc. Housing tenure and housing-related problems of older people in Wales and implications for health. Ethical implications
Direct Payments	N=8 Glendinning et al. 2000; Glendinning et al. 2000; Leece, 2007; Leece, 2008; Leece and Peace, 2010; Spandler, 2009; Timonem, 2006; Philpot, 2002;	Staff-client relationships Benefits and challenges Nearly all relate to disabled persons rather than older people Comparison of cash for care programmes in four countries including England.
Home care research	N=2 Miller et al. 2003; Thome et al. 2003;	Recruitment of research subjects-challenges in home care sector Defining home care: empirical literature review for the description of home care as a phenomenon and as a concept.

Theme/ Heading	No. of papers	Key areas covered
Informal care	N=8 Adamson and Donovan, 2005; Arksey, 2002; Georges, 2008; Grundy 2005; Smith, 2003; Pickard, 2002; Hatfield, 1994; Chiu, 2001;	Ethnic minority experiences of caring for relatives Models that facilitate informal carers in the labour force and strategies they employ for this dual role Carer's experience of caring for relatives with dementia and perceptions of support services Intergenerational exchange and reciprocal relationships around informal helping Attitudes towards the informal care of older people Comparison of care-giving approaches adopted by family caregivers and professional care givers. Service needs of informal carers

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YOUR EXPERIENCE OF HOME CARE

QUESTIONNAIRE FROM THE OLDER PEOPLE'S COMMISSIONER FOR WALES

Completing this questionnaire – instructions

When completing this questionnaire we want you to think about the service you **currently** receive from **paid care workers** employed either directly by the local authority or by an agency working on behalf of the local authority. As far as possible we want you to answer about your **usual** team – the care workers that you see most typically and routinely. For information, home care is also sometimes called domiciliary care.

Below, please find answers to some questions you might have.

Do I have to complete this questionnaire at all?

No – it is entirely up to you – but we would very much welcome your response about these important issues.

Do I have to complete this questionnaire on my own?

We'd like you to fill this in as far as possible on your own – after all it's **your** views that really count. However, you should seek help if you need to.

What do I do if more than one agency currently provides my care?

Please let us know about this in your response to question 9. We'd like you to answer the remaining questions on the basis of your complete experience, so try to think about the care workers as a whole.

Will my identity be kept confidential?

Of course. No-one will know whether you have completed the questionnaire, nor what you have said.

What will the information be used for?

It will be used to help the Commissioner to improve home care services for older people in Wales.

How should I return the questionnaire to you?

Please complete the questionnaire and return it in the freepost envelope provided as soon as possible and at the very latest by **Wednesday 8th February 2012**. You do not need a stamp.

If you have any queries at any time please don't hesitate to contact Mark Llewellyn from the University of Glamorgan on 01443 483070 or mrllewel@glam.ac.uk who will be very happy to help.

ABOUT YOU

Please place a tick in the appropriate box for each question.

1. What is your gender?

Female	Male	I do not want to say

2. What is your age?

60-69	70-79	80-89	90 or above	I do not want to say

3. What is your ethnic origin?

White	Black	Mixed heritage	Other (please specify)
Chinese	Asian	I do not want to say	

4. Who is filling in this questionnaire?

I (the service user) am doing it on my own
I'm having some help from my care worker
I'm having some help from someone else

5. What is your preferred language?

Cymraeg/Welsh	English	Other	I do not want to say

6. How frequently are you able to receive personal care at home in this language?

Always	Often	Sometimes	Rarely	Never

7. For how long have you received personal care at home?

6 months or less	7-12 months	Between 1 and 2 years	More than 2 years

8. How many visits do you have from paid care workers and how long do they last each day?

	Mon	Tue	Wed	Thu	Fri	Sat	Sun
Number of visits							
Total length of visits (minutes)							

9. **Who employs the paid care workers who currently care for you at home?**

Please place a tick the appropriate box. If more than one agency provides your care, please tick the correct number of boxes accordingly.

Your Local Authority (i.e. workers directly employed by the Council)
A private sector agency on behalf of the Local Authority
A voluntary sector agency on behalf of the Local Authority
A mixture of some or all of the above
Other (please specify)
I am not sure where the workers come from

VIEWS ABOUT YOUR CARE WORKERS

We want you to answer the questions in this section about the **usual care workers** that **currently** provide you with personal care in your own home. Please place a tick in one of the boxes for each of the questions below.

10. **How frequently do your care workers listen to you about important things?**

Always	Often	Sometimes	Rarely	Never	Don't know

11. **How frequently do your care workers demonstrate that they have the right skills, knowledge and training to care for you?**

Always	Often	Sometimes	Rarely	Never	Don't know

12. **How frequently do your care workers have as much time as they need to care for you?**

Always	Often	Sometimes	Rarely	Never	Don't know

13. **How frequently do you receive visits from the care workers with whom you are familiar?**

Always	Often	Sometimes	Rarely	Never	Don’t know

14. **How frequently do you receive good quality care?**

Always	Often	Sometimes	Rarely	Never	Don’t know

15. **How frequently are you given useful information by your care workers about other services that would help you?**

Always	Often	Sometimes	Rarely	Never	Don’t know

16. **If you would like to tell us more about the answers you have given to questions 10-16 above please provide this information in this box.**

We know that sometimes things can go wrong. When the following things do happen, how much do they **matter to you**? Please place a tick in one of the boxes for each of the questions below.

17. **When my care workers do not listen to me about important things…**

It matters to me a lot	It matters to me a bit	It doesn’t matter to me at all	This has never happened	Don’t know

18. **When something happens to show that my care workers do not have the right skills, knowledge and training…**

It matters to me a lot	It matters to me a bit	It doesn’t matter to me at all	This has never happened	Don’t know

19. When my care workers are under time pressure when they visit…

It matters to me a lot	It matters to me a bit	It doesn’t matter to me at all	This has never happened	Don’t know

20. When I have to deal with lots of different care workers outside of my usual team…

It matters to me a lot	It matters to me a bit	It doesn’t matter to me at all	This has never happened	Don’t know

21. When the quality of care provided by my care workers is lower than I would hope for…

It matters to me a lot	It matters to me a bit	It doesn’t matter to me at all	This has never happened	Don’t know

22. When I am not given useful information by my care workers about other services that would help me…

It matters to me a lot	It matters to me a bit	It doesn’t matter to me at all	This has never happened	Don’t know

23. If you would like to tell us more about the answers you have given to questions 18-23 above please provide this information in this box.

VIEWS ABOUT THE PEOPLE WHO MANAGE YOUR CARE

There are lots of people who make decisions about and organise the care you receive at home. When answering the questions below we'd like you to think about these managers **as a whole**. Please place a tick in one of the boxes for each of the questions below.

24. How far do you agree or disagree that you are able to speak to, and get answers from, managers whenever you need to?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know

25. How far do you agree or disagree that managers ensure that your care workers have the right skills, knowledge and attitude?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know

26. How far do you agree or disagree that managers ensure that your care workers have enough time to do everything they need to?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know

27. How far do you agree or disagree that managers ensure the service you receive is delivered by as few care workers as possible?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know

28. How far do you agree or disagree that managers do all that is reasonable to ensure that you receive good quality care?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know

29. How far do you agree or disagree that managers provide useful information about other services that would help you?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know

OVERALL

Please place a tick in the appropriate box for each question.

30. **Over the last year, how satisfied or dissatisfied do you feel with the service that has been provided to you in your own home?**

Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied	Don't know

31. **Over the last year, has the service that is provided to you in your own home got better or worse?**

Much better	A little better	About the same	A little worse	Much worse	Don't know

32. **If you are able to, please give reasons to explain the answers given to questions 30 and 31.**

33. **Finally, if there is anything you haven't had the chance to say which you feel is important for us to know, please record it here.**

Thank you for completing this questionnaire. Your answers will remain confidential and we are sure that they will be useful in helping the Commissioner to improve home care services for older people in Wales.

APPENDIX V · Glossary of statistical terms

Below are the principal forms of statistical test that we have used in the course of this analysis to demonstrate association between variables.

CHI SQUARE TESTS

Chi square tests are used to check for association between categorical variables. If the p-value that is calculated is lower than 0.05 (5%) then we usually consider the result to be statistically significant and reject the null hypothesis that there is no association between the variables that have been analysed. P-values are estimates of the probability of detecting a result if there were no true effect/ association/correlation. P-values can vary in magnitude between 0 and 1, the smaller the p-value, the more significant the result, i.e. the less likely we are to see such a result due to chance. 0.05 (5%) is generally accepted as being the cut off to consider results to be statistically significant, so any results where the value is smaller than this can be considered to be unlikely to be due to chance – they exist because there is an effect.

STANDARDISED RESIDUALS

When significant results are achieved, standardised residuals can then be analysed in order to identify which outcomes have contributed to such a result. Briefly, a negative standardised residual means that the number of subjects within a cell can be considered to be lower than expected if there were no association, while a positive standardised residual means that the number of subjects within a cell can be considered to be greater than expected. When the magnitude of the standardised residual is greater than 1.96, the cell can be considered to be statistically significantly under- or over-represented at the 5% significance level.

SPEARMAN CORRELATION TESTS

Spearman correlation tests have been applied in order to detect whether there is a relationship between two ordinal variables. A p-value below 0.05 leads us to conclude that there is a statistically significant correlation between the variables. A positive correlation coefficient then tells us that positive correlation is present (both variables increase together), a negative correlation coefficient tells us that negative correlation is present (as one variable increases, the other decreases).

FRIEDMAN TESTS

A Friedman test is a non-parametric test that can be used to compare multiple non-independent groups in terms of an ordinal outcome. A p-value below 0.05 leads us to conclude that there is a statistically significant difference between the groups, in terms of the mean ranking allocated to each variable. In the context in which it is presented here, a significant result tells us that there is an effect in terms of how the answers provided by subjects have ranked the compared questions. Examining the mean ranks indicates the order in which such rankings have been applied.

Further details on these can be obtained from the project statistician, Dr Paul Jarvis (psjarvis@glam.ac.uk).

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