



DementiaUK

Helping families face dementia

Lincolnshire Admiral Nurse service

**Evaluation summary
2019-21**

Introduction

This report summarises achievements of the Lincolnshire Admiral Nurse service against evaluation objectives for years one and two.* It presents evidence on the impact and experience of the service for professionals and families affected by dementia and demonstrates how the service has embedded within the local health and social care system. The Lincolnshire Admiral Nurse Service was commissioned in June 2019 to provide specialist nursing support and interventions to families and carers of those living with dementia. The service is hosted by St Barnabas Hospice with support from Dementia UK, Lincolnshire County Council and Lincolnshire CCG.

The evidence presented covers the period August 2019 to June 2021 (the first 23 months of the service) and includes data collected from surveys, a validated quality of life measure, clinical database, pre- and post-training questionnaire and a case study.

The service, like many others, has been impacted over the last 18 months by the COVID-19 pandemic. The service adapted to this by continuing to deliver support via phone and video contact, to ensure that much needed support was provided during increasingly difficult circumstances to families affected by dementia.

During this evaluation period, the service has become more embedded within Lincolnshire, enabling more opportunities to provide expertise and support alongside other services. Relationships continue to be developed with other organisations and groups to ensure a more joined up approach to dementia support in the county is sustained.

The key achievements of this service have been improving access to palliative support for those affected by dementia, supporting existing services via collaborative working to improve the wellbeing of carers, and supporting carers to improve quality of life for themselves and for loved ones.

*An additional Technical Report is also available, which provides the data to support this report.

Summary

There were **1,093 referrals** into the service with **39% of these from Primary Care**

A total of **8,611 interventions were recorded** by the Admiral Nurse service

A total of **10,262 activities were recorded** by the Admiral Nurse service

23 out of 24 Professional Stakeholders said the Admiral Nurse had improved **quality of life** for the person with dementia and for families

32 out of 51 carers said they would have **struggled on their own** without the support of the Admiral Nurse

214 Supporting Best Practice activities were delivered by the Admiral Nurse service

Contents

Embedding within the local system.....	5
Professionals survey results.....	11
Carer survey results	19
Adult Carer Quality of Life measure results.....	24
Case study.....	25

Embedding within the local system

Receiving referrals

Between August 2019 and June 2021 (23 months) the Admiral Nurse service received 1,093 referrals* – 1,007 new referrals and 86 re-referrals.

Referrals came from a variety of sources – the three most common sources were:

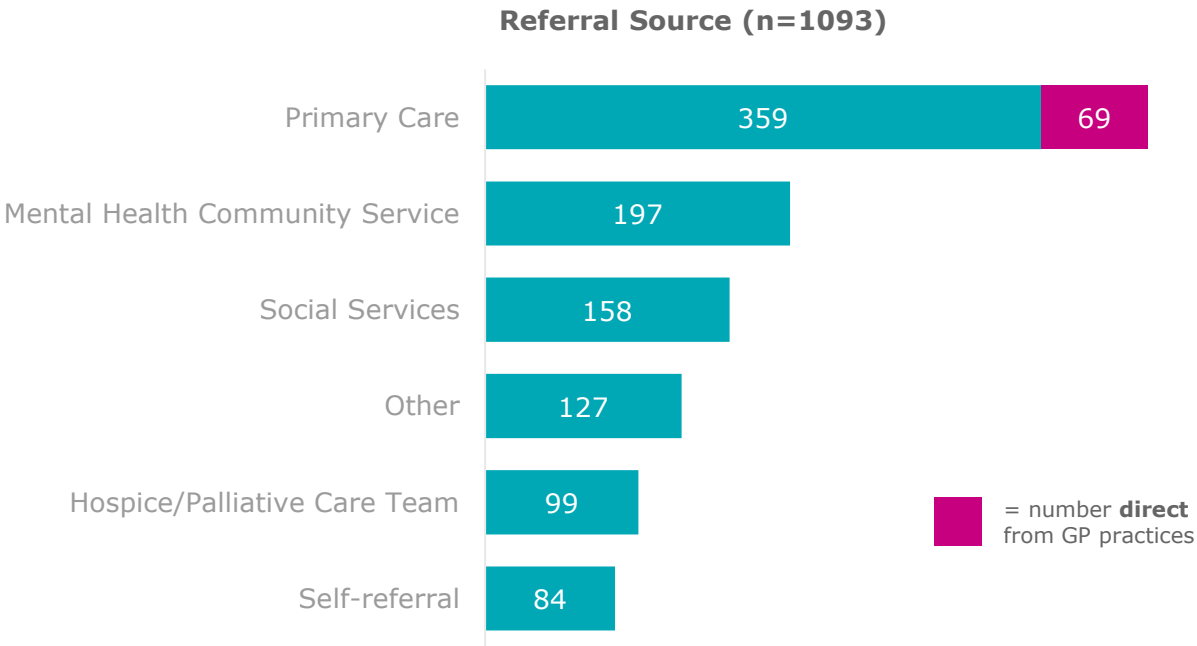
- Primary care (39% of all referrals recorded)
- Mental health service (18%)
- Social services (14%)

Reason for referral

Each referral is recorded with a primary reason for referral (i.e. the main presenting need), however, multiple options can be recorded for secondary reasons. The most common primary reason for a referral recorded was **change in presentation of the person with dementia and/or high level of distress** (n=242 22%), followed by:

- Need for information (n=165, 15%)
- Skills acquisition for carer (n=155, 14%)
- Referrer request assessment or triage (n=152, 14%)
- Carer/family need support with managing risk (n=109, 10%)

* Referrals for July 19 before clinical activity started are included in August 19 figures
Further referral data can be found in the appendices



Who was referred to the service?*

- Most of the carers referred were female (70%, n=603); 56% (n=474) of people with dementia were male
- There were **22 referrals with young onset dementia** recorded
- The majority of carers referred were the **spouse or partner** of the person with dementia (67%, n=570)
- Most of the carers (n=718) and people with dementia (n=739) referred into the service were **White British**
- Carers were aged between 18 and 99, with most between 70-92 years old
- People with dementia were aged between 50 and 105, with most between 75-92 years old
- **The top two recorded dementia diagnoses of the people with dementia were vascular dementia (n=236) and Alzheimer's disease (n=202)**

Outcome of referral requests

Of the total 1,093 referrals received into the service:

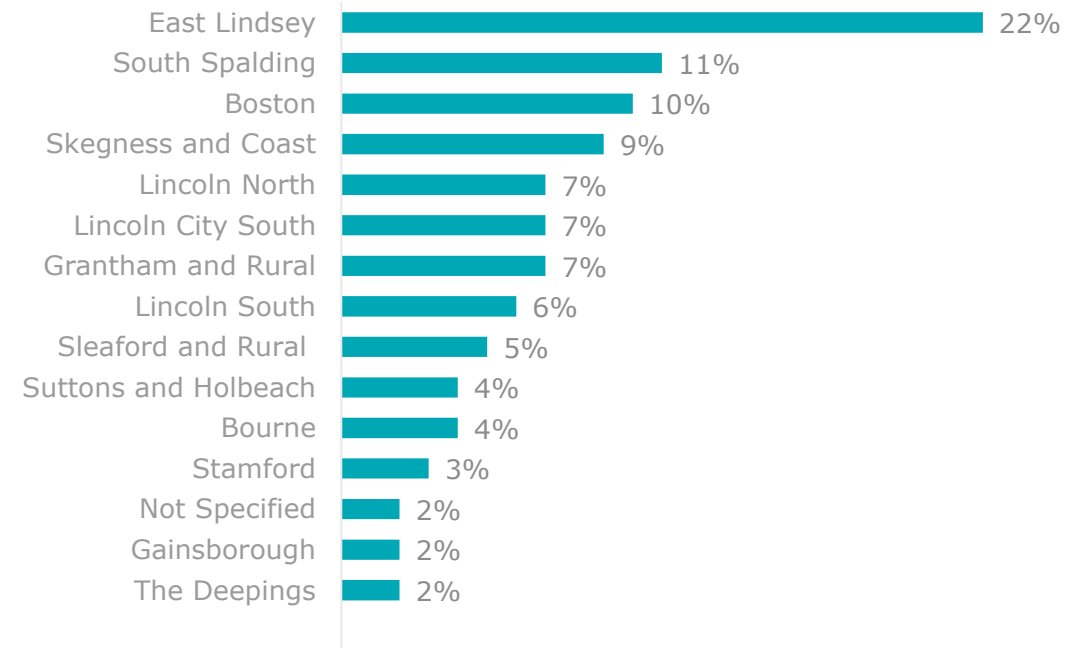
- 171 were recorded as inappropriate referrals following triage**
- 203 of these referrals declined*** the support offered by the Admiral Nurse service. In these cases the service may signpost/refer onto other services.
- A total of 719 referral requests were taken onto the Admiral Nurse caseload.

* Where data was recorded

** Inappropriate referrals primarily consist of referrals not meeting the referral criteria, out of area or not demonstrating sufficient complexity for a tier 3 service

***Cases where the carer feels they do not require the service or in the case of carer death

Referral requests by locality (2019-21)



Those referred came from across the Lincolnshire area with most of the referrals coming from the East Lindsey locality.

Signposting/referring to other services

Admiral Nurses work in partnership with other health and social care services, and voluntary organisations that operate in the same catchment area. As a specialist service, Admiral Nurses add a specialist dementia skill set. However, to holistically meet people’s needs, they recognise the specialism and key skills other services are able to provide as well. They will therefore signpost or make a referral for carers and people living with dementia to other services when appropriate.

Signposting* - **311** signposting activities were recorded. This includes signposting to information sources such as local amenities and services or groups. In 68 cases clients were signposted to GP or other Primary Care service, 55 cases to the Local Authority/Social Services and 55 cases to Voluntary/third Sector.

Referrals to other services* - There were **138 recorded occasions when the Admiral Nurse made a direct referral** to other services. The majority of referrals were made to Social Care Services (35), voluntary sector (25) and the Hospice/Palliative Care Team (23).

Key Performance Indicators

The service recorded data on the **time between referral and initial contact with a carer** and **time between referral and commencement of assessment**. The table below shows the achievements of the service in relation to these KPI’s during both year 1 and year 2.

	80% of those referred to the service are contacted within 5 working days of referral	80% of those clients on the caseload have an initial assessment started within 28 calendar days
Aug 19-Jun 21	759, 77% (31% on the same day) Average time to response 5.3 days	159, 39% Average time to assessment – 42 days
Year 1	485, 80% (min 60%, max 95%) 144 same day, 24%	125, 42% (min 13%, max 77%)
Year 2	274, 74% (min 45%, max 84.4%) 189 same day, 50%	34, 34% (min 11%, max 53%)

* This is not automatically recorded within clinical database system and is likely to be significantly under-reported

Assessing need

Although referrers are asked to state a referral reason, the Admiral Nurse conducts an individual assessment with the carer to identify and assess complexity and severity of needs, begin care planning, and prioritise interventions accordingly. The Admiral Nurse Assessment Framework provides the structure within which to assess the needs of the family carer.

The **most common areas of unmet** need highlighted at initial assessment were:

- Mental health and wellbeing - carer (152)
- Skills in coping with behaviour/symptoms (143)
- Looking to the future – carer (129)
- Time for self – carer (127)
- Mental health and wellbeing – person with dementia (106)
- Knowledge and understanding about dementia (95)
- Adjustment and loss (94)

Most commonly, carers on the caseload had between **3-4 unmet needs** following assessment, which form the basis of care planning and future interventions by the Admiral Nurse.

Admiral Nurse Activities

Admiral Nurse activity is divided into 3 types of contact; clinical, liaison, administrative.

The table opposite shows the number of clinical, administrative and liaison activities recorded during the reporting period and the total duration for each.

There were a total of 10,262 activities recorded by the Admiral Nurse service

Activity Type	Number contacts	Time (Hrs)
Administrative	2976	326
Clinical	5377	1329 (phone) 1256 (F2F)
Liaison	1909	351

Interventions with families

Clinical activities delivered by Admiral Nurses involve a range of interventions to support families, which are person-centred and follow the carers assessment of need (identified using the Admiral Nurse Assessment Framework Tool).

Between August 2019 and June 2021, a total of **8,611** interventions were recorded

The most common interventions recorded were:

- **Providing emotional and psychological support (n=2,293)**, which has been particularly important during the COVID pandemic when resilience and mental wellbeing of carers may have been strained
- **Assessment (n=2,074)** is a key skill of any nurse, both on initial contact with the carer, but during ongoing involvement to evaluate risk, ascertain progress against current care plan and the formulation of new plans
- **Sharing of knowledge and information (n=1,799)** utilising the Admiral Nurse specialist knowledge about diagnosis, prognosis, case management, medication, behaviour that challenges, and physical and mental wellbeing to educate and support carers

Supporting best practice

Alongside working directly with families, Admiral Nurses work with others to promote best practice in dementia care.

The service has recorded **214** supporting best practice activities from August 2019 to June 2021. Most of these activities were related to clinical meetings - attendance at these meetings is often to advocate for carers and liaise with other services e.g. Neighbourhood or Hospice MDT meetings (n=73), advice and support to other health and social care professionals (n=47) and promoting and informing audiences about the Admiral Nurse service and dementia (n=51).

Examples:

1. St Barnabas is a Project ECHO* hub for supporting best practice at pace and scale across the whole health and social sector. The Admiral Nurses have contributed to sessions within ECHO networks including sessions on Mental Capacity Assessments, prescribing in dementia, supporting complex relationships, pain management, End of life care and Behaviour that challenges
2. The service has also provided teaching sessions for Lincoln Medical School, Bishop Grosseteste University and Lincolnshire Care Organisation
3. St Barnabas – sessions provided by the Admiral Nurses to provide updated practice information to hospice nurses
4. L.I.V.E.S. teaching session – Session for first responders on dementia awareness and approaches to support people with dementia in an emergency situation

*Extension for Community Healthcare Outcomes
Further details on training outcomes can be found in the appendices

Impact of Admiral Nursing – professional survey

The professionals survey was designed to include questions around core outcomes to demonstrate the impact of the Admiral Nurse service as follows:

Outcomes for families affected by dementia (in the professionals' opinion)

- Families receive the most appropriate care for their needs, resulting in improved utilisation of local health and social care resources
- Enhance quality of life and well-being for families affected by dementia
- Enable families to be involved in decisions about care

Outcomes for professionals and contribution to system-wide outcomes

- Embed service and establish partnerships within local system, resulting in better coordination between services and improved case management for families affected by dementia
- Increase professionals understanding of dementia and confidence in assessing need
- Improve utilisation of local health and social care resources

The following pages present the findings from the professional survey for the outcomes detailed above – **33 professionals** provided feedback.

Note about the data from the questions on outcomes:

Respondents were given a number of statements and asked to say whether the Admiral Nurse service had done any of these. As the survey was designed to be completed by any professional this question included wording saying that 'some of the statements might not be relevant to you' and asked respondents to choose 'not applicable' if the statement was not relevant or to choose 'don't know' if they felt they were unable to comment. Numbers reported exclude 'not applicable' and 'don't know' i.e. responses shown are those where statements were applicable and respondents felt they could comment. This also means that response rate to each question varied.

Outcomes – for families (in professionals' opinion)

Professionals felt that the service was making a difference to key aspects of people's lives and improving their care

Most professionals responding*, said the Admiral Nurse had:

- Improved care (23 out of 28)
- Improved quality of life for the person with dementia and for families (23 out of 24)
- Enabled the inclusion of the person with dementia and their families in decisions about their care (21 out of 24)

Outcomes – for professionals and contribution to system-wide outcomes

Responses also demonstrated how the Admiral Nurse service was embedding within local systems. In response to a question about their reasons for contacting the Admiral Nurse service (n=33**):

- 25 said 'to make referrals'
- 24 said 'our services work together'
- 19 said 'to get advice or information'

.. and contributing to improved coordination and case management

- 22 (out of 27) said the service had increased their awareness of other services available to support families affected by dementia
- 16 (out of 22) said the service had improved case management/coordination

* Total responses given for each question are numbers saying 'yes' and 'no'

** All respondents answered this question, respondents could tick more than one option

Professionals felt there had been an impact on their understanding and confidence:

- with 20 (out of 25) professionals saying the service had **increased their understanding of dementia and its effects**
- 12 (out of 20) said the service had **increased their confidence** in assessing need for families affected by dementia

Professionals also felt that Admiral Nurse service was contributing to improved utilisation of health and social care resources, with respondents saying that the Admiral Nurse service:

- helped them **avoid crisis points** for families affected by dementia (21 out of 24 said this)
- had an impact on **delaying long term care home placements** (16 out of 20 said this)
- had an impact on **reducing unplanned hospital admissions** (14 out of 19 said this)

The service was having a role in **Advance Care Planning** - 14 (out of 19 respondents) said the service had introduced the concept of Advance Care Planning to families.

Half of those responding said there had been an impact on reducing their and their services contact time with families affected by dementia.

Impact if service no longer existed

*"This service supports clients to stay at home as long as possible, as once part of the admiral system, there is support for families during times of change with dementia. This service fills a valuable gap in the caring service and would be sorely missed as a **clients quality of life would change.**"* **Professional stakeholder**

*"Families/patient's would contact the service more for advice and support around their dementia/issues. **Patients/families would no longer have a specialist point of contact** for advice/sign posting. Potential to increase GP workload. Increase on LPFT dementia support."* **Parkinson's Nurse Specialist**

Over two-thirds of respondents felt there would be an impact if the Admiral Nurse service no longer existed (only two respondents said no and eight were unsure). The type of impact described by the 23 professionals included:

- **Reduced support for families**
- **Reduced support for dementia patients**
- **Additional pressures on other services**
- **Poorer outcomes for families**
- **Loss of specialist advice/support**

*Without this extra support, many families feel that they cannot cope and this can lead to family/carer breakdowns which can result in the service user going into residential care on a temporary basis. The families often then feel that they are not able to manage at home anymore and this **temporary placement becomes permanent resulting in a loss of independence.*** **Professional stakeholder**

'Now that we have the Admiral Nurses, I don't know how we ever managed without them and how we ever could.' **HEC Manager, Extra Care Housing**

Selected feedback on the Admiral Nurse service

The following pages provide an illustration of the impact of Admiral Nurses and impact if the service no longer existed, from respondents working in the following settings:

- Adult care/Lincolnshire County Council
- Neighbourhood teams
- Primary care
- Voluntary sector

"The only improvement you could make is making sure the service is kept up and running, if not expanded."

HEC manager, Extra Care Housing

"It is much welcomed that there is a specialist support service for our dementia carers."

Professional stakeholder

"It has taken away some of the pressures from other services who do not have the specialist knowledge to support this patient group."

Professional Stakeholder

Adult Care/Lincolnshire County Council

Community Care Officer, Lincolnshire County Council Adult Care

Admiral Nurses are a valuable service who give great advice and support to both their clients and other supporting teams.. Absolutely fabulous service and I am happy to have been working alongside them during a crisis prevention.

I had a client and [spouse] whom were affected considerably by Covid-19 lockdown restrictions and after making contact with your team who offered fabulous support and regular feedback and what they intended on completing next, this made the care and support much easier on the couple and it reduced considerable strains and stresses within the household. It also reduced the risk of hospital admission, injury and a host of other potential risks. I thank you very much for your services.

Would there be an impact on you/your service if the Admiral Nurse service/post no longer existed?

The case in particular I dealt with could have potentially resulted in injury, safeguarding concerns possible hospital admissions as well as the family being at crisis point. It also would have put extra on to Adult care services as well as pressurising the family and involving family who were shielding due to Covid-19.

Professional stakeholder

Without this extra support, many families feel that they cannot cope and this can lead to family/carer breakdowns which can result in the service user going into residential care on a temporary basis. The families often then feel that they are not able to manage at home anymore and this temporary placement becomes permanent resulting in a loss of independence.

I feel that the Admiral Nurses are a vital support service for families and the individual diagnosed with dementia, especially in the early stages when it may be hard for them to adjust to their new way of living. They are a valuable service who work really well alongside Adult Social Care.

OT/Practice Lead, Lincolnshire County Council

Enabling our clients to remain in their own home by having a specialist service in which to gain further advice support, and specialist advice further reassures family and registered care providers.

Neighbourhood teams

Neighbourhood lead

It's how the service compliments or forms part of a coordinated response to need which is neighbourhood working. Within the Neighbourhood context I have regarded them as a source of specialist dementia care knowledge which has been helpful in supporting all people coming through the neighbourhood irrespective of whether they meet the criteria to be on the AN case load - This in turn can be informative for partners around the table and have a positive impact on how they support people and families with dementia - that has been an important neighbourhood resource.... Specialist knowledge of dementia input to safeguarding meeting..

Neighbourhood coordinator

Admiral Nurses have become an integral partner of the coordinated care being delivered within Neighbourhoods across the county. I have always found the Admiral Nurses to be approachable, receptive and perceptive as well as willing to collaborate and always keeping involved practitioners well informed.

Would there be an impact on you/your service if the Admiral Nurse service/post no longer existed?

The workload that the Admiral Nursing service currently manages would drastically impact the volume and nature of the workload that we currently experience. With many services continuing to operate at full or near full capacity, it is highly likely that a prospective end to Admiral Nursing services would lead to significantly poorer health and wellbeing outcomes for all those affected by Dementia and an increase in workload for other community services that would be unmanageable.

Professional stakeholder

Would there be an impact on you/your service if the Admiral Nurse service/post no longer existed?

Families and informal carers would not have the support and knowledge that the Admiral Nurses are able to provide this would lead in my opinion to carer breakdown and potential harm to both the informal carer and/or the person they are caring for. They are such an important member of the team and in my opinion must continue and be invested further in as we have an ageing population and the need is just going to increase.

Primary Care/voluntary sector

Care Coordinator for Older Adults, GP Practice

I have worked closely with the Admiral Nurse to support my patient and her family when she was admitted for respite and social work felt her needs were not being met by [family member] and completed a DST and she is now in nursing care. Care home care has not been as good as it should be and family have found huge problems getting the information they require to know the patient is safe and looked after. By working together with the Admiral Nurse we have been able to support the family to ensure care given is the gold standard.

Would there be an impact on you/your service if the Admiral Nurse service/post no longer existed?

Patients would not have that expert support, they would go back to being isolated and uneducated. The burden on my service would mean that I am not able to support appropriately and I do not have the depth of knowledge that the Admiral Nurses have to ensure the patients and their families have the right information to ensure they can continue caring for their loved ones.

Any other comments about the service?

As with any service more staff would be brilliant. the expert knowledge that the Admiral Nurses have is essential, they cover a huge area and can only see the most complex of patients. If we had more of them they would be able to see more patients and families and the waiting time would be shorter. They would also have time to provide more education for professionals to ensure more clinicians were dementia aware, which at present they are not.

Nurse, Voluntary sector

Admiral service has been developing over the past year in my area and has made a significant impact to many patients and their families/carers as well as supporting education through attendance at MDT's / bespoke packages / direct contact with other clinician's etc. Before the admiral nurses were in post I regularly heard comments like 'we really don't know what to do for this patient with dementia'. Now we can discuss with the admiral team and support or refer as appropriate. A great resource.

Would there be an impact on you/your service if the Admiral Nurse service/post no longer existed?

Reduced support for dementia patients in an area where it is essential (older population / higher incidence). No Dementia education to raise awareness. Additional pressures on other services who are not able to give the same amount of time required for advance care.

Impact of Admiral Nursing – carer survey

The carer survey was designed to include questions around core outcomes for families affected by dementia to demonstrate the impact of Admiral Nursing:

- Positive experience of the service
- Feeling supported by the service
- Enhancing caring abilities and well-being
- Improved utilisation of local health and social care resources

The following pages present findings from the carer survey for the outcomes detailed above – **54 carers** provided feedback.

"I was at breaking point when I first met [Admiral Nurse] and she helped me so much. I will always be grateful to her and the system for providing her care to me - Thank you". Carer

"My Admiral Nurse empowered me by listening and understanding how stressful the situation was. She was amazing, just to talk to someone who cared, was kind and could explain and put into words how I felt whilst providing practical advice". Carer

Outcomes – positive experience

89% of carers responding*, said they would recommend the Admiral Nurse service to someone they know who looks after a person living with dementia (48 out of 54).

To capture positive experience, carers were asked about accessibility of the service, how the service was delivered (attributes of Admiral Nurses), whether the service assessed needs, involved them in decisions, answered their questions and informed them of next steps.

Most carers responding told us the Admiral Nurse had:

- assessed the person living with dementia's needs (34 out of 37)
- assessed their needs (40 out of 45)
- involved them in decisions (27 out of 36)
- answered all questions (35 out of 46)
- kept them informed of next steps (27 out of 40)

"Just knowing someone was there at the end of the phone. Not judging me when I couldn't cope and disliking the change dementia has made to parent".
Carer

92%
said it was **easy to make contact**
with the service (n=50)

91%
said the nurse **showed compassion**
and respect (n=54)

91%
said the nurse **listened to them**
(n=54)

"The Admiral Nurses have made a huge difference to our family. Offering a very kind and caring person to just listen and not judge in any way".
Carer

*Response rate to each question varied as: respondents could choose not applicable (N/A) if a statement or option wasn't relevant to their experience; questions weren't mandatory so respondents could skip questions. n= is total number responding to a question minus N/A and number skipping a question. Numbers and percentages shown are calculated on total number responding to each question.

Outcomes – support

The survey also collected information on whether carers felt supported by the Admiral Nurse in their caring role and in their interactions with other health and social care professionals.

"Great relationship built. It helped because I was talking to someone who was a professional and who understood my journey. She looked out for my needs. She was my advocate when I needed someone to liaise with the care homes". Carer

Carers felt supported by Admiral Nurses:

- through the provision of **support and advice to manage risk and prevent crisis** (33 out of 34)
- with **making decisions at important times** of change (31 out of 34)
- with **identifying the person with dementia's wishes** and preferences for end of life care (13 out of 15)

Carers also felt supported in their interactions with other health and social care professionals:

- 20 (out of 24) felt the service had **been helpful in co-ordinating support** from other health and social care professionals
 - 19 (out of 25) felt the service had been good at **speaking up on their behalf** with other health and social care professionals
-

Outcomes – caring abilities and well-being

Ability to care – we asked carers whether support from the Admiral Nurse service had made any difference to their ability as a carer:

- Almost all (43 out of 45) said support from the service had been helpful in providing them with ways of responding to and coping with changes in behaviour of the person with dementia.
- Two-thirds or more said the service had made a difference to their confidence in coping (32 out of 48), their ability to care for person living with dementia better (34 out of 48) and their ability to influence or make important decisions about the care of the person they look after (34 out of 43).
- Support from the service had also made a difference to carers' ability to maintain their relationship with the person living with dementia (26 out of 40).

Well-being - the Admiral Nurse service also provided support which directly enhanced the well-being of carers:

- 90% said the service provided them with emotional support (45 out of 50) and two-thirds said the service had made a difference to their ability to take better care of themselves (32 out of 47).
- Some carers said the service had helped to organise support to enable them to take a break from caring (15 out of 18) and made a difference to the opportunities they had for time off from caring (16 out of 26)
- 32 (out of 51) said they would have struggled on their own without the support of the Admiral Nurse.

Outcomes – improved utilisation of health and social care resource (n=51)

We asked carers if they did not have access to the Admiral Nurse service what difference they thought it would have made to them:

- **Just under a third** would have seen the GP more for the person living with dementia’s needs (16 out of 51)
- **Just over a quarter** would have seen the GP more for their needs (14 out of 51)
- **One-fifth** would have been unable to continue as a carer (10 out of 51)
- **Seven** people said the person living with dementia would have needed to move into care
- **Three** people said the person living with dementia would have had to go to A&E more often

Some additional comments by carers

<p>The support was always at the end of the phone if needed. It took so much stress away because we wasn't just caring on our own, we had the support from the Admiral Nurse. That made so much difference because of their support. Thank you so much you made such a difference.</p>	<p>From the beginning, [AN] began to build my confidence in myself, and contacted other organisations to support me. These outreaches ... proved very fruitful and greatly helped me to cope.</p>
<p>The Admiral Nurse helped me to come to terms on how things are changing and they gave me the confidence to go on because at one time I was in a crisis and she helped me a great deal.</p>	<p>Helped me to understand the progression of dementia and how it presents itself.</p>
<p>I just hope in future that more people have access to these amazing caring people (nothing was too much trouble).</p>	<p>I no longer have an Admiral nurse and am desperate to know when I will have this reinstated.</p>

Quality of Life measure for family carers

The Adult Carers Quality of Life Scale (AC-QoL)* is a validated tool that measures family carers quality of life across eight domains (*Support for Caring, Caring Choice, Caring Stress, Money Matters, Personal Growth, Sense of Value, Ability to Care, Carer Satisfaction*).

There were 40 carers with both a baseline (assessment) and at least one repeated (review) AC-QoL measure.

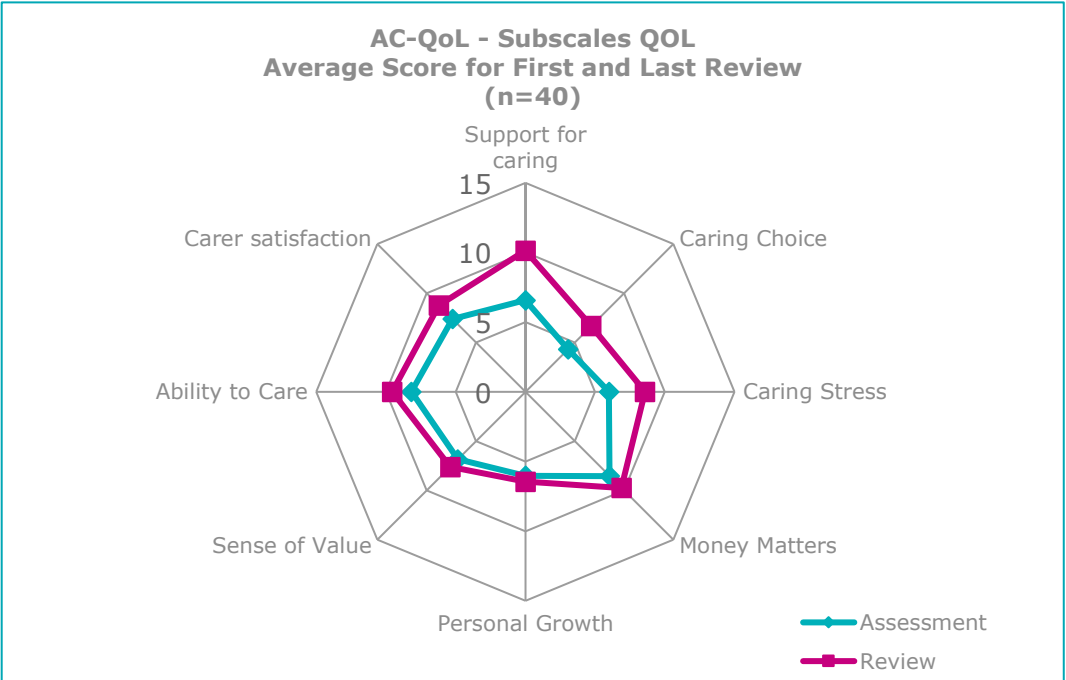
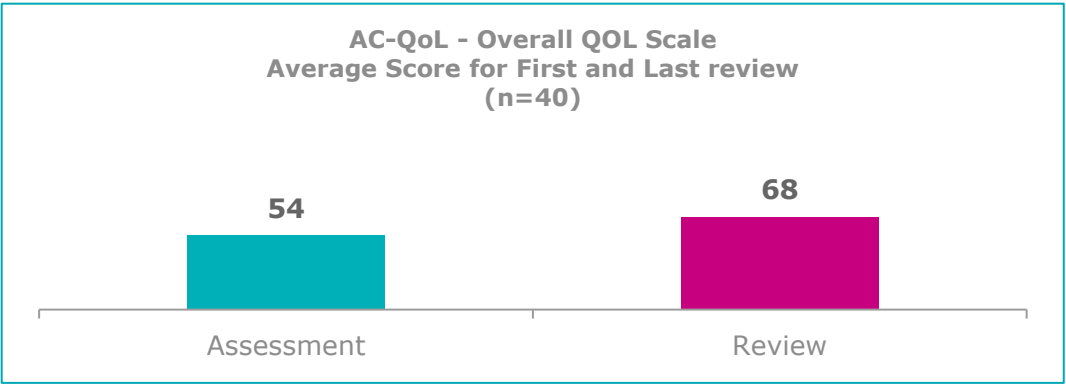
The results for these 40 carers are presented here as an insight into a sub-sample of those on the Admiral Nurse service caseload.

The findings highlight an improvement for carers, from an overall mean score of **54** at baseline (mid quality of life), to **68** at review (mid quality of life).

The overall Quality of Life score is derived by the sum of the scores of the eight subscales looking at key aspects of adult carers' quality of life. Results for the sub-scales show increases (in average scores) for all subscales except personal growth (which remained the same):

The sub-scales with the larger increases were:

- **Support for caring**, which measures the extent of support carers perceive they receive, (from **7** to **10**)
- **Caring Choice**, the extent to which carers feel that they have control over their own lives, (from **4** to **7**)
- **Caring Stress**, the mental and physical stress from caring, such as exhaustion and depression – the *higher scores* for this subscales indicate a *reduction* in stress, (from **6** to **9**).



* Elwick, H., Joseph, S., Becker, S & Becker, F (2010) Manual for the Adult Care Quality of Life Questionnaire (AC-QoL). London: The Princess Royal Trust for Carers.

Key for above charts			
Overall QoL Score	Low 0-40	Mid 41-80	High 81+
Individual Sub-Scales Score	Low 0-5	Mid 06-10	High 11+

Case study – Janet and Roger

Introduction - This case study will demonstrate:

- the complex role of the Admiral Nurse
- reduced uptake of other services such as GP appointments
- improved carer/person with dementia wellbeing/quality of life

I was involved with a husband and wife for two and a half months. The referral was to support Janet (the wife) who was struggling to manage her husband (Roger) with dementia. He was, at times, becoming very frustrated and angry, Janet did not know how to handle this change in her husband.

Interventions – complexity of the role

An initial care plan was developed to provide education to help manage some behaviours, de-escalation techniques, understanding how the dementia affects individuals. Offering emotional and psychological support to Janet, adapting to the change in her relationship with Roger. There was also some liaison with the Community Mental Health Team (CMHT) key worker to ensure flow of communication and a consistent approach.

The aggressive episodes continued to occur. Many attempts were made to arrange emergency respite for Roger, but with behaviour escalating, it was difficult to find a placement for him. Medication prescribed through the CMHT also needed to be chased via the General Practitioner (GP). When no bed was found, I continued to have regular contact with Janet and her son, to offer support and keep them informed.

Crisis then occurred over one weekend when Roger became more physically aggressive towards Janet and threatened her with a knife. Their son was there but they could no longer manage this safely longer term. A bed needed to be found and I raised a safeguarding to alert all the appropriate services to the urgency. Roger was finally admitted to a mental health unit for assessment.

Outcomes

Coordination of care and reduced uptake of other services

The strength of my being involved was the coordination of care. I was able to liaise with all the necessary healthcare professionals; CMHT (key worker discussions about current meds and plans) Social Services (urgent referral for respite, safeguarding raised) GP (prescription) to ensure that whilst Roger was being looked after and treated, his family were also being fully supported, preventing deterioration in their mental health and well-being - this reduced the possible uptake of other services such as GP and mental health services.

Improved wellbeing – through identifying risk

Risk was identified through disclosure by Janet. This occurred through development of a therapeutic relationship between Admiral Nurse and the family; active listening and allowing time to sit with Janet (alone) so she felt confident and safe to talk openly. A non-judgemental attitude made her feel comfortable to express her feelings and how scared she was. Support was also given to their son, who was having to stay with his mother and father to prevent his mother from being hurt.

Improved wellbeing - coping

Following admission to the mental health unit, I maintained ongoing visits & contact with Janet and their son, to manage expectations and provide up-to-date information, guidance and support that was appropriate. I also provided support to Janet to understand and accept the changes in Roger and reduce her feelings of guilt at being unable to care for him at home. This was viewed by the family as essential in helping them to cope with the situation and they expressed their thanks for the Admiral Nurse service.

Summary/conclusions

This report has shown the impact of the Admiral Nurse Service in Lincolnshire. It has highlighted the work of the service in providing support for families living with dementia through direct clinical activity and interventions. It has supported best practice through engagement with other services and sharing of expertise.

The service has faced challenges in responsiveness but continually reflects and assesses the most effective way of providing support despite the arrival of COVID-19.

The service has provided a supportive and essential role in advocating for carers by working directly and intensively with them to identify and meet their needs in a person-centred way.

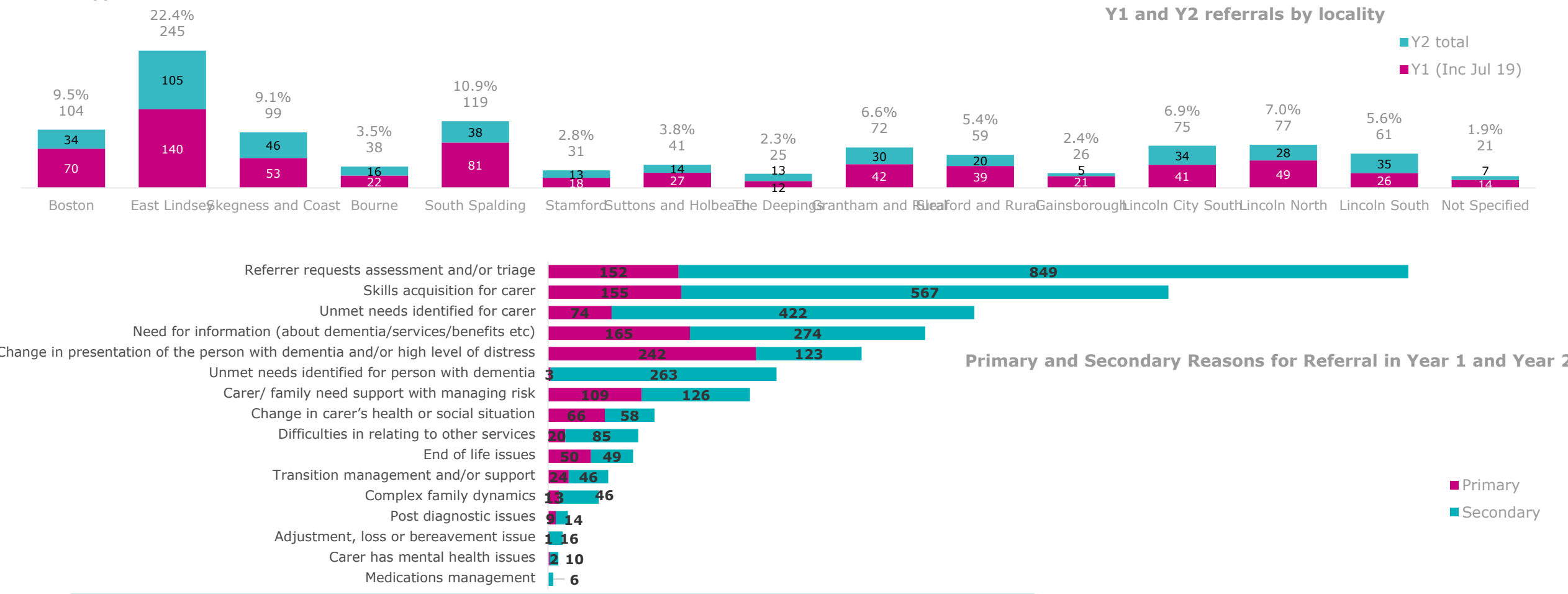
Feedback from other professionals and carers has demonstrated the value of the service. That feedback has been positive and suggests that the service has been able to avoid crisis points in care, impact decision making, and help coordinate support.

Without the Lincolnshire Admiral Nurse service, carers would be left without a clinically-based, dedicated team providing the specialist dementia support that families need and enabling people with dementia to live and die well with dementia.

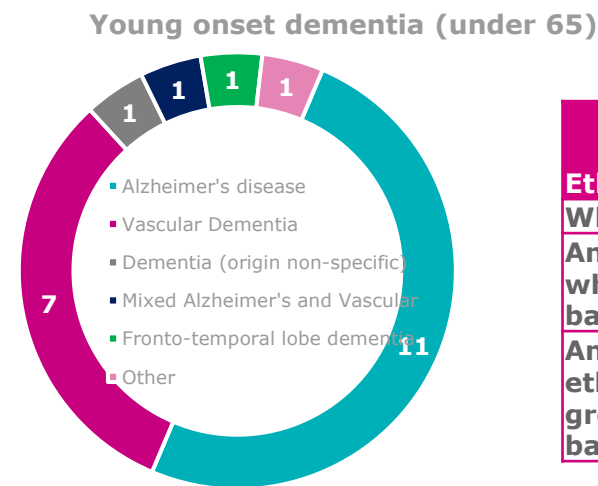
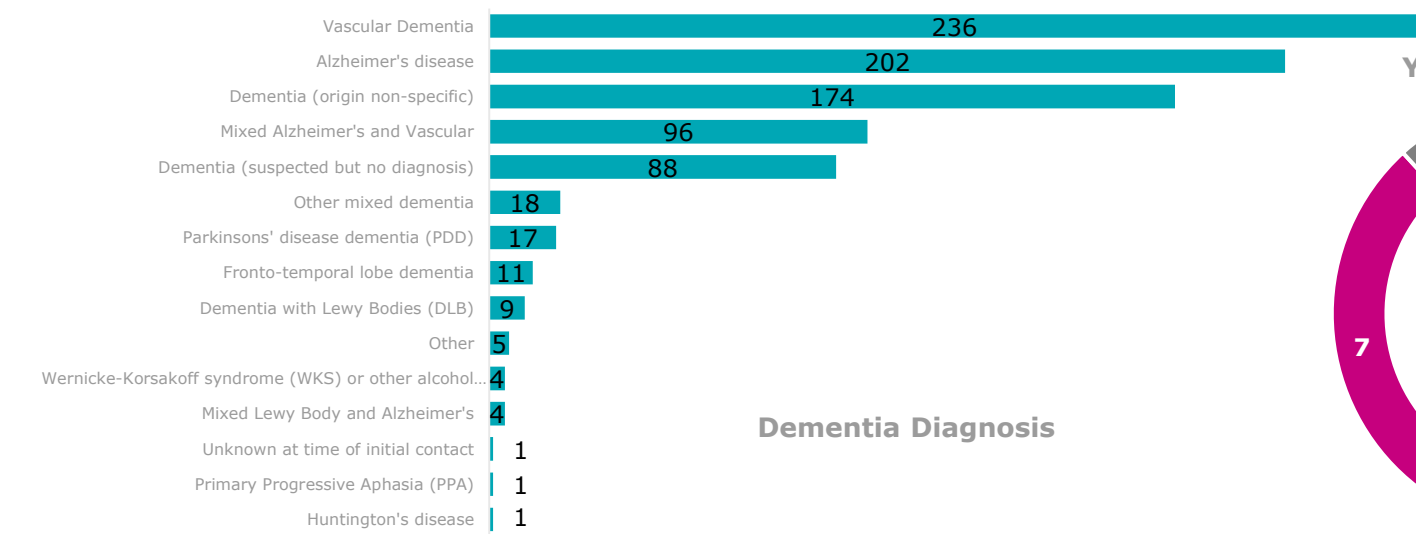
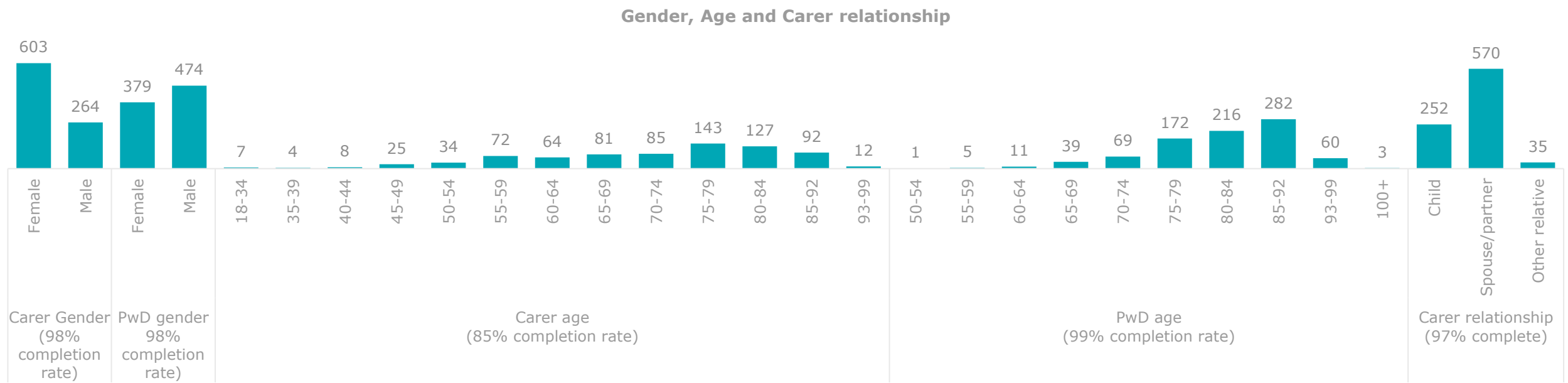
Appendices

Referral Sources and Reasons

The charts below provide more information on the referrals made into the Lincolnshire Admiral Nurse service. The chart here shows a breakdown of the locality which referrals came from, across year 1 and year 2 of the reporting period. The chart below show the referral reasons (both primary and secondary) for those referrals.



Demographics of all those referred into the service



Ethnicity	Carer (83% complete)	PwD (88% complete)
White British	718	739
Any other white background	7	11
Any other ethnic group/mixed background	4	9

Supporting best practice

Two training sessions, delivered by the Admiral Nurses, included pre and post questionnaires to measure any change in professionals understanding, confidence and competence in dementia care. Results below show the numbers where an increase was recorded in the post training questionnaire:

1. Sessions provided within St. Barnabas - 40 nurses completed the pre and post questionnaire:
 - Confidence in ability to recognise someone living with dementia – increased for 16
 - Confidence in ability to care for someone with dementia – increased for 21
 - Confidence in ability to make a difference to PWD and their families – increased for 22
 - Knowledge of dementia care provision in hospice & how to access – increased for 21
 - **At the end of the session, 29 nurses stated they would now do something differently in their practice**
2. Session for LIVES (Lincolnshire Integrated Voluntary Emergency Service) is a First Responder organisation in Lincolnshire – 35 pre and post evaluation forms were completed:
 - Knowledge of most common types of dementia – increased for 27
 - Ability to recognise delirium in patients – increased for 20
 - Understanding causes of distressed behaviour in PWD – increased for 25
 - Understanding role of family carers in enabling PWD to live well – increased for 17
 - Confidence in supporting people with dementia as a responder – increased for 21



If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org
Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm
All bank holidays except 25th December
@DementiaUK • www.dementiauk.org

Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429).