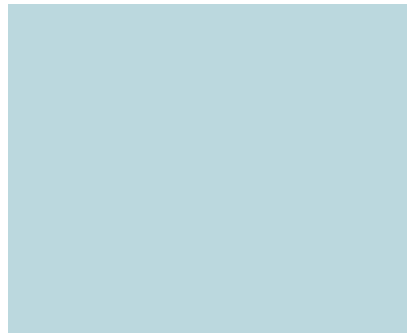


Supporting Older Carers

Examining the reasons for the low level of uptake of Carers Assessments by Older Carers in Northern Ireland

| June 2014 |





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1. Foreword



More people in Northern Ireland are living longer and healthier lives than ever before, and this is very good news indeed. Average life expectancy has increased by over 11 years from 1950, and by 2060, there will be five times as many people living beyond 100 years of age as there are today.

Older carers make an invaluable contribution to the increasing number of older people with care needs who wish to remain as independent as possible in their own homes. Government policy initiatives such as Transforming Your Care (TYC) promote a move away from residential models of care towards programmes centred around providing care in the home. While many older people live independent lives without the need for help and support, the number of older people providing care to a family member, friend, neighbour or dependent is set to increase. Older carers deserve the best support and information to assist them in their caring role.

A Carers Assessment is the process of the collection of information by local Health and Social Care (HSC) Trusts so they can assess an individual's support and information needs to assist them in their caring role.

The process examines information from all the different aspects of an individual's life as a carer and provides the opportunity for that carer to talk to a social care professional about what could make caring easier and to advise on help and support available.

Every carer providing "regular and substantial care"¹ is entitled to have an assessment of their caring needs undertaken by a social care professional.

The level of uptake of a Carers Assessment by older carers is low in Northern Ireland – 64% of older carers declined the offer of an assessment in 2013. The impact of an older carer not getting a Carers Assessment is significant. Older carers do not get the support they need. The HSC Trusts cannot fully understand the scale and scope of carers needs so as to plan for growth and changing levels of need and demand for future services.

Many older people provide a significant amount of care to a family member or friend, and make it possible for thousands of people to live dignified and fulfilled lives at home. According to research carried out by Commissioner for Older People for Northern Ireland (COPNI), older carers in Northern Ireland contributed £1.02 billion to the economy during 2012.²

¹ Carers and Direct Payments Act (Northern Ireland) 2002, 10.1

² Development Economics, COPNI Independent Research, 2014 (to be published October 2014)

There is much good work being done to support older carers in Northern Ireland. Older carers deserve to be provided with the very best support to help them both in terms of their caring role, and in maintaining their own health and well-being. Sadly, too often, they do not get all of the practical and emotional support they need, and often struggle on their own with the challenges of caring.

I am grateful to the older carers who shared their experiences as part of this report. I would also like to acknowledge and thank the carers organisations, co-ordinators, and the HSC Trusts for their co-operation and encouragement with COPNI as we reviewed the reasons for the low level of uptake of Carers Assessments by older carers. Their work supports many older carers in securing much needed support and assistance; however, the findings contained within this report show that there is much more that government can do to support older carers across Northern Ireland in the vital role they play.

This report is the result of research which my office has carried out to examine reasons for low uptake of Carers Assessments by older carers, with an analysis of the barriers to uptake, and a consideration of the impact that this has on them.

I have made a series of recommendations to the Minister for Health, Public Services and Public Safety which call for action to improve the level of uptake of Carers Assessments by older people so that the real needs of older carers can be identified and met.



Claire Keatinge

Commissioner for Older People for Northern Ireland



2. Executive Summary

Commissioner for Older People for Northern Ireland (COPNI) Priorities for Action

One of the key priorities in the COPNI Corporate Plan, “Hope, Confidence and Certainty,” is to examine the reasons for the low level of uptake of Carers Assessments by older people in Northern Ireland.³

This report has three main objectives:

- I. To find out why Northern Ireland has such a low uptake of Carers Assessments by older carers.
- II. To analyse the barriers to the uptake of Carers Assessments and the impact of this on older carers in Northern Ireland.
- III. To make recommendations to the Minister for Health, Social Services and Public Safety on how the level of uptake by older carers could be improved.

Older Carers

A carer is considered to be someone who provides or intends to provide a substantial amount of care on a regular basis.⁴ An older person as defined in COPNI legislation is a person aged 60 or over, and in exceptional cases can be someone aged 50 or over.

Carers and Carers Assessments

All carers providing regular and substantial care are entitled to a Carers Assessment. The process itself involves the collection of information by local HSC Trusts to assess formally the support needs of carers. The process examines information from all the different aspects of an individual's life as a carer and provides the opportunity for that carer to talk with a social care professional about what could better support them in their caring role. The outcome of a Carers Assessment can result in the provision of help and support to assist the carer with their needs.

Research Process

This project involved the following methods of research:

- A literature review;
- Meetings with carers organisations and older carers;
- Engagement with Health and Social Care representatives;
- Primary research to better understand the barriers to uptake of a Carers Assessment.

³ Commissioner for Older People for Northern Ireland, ‘Hope | Confidence | Certainty: Corporate Plan 2013-2015.’

⁴ http://www.dhsspsni.gov.uk/carers_statistics_for_northern_ireland_-_december_2013.pdf

Legislative and Policy Background

The *Carers and Direct Payments Act (Northern Ireland) 2002* placed a statutory duty on the HSC Trusts to inform carers of their right to a separate assessment of their needs and places an obligation on them to identify and provide information to carers. The 2002 Act also makes it possible for carers to receive services in their own right and allows them to be considered for receipt of Direct Payments⁵ as an alternative to direct service provision.

Transforming Your Care (TYC) (2011) marked a change in direction in health policy in Northern Ireland.⁶ The principle that TYC sets out is that more people will receive more care at home. It is vital that carers are well supported with their caring needs and that carers' needs are both assessed and met. This policy direction and the increasing numbers of older people is likely to have an impact on both the number of carers needed to provide care and on the level of care being provided at home. Older carers make a vital contribution to supporting older people now and will continue to do so in the future.

Within other UK jurisdictions the level of statutory "obligation" associated with a carers assessment differs slightly;

- In Northern Ireland, the Carers and Direct Payments Act (Northern Ireland) 2002 places a requirement on the HSC Trusts to make sure carers know about their right to a Carers Assessment.
- In Scotland, under the Community Care and Health (Scotland) Act 2002 local authorities have a duty to inform eligible carers of their right to an assessment.
- In Wales, it is a legal requirement under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Persons Carers Act 2000 that carers have the right to ask for an assessment. The Carers (Equal Opportunities) Act 2004 places a duty on the local authority to inform the carer that he/she has a right to an assessment under both Acts. The Carers (Equal Opportunities) Act 2004 requires that any assessment undertaken under the Carers (Recognition and Services) Act 1995 or the Carers and Disabled Children Act 2000 considers whether a carer (i) works or wishes to work (ii) is undertaking or wishes to undertake, education, training or any leisure activity.
- In England, under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Persons Carers Act 2000 carers who provide or intend to provide a substantial amount of care on a regular basis have the right to ask for an assessment. The Carers (Equal Opportunities) Act 2004 places a duty on the local authority to inform the carer that he/she has a right to request an assessment under both Acts. The Carers (Equal Opportunities) Act 2004 requires that any assessment undertaken under the Carers (Recognition and Services) Act 1995 or the Carers and Disabled Children

⁵ Direct payments are cash payments given to persons in lieu of services that would otherwise have been arranged for them by HSC Trusts, so that they may arrange the provision of their own services (Carers and Direct Payments Act (Northern Ireland) 2002).

⁶ <http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf>

Act 2000 considers whether a carer (i) works or wishes to work (ii) is undertaking or wishes to undertake, education, training or any leisure activity.

The availability of data on the level of uptake of a Carers Assessment across the different age categories is inconsistent or absent which means that direct comparisons between Northern Ireland, England, Scotland and Wales cannot be made.

Evidence and Statistics

In Northern Ireland, one in every eight adults is a carer. In 2013, 64% of older carers who were offered a Carers Assessment declined that offer and therefore their needs have not been formally assessed.⁷ The Commissioner has, through this report, set out to examine the reasons for this.

Currently there are 214,000 carers in Northern Ireland. Census data released by NISRA (2011) reveals that the number of carers aged over 60 has increased from 33,267 to almost 50,000 in Northern Ireland between 2001 and 2011.⁸

The body of evidence collated for this report shows that there are six broad categories of help which older carers would welcome in order to be able to cope and continue providing care:

- I. Carers Assessments being offered and carried out at an appropriate time;
- II. Reliable and high quality services to meet assessed need which assists them in their caring role;
- III. Confidence in the availability of high quality appropriate services for the 'cared for;'
- IV. A range of information and care for their own physical, emotional and mental wellbeing;
- V. Recognition of their role and positive contribution;
- VI. Opportunities for a break from caring including high quality reliable respite care that meets the need of the people who need care, as well as the carer.

⁷ http://www.dhsspsni.gov.uk/carers_statistics_for_northern_ireland

⁸ <http://www.ninis2.nisra.gov.uk/Public/Home.aspx>

COPNI Research Findings

Research by the Commissioner in 2013 with older carers directly across Northern Ireland found that:

- 60% of older carers stated that they did not receive information to assist them in their caring role.
- The majority of older carers cared for their spouse/partner.
- Over 60% of older carers were not aware that they were entitled to a Carers Assessment.
- 70% of older carers stated that they had not been offered a Carers Assessment.
- 75% of older carers were of the opinion that an assessment would not result in more support for them.
- 80% of older carers felt that the HSC Trusts did not understand the impact of their caring role on them.
- The five most important supports that older carers said would help them were: respite, support, friendship, help from family, and financial support.

COPNI also carried out both quantitative and qualitative research, and engaged with a range of relevant organisations which revealed the following findings:

- Older people who carry out caring roles do not always recognise themselves as “carers.” As a consequence, many older carers do not ask for help and decide to provide care without any additional support.
- Carers organisations across Northern Ireland consistently state that the term “Carers Assessment” itself can cause fear amongst older carers. The fear is that getting a Carers Assessment may cause them to either lose services or other benefits or entitlements.
- The HSC Trusts’ Carers Coordinators state that the three big issues cited as barriers for older carers were recognition, effective communication and the title of the assessment form itself.

Conclusions

- The level of uptake of Carers Assessments by older carers remains unacceptably low, despite a statutory obligation by the HSC Trusts to inform carers of their right to an assessment.
- There are no targets set for the HSC Trusts to help to identify older carers and to deliver on their statutory requirement.
- Many older carers do not recognise themselves as carers.
- More information and support would be welcomed by older carers.
- The process is viewed by many older carers as a “paper exercise” that does not result in the support and services needed by the older carer.
- The administration process of the Carers Assessment needs to be carried out in a way that reassures the older carer and is flexible to their needs.
- Fear by older carers that receiving a Carers Assessment is somehow linked to their benefits and entitlements, and could cause a loss of service or support, needs to be acknowledged and steps taken to allay these fears.

Recommendations

- Older carers must receive the services, information and support that they need to enable them to support people who rely on their care.
- Clear targets should be set to significantly increase the uptake of Carers Assessments by older carers. There should also be transparent recording of need and unmet need.
- Older carers need a commitment that the services and support needs identified in a Carers Assessment will be met and implemented.
- The assessment must be carried out at an appropriate time. There should be a systematic and consistent review or reassessment process so that people are supported through gradual changes in their circumstances. This could help prevent a crisis point.
- The use of the term “Carer Assessment” has negative associations of judgement and stigma for an older carer. Changes are needed to improve user-friendliness and strengthen the current process to become a more useful and collaborative approach.

3. Introduction

The Northern Ireland 2011 Census indicated that there are approximately 214,000 carers in Northern Ireland. This data indicates that 23.2% of unpaid care is being provided by those aged 60 and over.⁹

Many older people provide a significant amount of care for others who have been assessed by social services as needing care and support. These carers may be looking after a spouse, partner, friend, neighbour or a dependent with disabilities.

Older carers make it possible for thousands of people to live dignified and fulfilled lives at home, and make a significant and positive contribution to the Northern Ireland economy. Around £1.02 billion worth of unpaid care was provided by older people in Northern Ireland during 2012. The total value of “unpaid for” care provided by people aged over 60 is expected to total £81.1 billion over the 2012-2062 period (2012 prices).¹⁰ Their caring should not be taken for granted, nor should it be undervalued.

In Northern Ireland, carers are entitled to an assessment of their needs if they provide or are intending to provide regular and substantial care. However, the majority of older carers do not have their needs assessed, recognised nor met. Latest Department of Health, Social Services and Public Safety (DHSSPS) statistics confirm that 63% of carers aged 65 and older declined an assessment and 65% of carers aged 75 and over declined an assessment (December 2013).¹¹

There have been several policy and legislative initiatives which have sought to better support carers. In 2003, the Carers and Direct Payments Act provided the HSC Trusts with the power, following an assessment, to supply services directly to carers themselves, but also placed a statutory duty on them to inform carers who provide substantial and regular care of their right to a Carers Assessment.

Despite the legislation with these associated powers and duties in place, the low level of uptake of Carers Assessments by older people continues, and it is for this reason that COPNI has made an examination of the reasons for low uptake a priority for action. This action took the form of desk research, as well as engagement with older carers, carers organisations and carers co-ordinators, and sets out recommendations for government on how to increase the level of uptake of Carers Assessments by older carers.

⁹ [http://www.ninis2.nisra.gov.uk/public/Theme.aspx?themeNumber=136&themeName=Census 2011](http://www.ninis2.nisra.gov.uk/public/Theme.aspx?themeNumber=136&themeName=Census%202011)

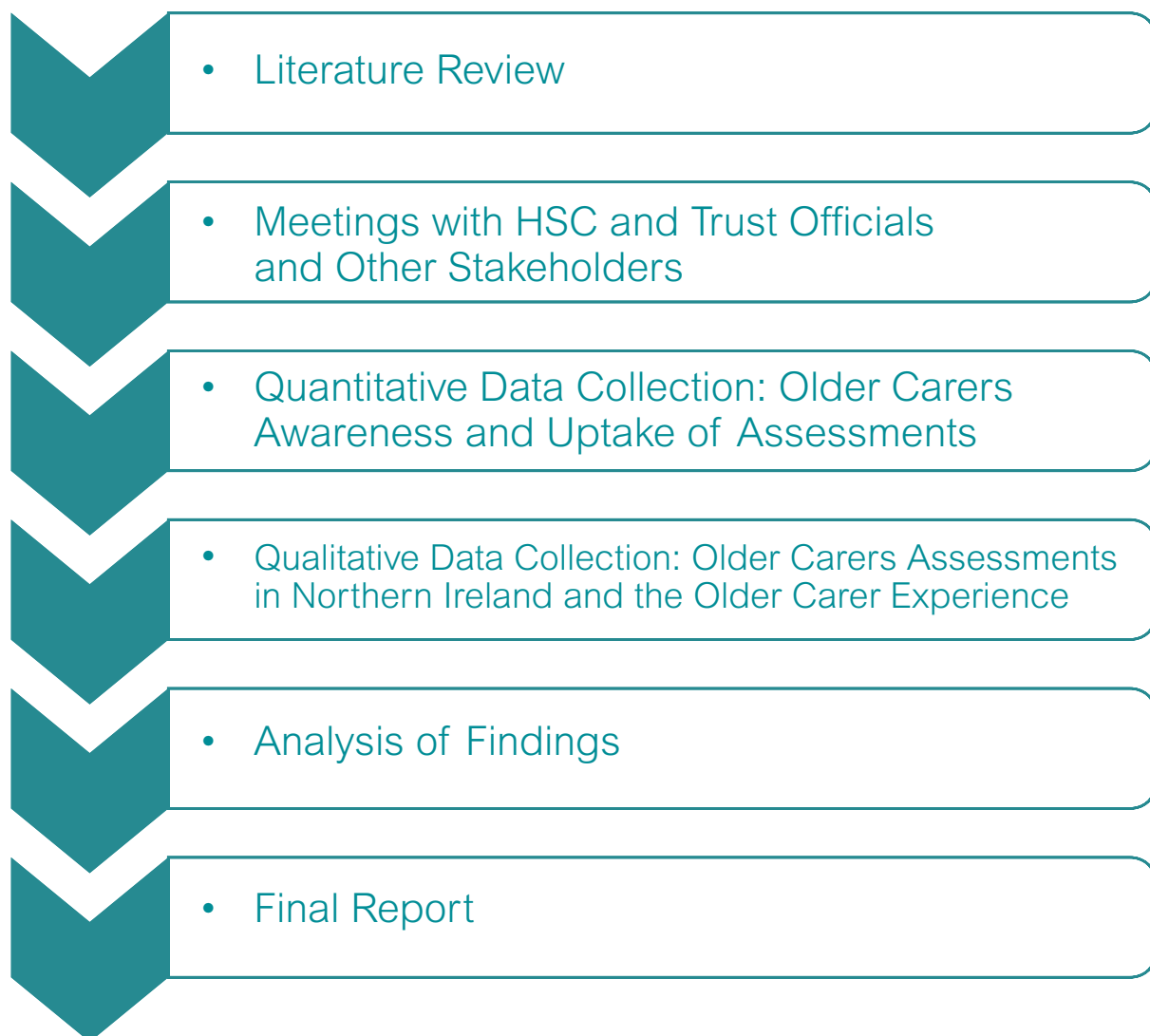
¹⁰ Development Economics, COPNI Independent Research, 2014 (To be published October 2014)

¹¹ http://www.dhsspsni.gov.uk/carers_statistics_for_northern_ireland_-_december_2013.pdf

4. Research Process

In seeking to gain a clearer understanding of the low level of uptake of Carers Assessments by older carers, this project involved a range of steps as set out below.

COPNI reviewed recent Northern Ireland Executive policy and statistics, as well as carer-specific information relating to Carers Assessments. COPNI representatives also carried out a series of engagement and research meetings with stakeholders, older carers through carers organisations and directly through a survey specifically targeted at older carers.





5. Older Carers and Carers Assessments

One of the reasons for a low level uptake of Carers Assessments is the fact that many older carers do not identify themselves as a carer. When the person they are caring for is a family member or friend, many older people do not associate their caring role as something which they might receive support for. For the purposes of this report, outlined below is an explanation of what is meant by an “older carer,” what a Carers Assessment is, as well as how a Carers Assessment can be obtained.

What is an older carer?

A carer is defined by the Department of Health, Social Services and Public Safety as the following:

“Someone who provides or intends to provide a substantial amount of care on a regular basis. The term ‘carer’ includes a person who may or may not be a relative and who may or may not be living with the person for whom they are caring. A carer provides help and support to someone, such as a family member, friend or neighbour, who may not be able to manage at home without this help because of frailty, illness or disability. A carer can be an adult caring for another adult, parents caring for ill or disabled children or young people of 16 or 17 years of age who care for someone. It does not include someone who is providing care by virtue of a contract of employment, a volunteer working on behalf of a voluntary organisation, a foster carer or anyone who is providing personal assistance for payment either in cash or kind.”¹²

For the purposes of this report, an older carer is a person aged 60 or over who meets the above description.

What is a Carers Assessment?

A person who provides a significant amount of care for a close family member, relative or friend on a regular basis without payment has a right to a Carers Assessment. A Carers Assessment is the process of the collection of information by local HSC Trusts so they can assess an individual’s support and information needs to assist them in their caring role.

The process examines information from all the different aspects of an individual’s life as a carer and provides the opportunity for that carer to talk to a social care professional about what could make caring easier and to advise on help and support available.

How can a Carers Assessment be obtained?

A carer can either contact social services in their local HSC Trust area themselves or through a referral to social services by a GP or someone who works for the Trust such as any of the following:

- Social Worker
- Community Nurse
- Mental Health Nurse
- District Nurse/Health Visitor
- Care Manager
- Key Worker
- Allied Health Professional e.g. Physiotherapist, Podiatrist, Speech and Language Therapist, Occupational Therapist

¹² http://www.dhsspsni.gov.uk/carers_statistics_for_northern_ireland_-_december_2013.pdf

6. Legislative and Policy Background

There have been several policy and legislative changes in Northern Ireland around the issue of carers, including older carers, as government has become more aware of the important role they play. These initiatives have included practical support for carers such as inclusion of respite for carers within care plans, investment in improving support services, as well as the introduction of a legal entitlement for carers to receive an assessment.

The table below provides a summary of key policy and legislative initiatives which provide the context upon which this report builds.

Year	Policy	Legislation
1990	People First: Community Care in Northern Ireland in the 1990s	
1991	People First Management: Guidance on Assessment and the Provision of Community Care	
1995		The Carers (Recognition and Services) Act
2002	Valuing Carers: Proposals for a Strategy for Carers in Northern	Carers and Direct Payments Act
2003		The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order
2006	Caring for Carers: Recognising, Valuing and Supporting the Caring Role	
2011	Transforming Your Care	No legislation enacted yet



Current Policy Context: Transforming Your Care

The Minister for Health, Social Services and Public Safety recently introduced a policy which changes the provision and delivery of health and social care in Northern Ireland across the health sector, known as “Transforming Your Care (TYC).”¹³

Introduced in 2011, TYC seeks to place the individual at the centre of their care, and to shift care from the hospital setting towards community or primary care.

Of the 12 key principles underpinning the approach, one relates to placing the individual at the centre of any model by promoting a better outcome for the user, carer and their family. Other key proposals included:

- A holistic and consistent approach to assessment of older peoples’ needs across Northern Ireland and an equitable range of services (2011:70 &136);
- A policy review of Carers Assessments and more practical support for carers including improved access to respite provision (2011:70&136);
- Better recognition of carers’ roles as partners in planning and delivering support and more practical support for carers (2011:81&137);
- More respite and short breaks provision (2011:81& 137);
- Enhancing the support for carers, to ensure they have access to services in their community which enhance their quality of life (2011:77).

This policy direction, alongside the increasing number of older people, is likely to have an impact on the number of carers who support people to live at home, and on the level of care being provided at home.

¹³ <http://www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf>

7. Facts and Figures about Carers

As part of the research process, a literature review was conducted of other reports relating to issues affecting carers, such as the increase in the number of carers, their economic value, as well as reports which specifically considered the challenges facing older carers. The excerpts below highlight the key findings from previous reports in chronological order, and provide the basis upon which this research was developed.

Carers Matters, 2010¹⁴

Carers identified the following issues as important:

- > Information on benefits, finance and services.
- > Needing time for themselves and stress management to sustain them in their caring role.
- > Looking after their own health and well-being.
- > Practical training on statutory services, direct payment and managing finances.
- > Access to support, advice and information.

Carers NI, 2011¹⁵

By 2037 the number of carers could increase to 400,000.

Northern Ireland Census, 2011¹⁶

There are approximately 213,980 people in Northern Ireland who provide unpaid care each week.

Carers UK, 2011¹⁷

Carers save the Northern Ireland economy an estimated £4.4 billion a year. The economic value of the contribution made by carers (of all ages) in the UK is £119 billion per year.

¹⁴Carers Matter 2010 - Response from Cares Matter to COPNI. Response dated 23 April 2013.

¹⁵Carers NI 2011- <http://www.carersuk.org/northernireland/news-ni/facts-and-figures>

¹⁶Northern Ireland Census - <http://www.ninis2.nisra.gov.uk/Public/Home.aspx>

¹⁷Carers UK 2011- <http://circle.leeds.ac.uk/files/2012/08/110512-circle-carers-uk-valuingcarers.pdf>

Always on Call, Always Concerned 2011¹⁸

- > 68% of carers reported a negative impact on their physical health.
- > 68.8% identified a detrimental effect on their mental health.
- > 65% have a long term health problem or disability themselves.
- > 38.5% reported that they were not able to have a break from their caring role.

Mind the Gap, 2012¹⁹

The pressures of caring were significantly evident in several key areas including health, social isolation, finances, training and support.

- > Carers aged 60-69 feel caught in a 'sandwich' of caring for multiple generations which was difficult to balance with work and financial anxiety.
- > 78% of respondents had concerns about what will happen to those they care for in the future.
- > 35% of respondents believed they did not feel sufficiently trained and supported as their caring role changes, and only half felt safe or confident in lifting the person they care for.

Carers Trust NI, 2013²⁰

In Northern Ireland there are around 49,000 carers over the age of 60. Almost 11,000 provide care more than 50 hours per week.

¹⁸Always on Call, Always Concerned 2011 - http://www.carers.org/sites/default/files/always_on_call_always_concerned.pdf

¹⁹Carers Trust 2013¹⁹- http://www.carers.org/sites/default/files/mind_the_gap_leaflet_final_draft_november_2013_3.pdf

²⁰Mind the Gap 2012- The Carers Trust Mind the Gap (2012) A survey of Older Carers in Northern Ireland (pgs 7; 8; & 10)



8. Carers Assessments in other UK jurisdictions

Northern Ireland, England, Scotland and Wales have each taken a slightly different legislative approach to the provision of information on and promotion of Carers Assessments. These approaches are based on the fact that each jurisdiction's legislation is worded differently. Certain jurisdictions are bound to inform carers on their right to request an assessment, and others are bound to inform of their right to one.

The Commissioner was concerned at an apparent differential in the level of uptake between Northern Ireland and other jurisdictions, but it became clear that COPNI could not conduct a like-for-like comparison on this basis. There is an inconsistent approach to the way the uptake of older carer statistics are collated and presented. This was further complicated by differences in legislative arrangements which mean that each country within the UK has a different approach to promoting and analysing uptake of Carers Assessments. The table overleaf sets out the different legislation which governs each country:

Carers entitlement to a Carers Assessment

Northern Ireland	The Carers and Direct Payments Act (Northern Ireland) 2002 places a requirement on HSC Trusts to make sure carers know about their right to a Carers Assessment. This includes a statutory right to a Carers Assessment which allows for an assessment to be carried out even where the person being cared for has refused an assessment or the provision of personal social services.
England	Under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Persons Carers Act 2000, carers who provide or intend to provide a substantial amount of care on a regular basis have the right to ask for an assessment. The Carers (Equal Opportunities) Act 2004 places a duty on the local authority to inform the carer that he/she has a right to request an assessment under both Acts. The Carers (Equal Opportunities) Act 2004 requires that any assessment undertaken under the Carers (Recognition and Services) Act 1995 or the Carers and Disabled Children Act 2000 considers whether a carer (i) works or wishes to work (ii) is undertaking or wishes to undertake, education, training or any leisure activity.
Scotland	In Scotland, under the Community Care and Health (Scotland) Act 2002, local authorities have a duty to inform eligible carers of their right to an assessment.
Wales	It is a legal requirement under the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Persons Carers Act 2000 that carers have the right to ask for an assessment. The Carers (Equal Opportunities) Act 2004 places a duty on the local authority to inform the carer that he/she has a right to an assessment under both Acts. The Carers (Equal Opportunities) Act 2004 requires that any assessment undertaken under the Carers (Recognition and Services) Act 1995 or the Carers and Disabled Children Act 2000 considers whether a carer (i) works or wishes to work (ii) is undertaking or wishes to undertake, education, training or any leisure activity.

Uptake of Carers Assessments

Northern Ireland	63% of carers aged 65 and over and 65% of carers aged 75 and over declined a Carers Assessment. ²¹
England	29,105 carers aged 65-74 were assessed - 5,945 declined an assessment. 37,035 carers aged 75 and over were assessed - 16,835 declined an assessment (2013). ²²
Scotland	It is unclear what the level of uptake of Carers Assessments by older people providing care is. Recording and data collection is carried out differently in each local authority and tends to be on the basis of over 18s and under 18s. Carers Scotland has stated that the level of uptake of the carer assessments across all age groups is low and therefore it can be assumed this is the case for older carers too. Evidence of the real reasons for levels of uptake is unreliable. The Scottish Government proposes to amend Carers Assessments in future to ensure greater access and consistency.
Wales	In 2012/2013, 86.8% of carers were offered an assessment. ²³ The Welsh Government do not collect any carer data by age group, or the number of those who decline an assessment, hence a direct comparison with Northern Ireland statistics was not possible.

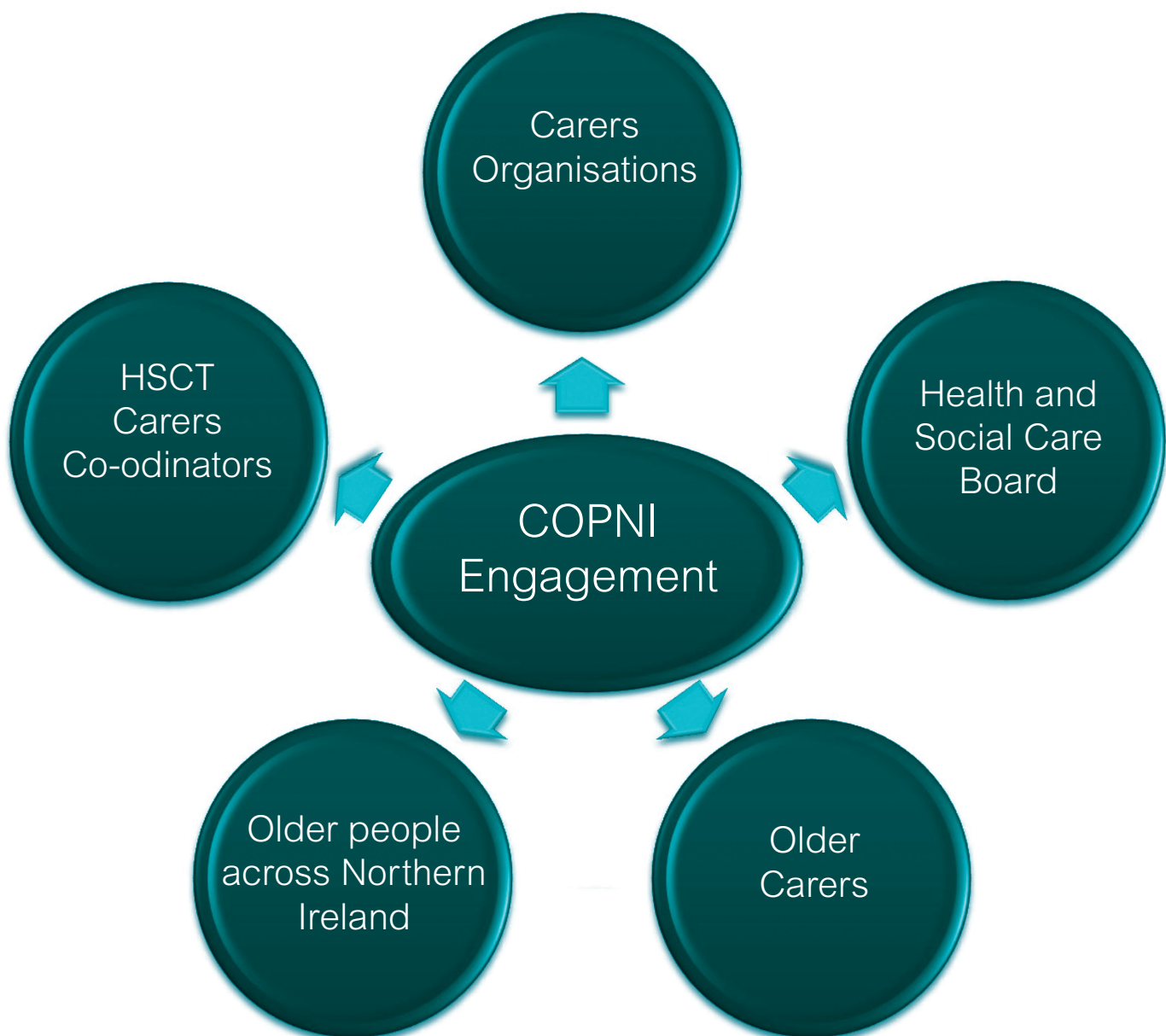
²¹ http://www.dhsspsni.gov.uk/carers_statistics_for_northern_ireland_-_december_2013.pdf

²² <http://www.hscic.gov.uk/searchcatalogue?productid=13822&topics=1%2fSocial+care%2fSocial+care+activity&sort=Relevance&size=10&page=1#top>

²³ <http://www.dataunitwales.gov.uk/>

9. COPNI Key Findings

COPNI engaged with various stakeholders, professionals working with and on behalf of carers, as well as older people, including older carers, to seek a better understanding of policies and practices relating to Carers Assessments. It was important to combine the evidence gathered via other research with COPNI-led engagement to understand what the barriers to uptake are and to make recommendations on how this could be improved.



COPNI Primary Research

In order to support evidence gathered from other sources, COPNI conducted independent research to further understand the reasons for a low uptake of Carers Assessment by older people in Northern Ireland and did so in the form of two surveys.

The **first survey** asked older people across Northern Ireland general questions about caring. This took the form of a quantitative assessment of the number of older people who identified as carers by asking targeted questions to identify the level of public awareness and understanding of the role of a carer, and to establish whether older people were generally aware of the Carers Assessment. The key findings were as follows:

- Nearly 30% of older people who provided care to someone living with them reported that they received a Carers Assessment.
- 20% of older people who provided some regular service or help for a sick, disabled or elderly relative, friend or neighbour not living with them said they had received a Carers Assessment.
- 59% of respondents stated that they had not received any information on Carers Assessments.
- The source most commonly used for information about caring was GP surgeries, with 16% of respondents reporting that they obtained the most information about their role as a carer from their GP, followed by the HSC Trust (14%) and then from carers organisations (11%). This statistic mirrors research published in 2012 in a report entitled Prepared to Care?²⁴ which found that carers are being let down by a lack of information and support when they take on a caring role.

The **second survey** was a specially designed qualitative survey aimed directly at older carers asking more in-depth questions about the carers' knowledge, experience and outcomes of a Carers Assessment.

A selection of the key findings have been enclosed in the report to illustrate the reasons that carers themselves believe contribute to the low uptake of assessments.

²⁴ http://www.carersweek.org/media/k2/attachments/Prepared_to_Care_FINAL.pdf

Do you know you can have a separate assessment of your needs as a carer?

66% of respondents stated that they did not know they could have or had a right to a separate assessment of their needs as a carer.

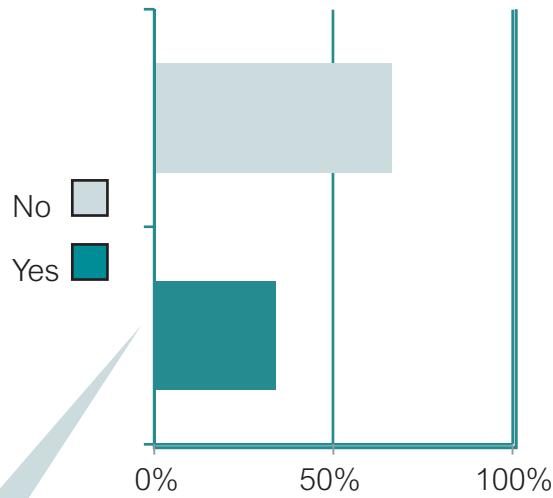
This finding confirms other research evidence that states many older carers have no knowledge of the Carers Assessment and did not understand what it involved.

Have you been offered a Carers Assessment?

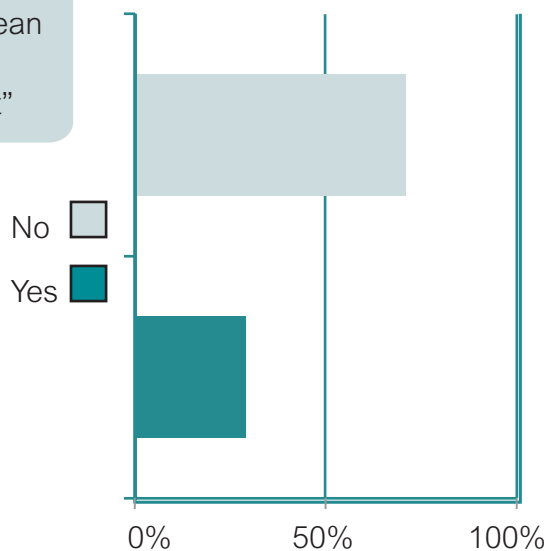
70% of respondents reported they had not been offered a Carers Assessment. The evidence corresponds to evidence collected by Carers NI that states that few of the carers they spoke to had an assessment or knew of their entitlement to one.

Do you feel that the HSC Trusts have understood the impact that caring has on you?

80% of respondents felt the HSC Trusts did not understand the effect caring had on their role as carer. This finding suggests that the majority of older carers felt the HSC Trusts do not always recognise the impact caring has on their lives.

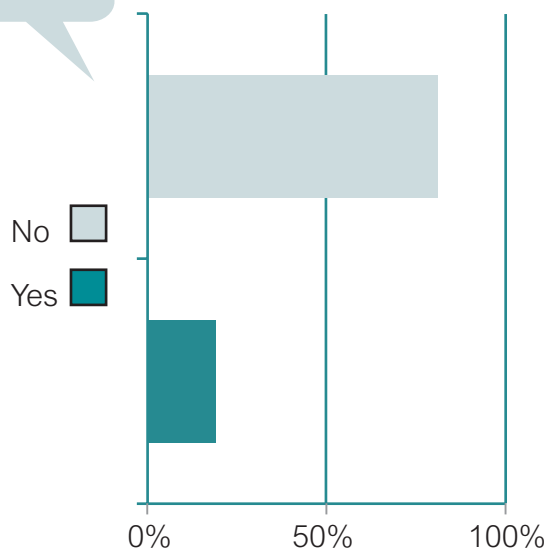


“Don’t understand what you mean by Carers Assessment”



“I didn’t know about it”

“Didn’t know it was available”



Older carers were asked to name the five most important issues for them in their caring role. These were:

- 1. Support in an emergency:** Older carers felt it was important to have support in case of an emergency. Research has indicated that an agreed plan of action and alternative care options in the event of an emergency that would affect a carers ability to continue to provide care would ensure peace of mind for the carer.²⁵
- 2. Respite and breaks:** Older carers reported that having regular breaks from their caring role, even for a few days, was important. This finding confirms other research conducted about carers and the importance of respite to people who provide regular care, which states that breaks “provided invaluable opportunities to alleviate the physical and emotional demands of the caring role.”²⁶
- 3. Maintaining friendships and having a social life:** Responses from older carers highlighted the importance of maintaining friendships and enjoying a social life. The report, Prepared to Care? (2013)²⁷ reinforces what older carers told COPNI, that older carers value greater social support and that carers can become very isolated, particularly if they are not provided with support in their caring role which, as a consequence, has an effect on their mental health and wellbeing.
- 4. Help from family:** Older carers said it was important to them to have help from family members to assist in their caring role. Some carers said they needed support from their families to be able to juggle their work and caring roles. Evidence has indicated that day-to-day can be exhausting and stressful for the older carer and emotional and practical help from family is seen as crucial for the older carer to carry out their caring roles.²⁸
- 5. Financial support:** An older carer’s needs for support are not limited to emotional and practical support, but also encompass financial matters. The fifth most important issue mentioned by carers that was important to their role was financial support. This finding concurs with recent research which highlighted the financial hardship carers across the UK including Northern Ireland are facing due to their caring role (Caring & Family Finances Inquiry, 2013).

Older carers were also asked what, in their opinion might improve the uptake of Carers Assessments in Northern Ireland:

- 1. More information:** The most common theme identified was the lack of information provided to the carer. Older carers suggested that more awareness was needed to advise them of a Carers Assessment as research showed that many people were not aware of the assessment. Some said they did not receive any information from the HSC Trusts nor were they offered a Carers Assessment. There was a suggestion that information should be made available through media and educational routes. Some older carers said specific information on benefits would also be helpful.
- 2. Extra support:** Older carers suggested a way of improving the uptake of Carers Assessments would be to provide more assistance and help from the point of initial assessment, not only when an emergency arises. Another concern was the need to establish and maintain contact between the HSC Trust and carer.
- 3. Easier access to support:** Older carers were not satisfied with the HSC Trusts handling of services. Some felt there was too much red tape hindering the support older carers should receive, and others suggested that the funding provided to different HSC Trusts varied enormously which disadvantage some older carers.

²⁵ <http://www.communitycare.co.uk/2009/07/24/lifeline-for-carers-thanks-to-birmingham-carers-emergency-response-service/>

²⁶ <http://www.iriss.org.uk/resources/rest-assured>

²⁷ http://www.carersweek.org/media/k2/attachments/Prepared_to_Care_FINAL.pdf

²⁸ <http://www.carers.org/mind-gap-northern-ireland>

Summary of Findings

Experience

Over 60% of older carers were not aware they were entitled to a Carers Assessment.

70% of older carers had not been offered a Carers Assessment.

32% of older carers who said they were offered an assessment did not accept the evaluation of their needs and support differed.

18% of older carers were very dissatisfied with the administration of their assessment.

10% of older carers reported a satisfaction with the administration of the form.

20% of older carers were satisfied with the way their questions were dealt with.

Outcomes

Nearly 20% of older carers were dissatisfied with the administration and outcome of their Carers Assessment.

42% of respondents did not have contact with a named person who organised their services.

70% of older carers were of the opinion that an assessment did not result in more support for them.

85% of older carers felt HSC Trusts did not understand the impact of their caring role.

The five most important areas carers cited that were important to their role were:

1. Support
2. Respite
3. Friendship
4. Help from family
5. Financial support



Secondary Research

In order to support the findings from the primary research carried out by COPNI, a phase of secondary research was conducted with a range of carers organisations as well as HSC Trust Carer Co-ordinators to further understand the low level of uptake of Carers Assessment by older carers from others working in this area.

Key findings from engagement with carers organisations

- **Terminology:** The title itself “Carers Assessment” carries a stigma which sometimes creates a fear that the assessment may have an effect on other benefits. The name of the form “Carers Assessment” suggests to some carers a test of their caring ability.
 - **Self-identification:** People who carry out caring responsibilities do not always recognise themselves as “carers.” Representatives of carers organisations stated that carer identification was a significant barrier to supporting carers. This applies particularly to older people who carry out caring responsibilities.
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- **A more carer-centred approach:** The assessment process needs to be improved and much more focused on the needs of the older carer. Terminology which will enhance accessibility to carers and reinforce the participatory and collaborative approach was seen as a way forward.
- **“Just getting on with it:”** Many older carers prefer not to ask for help and prefer to “just get on with it.”
- **Increased services and support:** Older carers want and need more services and support, and require more engagement with the HSC Trusts so as to ensure they understand the needs of the older carer.

Key findings from engagement with HSC Trust Carer Co-ordinators

- **Self-identification/Recognition:** Older people often don't recognise themselves as carers as they believe they are “just doing what anyone would do” by looking after a loved one and therefore are not accessing the help available to them. Although prevention and early intervention is promoted, it usually takes a crisis to identify an older carer.
- **Terminology:** There are negative connotations with the assessment form and process. The older carer might be reluctant to discuss the emotional impact caring has had on them or may see the questions in the Carers Assessment as an intrusion of their privacy. The name of the form itself was also found to be off-putting as it is considered to be value-laden. It also focuses on “carers views” rather than on practical help that is needed.
- **Effective communication:** Access to relevant and timely information and advice was cited as vital for the older carer. Through COPNI's engagement it was found that a major barrier to an older carer accessing services was the lack of good, relevant, timely, and up-to-date information.
- **Completion of assessment:** The administration of the Carers Assessment is a long process, taking between 1.5-3 hours, and it is not user-friendly; older carers and staff do not have the time to carry out the assessment. Time should be given for health and social care staff to understand the carer's needs and requirements, and to develop a good relationship between the carer and the key worker.
- **Reassessment:** There is no abridged form for a re-assessment; instead some HSC Trusts have introduced a document entitled “Any Significant Change” to capture new or changed information. The Northern Ireland Single Assessment Tool, specifically designed to capture the information required for holistic and person-centred assessment of the older person, is not always appropriate for assessing changing support needs and circumstances.
- **Need and unmet need:** Assessed needs should be fully met through provision of high quality services. There is no record of unmet need and barriers to accessing services which would better inform future commissioning. There is also a concern that core services are constantly being reduced, and that the only needs now being met are ‘critical’ needs.

10. Conclusions

This report shows that the level of uptake of Carers Assessments by older carers remains low despite efforts by DHSSPS to encourage carers to undergo an assessment. COPNI's research has identified a number of reasons for this, below are the conclusions from the report:

1. Whilst targets are in place which compare the number of Carers Assessments offered and accepted, it would appear that no targets are in place to measure the following:
 - The number of older carers identified (by HSC Trust area);
 - The number of Carers Assessments offered to all new older carers identified;
 - The provision of adequate and timely information to older carers; and
 - The services and support in place following a Carers Assessment.
 2. Many older carers do not recognise themselves as a 'carer' but rather see their role as "simply looking after" their spouse, partner, child, parent, friend or neighbour. Older carers are not aware of their right to an assessment and of those asked, a significant proportion stated that they were not offered a Carers Assessment, despite this being their statutory right. Therefore a substantial number of older carers remain outside the network of advice/carer organisations, social services and HSC Trusts' remit.
 3. Older carers reported a lack of information about the range and types of help and support available through the Trust's services, including the promotion of carers' rights, local resources, and links to other sources of information provided to the older carer to assist them in their caring role.
 4. Carers organisations and older carers reported that the actual assessment process was viewed as being a "paper exercise" yielding no benefits for the older carer. Older carers wanted staff to be sensitive to their needs and their concerns.
 5. The administration process and timing of the assessment meeting is considered to be crucial in whether or not an older carer accepts the offer of a Carers Assessment. There needs to be an adequate amount of time to establish and develop a good relationship between the older carer and Trust representative to discuss their needs and experience in private at a time and place convenient to the older carer.
 6. General Practitioners play an important part in identifying and signposting older carers, providing information and explaining the benefits of why they should have a Carers Assessment. Good practice in England encourages practice staff to support the healthcare of carers and set achievable targets to measure the increase in registered carers. Increased focus by GPs on encouraging uptake of Carers Assessments by older people would be welcomed.
 7. There are negative connotations associated with the Carers Assessment as if it is somehow a test of the older carers ability to care. Further to this, if a Carers Assessment is accepted, there is a fear that this could have an adverse impact on the level of benefit or entitlements a person would receive.
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11. Recommendations to Government

Following on from the conclusions of the research conducted by COPNI, the Commissioner has identified a series of recommendations to the Minister of Health, Social Services and Public Safety. The recommendations follow on from the conclusions outlined in the previous section, and propose a series of initiatives which could improve the uptake of Carers Assessment by older carers.



The recommendations are as follows:

1. Clear targets should be set to significantly increase the uptake of Carers Assessments by older carers.

There are gaps in targeting and monitoring the number of carers being assessed and so targets for improving uptake of Carers Assessments by older carers should be put in place to monitor need and demand as well as unmet need.

2. Older carers must be aware of the services, information and support that could better enable them to support people who rely on their care.

This should include public awareness campaigns using a variety of communication mediums to highlight what is meant by an “older carer.” Campaigns should have a focus on “hidden carers” so as to identify people who are unaware of support available to them, and should encompass a wide range of communication mediums, such as within GP surgeries, in order to improve the chances of increasing the number of older carers receiving an assessment. Information should also be widely available to carers on advice and support.

3. Older carers need an assurance that the services and support needs identified in a Carers Assessment will be met and implemented.

This includes high quality respite for the older carer, as well as information, training and emotional support. It is essential that the assessment is not merely a “paper exercise.”

4. Increased flexibility and support for Carers Assessment process.

Older carers should be able to undertake a Carers Assessment in a timely manner in a location that is suitable to them, and should be supported by a key point of contact within the Trust. There should also be a consistent review or reassessment process.

5. Changes to Carers Assessment form.

The title “Carers Assessment” should be reconsidered, and the assessment process should be focused on practical help and services available to older carers. This should be accompanied by a commitment to providing that help.

