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DementiaUK Helping families face dementia

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Lincolnshire COUNTY COUNCIL Working for a better future

Lincolnshire Admiral Nurse Service

Year 1 Evaluation report

1/8/2019 – 31/07/2020

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This report was written in partnership with Dementia UK, St Barnabas Hospice and Lincolnshire County Council and covers the data collection period from August 1st 2019 to July 31st 2020. The aim of this evaluation report is to showcase the work of the Lincolnshire Admiral Nurse service and to highlight the achievements within it's first year. This report provides a summary of who Admiral Nurses are, what they do, and the positive impact they are having in Lincolnshire.

The report provides an overview of the service activity, outputs and outcomes during the reporting period and using a range of evaluation methodology showcases the reach of the service in terms of numbers of carers supported, the Admiral Nurse interventions and activity and the difference this has made to both carers and professional stakeholders across Lincolnshire County.

Whilst reflecting on the highlights of this past year, the whole team thank our colleagues and partner services for the warm and supportive welcome we have received, the enthusiasm for working with us, and eagerness to ensure that the people of Lincolnshire have an innovative service that will meet the needs of those living with dementia. I am proud of the team and the progress made in this first year. I would like to thank them for their hard work and dedication to making this project a success and to improve the support for families living with dementia in Lincolnshire.

Tom Rose

Admiral Nurse Clinical Lead,

Lincolnshire Admiral Nurse Service

What is Admiral Nursing?

https://www.dementiauk.org/togetheragain/

Admiral Nurses provide the specialist dementia support that families need *(See Appendix One).*

When things get challenging or difficult, Admiral Nurses work alongside people with dementia, their families and carers: giving the one-to-one support, expert guidance and practical solutions people need, and that can be hard to find elsewhere.

Admiral Nurses are continually trained, developed and supported by Dementia UK. Families that have their support have someone truly expert and caring by their side - helping them to live more positively with dementia in the present, and to face the challenges of tomorrow with more confidence and less fear.

The specifics of their role vary according to where they are hosted but they all focus around case management, dealing with complexity, partnership working and offering support at critical points in a family's experience of dementia.

Video source Dementia UK – www.dementiauk.org

Evaluation Methodology

In compiling this evaluation report for the first 12 months (August 2019-July 2020) of clinical activity for the Lincolnshire Admiral Nurse Service, a range of methodologies and datasets was used to demonstrate reach of the service, activity levels, outputs and impact.

COMPASS – Clinical Database used for data inputting and extraction

- Quantitative data to show reach of Admiral Nurse service and activity including referrals, caseload, interventions, outcomes, assessment needs and carers quality of life

Carers Survey – Developed by the Insights & Evaluation team at Dementia UK

- Quantitative and Qualitative feedback from carers who have accessed the Admiral Nurse service

Professional Stakeholders Survey – Developed by the Insights & Evaluation team at Dementia UK

- Quantitative and Qualitative feedback from professional stakeholders who have referred into or worked alongside the Admiral Nurse service

Pre and Post Training Measures

- Survey completed by those who have attended training delivered by the Admiral Nurse service to show levels of knowledge, skills and change to practice pre and post training

Case Studies

- Family case studies to show breadth and complexity of cases supported by the Admiral Nurse service and to highlight the range of interventions delivered and outcomes achieved

Carers Quality of Life Tool (AC-QoL)

- A validated tool used to show changes in carers quality of life following Admiral Nurse service interventions and support

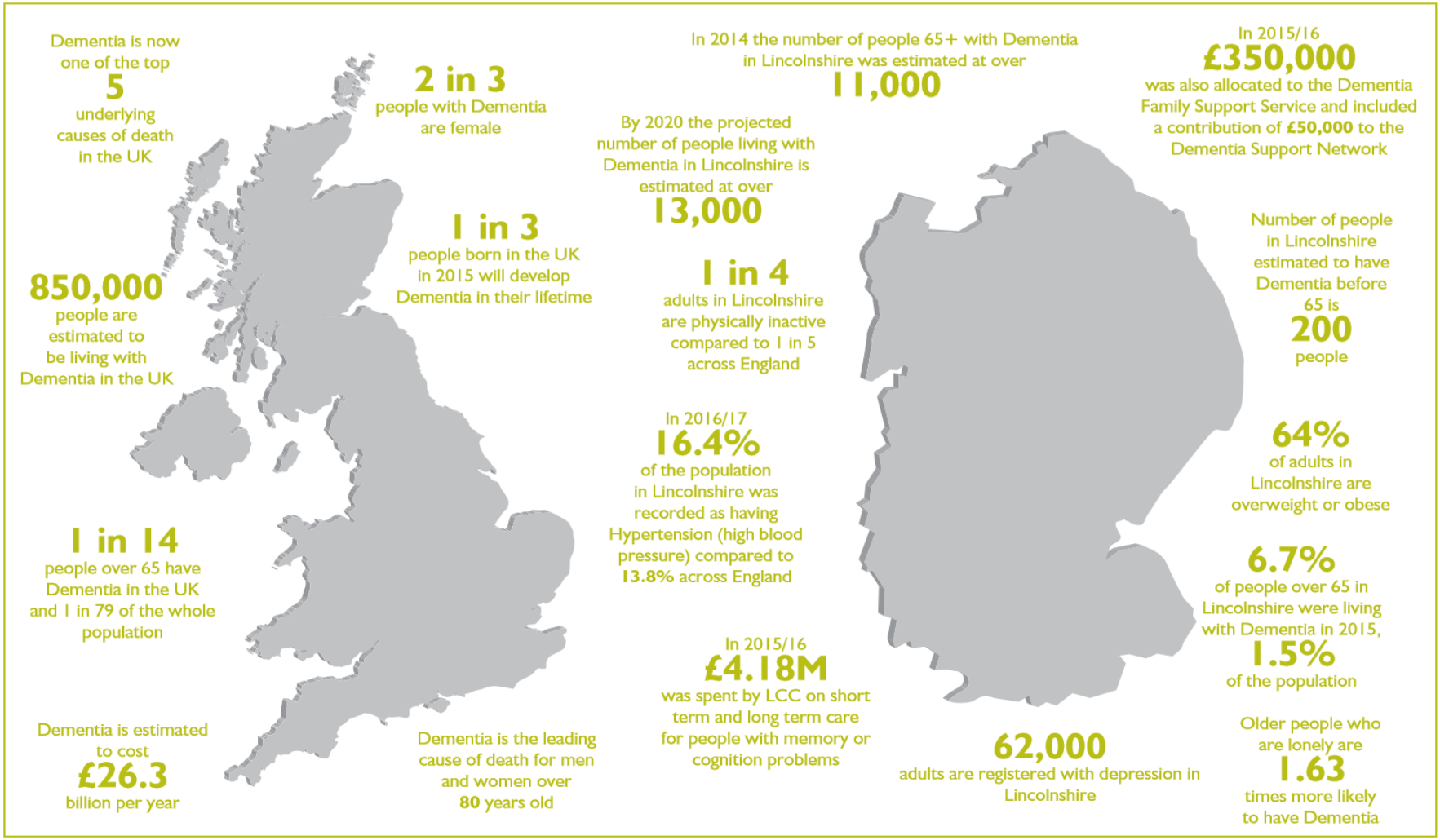
Report Summary

There were **634 referrals** into the service These primarily came from primary care and mental health services	**599** families were supported by the Admiral Nurse Service	The **main reason for referral** was a **change in presentation** for the person with dementia and **need for information**	The most **common identified needs** were the m**ental wellbeing of the carer, skills with coping with changing behaviour, and looking to the future**
The average length of stay with the service is between **66-101 days**	**Most carers** supported by the service are **female** Most carers were **spouses**	The **largest group of people living with dementia** were **over the age of 75** 15 people with dementia were diagnosed under the age of 65	**74%** of cases began formal assessment within 28 calendar days
The majority of carer survey responders said they would be **likely or extremely likely to recommend the service**	**The majority** of respondents thought the Admiral Nurse had made a difference **to their ability to take better care of the person they look after**	Without access to this service the majority of respondents **would have struggled on their own**	**105** activities were delivered to support best practice

Contents

Introduction

Dementia….. in the UK and locally



Infographic taken from Lincolnshire Joint Strategy for Dementia 2018-2021

Lincolnshire Admiral Nurse Service

The Lincolnshire Admiral Nurse service is hosted by St Barnabas with additional funding by Lincolnshire County Council and Dementia UK.

The area covered by the Admiral Nurses, is within the bounds of the previous four CCGs that merged in April 2020 and covered by Lincolnshire County Council. The table below shows the confirmed dementia diagnosis figures in 2019 for the four CCGs.

The service was commissioned with the aim of recruiting 4.5WTE (whole time equivalents) Band 6 Nurses, 0.6WTE Team co-ordinator, and 1.0WTE Clinical Lead. Through four rounds of recruitment we were able to recruit 4.1WTE Band 6's and 1WTE Clinical Lead and the 0.6WTE Team Co-ordinator. Each nurse is based within a St Barnabas hospice site and covers the surrounding area.

St Barnabas main bases are at Lincoln, Boston, Gainsborough, Louth, and Grantham.

CCG (former)	Confirmed diagnosis	% of over 65's
Lincolnshire West	2,146	4.52%
South Lincolnshire	1,617	4.11%
Lincolnshire East	2,670	4.03%
South West Lincolnshire	1,126	3.60%
Total	7,559	4.15%

Meet the team

Tom Rose
(Admiral Nurse Clinical Lead)

Marion Christopher
(Team Coordinator)

Mandy Crabtree
(Admiral Nurse)

Mark Challinor
(Admiral Nurse)

Lesley White
(Admiral Nurse)

Christa Spencer-Davies
(Admiral Nurse)

Sarah Bedward
(Admiral Nurse)

Service Model

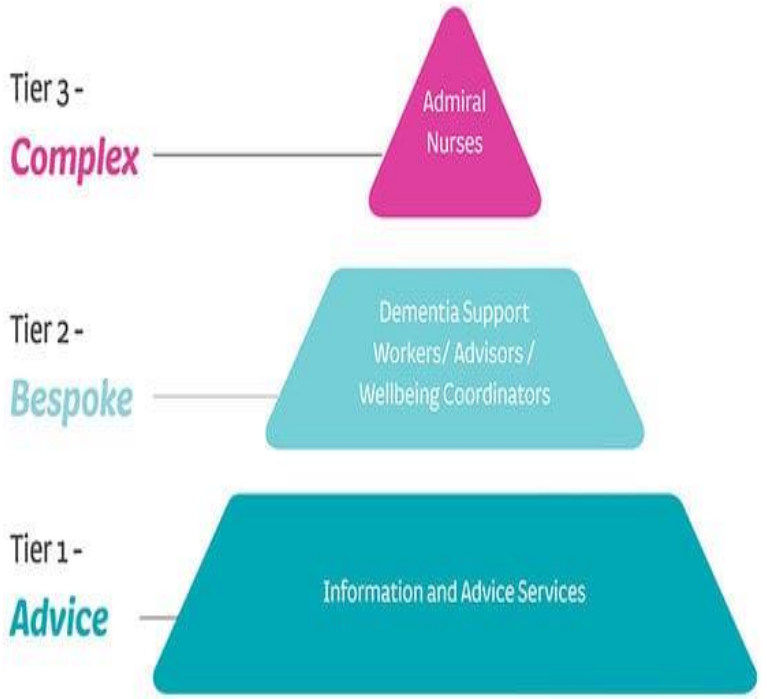
The Lincolnshire Admiral Nurse service is provided by a team of Admiral Nurses providing Tier 3 interventions (see opposite)[1] for those who have complex and unresolved needs requiring individualised and intensive levels of support.

Admiral Nurses provide a highly specialised skill set and their placement within services is demonstrated in the Three Tiered Model highlighting the role of Admiral Nurses in providing complex, specialised, nursing interventions for families affected by dementia. Admiral Nurse support is available at any point from pre-diagnosis to post bereavement.

Service Model

Admiral Nurses utilise a casework work model *(see Appendix Two)* to support decision making, care planning and assessment of the required level of support. Following assessment, the Nurse allocates the carer to a particular case work zone. This will be based on a range of factors such as number and level of unmet needs, complexity of those needs, amount of liaison needed, risk, and stability of the situation.

Support from an Admiral Nurse is not limited by time; the nurse will continue to support the family as long as there is a mutually recognised need.



1. Aldridge, Z., Burns, A., Harrison Dening, K. (2019) ABC model: A tiered integrated pathway approach to peri and post diagnostic support for families living with dementia (Innovative Practice) Dementia. doi: 10.1177/1471301219838086 (E-pub ahead of print)

Referral Criteria

The Lincolnshire Admiral Nurse service works alongside services and organisations providing support to families affected by dementia. The Lincolnshire service receives referrals from many sources across the County ranging from the Hospice/Palliative care team, GP practices, acute inpatient hospital service, social services, voluntary sector, self referrals and more. The referral criteria is set out below. The service does accept referrals for cases where dementia is strongly suspected but no formal diagnosis has yet been made. If the person does not meet the criteria for referral, the Admiral Nurse will seek to provide support by signposting onto other services.

Referral Criteria which must be met
The person being supported has a diagnosis or suspected diagnosis of dementia and is registered to a GP in Lincolnshire
Family carers of people with dementia are able to access the service as long as the person supported has ordinary residence in Lincolnshire
One or more of the following criteria must also be met
High risk of carer breakdown and stress; lack of services involved
Carer is struggling to understand or come to terms with the diagnosis and the presentation of the condition
Family affected by dementia have complex health and care needs requiring specialist intervention
Multiple hospital admissions or high risk of further admission relating to dementia
Family affected by dementia is socially isolated and have difficulty identifying and accessing support services
Carer requires specialist practical skills training and support that cannot be provided by other services
There is conflict between the needs and wishes of the carer and person with dementia
The family need support to make decisions about end of life care and advanced care planning
The family need advocacy in liaison with other organisations and services
Exclusion Criteria
Crisis management requiring response within 120 hours
Referrals specific only to the person with dementia and not the carer
Head injury that is a primary diagnosis to cognitive impairment
Carers primary need is not related to dementia

Describing the activity August 19 - July 20

In this section we describe:

- **Referrals into the Admiral Nurse Service**
- **The Admiral Nurse caseload**
- **Caseload demographics**
- **Admiral Nurse activity**
- **Supporting best practice**

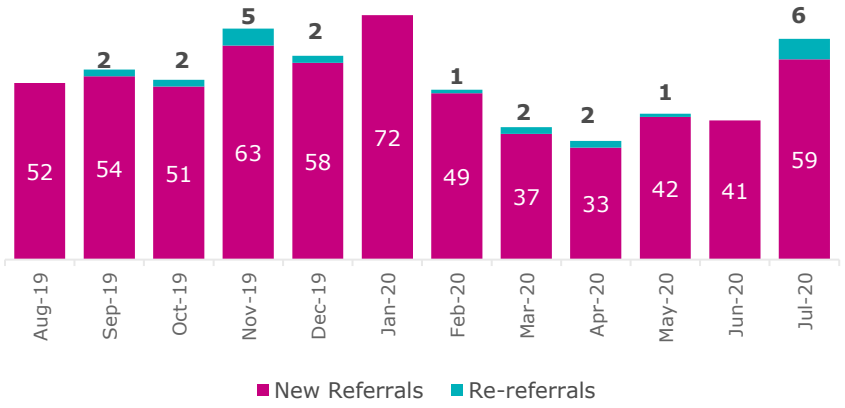
Reach of the Admiral Nurse service – referrals

Referrals

Between August 19 and July 20, **634 referrals** were recorded, with an **average of 53 referrals per month**. These were mostly new referrals, with only 23 being re-referrals.

The service had an increase in referrals in January 2020 followed by a decline to the lowest number of monthly referrals recorded in April 2020. This is aligned with the onset of COVID-19 and the subsequent changes to service. In July 2020 the service saw the number of referrals begin to increase again.

Total referrals by month



Referral source

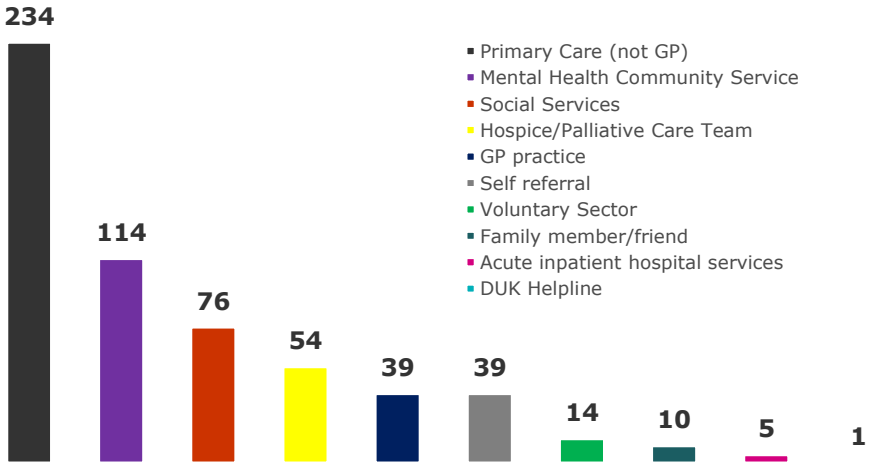
Our referrals came from a range of sources[1]

The single **largest referral source was Primary Care - not GP (n=234)[2]** which accounted for 37% of the referrals. Together with those referrals direct from GP practices (n=39) accounted for 43% of the total referrals.

Mental Health Community Service[3] were the next highest referral source (18%), followed by Social Services (12%) and the Hospice/Palliative Care Teams (9%).

Self referrals accounted for 39 of the 586 recorded referrals

Referral Sources

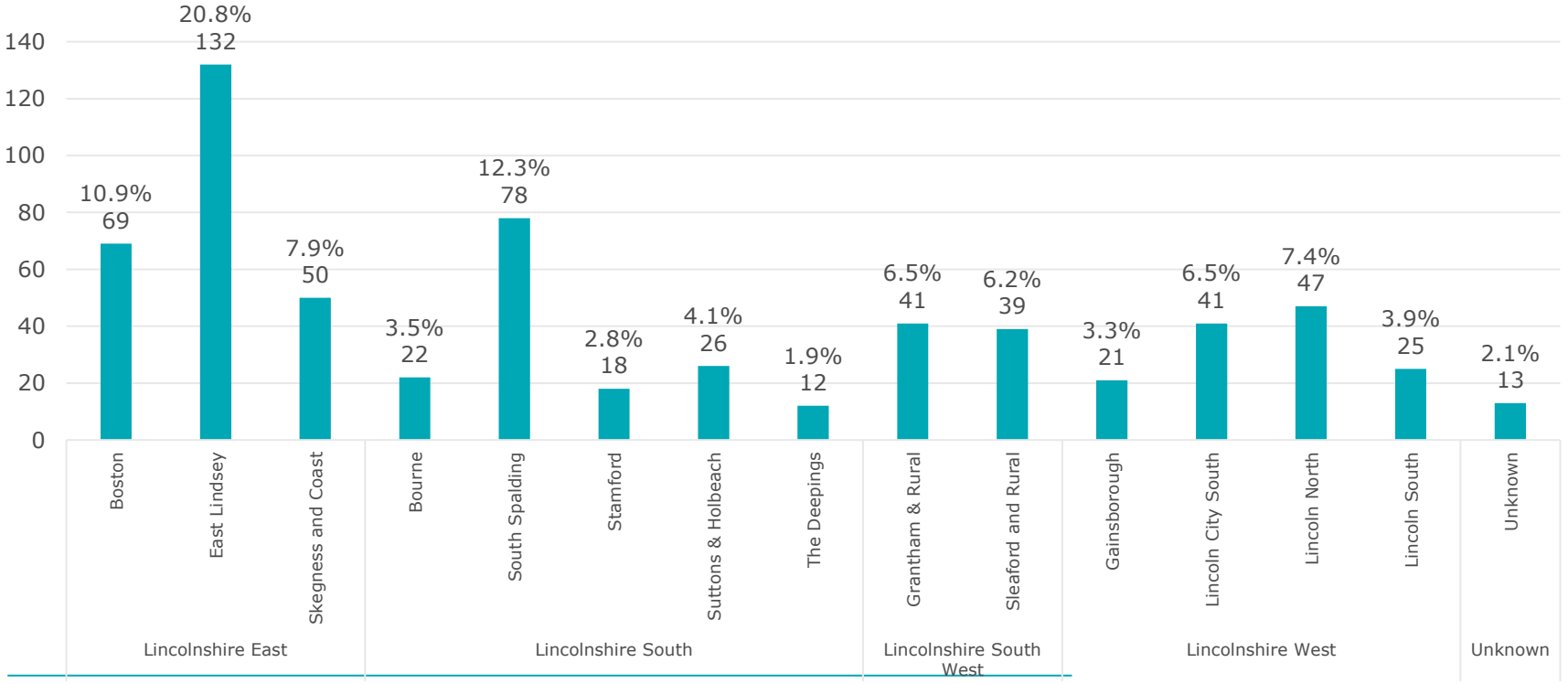


1. There were 13 referral sources recorded as 'other' and 35 referral sources recorded as 'not specified'
2. Primary Care – not GP includes those received direct from the Neighbourhood areas
3. Mental Health Community Service includes the Tier 2 Dementia Support Service

Referrals by Area

The primary referral areas have been East Lindsey, South Spalding and Boston, accounting for 44% of all referrals. Reasons for this have been explored and it is likely that there are a number of factors.

For example, we know that East Lindsey has the largest population percentage over the age of 65 compared to Lincoln which has the lowest[1]. Initially, Skegness was expected to be a high referring area based on the health profile of the area, but we now better understand some of the challenges for the area, such as, health literacy, low rates of presentation to primary care and other support services. Understanding these differences is an ongoing piece of work, but an important one in order to understand both the demand and therefore impact on the service, but also what this tells us about the profile of each neighbourhood and the people who live there.



1. Lincolnshire Research Observatory https://www.research-lincs.org.uk/idoc-Population-Trends-Lincolnshire.aspx

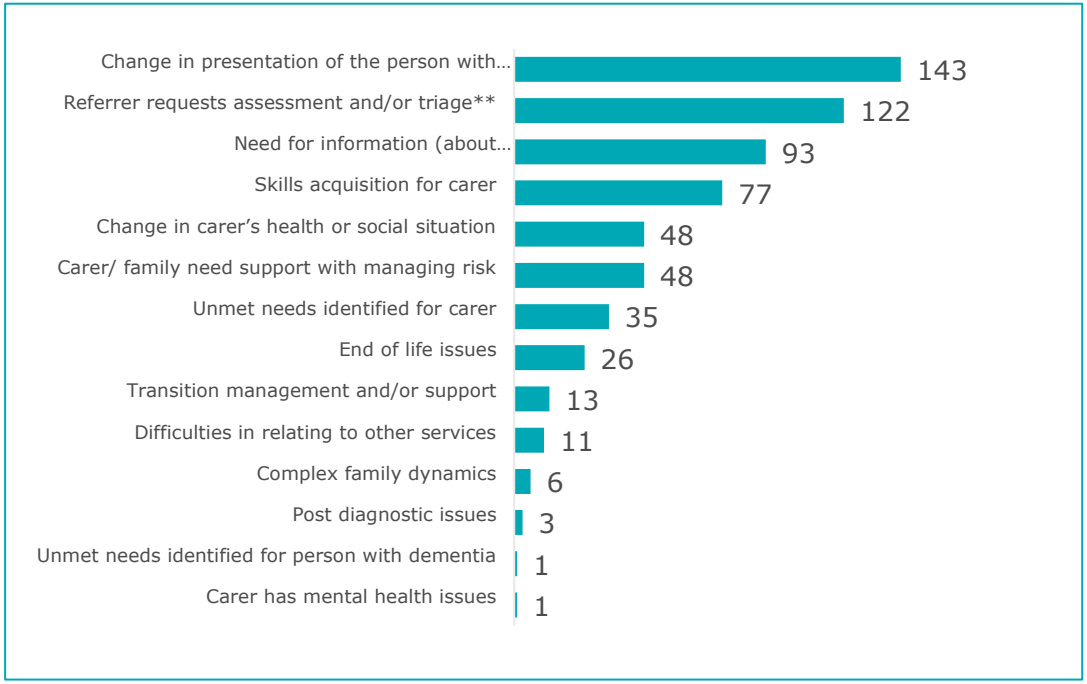
Primary Reasons for Referral

Understanding the main reasons why people are referred to the service allows us to better understand the needs of the community being served but also points to means by which the Admiral Nurse Service can support other services in identifying and addressing these needs.

Primary reasons for referral

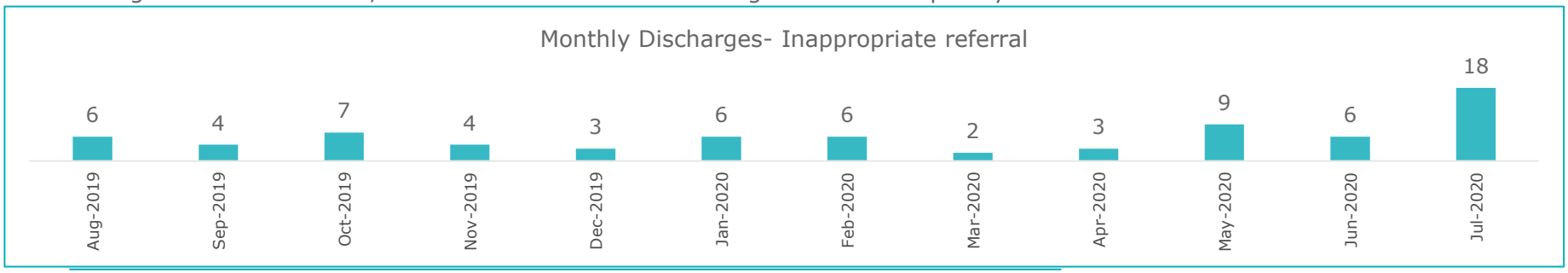
There were 627 recorded primary reasons for referral[1] with the most common primary reasons for referral being:

- Change in presentation of the person with dementia and/or high level of distress (23%)
- Referrer requests assessment and/or triage (19%)
- The top 4 primary reasons for referral account for 69% (n=435) of all referrals



Inappropriate Referrals

Of the 634 referrals **74 of these were 'inappropriate referrals'** following triage. Inappropriate referrals primarily consist of referrals not meeting the referral criteria, out of area or not demonstrating sufficient complexity for a tier 3 service.



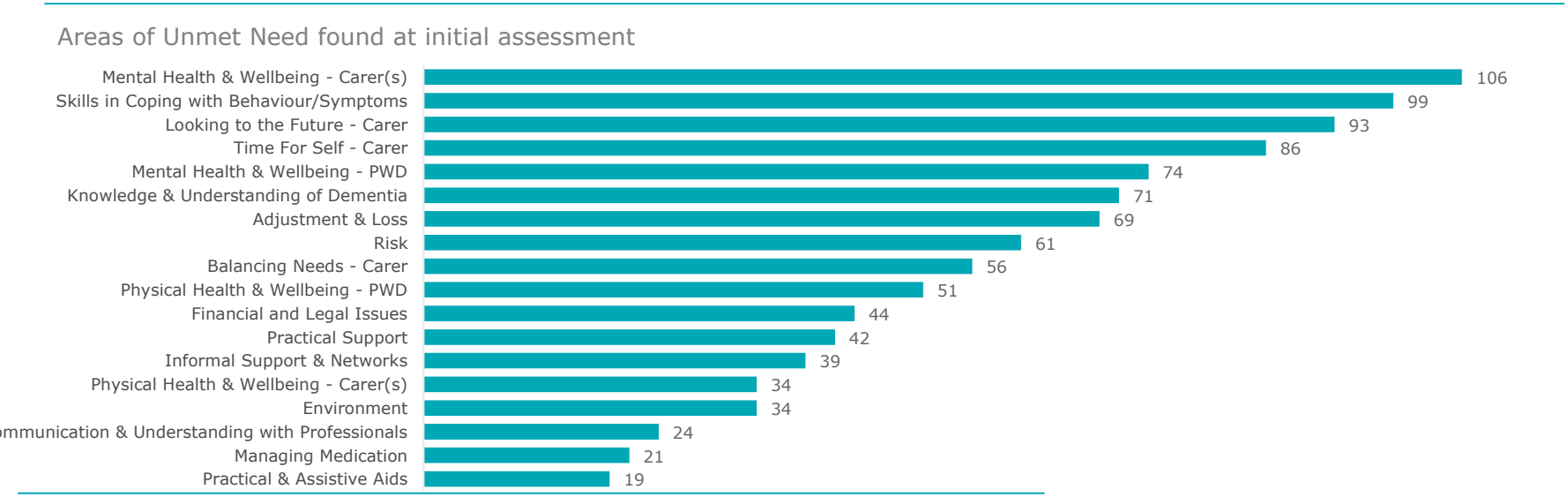
1. In addition there were 7 recorded as 'not specified'

Reasons for referral and needs found at initial assessment

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 (ANAF) provides the structure within which to assess the needs of the family carer. The assessment has 18 domains *(see Appendix Three).* Based upon the assessment, clinical judgement, and observation of the Admiral Nurse, these domains are then rated as to whether these areas of need are currently being met. The most common areas of unmet need highlighted at initial assessment using the Admiral Nurse Assessment Framework were:

- Mental health and wellbeing- carer (106)
- Skills in coping with behaviour/symptoms (99)
- Looking to the future – carer (93)
- Time for self – carer (86)

The most common referral reasons (see previous slide) are a change in presentation, information needs, and skills acquisition; the most common needs identified at assessment (see chart below) were mental wellbeing of the carer, skills at coping with behaviour/symptoms, and looking to the future. This helps demonstrate the impact that changing symptoms of dementia has on the wellbeing of the carer.

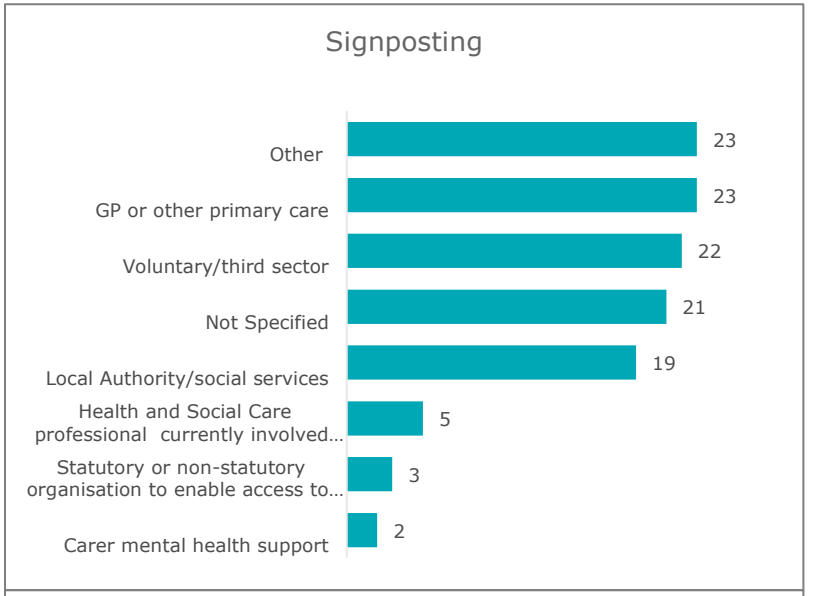


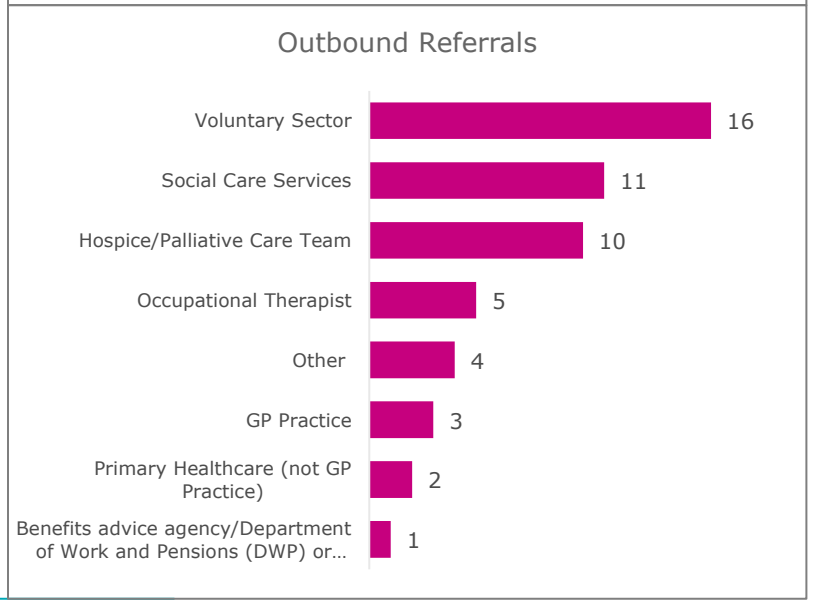
Signposting and referral activity to other services

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 to other services when appropriate.





Signposting

Between August 19 and July 20 a signposting activity was recorded in **118** instances. This includes signposting to information sources such as local amenities, groups, legal services or the internet.

In 23 cases clients were signposted to the **GP or other Primary Care service**, in 22 to the **Voluntary/third Sector.**

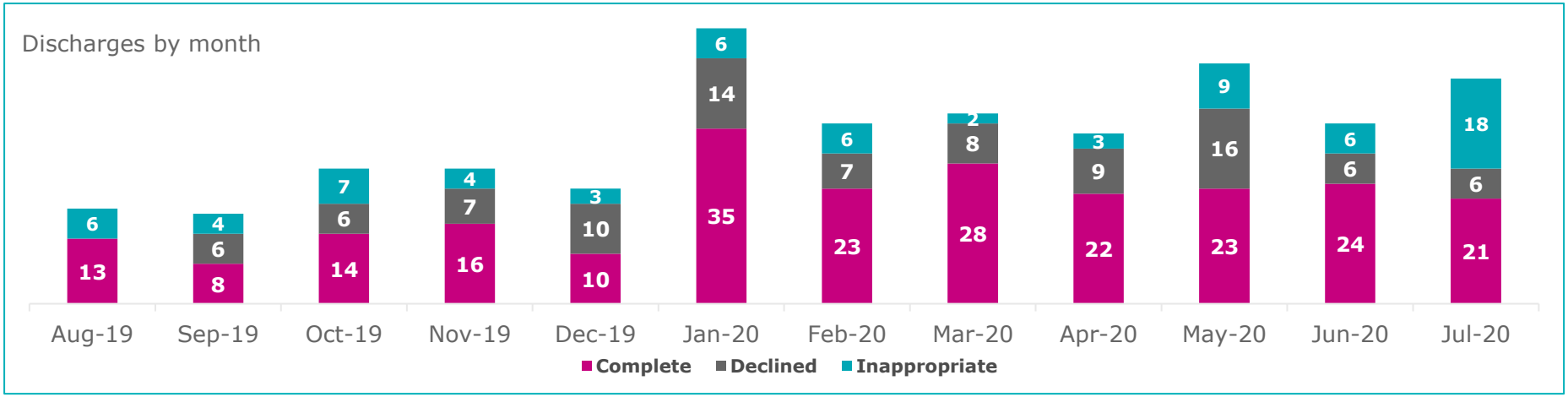
Referrals to other services[1]

There were **52 referrals** made to other services. The majority of referrals were made to the **Voluntary sector** (n=16), **Social Care Services** (n=11) and the **Hospice/Palliative Care Team** (n=10)

1. This is not automatically recorded within COMPASS and is likely to be significantly under-reported in this period.

Discharges from the service

There were a number of discharges each month from the Admiral Nurse service; discharges from the service were made for three reasons; support from the Admiral Nurse/interventions were **complete**, the referral was **inappropriate** or the support from the Admiral Nurse service was **declined** by the person(s) who had been referred in.



Complete	•Cases which have been discharged from the service following completion of bespoke support and intervention
Declined	•Cases where the carer feels they do not require the service •In these cases we may refer onto other services, depending on the risks involved
Inappropriate	•Cases which do not fit within the referral criteria of the Admiral Nurse. •Cases which are not complex or have limited/no multi-agency involvement

Deaths of those on the caseload

The Admiral Nurse service works alongside St Barnabas colleagues and provides an additional support to those families who are being cared for by the Hospice at Home and Community teams. Some of these family carers are looking after people with dementia who need end of life care and the Admiral Nurse service is able to provide much needed support before and after bereavement. They also help support carers who are receiving palliative care for their own needs. During this reporting period **61 people with dementia died** and **8 carers died** whilst the family was being supported by the Admiral Nurse service**.**

Caseload

In this period a total of **557 people referred** were recorded as being in receipt of interventions from the service.

The number of those open on caseload varied each month. Although the average over the reporting period was 123 open cases per month, since February this has exceeded the recommended team caseload capacity of 221 cases[1].

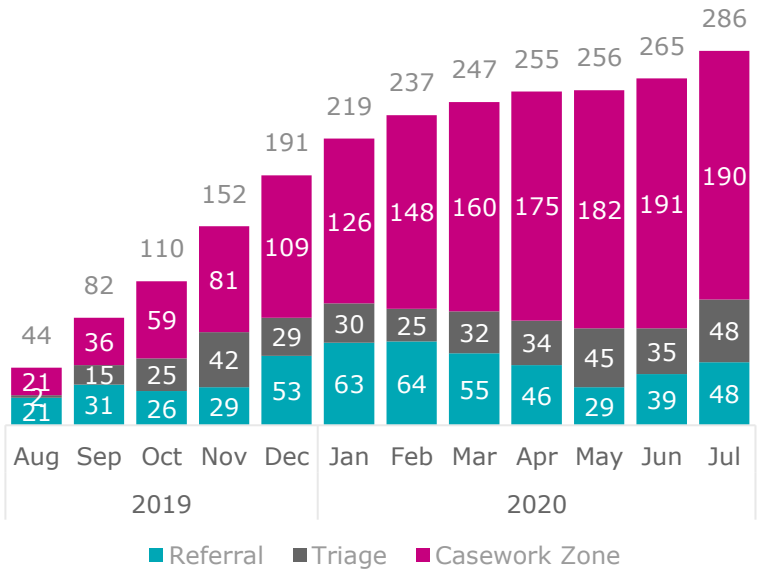
Length of stay (LoS)

Length of stay is an average measure of the amount of time people spend on the case load of an Admiral Nurse.

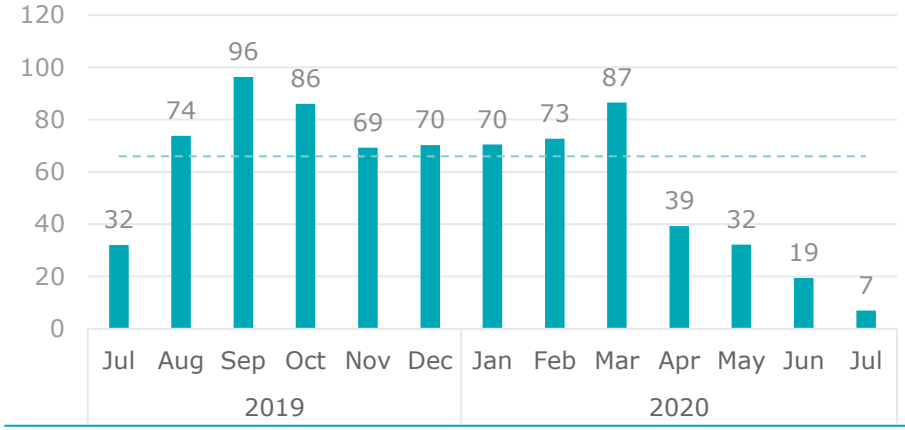
The shorter average time since April reflects the fact that a number of cases are ongoing and have not yet been closed.

The overall average **LoS for discharged cases is 66 days**. When including all cases (those still on the caseload) referred up to the end of the reporting period, that average rises to 101 days.

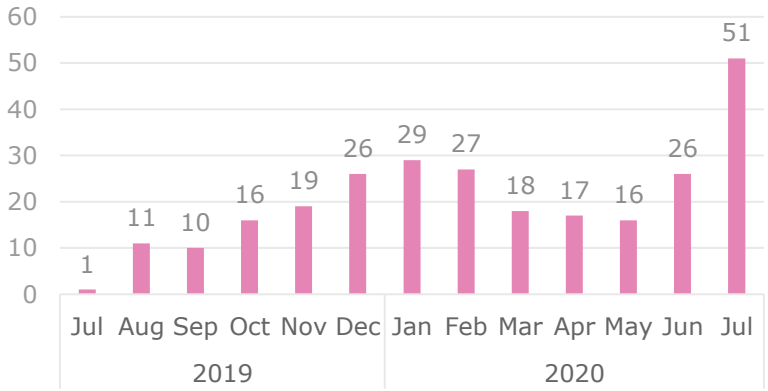
Clients on caseload (at end of month)



Average length of stay for closed cases



Number of Cases still open based on referral date

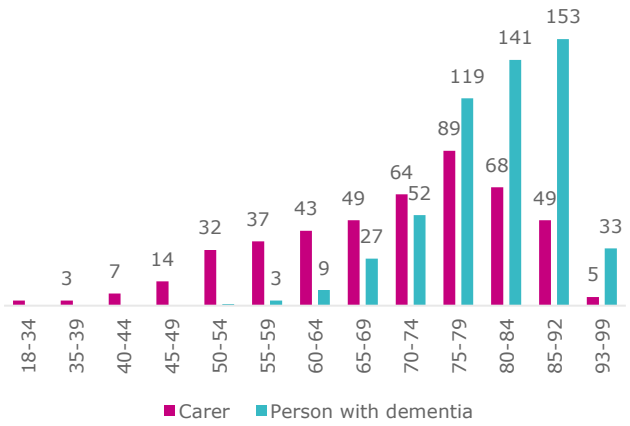


1. Based on a caseload size of 50 cases per full time nurse; this will vary depending on intensity of cases

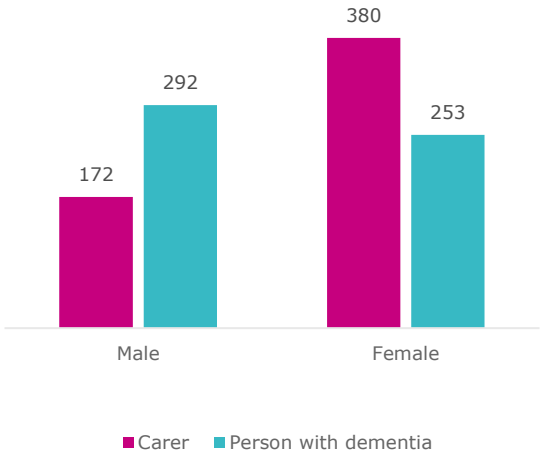
Demographics of those on our caseload

- Of the 557 carers (and 550 people with dementia) on our caseload[1] the majority described themselves as White – British (97% people with dementia, 99% family carers), which is broadly in line with the general demographic data for the Lincolnshire area, which are covered by the Admiral Nurse service (97.6% white in 2011 Census)[2]
- 69% of carers defined themselves as female. This is also broadly in line with nationally reported figures (60-70%). Nationally, women are also more then twice as likely to have provided care for more then 5 years[3]
- 54% of people with dementia identified as male. This is a higher percentage than the 35% national figure[3]
- People with dementia were mostly over the age of 70, with the largest group being between the age of 75 and 92 (n=413, 77%)
- 73% of carers (n=172) and 99% (n=209) of people with dementia were reported as retired, compared to 63% nationally
- The majority of carers, where this was recorded (n=538) were the spouse, partner, ex-spouse or ex-partner of the person with dementia (n=361); 161 carers were reported as being the child, step-child, 'in the care of' or child-in-law
- Nine carers had left work to become a carer

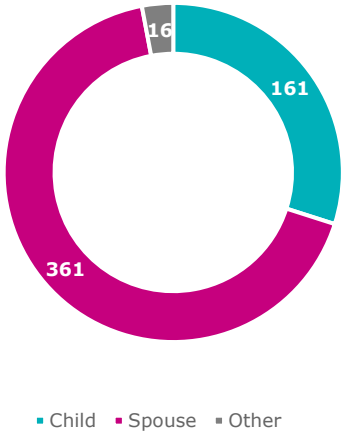
Age of carer and person with dementia



Gender of carer and person with dementia



Relationship of carer (to person with dementia)



Gender data relates to 99% of carers and 99% of PwD; Age data to 83% of carers and 98% of PwD; Ethnicity status data relates to 86% of carers and 91% of PwD

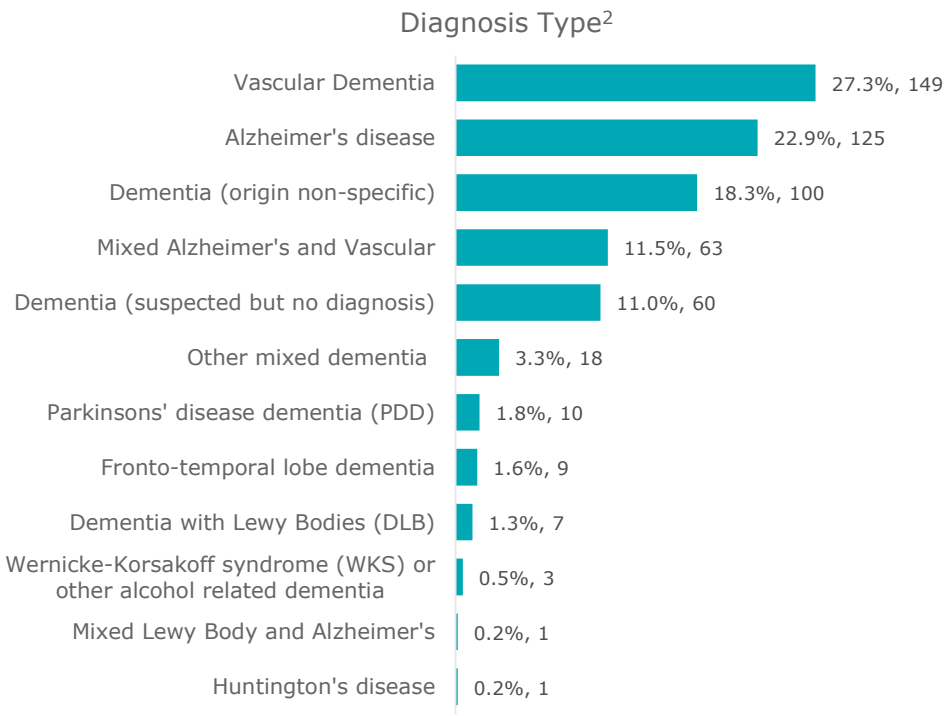
1. Numbers reported are where demographic data was recorded
2. Lincolnshire County Council (https://lincolnshire.ckan.io/dataset/ethnic-minority-populations)
3. Alzheimer's Research UK (https://www.dementiastatistics.org/statistics/impact-on-carers/)

Dementia Diagnosis

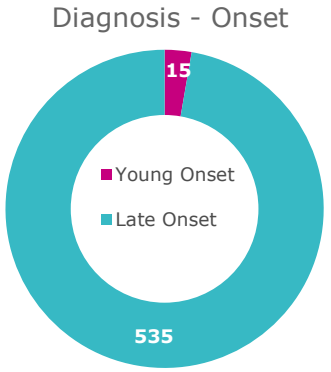
Understanding of a person's dementia diagnosis is important in understanding how it effects their cognition and the likely prognosis of their dementia. It also allows for an honest conversation with carers about the impact this has on them and how they can continue to support their loved ones.

Vascular Dementia (n=149, 27.3%) was the most common diagnosis, followed by **Alzheimer's Disease** (n=125, 22.9%). This compares to about 20% and 66% nationally[1].

Of the 550 people with dementia, 15 had a **young onset** dementia (diagnosed under the age of 65). Nationally about 3.4% of people with a diagnosis of dementia are under the age of 65[3].



Dementia Type (Young Onset)	
Alzheimer's Disease	8
Vascular Dementia	5
Mixed Alzheimer's and Vascular	1
Dementia (origin non-specific)	1



1. Alzheimer's Research UK https://www.dementiastatistics.org/statistics/different-types-of-dementia/
2. Diagnosis type for 4 people with dementia was recorded as 'other'
3. Public Health England - https://www.gov.uk/government/publications/dementia-profile-april-2020-data-update

Admiral Nurse Activity

The team carries out a variety of activities to support families affected by dementia, including:

- Direct clinical work with families (through face to face appointments, phone calls, emails or texts)
- Liaison work (MDT, interagency work, liaison carried out face to face, or via phone, email or letter)

There were **3612 clinical and liaison** activities recorded between August 19 and July 20

The direct clinical **work with families** included **face to face** (n= 669) or via **telephone** (n=2078)

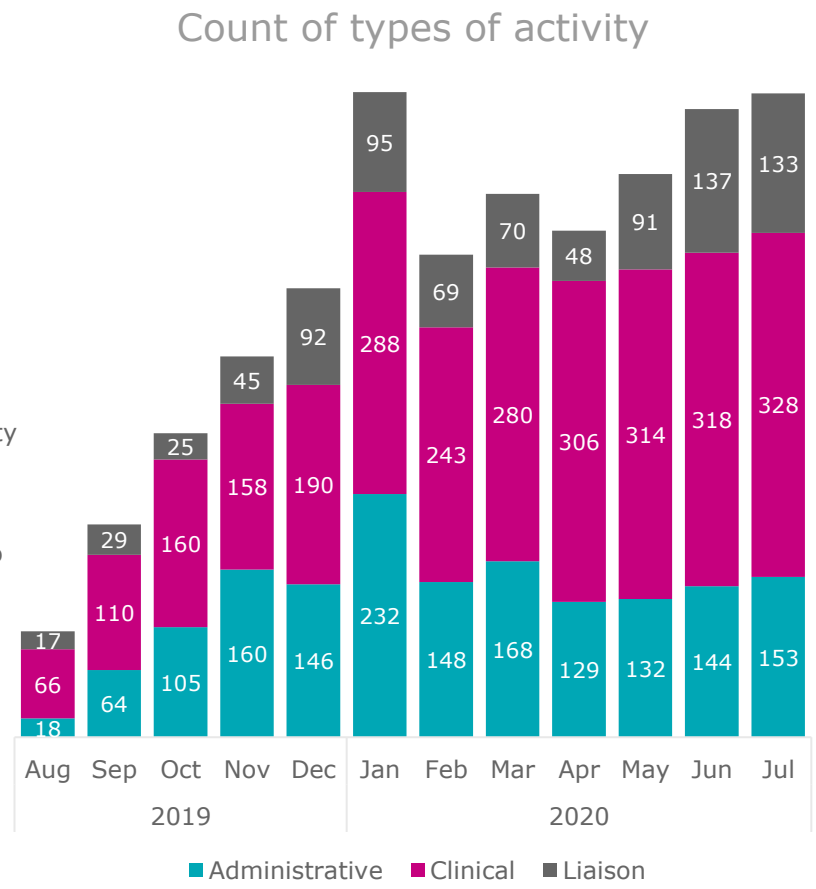
Due to the impact of the Covid-19 pandemic, families have been increasingly supported via telephone. Video conferencing technology was also used where accessible and appropriate.

Comparing the first (August – January) and second 6 (February – July) months of the service, there were a number of factors to increase clinical activity including recruitment, switching to phone and video based contact during COVID and a corresponding reduction in travel time. This led to a 84% increase in clinical activity when comparing the two time periods.

Following the easing of the lockdown restrictions, the service has increased face to face support where this is safe and appropriate to do so. The main channel of support for families, however, continues to be the telephone at this stage.

Liaison work complemented our work with families and was carried out via **email** (n=261), **telephone** (n=542), **face to face** (n=28), and **video** (n=20)

Admin activity includes recording of referrals, failed calls/visits, requests for information, recording of miscellaneous tasks and paperwork,

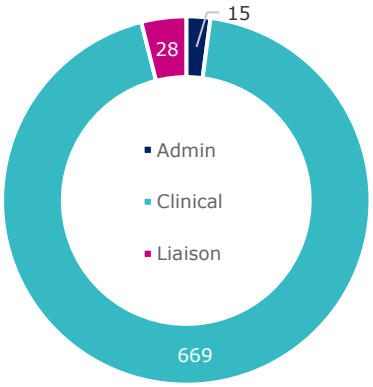


Face to face and telephone activity

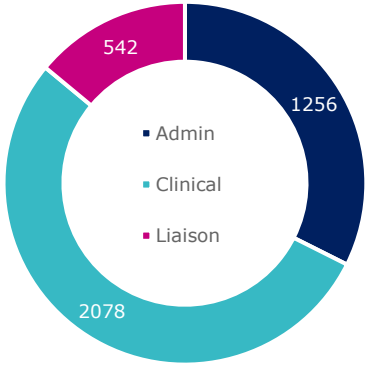
The majority of the 712 face to face activities were recorded as clinical (n=669/94%). The Lincolnshire Admiral Nurse service is a home based service, meaning that all visits usually take place in the carer or person with dementia's home. However, the Admiral Nurse can arrange to meet in alternative locations such as a St Barnabas base or public space when requested and if this is clinically appropriate.

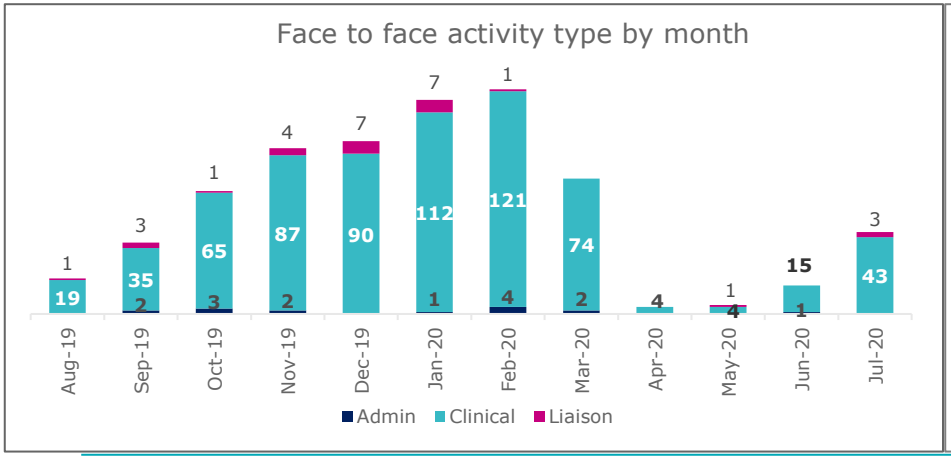
The **majority of the 3388 telephone activities were recorded as clinical** (n=2078/61%); 37% (n=1256) were recorded as admin.

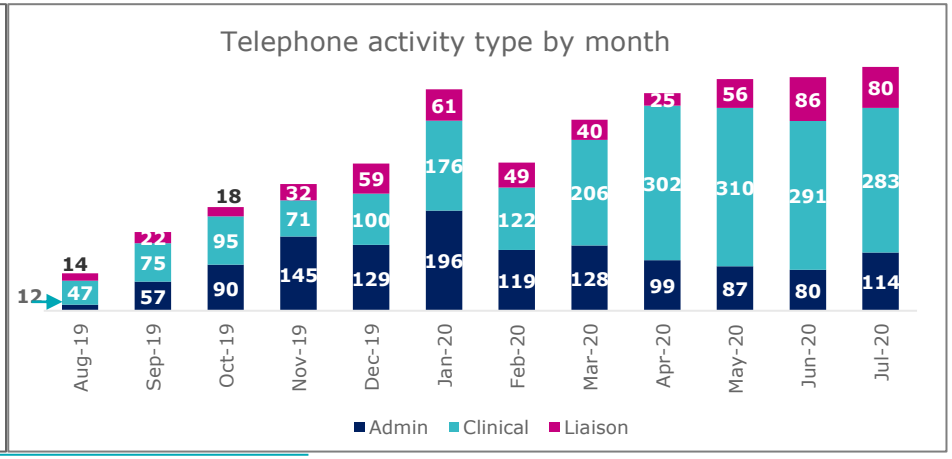
Face to face activity



Telephone activity

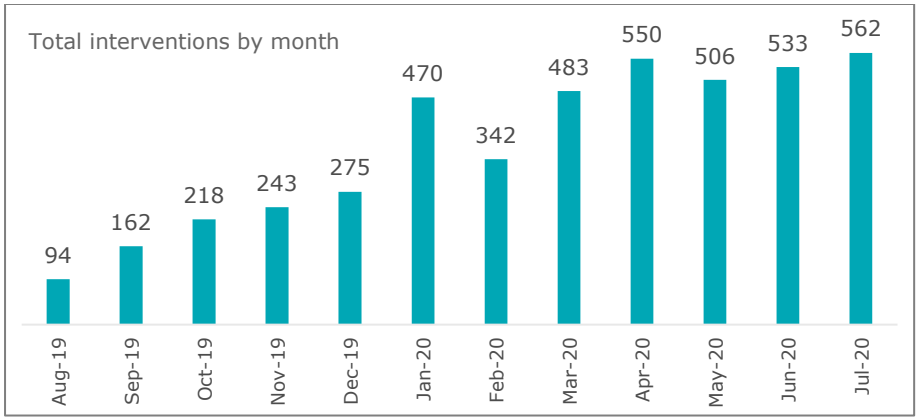


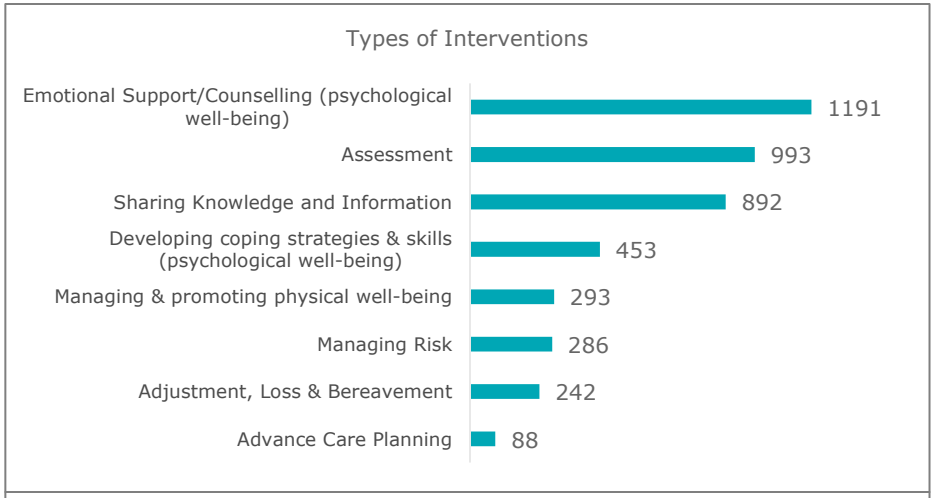


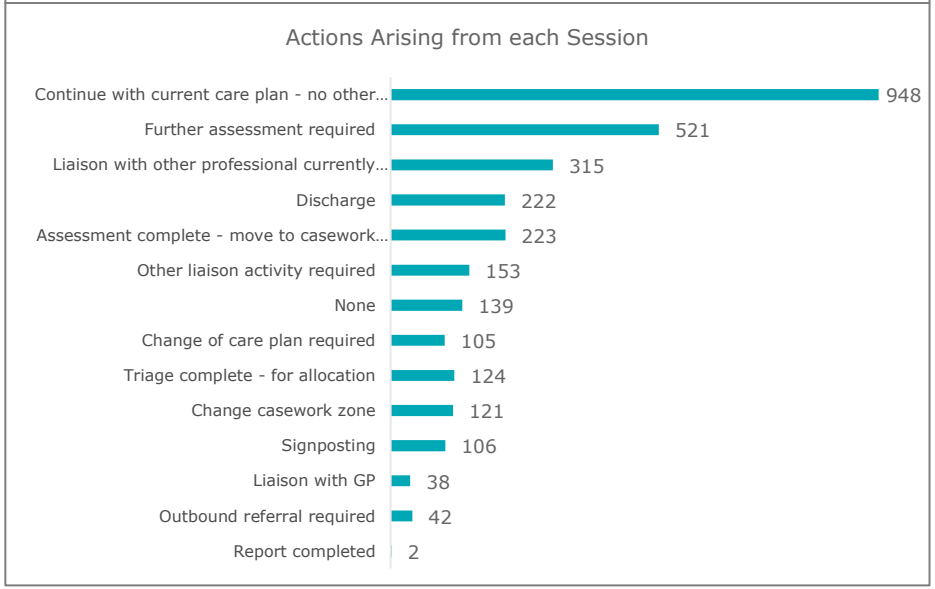


Admiral Nurse Interventions

The chart below shows a monthly breakdown of interventions delivered by the Lincolnshire Admiral Nurse service *(see Appendix Four).* There was a total of 4,438 with a monthly average overall of 370. The first 6 months averaged at 244 interventions whereas the second 6 months averaged at 496.







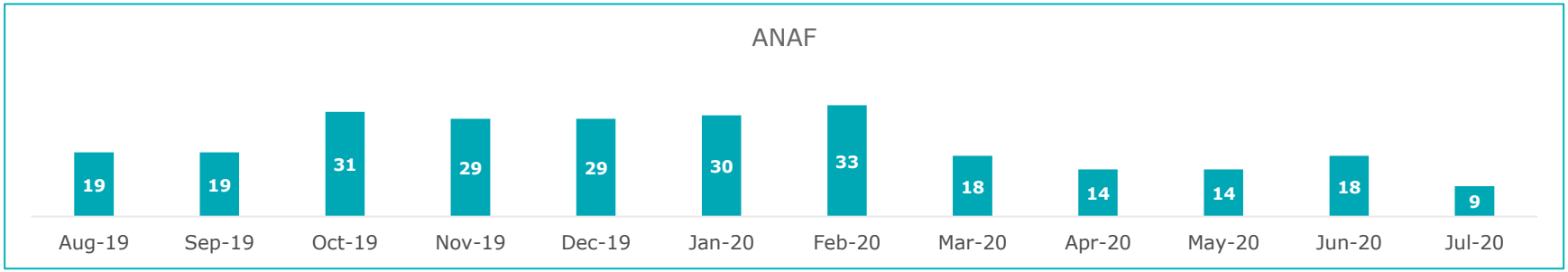
The most common interventions were…

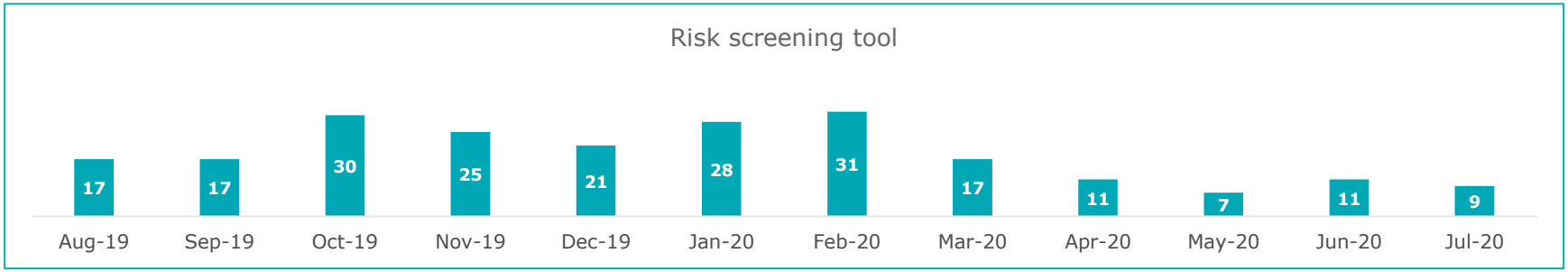
- **Providing emotional and psychological support**, which has been particularly important during the COVID pandemic when resilience and mental wellbeing of carers may have been strained. By providing clinical expertise in psychological and emotional support, Admiral Nurse seek to prevent crisis and delay early admission into care and hospital
- **Assessment** 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 formulation of new plans
- **Sharing of knowledge and information** 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

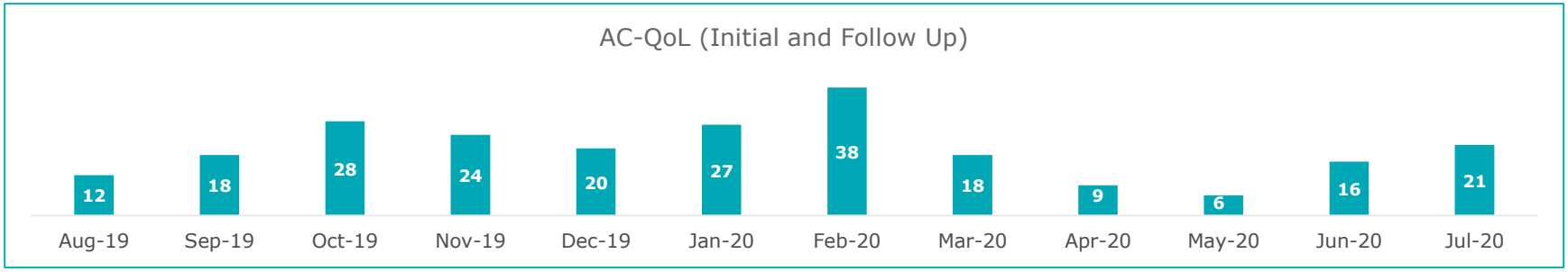
Monthly casework activity

The charts below show a monthly breakdown of casework activity for the reporting period of August 2019-July 2020.

- ANAF (Admiral Nurse Assessment Framework) is the tool used by the team upon initial assessment
- Risk screening tool is used to evidence significant risk for the carer or person with dementia
- AC-QOL (Quality of Life measure for family carers) is a validated tool to measure quality of life and add some quantitative analysis to outcomes.







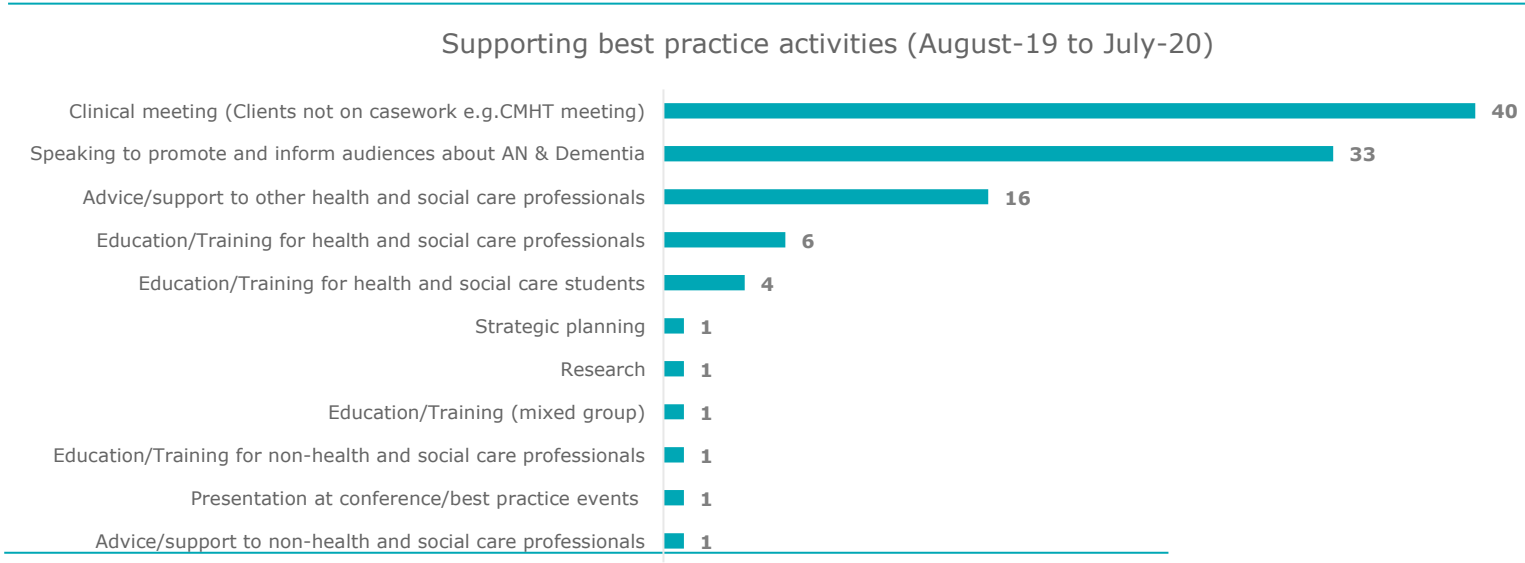
Supporting best practice

Direct carer contact is not the only means by which Admiral Nurses can influence and improve support for those with dementia. Alongside working directly with families, Admiral Nurses work with others to promote best practice in dementia care. The service has recorded **105**[1] supporting best practice activities from August 2019 to July 2020.

Most of these activities were related to clinical meetings, e.g. Neighbourhood or Hospice MDT meetings (n=40), promoting and informing audiences about the Admiral Nurse service and dementia (n=33) and advice and support to other health and social care professionals(n=16). Attendance at these meetings is often to advocate for carers and liaise with other services.

The Lincolnshire Admiral Nurse service, being a unique mix of hospice and community service, works alongside the Hospice at Home teams, hospice community service, Neighbourhood working areas, Mental Health Service, Social Care, voluntary agencies and education. Professional support can also be provided via informal advice and support. As a group with specialist skills and knowledge an Admiral Nurse is also able to contribute to more strategic planning and education.

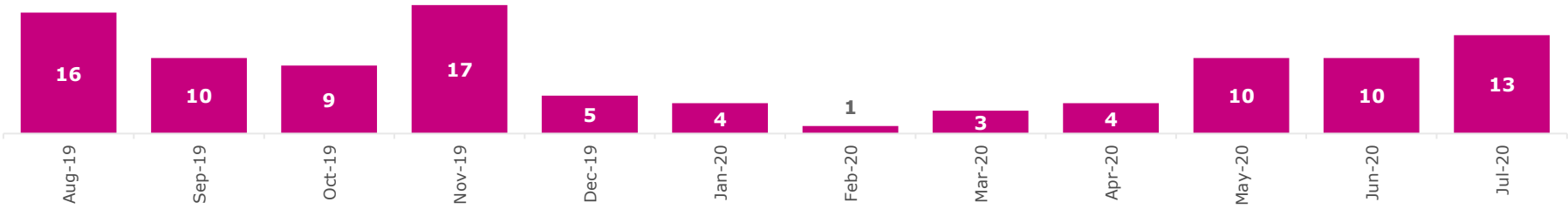
An outcome of the current COVID pandemic has been the transfer of many meetings to an online approach. This has meant that the team are more able to attend more clinical meetings with other professionals then before due to improved accessibility and a reduction in travel time.



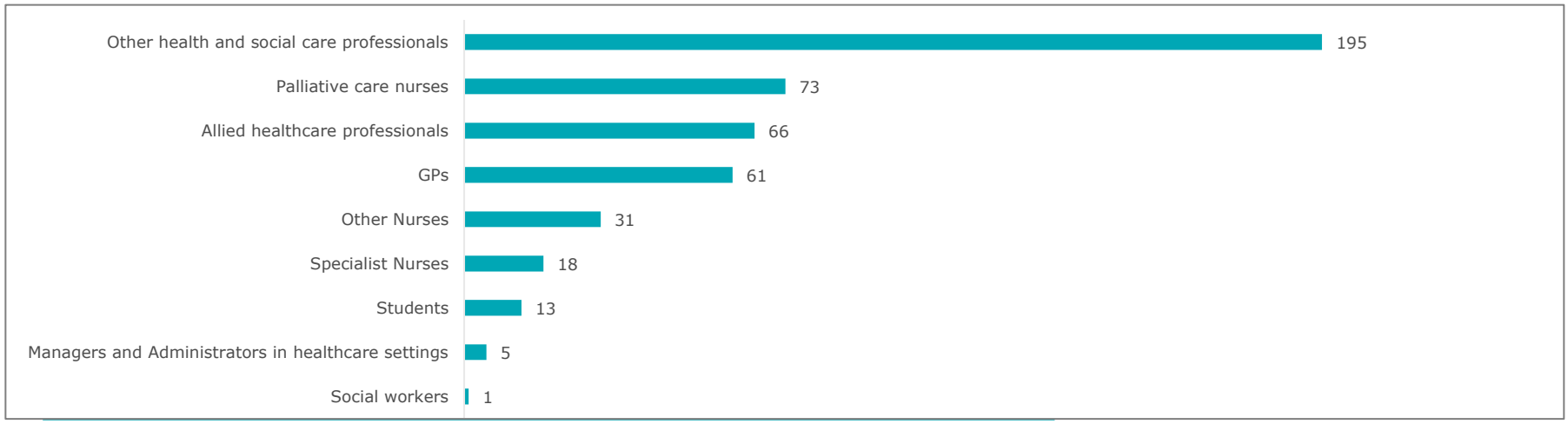
1. There were 2 additional activities recorded as 'other'

Working alongside different professionals and teams, ensures that Admiral Nurses are able to identify the correct support required for carers on their caseload, provide additional support to those other professionals and influence their local community.

Supporting best practice activities by month (August-19 to July-20)



The chart below shows the roles of those who have been involved with the Admiral Nurse service in the supporting best practice activities. The majority of roles involved were with health and social care professionals.



Evaluating our activity August 19 – July 20

In this section, we present data on:

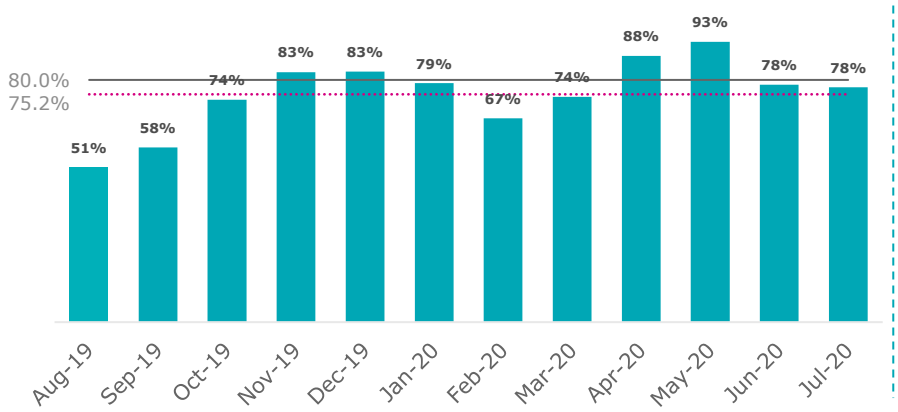
- Key Performance Indicators
- Carer Feedback
- Adult Carer Quality of Life (AC-QoL)
- Case Studies
- Training
- Professional Stakeholder feedback

Service Key Performance Indicators August 19 – Jul 20

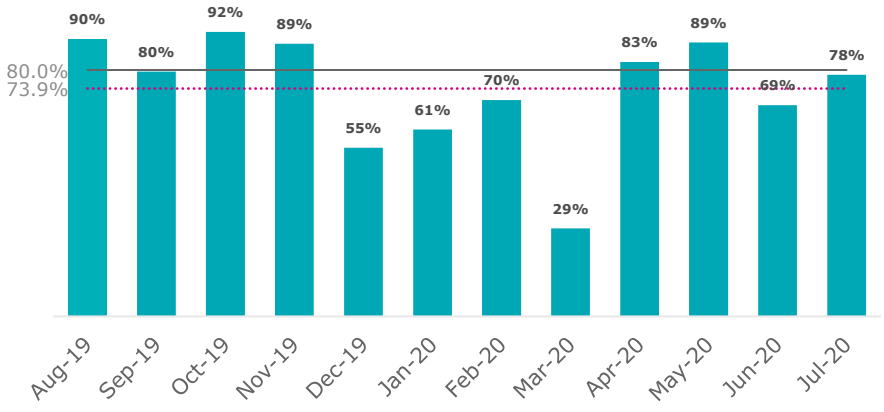
KPI 1 – **80%** of those referred to the service are contacted by within **5 working days of referral**

KPI 2 – **80%** of clients on the caseload have an initial assessment started within **28 calendar days**

KPI 1 Numbers contacted within 5 days of referral



KPI 2 Number commencing formal assessment within 28 days



KPI 1 - **75% of referrals received the first contact within 5 working days**

24% of referrals over the reporting period were contacted on the same day.

The triage/duty system was altered in June 2020 in order to increase the response time to initial referrals with a clinician responding on the same day to all referrals.

This average does not account for attempted contacts that were unsuccessful as it is not possible to extract that information at this time.

KPI 2 – **74% of the referrals began a formal assessment using the ANAF within 28 calendar days.**

However, the overall average number of days from referral to the start of the assessment process was 24 days. There were 163 carers who began an assessment within 7 calendar days (35%) of being referred into the service.

The impact of COVID can be seen in the March figures as the service responded to the necessary changes and contact methods.

Carers' experience of the Admiral Nurse service

Family Carers' Survey

To find out about carers' experience of the Lincolnshire Admiral Nurse service, a carer survey developed by the Insights & Evaluation team at Dementia UK was carried out towards the end of year 1. This sets out to capture information on the experience of people who have been on the Admiral Nurse caseload and the difference that the service has made to them. The survey also aims to highlight the particular strengths of the service, the added valve of Admiral Nurses, and identify any ways in which the service could be improved *(see Appendix Five for additional information).*

Family carers who had been discharged after receiving at least one intervention and had previously given consent to be contacted for such purposes were sent a survey (n=62, 26% of the 237). 14 participated, representing a 23% response rate (6% representation of total cases).

Most carers responding to the survey reported having a positive experience of the Admiral Nurse service in relation to the amount of contact and ease of contact. They were also asked how good the Admiral Nurse had been and the 'friends and family test' question on whether they would recommend the service (widely used in the NHS in England).

Respondents had had a varying number of contacts (see chart on the right) and these had either been face to face, by telephone or a mix of face to face, phone and/or email contact (see chart on the right).

Ease of contact

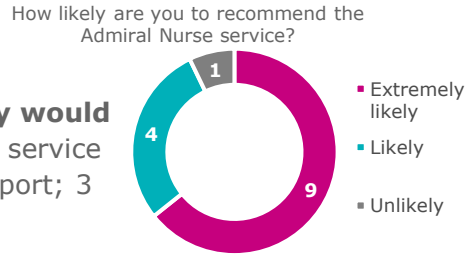
12 carers said it was 'easy' to make contact with the service; 1 carer hadn't tried.

Amount of contact

Most carers (n=10) felt that the amount of contact was 'about right', and 3 carers felt they would have liked more contact.

Family and Friends Test

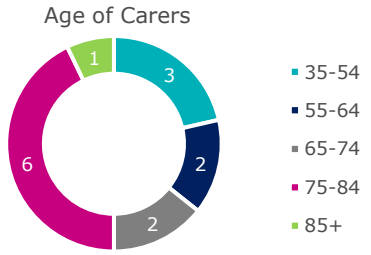
On the 'friends and family test', **9 carers said that they would be 'extremely likely'** to recommend the Admiral Nurse service to someone they know who needed similar care and support; 3 carers would be 'likely' to (see chart opposite).

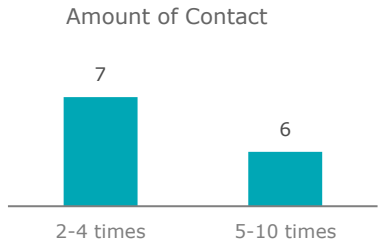


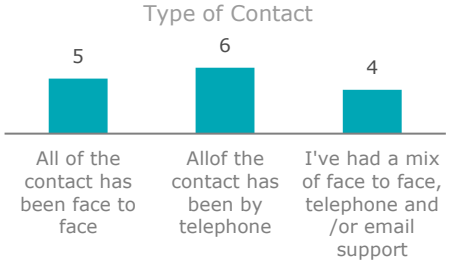
All family carers responding to the survey identified as **White British** (n=13). 4 of them identified as male, 10 as female.

They were most likely to be the **wife, husband or partner** of the person with dementia (n=8) and to care for **more than 71h per week** (n=6).

9 out of 13 carers reported that their own health or disability limited their day to day activity (8 said "a lot" and 1 said "a little").







How good the Admiral Nurse was in key areas

We asked carers how good the Admiral Nurses had been in a number of areas. The response rate to each area varies, depending on whether carers felt it was applicable to them. Most carers found the Admiral Nurse 'good' in all areas particularly around:

- **Listening** to carers (good=12, fair=1, poor=1)
- **Showing compassion, respect and understanding** to carers (good=12, fair=1, poor=1)
- **Explaining things** to carers in ways they can easily understand (good=12, fair=1)
- **Giving carers enough time** and ensuring that they didn't feel rushed (good=12, fair=1, poor=1)
- **Giving or getting answers** for questions the carers have in relation to their caring role and the needs of the person with dementia (good=11, fair=1, poor=1)
- **Building trust and establishing a good rapport** with carers (good=10, fair=2, poor=1)

"Offering a very kind and caring person to just listen and not judge in any way. They are amazing people."

Family Carer

"I can not speak highly enough of the support I received during the few times I met with my Admiral Nurse. He helped me enormously."

Family Carer

How helpful the Admiral Nurse was in key areas

We asked carers whether the Admiral Nurses had been helpful in a number of areas. Most carers said that the support received from the Admiral Nurse was helpful (where the type of support was applicable to them), particularly with regards to:

- **Sharing information and explaining the impact of dementia** on the person cared for (helpful=13, not helpful=1)
- Providing them with **emotional support** (helpful=12, not helpful=1)
- **Assessing their needs** with regards to their physical, mental and social wellbeing (helpful=10, not helpful=2)

"I just hope in future that more people have access to these amazing caring people (nothing was too much trouble)."

Family Carer

"The Admiral Nurses have made a huge difference to our family,(…).. just wish we'd found them earlier."

Family Carer

How is the Admiral Nurse support different

We asked carers 'How, if at all is the support that you have received from the Admiral Nurse different from that given by other health and social care professionals?"

- The majority of respondents (n=9) thought the Admiral Nurse has **a more personal approach**
- **Seven** of those who responded thought the Admiral Nurse has a more **specialist knowledge of dementia**
- The Admiral Nurse has **more time to spend with my family** (n=3)
- The Admiral Nurse **focuses on the whole family** (n=2)

Did the Admiral Nurse make a difference?

We asked carers "Please tell us whether the Admiral Nurse made a difference...'

- The majority (n=10) of respondents thought the Admiral Nurse had made a difference **to their ability to take better care of the person they look after**
- A difference had been made to their **ability to influence or make important decisions about the care of the person with dementia** that they look after and the **confidence in their ability to cope** (n-9)
- The Admiral Nurse had made a difference to respondents **(n=9) ability to influence or make important decisions about the care of the person they look after**
- Respondents felt that a difference had been made to their **ability to make adjustments and maintain their relationship with the person they look after** (n=7) and their **ability to take better care of themselves** (n=7) and the **coordination of support from other health care professionals** (n=7)

"it was sudden, so unexpected I would not have coped so well without (…), he picked me up as I was really low.."

Family Carer

"I found the service, (…) to be extremely supportive, helpful and knowledgeable."

Family Carer

"I just hope in future that more people have access to these amazing caring people (nothing was too much trouble)."

Family Carer

"Get more funding for more nurses in other counties"

Family Carer

Without access to this service the **majority of respondents (n=9) would have struggled on their own** and there would have been the **need for transition to a care home** for some people with dementia they care for (n=3). **Carers would have been unable to continue as a carer** (n=2), **more GP appointments would have been made for both the carer** (n=3) **and the person they look after** (n=4) and **increased visits to Accident and Emergency for the person with dementia** would have resulted (n=2).

AC-QoL - Quality of Life measure for family carers

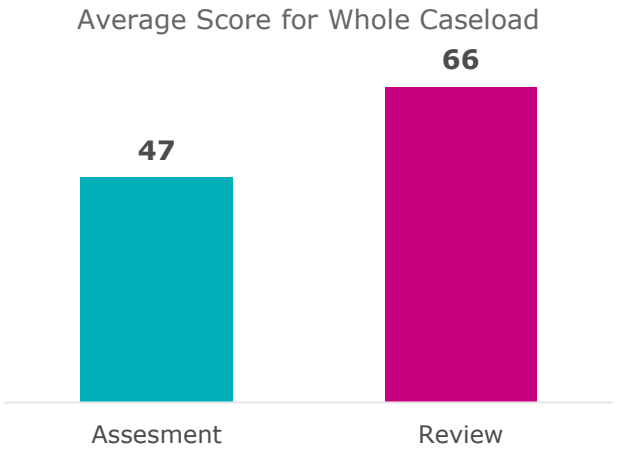
The Adult Carers Quality of Life Scale (AC-Qol) is a validated tool that measures family carers quality of life across eight domains (*Support for Caring, Caring Choice, Caring Stress, Money Matters, Personal Growth, Sense of Value, Ability to Care, Carer Satisfaction*). *(see Appendix Six)*

Baseline data for 219 family carers **and review data for 17** of these were collected. Those with completed baseline and reviews were analysed.

The service mostly administered the AC-QoL during the initial assessment and post-discharge to gather a baseline and post intervention overview to allow comparison of pre and post intervention.

The findings highlight an improvement for carers, from an overall mean score of **47** at baseline to **66** at review (mid quality of life). This increase by 19 points highlights the increase in quality of life amongst these carers and sits within the **NHS Outcomes Framework and Adult Social Care Outcomes Framework (ASCOF)** with regards **improving and enhancing carers quality of life**.

The 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. In the next page we present the results by subscale.



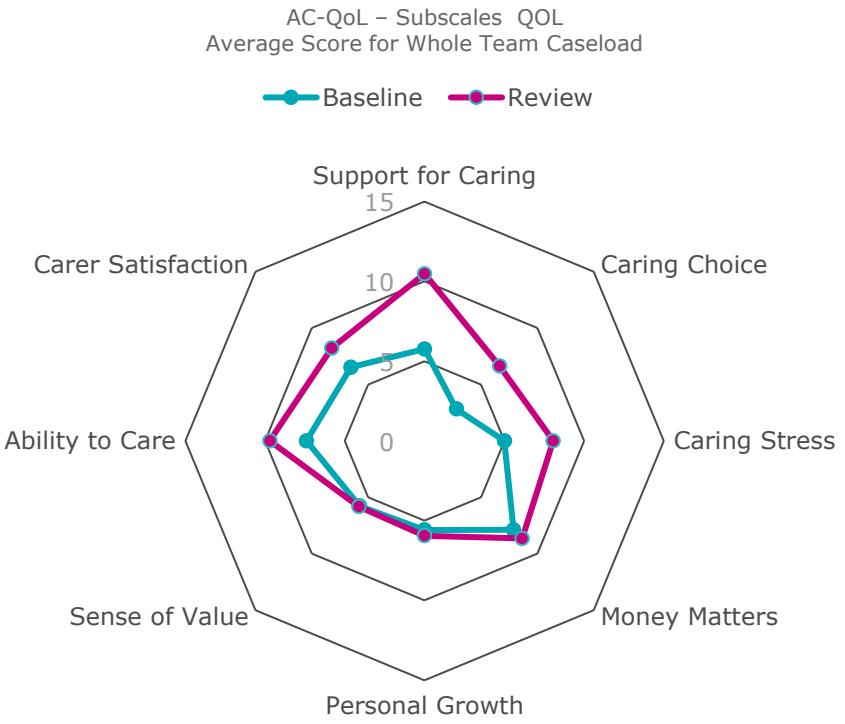
Key for above chart	Low	Mid	High
Overall QoL Score	0-40	41-80	81+

The biggest improvements were seen in the subscales of '**Support for caring**' (the extent of support carers perceive they receive) from an average score of 6 to 10, '**Caring choice**' (the extent to which carers feel that they have control over their own lives) from an average score of **3** to 7 **and 'Ability to care'** (the extent to which the carer is able to provide care for the person they care for, how they cope with the caring role, and how they feel about their competency to care) from an average score of 7 to 10.

The 'Caring choice' subscale improved from a low quality of life to a **mid** quality of life.

'**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 an average score of **5** to **8.**

The carers who completed these assessments and reviews had been caring between **1 and 15 years**, with an average of **4.5 years**. Of the 17 carers who completed assessments, **13** stated they provided **over 71 hours** of care per week.



Average Scores

	Support for Caring	Caring Choice	Caring Stress	Money Matters	Personal Growth	Sense of Value	Ability to Care	Carer Satisfaction
Baseline	6	3	5	8	6	6	7	7
Review	10	7	8	9	6	6	10	8

Total Scores

Baseline	98	48	85	134	95	98	126	111
Review	178	113	137	147	101	99	165	140

Key for above chart	Low	Mid	High
Individual Sub-Scales Score	0-5	06-10	11+

Case Studies

Improving carers quality of life and increasing coping mechanisms

This case study demonstrates how the Admiral Nurse has supported a carer (and her husband who is diagnosed with vascular dementia and has several co-morbidities) to be able to cope with and adjust to challenging behaviours during a difficult time. The support provided by the Admiral Nurse and use of person-centered and psychosocial interventions has contributed to an improved carer quality of life and sense of value.

Reason for Referral

Sue was referred to the Admiral Nurse service by the Community Respiratory Nurse (who was supporting Sue's husband Nigel).

Nigel's behaviour changes were becoming increasingly challenging for Sue and as a result she was becoming exhausted and struggling in her ability to cope and manage her daily responsibilities.

Names have been changed in these case studies to protect anonymity and permission has been given by those involved

Case Background

Nigel was diagnosed with vascular dementia in 2019 and his wife, Sue is his main carer. Nigel also lives with severe chronic obstructive pulmonary disease (COPD), atrial fibrillation, recurrent falls and obstructive sleep apnoea.

Admiral Nurse Needs Assessment

The Admiral Nurse assessment identified several unmet needs such as an increased need for knowledge with regards Nigel's vascular dementia diagnosis and the prognosis for Nigel. Sue also needed support with developing appropriate coping mechanisms in order to reduce her expressed feelings of guilt and anger.

Admiral Nurse Interventions

The Admiral Nurse developed a care plan to address the couple's needs and worked with Sue to understand her current situation. Using Beck's cognitive triad as a model for communication, Sue identified a negative, dysfunctional view of herself as a carer and was able to express her concerns about the future due to her change in life experiences. This work, combined with the use of the ' Adult Carer Quality of Life' tool identified that whilst there were no concerns about her ability to care, her perceived level of caring choice and sense of value identified the impact this was having on Sue as a carer.

Admiral Nurse Interventions (Continued)

The Admiral Nurse supported Sue through the use of a reflective diary and enabled Sue to safely and confidently express her feelings in an honest way, which she described as cathartic. This reinforced to Sue how some of her responses to Nigel had a negative impact on his behaviors, only serving to make Nigel more demanding and Sue more challenged. This continuous cycle was identified as a cause of a lot of frustration leading to anger and guilt. With the use of psychosocial interventions, Sue was able to see that whilst Nigel may not be able to change his response, Sue could modify her reaction to this and support a more positive outcome. Sadly Sue's husband, Nigel died whilst Sue was on the Admiral Nurse caseload, however, Sue continued to be supported by the Admiral Nurse service via post bereavement interventions.

Outcomes

The work with Sue has resulted in the following outcomes:

- More regular breaks from caring was identified as a need for Sue and put into place
- Increased resilience for Sue as she was able to work through her feelings of guilt during her breaks
- An improvement in Sue's perceived quality of life and improved wellbeing
- An expressed increase in mental stamina and confidence during post bereavement support from the Admiral Nurse

Coordination of care and support via triadic relationships

This case study demonstrates how the Admiral Nurse provided intensive support to a carer to enable the addressing of her own needs and ability to care; highlighting the effective management of the complexity in dementia via multi-disciplinary partnership working.

Reason for Referral

Sarah (a carer for her husband Mark) was referred to the Admiral Nurse service by the Community Mental Health Team (CMHT). At the time, Sarah was receiving intensive support from a carer's support worker but required more specialist input.

The reason for referral to the Admiral Nurse service was that Sarah was identified as being at high risk of carer breakdown due to her physical health and mental wellbeing and was expressing feelings of isolation.

Admiral Nurse Assessment

An Admiral Nurse assessment identified many unmet needs for Sarah. Her role as a carer for her husband, Mark was proving more and more challenging and she was displaying signs of carer breakdown and inability to cope. This was exacerbated by the fact that Mark's physical health had taken a downturn – his Type 2 Diabetes was uncontrolled, and he was having frequent hypoglycemic episodes that did not respond readily to medication. This, in turn was causing high levels of confusion for him and frequent visual hallucinations. The Admiral Nurse identified that options such as respite, befriending and day care were not appropriate interventions for Sarah at the time and the cause of poor carer wellbeing needed to be addressed.

Admiral Nurse Interventions

The Admiral Nurse supported Sarah in contacting the Community Diabetic Nurse to obtain a review of Mark's medication in order to stabilize his condition. However, Marks health continued to deteriorate and was admitted to hospital and end of life planning and support needed to be implemented. Despite having Power of Attorney, Sarah felt largely uninvolved with Mark's treatment and care decisions and the Admiral Nurse was able to support Sarah to address this during this highly emotional time.

Admiral Nurse Interventions (Continued)

The Admiral Nurse put a plan into place which would offer emotional support to Sarah and to monitor her wellbeing on a regular basis. The Admiral Nurse liaised with Sarah's GP regarding concerns about her mental wellbeing, which led to an assessment being undertaken and a prescription for antidepressant medication. Advocacy support was provided and liaison with other health and social care professionals took place to ensure Sarah was fully involved with Mark's care. Emotional and psychosocial support was provided to Sarah to equip her with the tools to prepare for distressing conversations including completion of RESPECT forms, advance care plans and end of life planning. The Admiral Nurse identified that Sarah's sleep was being significantly impacted and sleep hygiene education was provided.

Outcomes

The work with Sarah has resulted in the following outcomes:

- Joined up interdisciplinary communication between services increased control for Sarah
- Increased understanding of Mark's complex situation enabled the correct care to be given
- Timely interventions for Mark were initiated such as advance care planning
- Reduced levels (self-reported) of anxiety for Sarah was achieved
- Prescribing of antidepressant medication resulting in reduction of depression

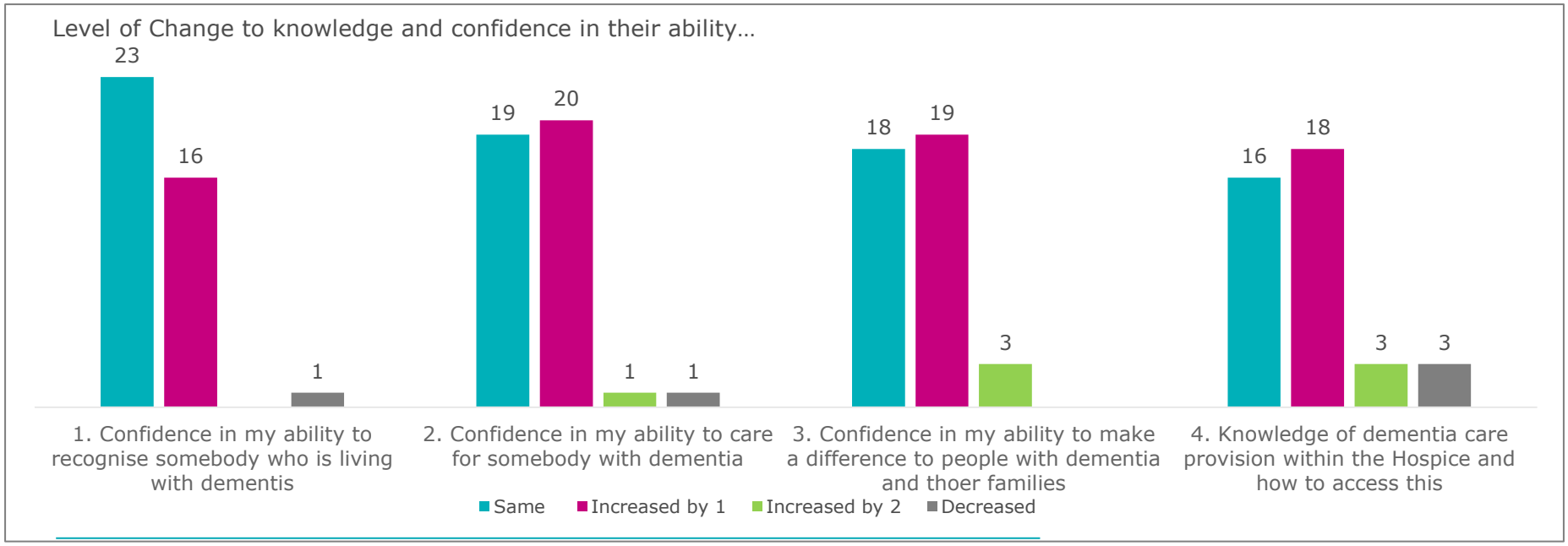
Training

St Barnabas staff – Clinical update sessions

Sessions were provided within St Barnabas during mandatory clinical update days to introduce the service, raise awareness of dementia, update on issues relating to dementia, medication, behaviours that challenge, communication skills and end of life care *(see Appendix Seven for additional information).* **The session ran for an hour, in four individual sessions, supporting 40 nurses**.

Attendees were asked to complete a short questionnaire prior to the session starting and then to complete a short questionnaire at the end of the session. This provided a self reported overview of each participant's change in knowledge and confidence in their ability and the results can be seen in the chart below.

Attendees reported their levels by indicating an answer of *Poor, Fair, Good, Very Good* and *Excellent* for each of the four questions stated below. For each of these questions the chart shows how many of the 40 attendees remained the same (i.e. no change was reported), increased by 1 scale (i.e. moved from fair to good or good to very good), increased by 2 scales (i.e. moved from fair to very good or good to excellent) or decreased (i.e. moved from excellent to very good).



Change to Practice

Attendees were asked **'what were the top 3 things you learnt?'**
It was clear that much was learnt during the session such as:

- The types and complexities of dementia
- The differences in symptoms and behaviours
  'Surprised by how many people affected'
- How to communicate with a person with dementia
  'how powerful meeting the communication needs are for people with dementia'
- Understanding behaviour of those with dementia
  'Behaviour is the expression of a unmet need'
- The difference in treatment and care required
  'Looking more at non-pharmacological ways of how different types affect behaviour, treatment, care'
- How to assess problems
- ABC Holistic Approach
- The role of Admiral Nurses
  'What Admiral Nurses do, how to refer; good to learn what the service is and what Admiral Nurses will provide'

At the end of the session, 29 nurses stated they would now do something differently in their practice.

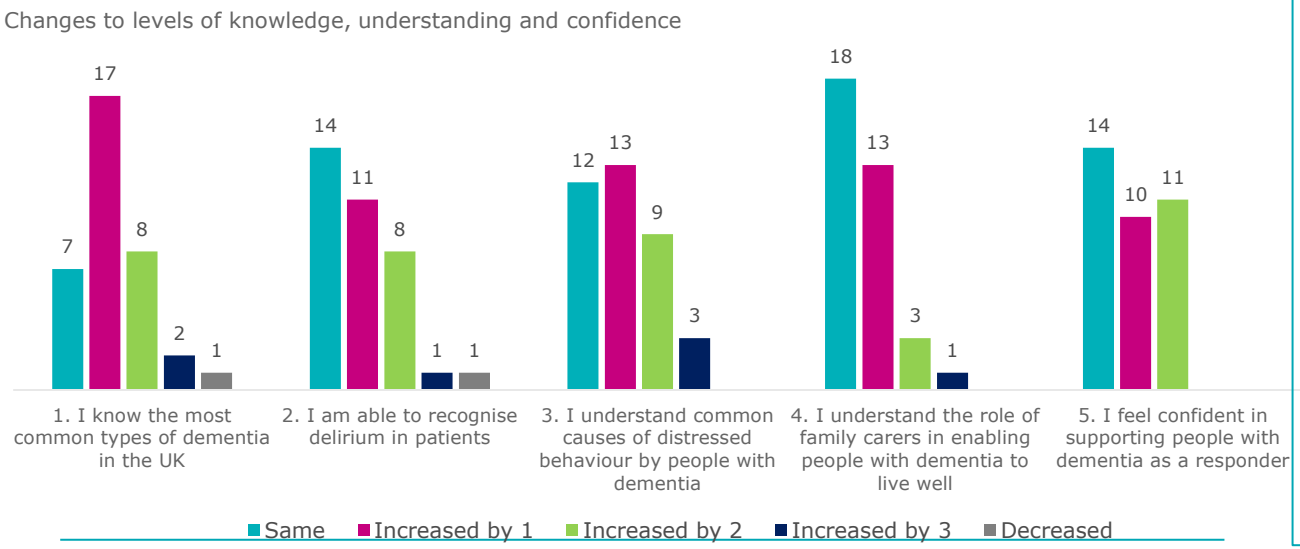
When asked to 'describe how your practice will change' here are some of the areas mentioned:

- **Communication**
  'Spend time exploring more communication links with patient'
  'Be more proactive about non verbal communication'
- **Behaviour Management**
  'Recognising behaviours and how to manage'
  'Change the way I interact with behaviour that challenges'
- **Understanding the person with dementia**
  'More time and try to find a link to connect to the patient'
  'Understanding why someone is behaving in the way that they are'
- **Awareness and assessment**
  'Be more aware of environment, use pinch me assessment,
- **Engagement**
  'Will further research non-pharmacological ways to engage person with dementia'
  'Try to find unmet need, power of physical contact'

LIVES – Awareness raising session

LIVES (Lincolnshire Integrated Voluntary Emergency Service) is a First Responder organisation in Lincolnshire. Emergency First Responders are volunteers from the local community, some of whom may be health professionals but many are not. A training session was organised within the AGM as an awareness raising session aimed at this wide audience, which would help prepare these responders for possible scenarios they may encounter if called out to a person living with dementia or their carer

There were over **70 attendees of this training session, which lasted 45 minutes**. Each attendee was asked to complete a brief questionnaire prior to the start of the session and then again at the end of the session. This provided a self reported overview of each participant's change in knowledge, understanding and confidence and the results can be seen in the chart below. Attendees reported their levels by indicating an answer of *agree, strongly agree, neutral, disagree or strongly disagree* for each of the five questions stated below. For each of these questions the chart shows how many of the 70 attendees remained the same (i.e. no change was reported), increased by 1 scale (i.e. moved from Agree to good or neutral to agree), increased by 2 scales (i.e. moved from Disagree to agree) or decreased (i.e. moved from strongly agree to agree).



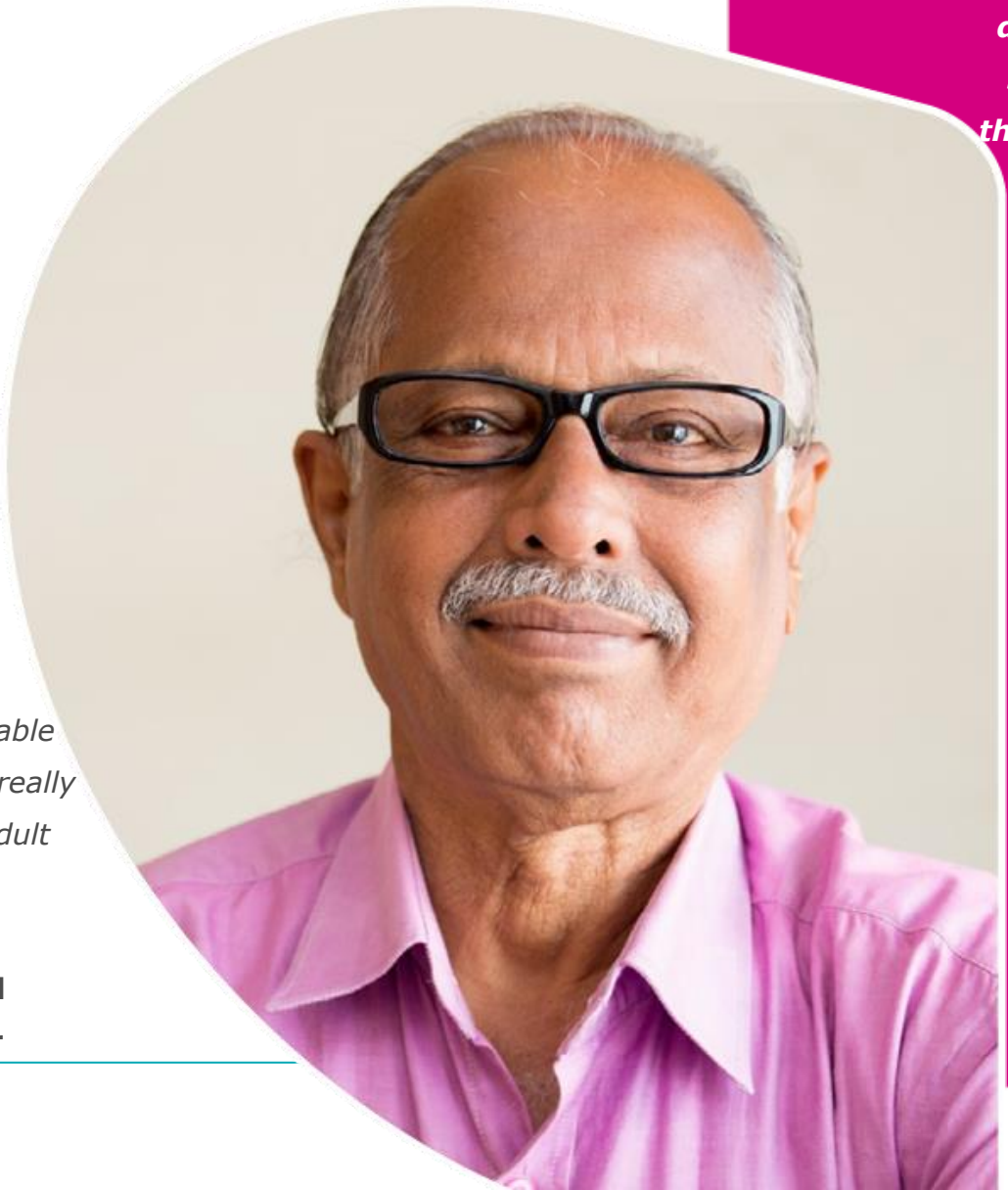
What, if anything, do you think you will do differently in your practice /work as a result of this session

"Talk to them as though they are one of the family, speak to them like you would want to be spoken to, if you were in that position, keep it simple."

"I will make more of an effort to speak to the patient, rather than the relative, ask question with an answer, yes/no."

"Consider slowing down my assessment where possible, 1 thing at a time."

Professionals' experience of the Admiral Nurse service



"They are a valuable service who work really well alongside Adult Social Care"

Professional Stakeholder

"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."

Professional Stakeholder

Professional Stakeholders Survey

To find out about professional stakeholders experience of the Lincolnshire Admiral Nurse service, an online survey was developed by the Insights & Evaluation team at Dementia UK. This sets out to capture information on the experience of those services which are in contact with the Admiral Nurse service, whether this be within the referral pathway or in another context. The survey aims to highlight the particular strengths of the service from the perspective of the stakeholders and understand the level of impact that would be seen if there was no Admiral Nurse service *(See Appendix Eight for additional information).*

A list of 26 stakeholders was provided by the Admiral Nurse Lead once consent had been given for Dementia UK to make contact. The stakeholders had agreed to be contacted regarding the Admiral Nurse service and came from a variety of roles including Neighbourhood Leads, St Barnabas Hospice Clinical Leads, Primary Care Network Leads, Lincolnshire Partnership NHS Trust Senior Clinicians, Lincolnshire County Council and Carers First.

All surveys were administered electronically**; there were 11 respondents to the survey, representing a 42% response rate.** Most stakeholders (n=8) had had contact with the Admiral Nurse service to make referrals (see chart opposite).

Responsiveness of service

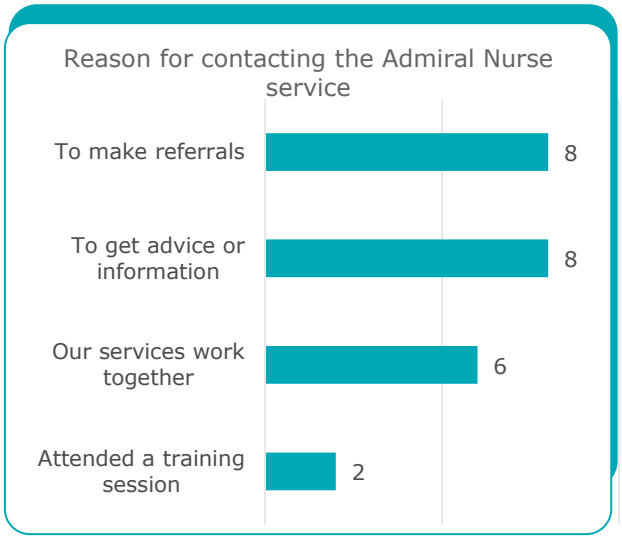
All respondents (n=11) thought that the Admiral Nurse service responded to requests in a timely manner

Reduced their contact time with families

- Two of those who responded thought the Admiral Nurse service had **reduced their contact time with families affected by dementia**
- Two of those who responded thought the Admiral Nurse service had **reduced their service's contact time with families affected by dementia**

"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 (…)."

Professional Stakeholder



Frequency of contact

All respondents (n=11) thought that the frequency of contact was appropriate to their/their service's needs

Stakeholders who responded to the survey[1] were asked to tell us whether the Admiral Nurse service had done any of the following to improve their understanding, confidence and awareness:

- **Increased my awareness of other services available to support families** affected by dementia (yes=8, no=1)
- **Increased my understanding of dementia and its effects** (yes=7, No=1)

Professionals also spoke about working alongside the Admiral Nurse service; here are some quotes:

"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."

"Good to know we can signpost to them if required. Has been useful in supporting staff affected by dementia outside of work environment."

"I have just valued the interactions that I have had with them - it broadens my thinking."

"Furthermore, when they attend our clinical meetings and MDTs, they can add an additional quality to the discussion, which I find invaluable. Although I have 20 years + experience within palliative care, I have limited experience of caring for patients with a dementia diagnosis and yet the two are so closely inter linked. To broaden and deepen our knowledge is vital as more patients with a** *dementia* ***diagnosis reach end of life."

1. This data includes all responses where the question was applicable

Supporting Families

Stakeholders were asked to state how the Admiral Nurses had supported the families affected by dementia in their service

- Improved quality of life for families (n=8)

  '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.'

- Helped avoid crisis points (n=5)

  'These nurse are currently the only support that family has, and I personally feel they have remained in touch because they know that very soon, extra support will be required'

- Improved care for families (n=8)

  'More focus on family/carers when other services main focus is the patient'

- Improved person-centred care (yes=8, no=1)

  'I gave him the Admiral Nurse number and they were excellent. They could see straight away how C was saying she was managing but possibly hiding the fact she was finding this whole situation difficult….

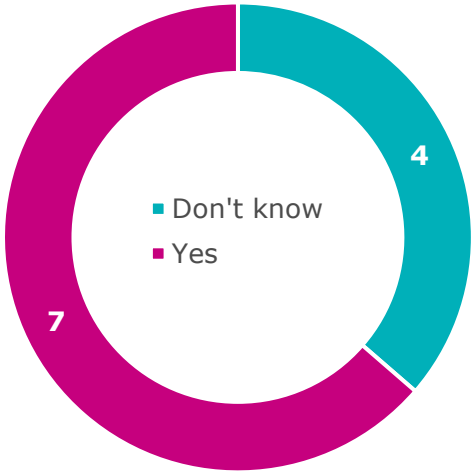
- Had an impact on reducing unplanned hospital admissions (yes=3, no=1)

  'I had a client and her husband 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 an host of other potential risks.'

- Enabled the inclusion of families in decisions about their care (yes=6, no=1)
- Improved case management/coordination (yes=4, no=1)

If the Admiral Nurse service no longer existed…

Stakeholders were asked whether there would be an impact on them, their service or families affected by dementia if the Admiral Nurse service no longer existed; **7 of the 11 respondents believe there would be an impact**



"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."

When asked what the impact would be……?

- 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 planning/carer support

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

Conclusions

The Lincolnshire Admiral Nurse Service has begun to address some of the unmet needs expressed by carers in Lincolnshire – providing a source of specialist knowledge, advocating for their needs, providing support and skills to enable them to care for their family member at home for longer.

Referrals and activity

The differing referral rate throughout Lincolnshire reflects the diversity of need, demographics and geography. The Admiral Nurse service will continue to work on understanding these differences to inform and support strategic work force planning and development.

The fact that demand has exceeded capacity in relation to caseload sizes highlights the need for robust processes. However, it should also be acknowledged that large caseloads are evidence that workforce establishment should be a consideration for future sustainability of the service.

Dementia as a palliative diagnosis

The Lincolnshire Admiral Nurse service is ideally placed to join up dementia and palliative care services. St Barnabas and the Admiral Nurse Team will continue to promote and increase the accessibility of hospice services to those with dementia.

Collaboration with other services

Working collaboratively, across the spectrum of agencies, ensures that those in receipt of those services receive a truly needs led, holistic, support plan. The Admiral Nurse service will continue to work with and integrate with the neighbourhood teams to maximise effectiveness of the service.

Conclusions

COVID response

The impact of COVID has been profound on people living with dementia in care and at home. For many it has increased the isolation and loneliness of having, and caring for someone with, dementia. The Admiral Nurse service has continued to provide a vital link for families living with dementia by providing increased support over this time period.

Supporting best practice

The provision of formal education to increase knowledge, as well as showcase specialist skills to upskill colleagues across the health and social community is a key element of the role of the Admiral Nurse. By tailoring formal and informal training around the needs of different services, Admiral Nurses are able to demonstrate improved care. The Admiral Nurse service will continue to seek innovative means of collaboration, facilitating education and learning within Lincolnshire.

Carer and stakeholder feedback

The carers survey was able to demonstrate improvement in quality of life for carers, enabled carers to be more involved in decision making, enabled the carer to support independence for the person with dementia, and enabled carers to better care for the person with dementia – all key outcomes for the service. This first year of service, has enabled individual nurses to develop into their role, gain an understanding of the area they cover and begin to influence at a local and personal level the lives of families living with dementia.

Main Achievements

The Lincolnshire Admiral Nurse service has achieved much in its first year, below are a few main achievements:

- Establishment of Admiral Nurse service in Lincolnshire
- Recruiting and holding specialist nursing posts in Lincolnshire
- Recognition of added value of Admiral Nurses at strategic level
- Continued support and positive impact for carers during COVID pandemic
- Positive regard generated with other professionals and services
- Intelligence gathering on profile of impact on dementia in Lincolnshire
- Improvement in the experience of dementia in Lincolnshire
- Enabled carers to be more involved in decision making, increase self-care, coordinate care and continue to support the person with dementia

Year 2 Priorities

Through this evaluation process, several themes have emerged to focus on in the next year and beyond:

- Use data generated by the service to better understand the needs profile of carers in Lincolnshire
- Utilise data gathered over the two-year project to articulate future workforce needs
- Continue to refine the process of case load management to ensure timely referral response and assessment
- Further develop multi-disciplinary working with hospice teams and neighbourhood areas
- Ensure accurate recording of supporting evidence such as supporting best practice
- Review education needs of dementia care in Lincolnshire and ascertain where the Admiral Nurse service can have most impact
- Continue with virtual consultation project
- Review activity data on the impact of the service

Appendices

Appendix One -What is Admiral Nursing?

Admiral Nurses are registered nurses who have specialist knowledge of dementia care

They provide support to families living with dementia

They provide education, leadership, development and support to other colleagues and service providers

We asked our Admiral Nurses to map how they work across the NHS Well Pathway for Dementia to provide expert clinical, practical and emotional support for families. This is what they told us:

Preventing Well

- Raising awareness
- Reducing stigma
- Health promotion
- Health checks
- Disseminating information
- Care education
- Community engagement
- Preventative management of risks to health, e.g. falls, delirium, poor nutrition, reduced mobility, incontinence, polypharmacy, depression etc.

Diagnosing Well

- Peri-diagnostic support
- Education others about varying and atypical symptoms of dementia to improve early identification
- Specialist navigation of services
- Encouraging timely assessment
- Identifying barriers to seeking diagnosis

Supporting Well

- Specialist holistic bio-psycho-social assessment
- Psycho-social interventions
- Family focussed interventions
- Managing and identifying co-morbidities and complex needs
- Person-centered care planning
- Developing coping strategies
- Non-pharmacological management of behavioural and psychological symptoms of dementia

Living Well

- Positive risk taking
- Managing transition
- Advance care planning
- Building resilience in families
- Symptom management
- Crisis prevention
- Relationship support
- Promoting independence
- Managing grief, loss and bereavement
- Enabling access to life outside caring
- Promoting/enabling inclusion and participation

Dying Well

- Difficult conversations
- Identifying end of life and access to preferred place of care
- Recognition of dying phase
- Emotional support and pre and post bereavement counselling for families
- Guidance on use of prognostic indicators
- Symptom identification e.g. pain

Admiral Nurse activities supporting people with dementia and their families throughout the pathway

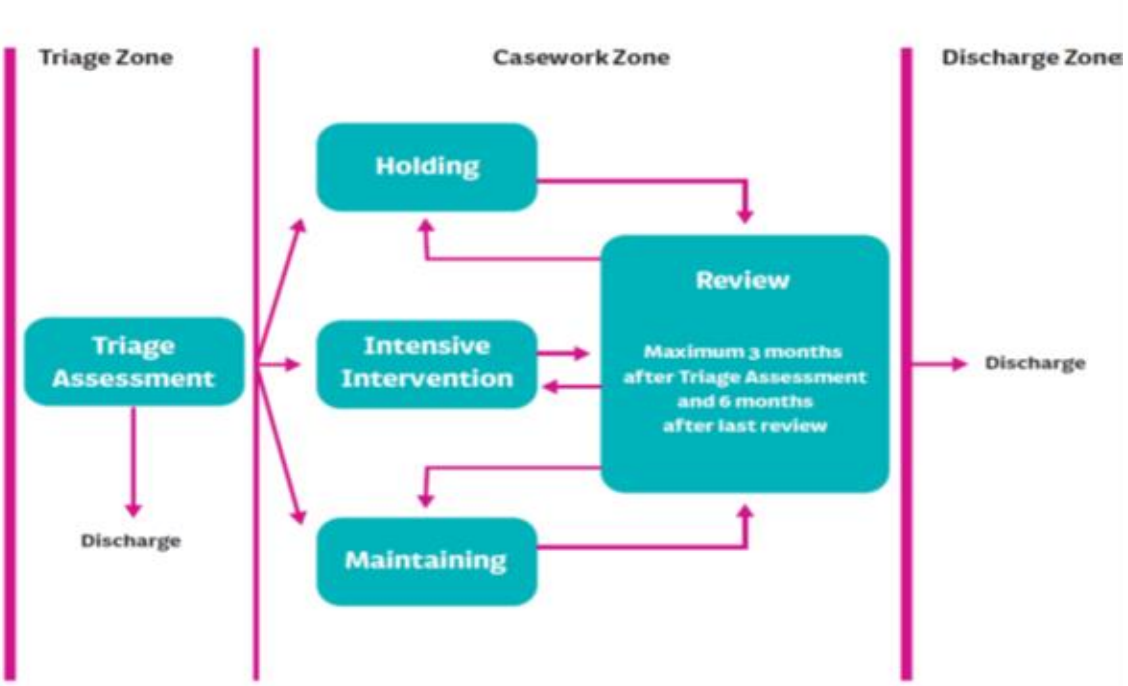
Case management and care co-ordination, advance care planning, integration and partnership working, specialist support and advice for professionals, education and training, influencing policy and strategy continuity and communication, research and evaluation, promoting best practice, navigation of health and social care system, advocacy, counselling, reducing stigma.

[1] https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf

Appendix Two -Service Model

The Lincolnshire Admiral Nurse Service is provided by a team of Admiral Nurses providing Tier 3 interventions for those who have complex and unresolved needs requiring individualised and intensive levels of support.

Admiral Nurses utilise a casework work model (see below) to support decision making, care planning and assessment of the required level of support. Following assessment, the Nurse allocates the carer to a particular case work zone. This will be based on a range of factors such as number and level of needs, complexity of those needs, amount of liaison needed, risk, and stability of the situation. The flexibility of this approach means that cases can transition between different zones as needed based on the outcomes of interventions with the Admiral Nurse.



Appendix Three -Admiral Nurse Assessment Framework

The Admiral Nurse Assessment Framework (ANAF) provides a structure within which to assess the needs of the family carer; to identify the key priorities for them and appropriate interventions. The assessment has 18 domains. Based upon the assessment, clinical judgement and observation of the Admiral Nurse, these domains are then rated as to whether these areas of need are currently being met. The table below shows the areas of concern **in order of unmet need** for the team caseload during this reporting period and compares with 'no need', 'needs currently met' and 'unknown (at the time of assessment)[1].

	Unmet Need	No need	Currently Met	Unknown
Mental Health & Wellbeing - Carer(s)	**106 (42.7%)**	61 (24.6%)	69 (27.8%)	12 (4.8%)
Skills in Coping with Behaviour/Symptoms	**99 (39.9%)**	61 (24.6%)	72 (29.0%)	16 (6.5%)
Looking to the Future - Carer	**93 (37.5%)**	16 (6.5%)	79 (31.9%)	**60 (24.2%)**
Time For Self - Carer	86 (34.7%)	38 (15.3%)	98 (39.5%)	26 (10.5%)
Mental Health & Wellbeing - PWD	74 (29.8%)	29 (11.7%)	138 (55.6%)	7 (2.8%)
Knowledge & Understanding of Dementia	71 (28.6%)	46 (18.5%)	111 (44.8%)	20 (8.1%)
Adjustment & Loss	69 (27.8%)	52 (21.0%)	55 (22.2%)	**72 (29.0%)**
Risk	61 (24.6%)	100 (40.3%)	60 (24.2%)	27 (10.9%)
Balancing Needs - Carer	56 (22.6%)	49 (19.8%)	117 (47.2%)	26 (10.5%)
Physical Health & Wellbeing - PWD	51 (20.6%)	39 (15.7%)	**153 (61.7%)**	5 (2.0%)
Financial and Legal Issues	44 (17.7%)	56 (22.6%)	122 (49.2%)	26 (10.5%)
Practical Support	42 (16.9%)	46 (18.5%)	**150 (60.5%)**	10 (4.0%)
Informal Support & Networks	39 (15.7%)	40 (16.1%)	**157 (63.3%)**	12 (4.8%)
Physical Health & Wellbeing - Carer(s)	34 (13.7%)	84 (33.9%)	122 (49.2%)	8 (3.2%)
Environment	34 (13.7%)	**109 (44.0%)**	89 (35.9%)	16 (6.5%)
Communication & Understanding with Professionals	24 (9.7%)	**132 (53.2%)**	81 (32.7%)	11 (4.4%)
Managing Medication	21 (8.5%)	71 (28.6%)	144 (58.1%)	12 (4.8%)
Practical & Assistive Aids	19 (7.7%)	**108 (43.5%)**	90 (36.3%)	**31 (12.5%)**

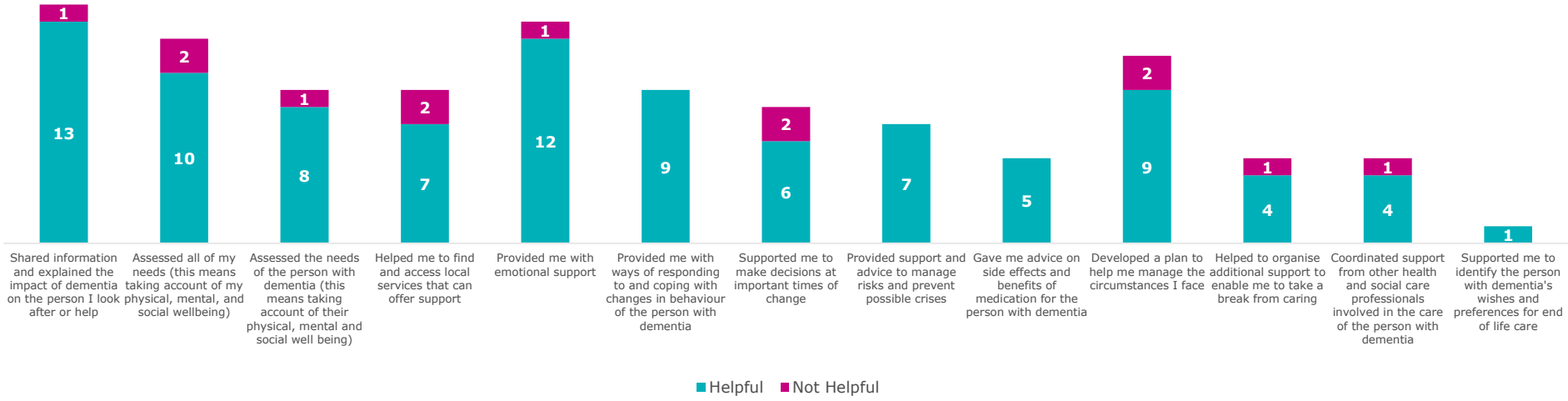
1. Generally this indicates that further investigation is needed

Appendix Four -Admiral Nurse Interventions

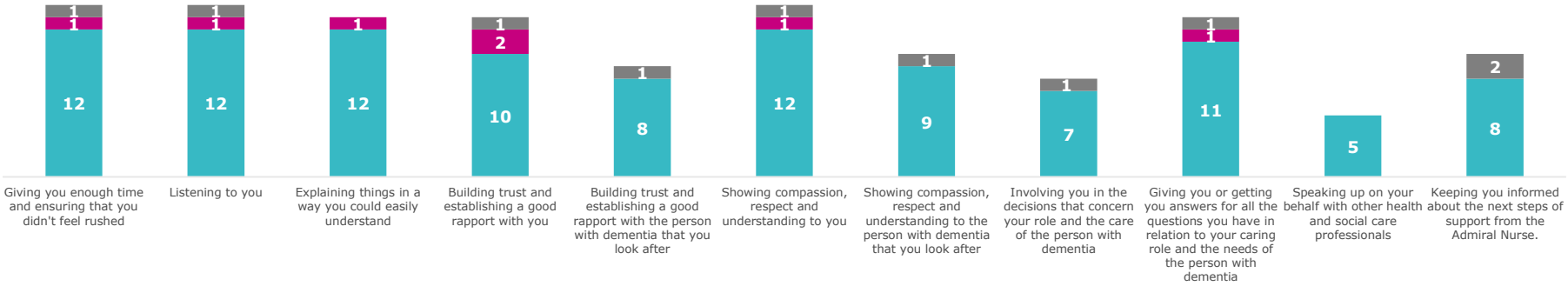
Managing and promoting physical well-being	•Review of physical health issues relevant to the person, signposting and advice on managing issues such as hydration, continence, mobility and frailty.
Assessment	•Both initial assessment and ongoing review on each contact with the person to evaluate current plan and decision making.
Sharing Knowledge and information	•Providing advanced clinical information about medication, diagnosis, and prognosis. Informing of other services, books/websites, and amenities. Discussing and implementing practical strategies to manage complex situations.
Developing coping strategies and skills (psychological well-being)	•Formulating individual plans of action based on identified needs and strengthens of the person. Providing education and knowledge about dementia to increase understanding. Supporting resilience and coping mechanisms.
Emotional support/counselling (Psychological well-being)	•Providing emotional support with therapeutic skills and strategies. Supporting emotional wellbeing for example through the use of counselling skills.
Managing risk	•Reviewing risks of current situation, advising on reduction and mitigation strategies, supporting safeguarding processes. Alerting other agencies as necessary.
Advance care planning	•Facilitating discussion with person with dementia and carer about current and future wishes for care, advising on likely support needs and completing documentation.
Adjustment, loss and bereavement	•Working with couples as relationships change, care needs increase and consider about future plans. Support with anticipatory grief, end of life and bereavement.

Appendix Five -Carers' experience of the Admiral Nurse service

We asked carers **whether the Admiral Nurses had been helpful** in a number of areas.*



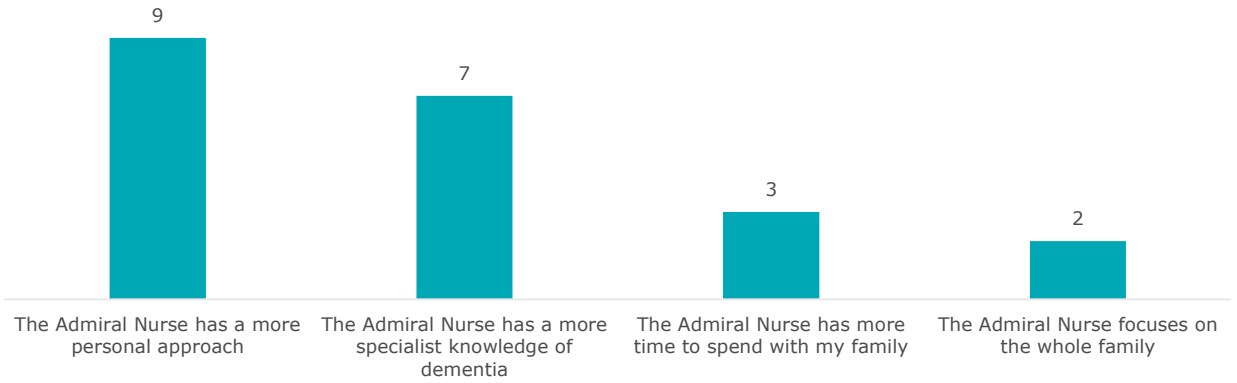
We asked carers **how good the Admiral Nurses had been** in a number of areas.*



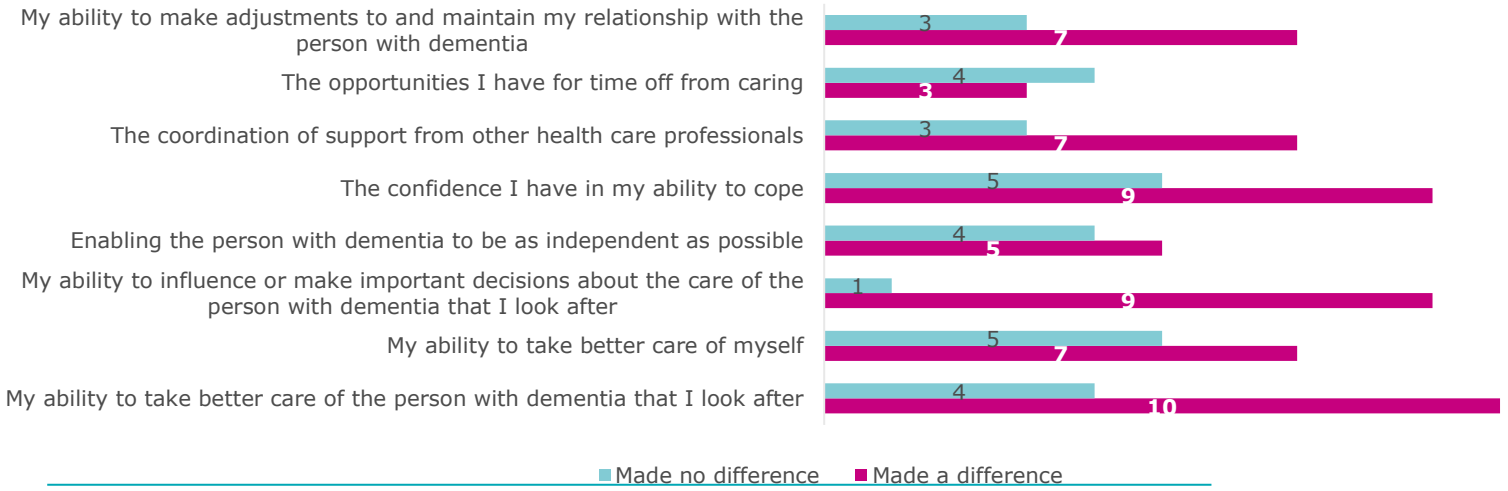
*The response rate to each area varies, depending on whether carers felt it was applicable to them

The Added Value of Admiral Nurses

Carers were asked 'How if at all, is the support that you've received from an Admiral Nurse different from that given by other health and social care professionals?"



Respondents were asked whether the Admiral Nurse made a difference to any of these areas……



Appendix Six -AC-QoL Subscale Domains

AC-QoL is a validated tool that was developed by the Princess Royal Trust for Carers, measuring the overall quality of life as low, mid and high, as well as giving the same indication for the 8 subscales below.

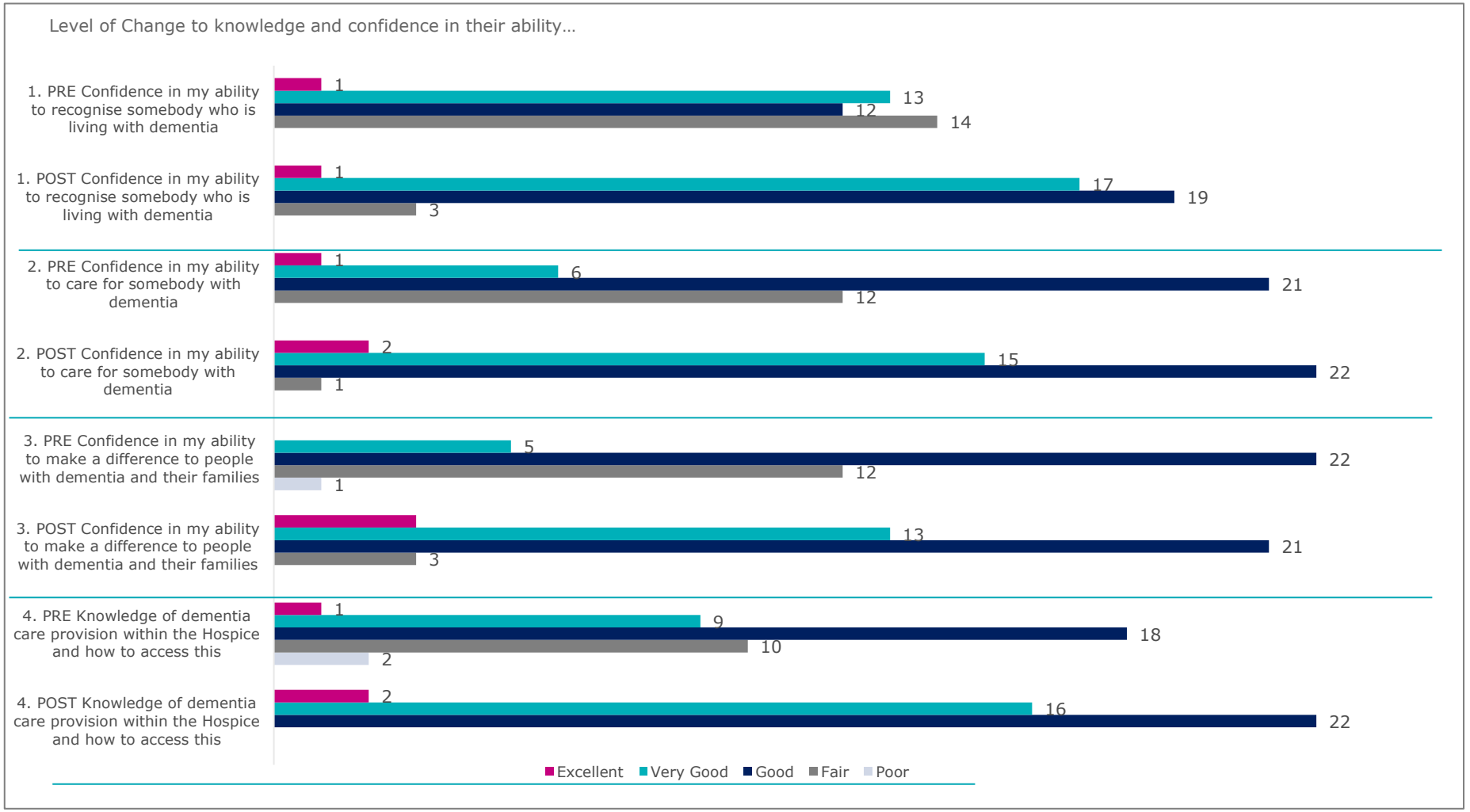
Domain	Description
Support for caring	This measures the extent of support carers perceive that they receive, encompassing emotional, practical and professional support)
Caring Choice	This subscale measures the extent to which carers feel that they have control over their own lives, and are able to choose ventures outside caring, such as social activities
Caring Stress	This subscale measures the mental and physical stress from caring
Money Matters	This subscale measures how carers feel about their financial situation
Personal Growth	This subscale measures how much the carer feels they have grown and developed, and the positive experience of the carers' circumstances.
Sense of Value	This subscale measures the extent to which the carer feels they are valued and respected, and the positive relationship between the carer and the person they are caring for
Ability to Care	This subscale measures the extent to which the carer is able to provide care for the person they care for, how they cope with the caring role, and how they feel about their competency to care
Carer Satisfaction	This subscale measures the extent to which the carer is satisfied with their life and role as a carer, and how they feel about being a carer

Appendix Seven

Training

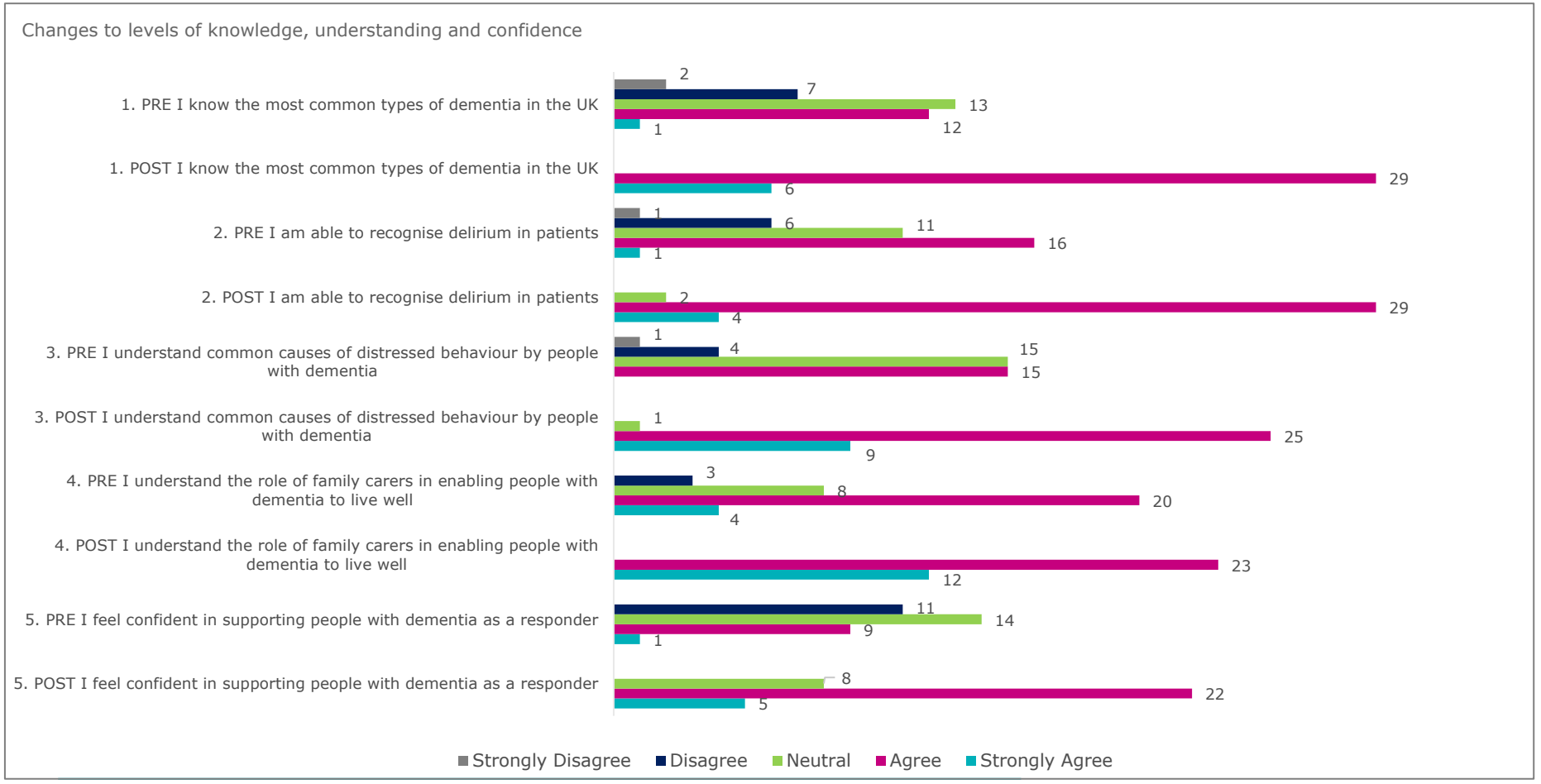
St Barnabas staff – Clinical update sessions

Sessions were provided within St Barnabas during mandatory clinical update days to introduce the Admiral Nurse service, raise awareness of dementia, update on issues relating to dementia, medication, behaviours that challenge, communication skills and end of life care. The chart below shows the self reported changes pre and post training session to knowledge and confidence.

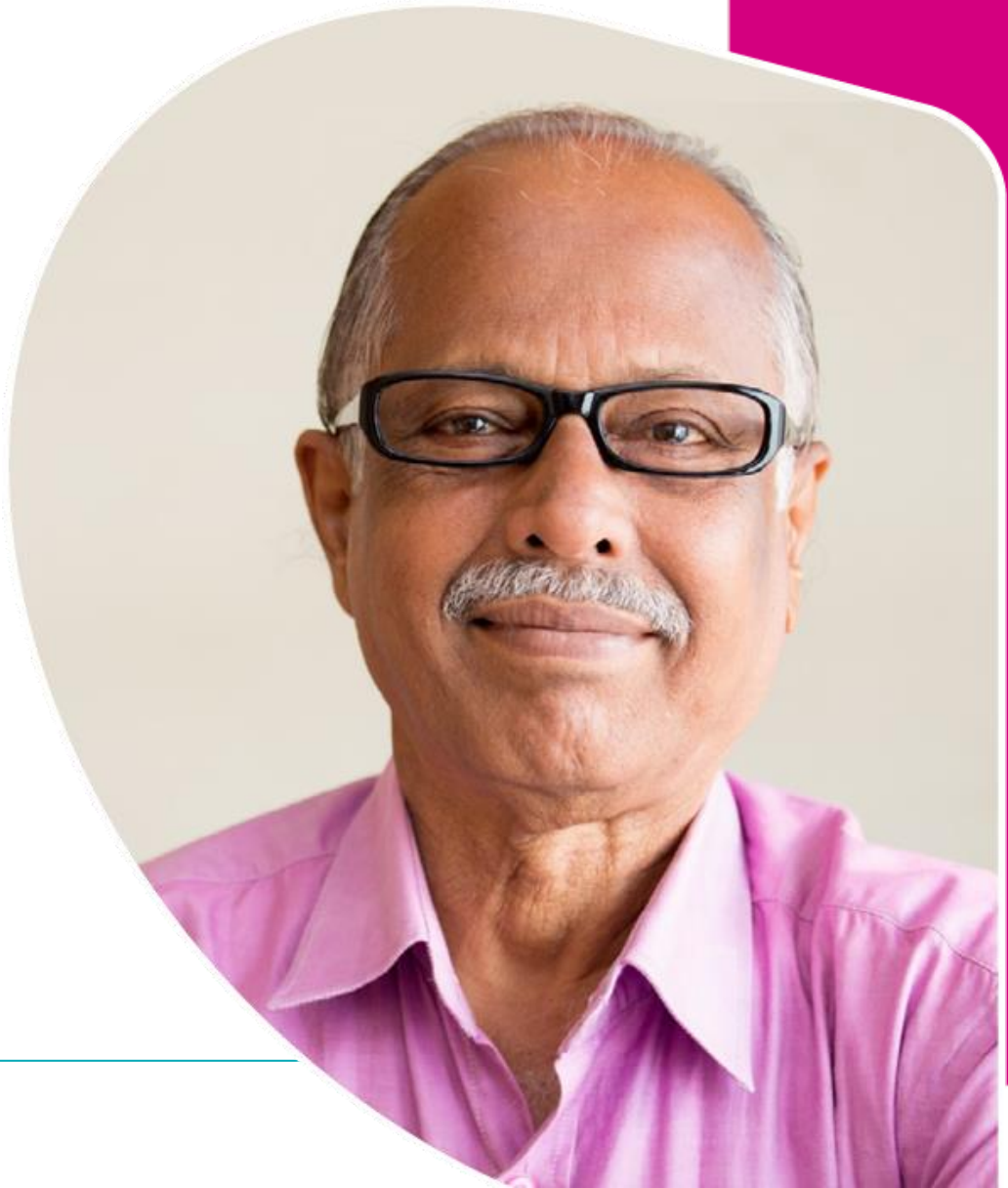


LIVES – Awareness raising session

LIVES (Lincolnshire Integrated Voluntary Emergency Service) is a First Responder organisation in Lincolnshire. First Responders are volunteers from the local community, some of whom may be health professionals but many are not. A training session was organised within the AGM as an awareness raising session aimed at this wide audience, which would aim to prepare these responders for possible scenarios they may encounter if called out to a person living with dementia or their carer.

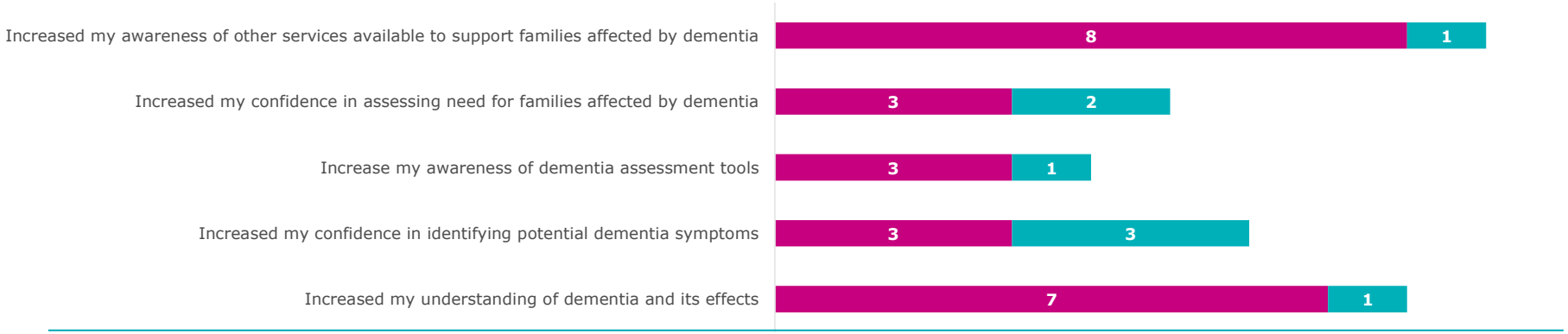


Appendix Eight -Professionals' experience of the Admiral Nurse service



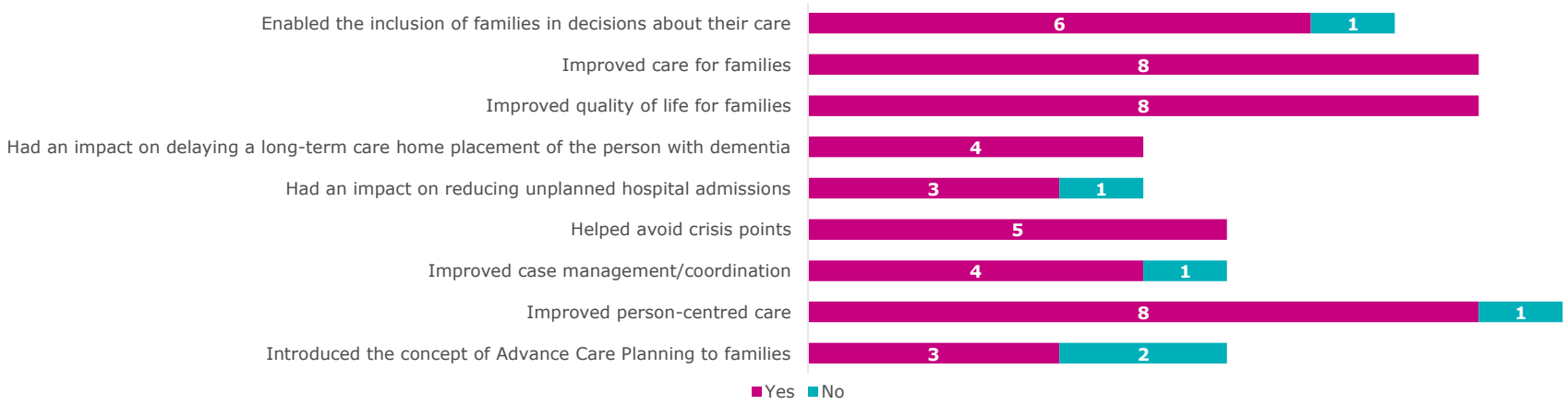
Working in Partnership

Please tell us whether the Admiral Nurse service has done any of the following to improve your understanding, confidence and awareness:



Supporting Families

Thinking of families affected by dementia in your service who have been supported by the Admiral Nurse, please tell us whether the Admiral Nurse service has..



* The charts above shows the response to the question where this was given – other than '*Don't know*'

Professionals also spoke about working alongside the Admiral Nurse service; here are some quotes:

"Admiral Nurses are a valuable service who give great advice and support to both their clients and other supporting teams and I have regularly passed on their great work to more of my clients for further support."

"It is good when services work together to support families and service users affected by dementia"

"..they have been very supportive in working jointly with the team to support our patients and their families."

"By working together, carers feel more supported"

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

@DementiaUK • www.dementiauk.org