

IW Dementia Stocktake

Long Read v2.0

Date 16/12/19

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1) Executive summary

Executive Summary

Dementia prevalence on the Isle of Wight is high, this impacts on all services on the island. This is particularly noticeable at St Mary's hospital where a high proportion of people have a diagnosis of dementia on all wards for adults.

There are many people on the Isle of Wight who live with dementia and who may need a range of flexible, high quality support across primary care, secondary care and community and voluntary sector organisations. Reviewing local provision through this stocktake has highlighted key local successes and challenges:

Local Successes

- Most people receive a diagnosis within national targets
- People's journey through a variety of services appear to be working well, but low staffing levels in some services can have a negative impact on peoples experiences
- Primary care reviews for people with dementia appear to meet national targets however further information is needed on the what these reviews consist of
- There has been an improvement in appropriate referrals to safeguarding for people with dementia
- Dementia training has been delivered to a wide and varied group, and positive feedback has been received on the training delivered and the impact this is making
- Voluntary sector campaigning though the Age Friendly Island work has impacted on how the wider community support people with dementia
- Generally, standards in local care and nursing homes have improved, leading to a better quality of service for the people who live there
- The Island voluntary and community sector provide 1,110 hours of services for people living with dementia, their family and carers every month

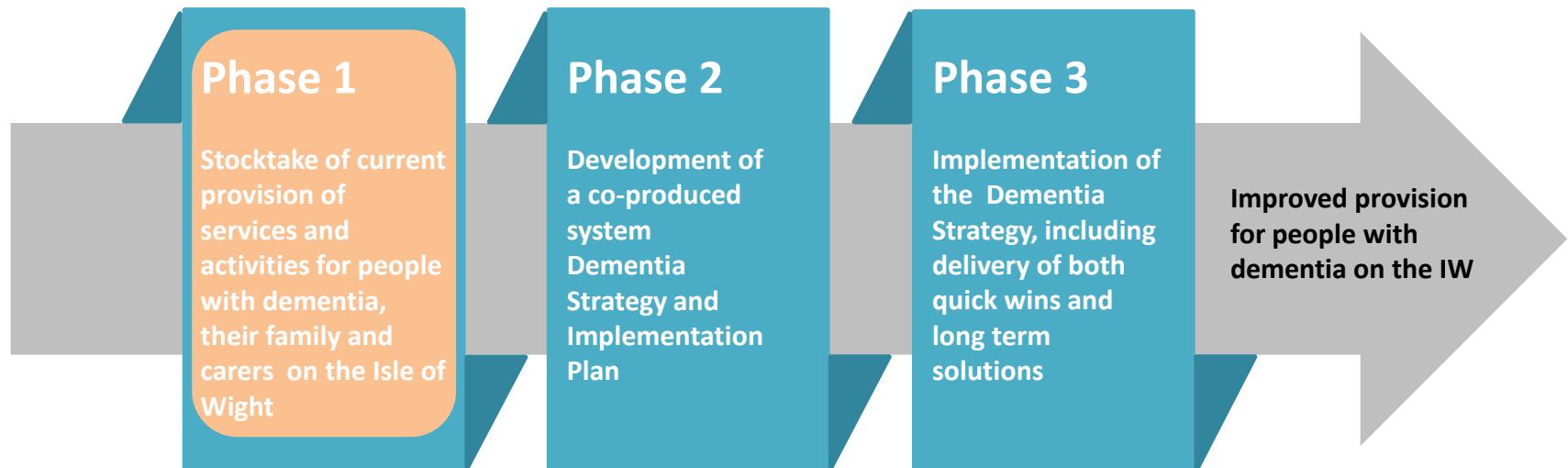
Local Challenges

- Secondary care for people with dementia with complex needs has received inadequate CQC ratings, and currently there is no community multidisciplinary mental health service
- People with dementia tend to have longer stays in hospital which can impact on their physical and emotional wellbeing
- Currently there is a high risk that the diagnosis rates recorded in primary care will fall below national targets
- More people are having to wait longer for a social care review
- Some people have a longer wait to see an admiral nurse
- Feedback from groups who provide services and people in the community suggests a lack of coordination or knowledge of what to 'do next' after diagnosis, or when somebody falls into crisis
- Data collected from the accident and emergency department as St Mary's does not appear to be correctly recording whether people have a diagnosis of dementia

2) Introduction

Purpose and objectives of the Isle of Wight Dementia Stocktake

It was agreed that there is an urgent need to better support people on the Isle of Wight living with dementia, their family and carers. To enable experience from pre diagnosis to end of life care to be improved. A three stage process was agreed with all local services working together to achieve a combined approach:



The stocktake is the initial stage to support the development of a strategy for dementia provision on the Isle of Wight taking into consideration the needs and aspirations of people with dementia, their families and carers.

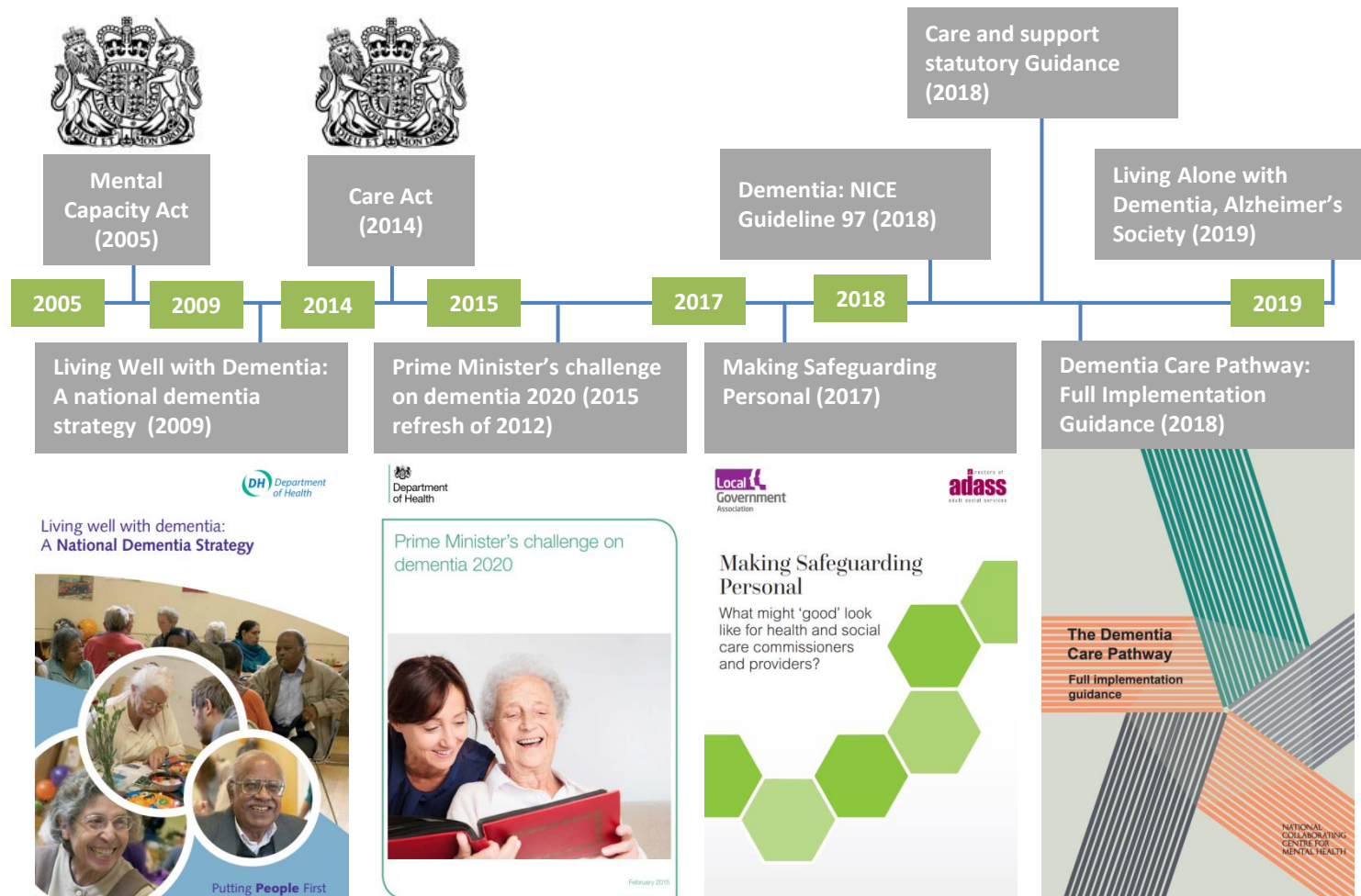
This document reviews the current position looking at data and listening to people's experiences and reports and reviews on local services, and will be used alongside best practice and further views from people with dementia, their family and carers to develop the strategy.

Over the last 10 years there have been fundamental changes to national policy around dementia

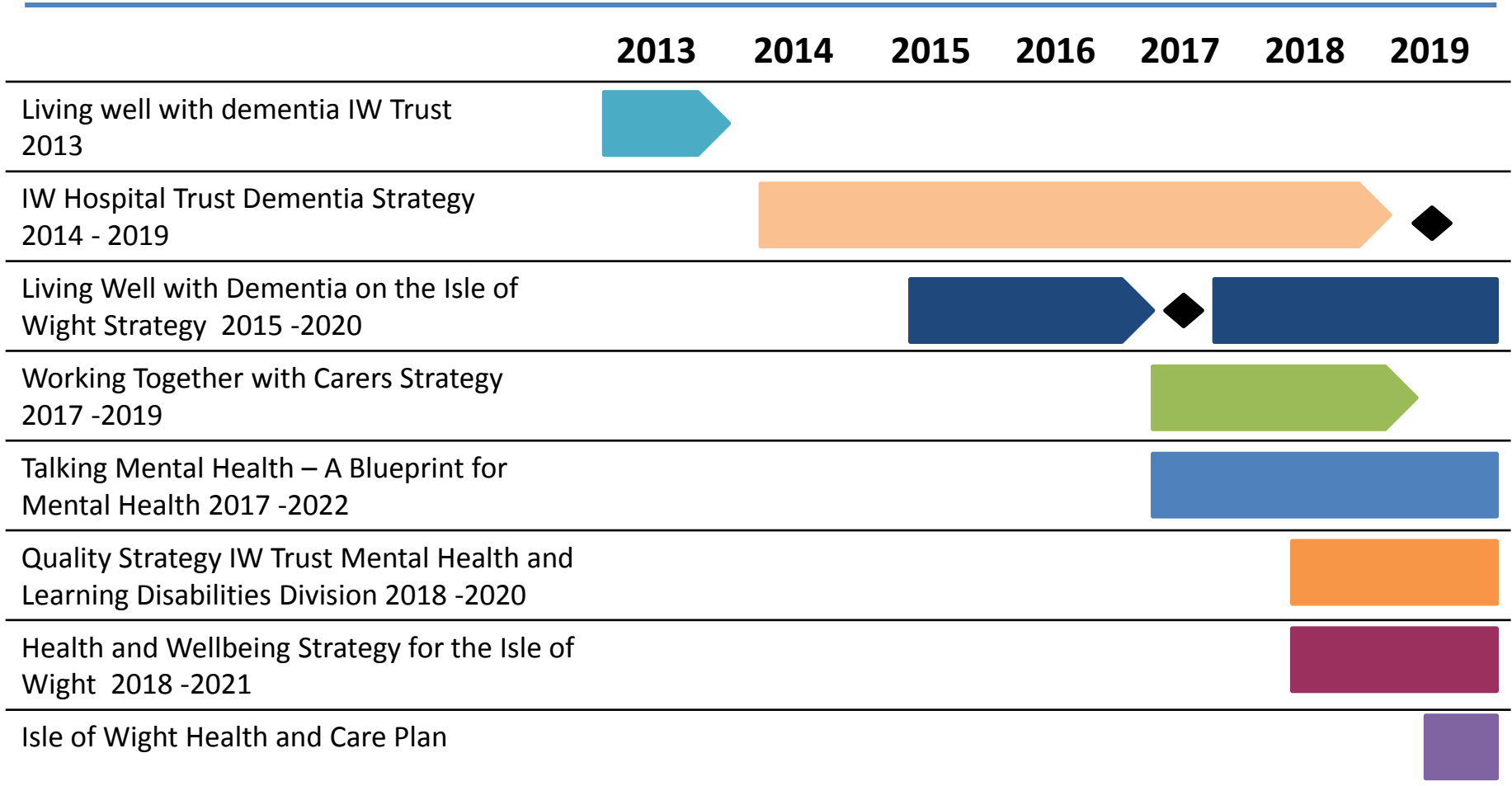
There have been a number of national policies on dementia over the last 10 years that have seen fundamental changes to the way people with dementia are supported by health and social care.

This includes dementia specific policies and those with a wider remit that impact on people with dementia their family and carers.

There are a number policies and documents that have changed the landscape, however, there are further policies that have contributed to this change than just the key documents shown.



Locally there has been significant specific dementia strategy and related strategy work over the last 6 years



Refreshed

Over the last years island partners including health, care, voluntary, community and independent sector have contributed to developing dementia specific strategies and strategies that impact on those living with dementia.

2) Introduction

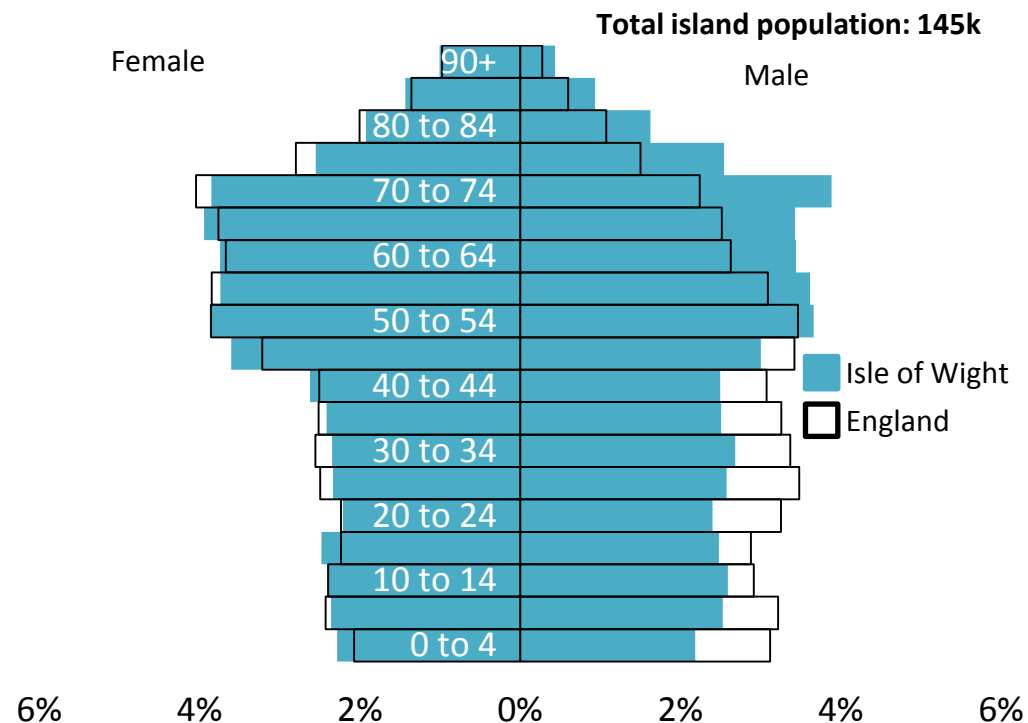
3) Context

The Isle of Wight population is older, more deprived, and has more people living alone than nationally

- The Isle of Wight population is **older than the England average by five years**.
- While there is variation in deprivation across the island, **the number of wards in the 20% most deprived has reduced but the number of wards in the 10% most deprived has increase between 2015 and 2019**.
- There are two wards in the top 10% most deprived in the West and Central locality and one ward in the north east locality
- More people **live alone on the Isle of Wight (15%)** than **nationally (12%)** (appendix i).

Population of the Isle of Wight and England in five year age bands 2015 - 2019

%

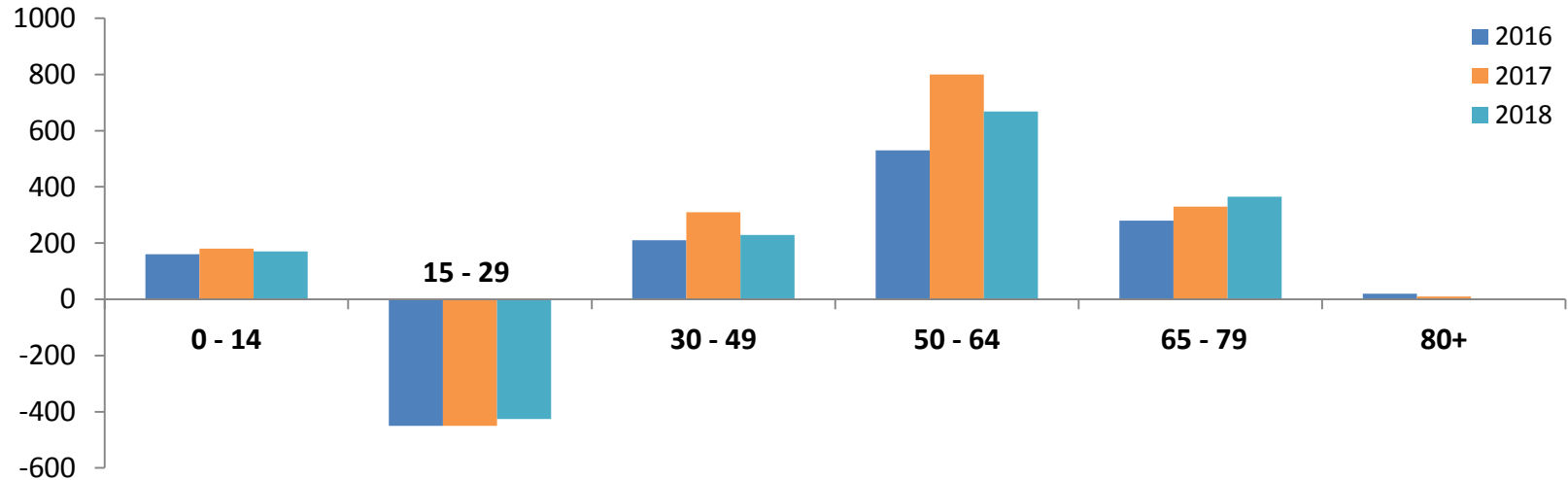


Source: English IMD, Sep 2019

The Isle of Wight net migration shows the largest net inflow is in those aged 50 – 64 impacting on our ageing population

Internal net migration by age 2016 - 2018

Count



The net migration figures show a net inflow of people aged 30+ with people aged 50 - 64 showing the largest net inflow. The net outflow for the Isle of Wight is mainly seen in those aged between 15 – 29. This may accelerate the ageing population of the Isle of Wight.

The last three years show a consistent trend for net inflow and net outflow, and this will be contributing to the Isle of Wight's ageing population. For those who are moving to the Isle of Wight for the first time they may also experience limited support networks when they first move.

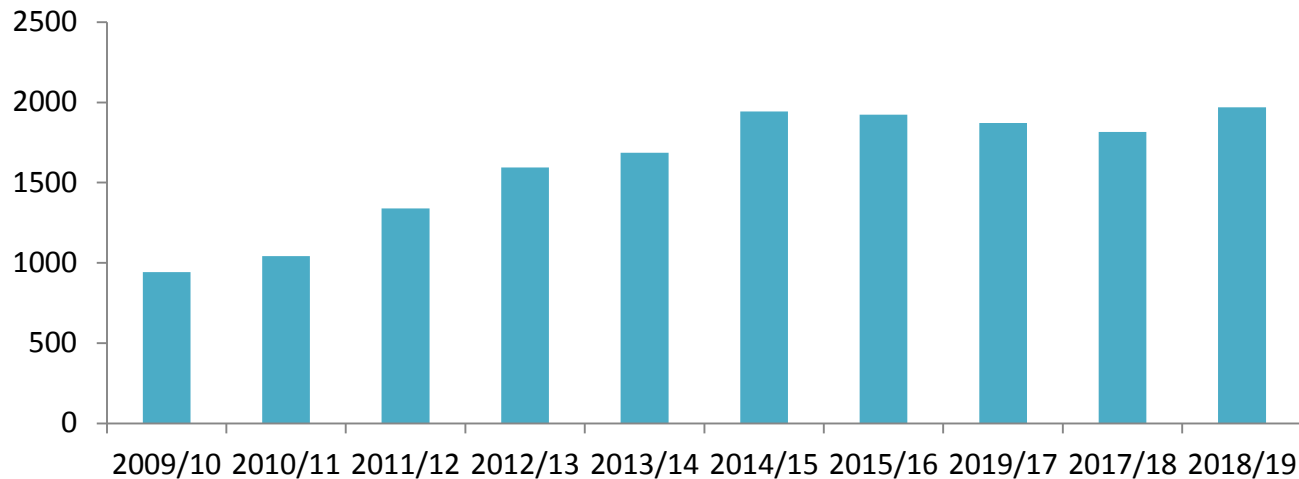
Source: ONS Internal net migration: by local authority and age group Jun 19

4) Prevalence

Dementia prevalence on the Isle of Wight has been increasing over the last 10 years

Dementia prevalence trends (all ages)

Count



Dementia prevalence in terms of diagnosis rates by GP's has been steadily increasing over the last 10 years.

When comparing to peer groups the Isle of Wight has a high prevalence of dementia for all ages and those over 65 when age adjusted (appendix ii).

In August 2019 on the Isle of Wight there were 1,764 people with dementia over 65 but it is estimated that there are actually 2,619. Therefore only 67.6% of the estimated population with dementia are known to primary care (NHS Digital)

The increase in population for over 70's is estimated to increase by 11% by 2024 and the number of people predicted over 65 to have dementia is estimated to increase by 4% .

Source: PHE finger tips; ONS subnational population projections; CCG peers

"[It] took too long for GP to acknowledge memory problems and refer to memory service"

"Extremely slow system"

"Had to wait 20 weeks for diagnosis"

"No confirmed diagnosis – no support"

Informal consultation 2019

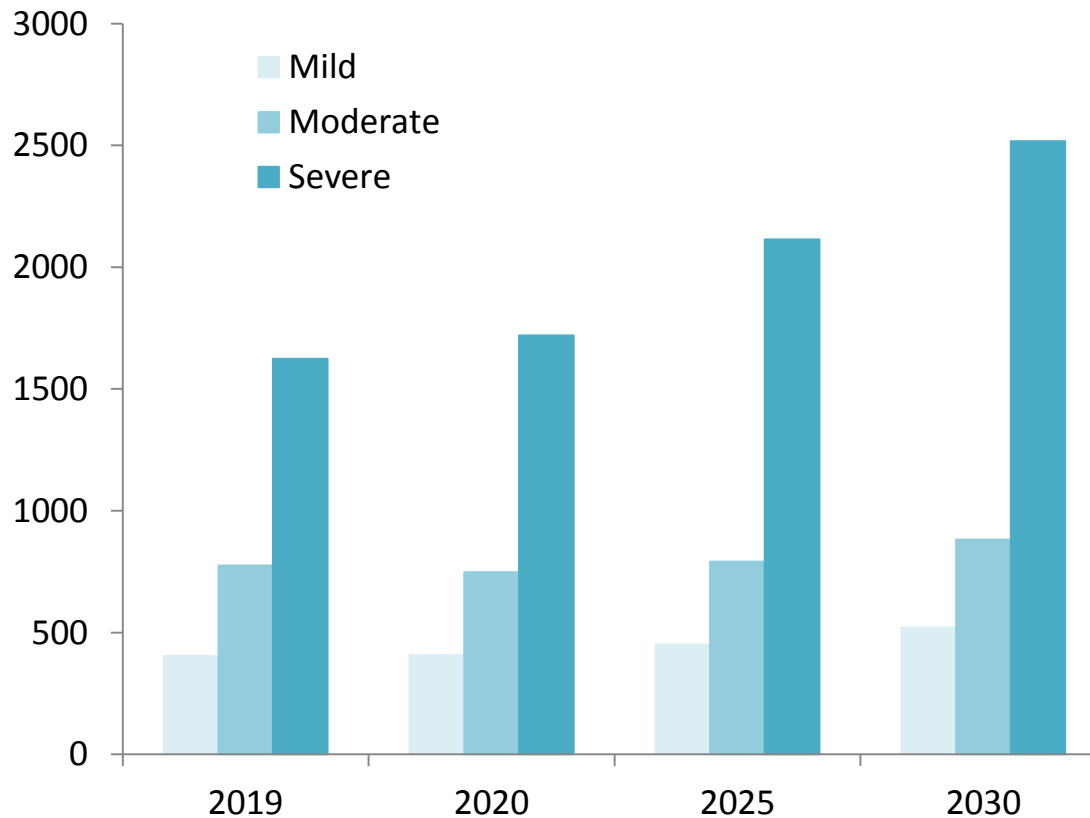
"No constructive help was given at the point of diagnosis, I didn't know what to do next and I remember crying and feeling helpless"

Alzheimer's Café Focus Group
August 2019

The number of people with severe dementia on the Isle of Wight is projected to increase by 55% by 2030

Projected number of older people living with dementia by severity

Count



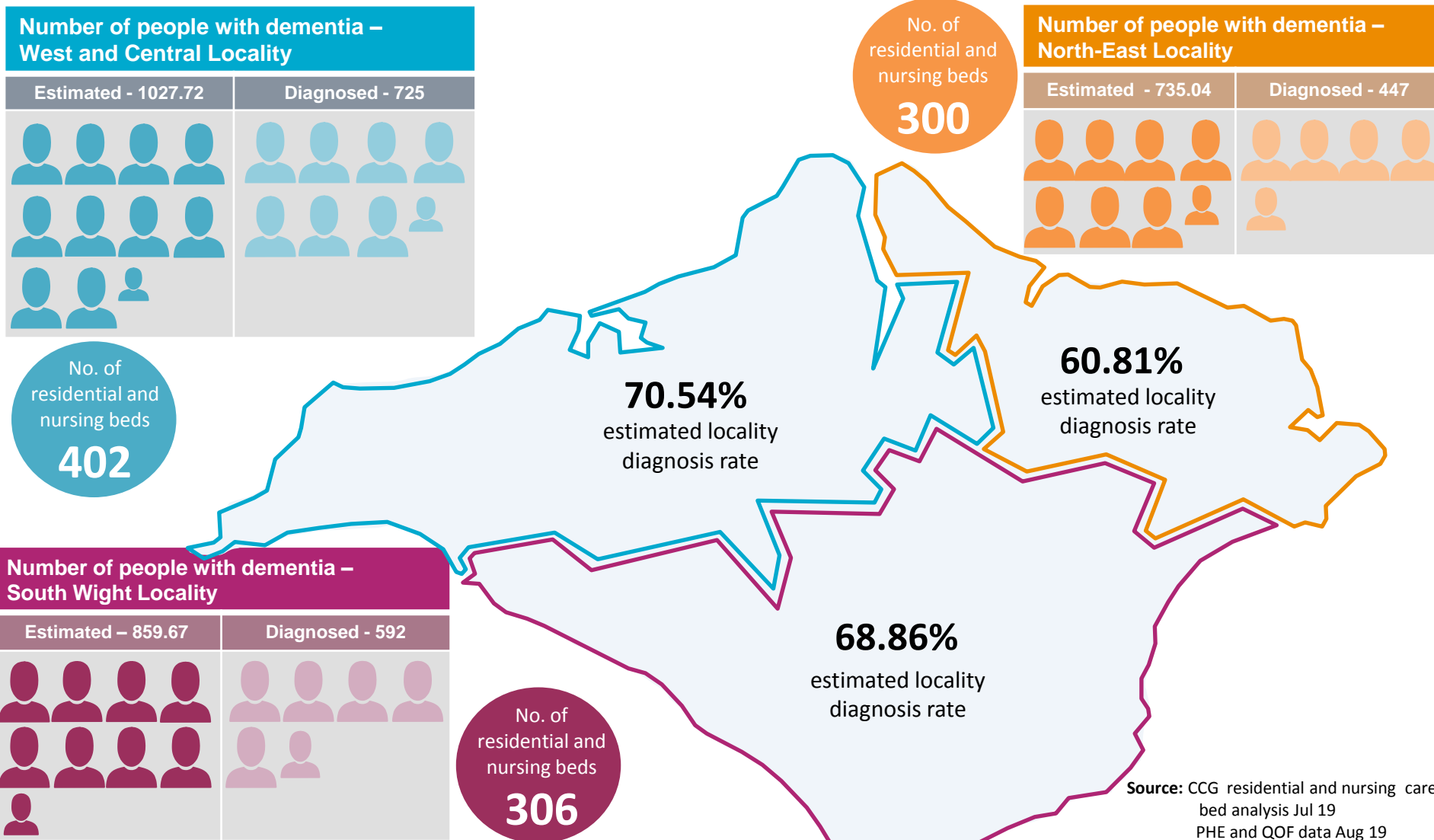
The number of people living with dementia is expected to rise for people with mild, moderate and severe dementia.

The biggest increase is expected to be in the number of people with severe dementia, which is expected to rise from 1,624 in 2019 to 2,517 in 2030.

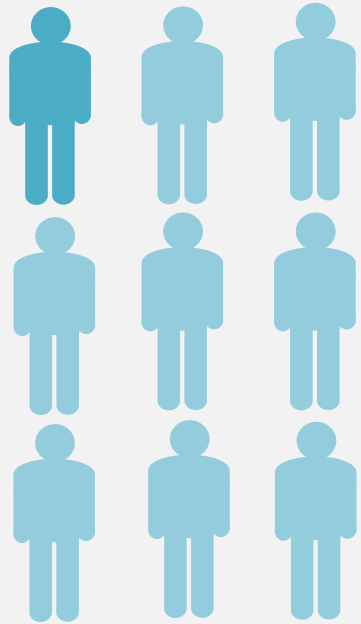
This would be a 55% increase in the number people living with severe dementia on the Isle of Wight.

Source: Projections of older people with dementia and cost of dementia care in the United Kingdom, London School of Economics : Care Policy and Evaluation Centre (November 2019)

The estimated number of people with dementia varies per locality as does the diagnosis rates



Over 10% of the island population have caring responsibilities on the Isle of Wight

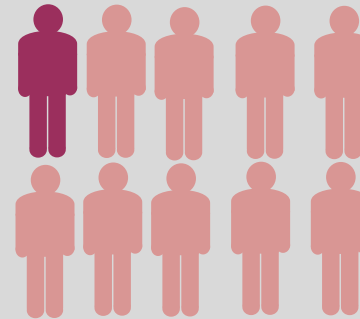


One in nine people on the Isle of Wight are currently **providing unpaid care**

11.9%

Of the population have **caring responsibilities**

Around **one in ten** of the population are **carers**



16,420 people on the Island provide 1 hour of care per week

4,104 carers provide 50+ hours per week

These figures are for all carers on the Isle of Wight which will include people caring for people with dementia, as well as people with other caring responsibilities. It is also worth noting that 2.3% of the island population claim carers allowance from the DWP in November 2016.

Source: Carers IW analysis of Census 2011 DWP Benefits claimant Nov 2016

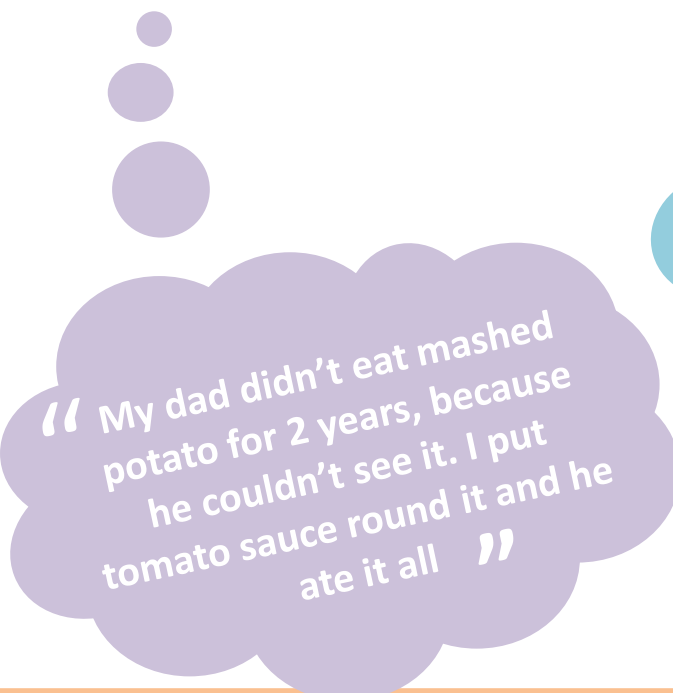
“Because the GP would not refer him, I was so alone for over a year, struggling with the fact my husband had an illness, but I had nothing but worries and no one to share it with, I felt so alone”

Carers focus Group August 2019

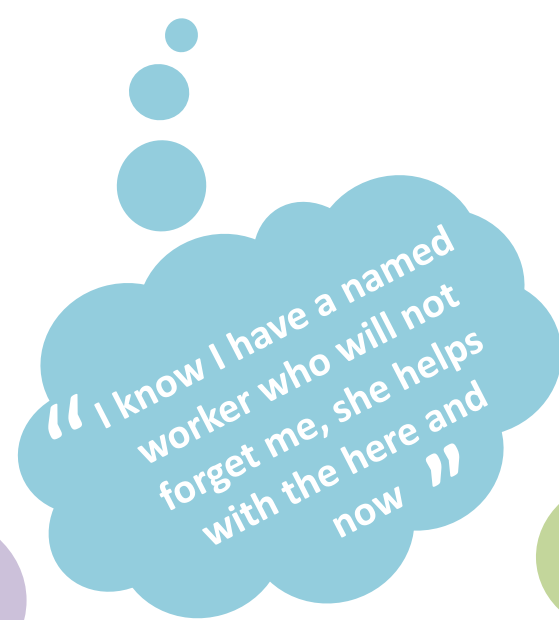
Carers IW have key services that carers find beneficial when providing unpaid care

Carers told Carers IW how their services had impacted them and those they care for, and that the most beneficial support they offer is:

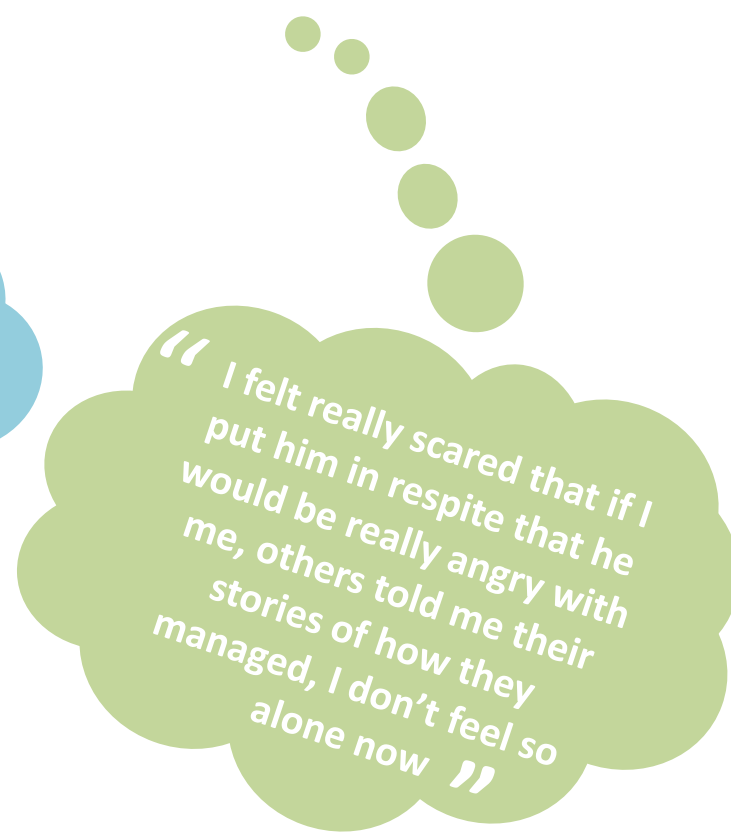
- Key worker support - appointments every 8 weeks
- Peer support
- Dementia Education



“ My dad didn't eat mashed potato for 2 years, because he couldn't see it. I put tomato sauce round it and he ate it all ”



“ I know I have a named worker who will not forget me, she helps with the here and now ”



“ I felt really scared that if I put him in respite that he would be really angry with me, others told me their stories of how they managed, I don't feel so alone now ”

Source: Carers IW feedback, Oct 19

5) Activity

Dementia services delivered for older adults by the IW NHS Trust as of July 2019

The Isle of Wight NHS Trust has several services that specifically support people with dementia from initial diagnosis to support with complex needs, as identified in the table below.

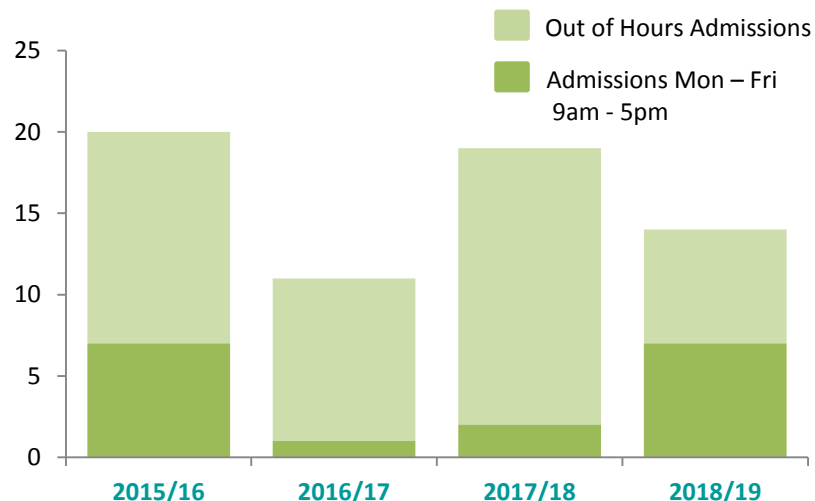
Service Areas	Service	Bed Numbers	Nurses and other medical professionals	Doctors	Service Hours
Inpatient Older Adults	Dementia Assessment Unit (Shackleton)	4	27.39	3 consultants (1 agency) 1 SP ST 1 FY2	24/7
	Service now closed as of July 2019				
Memory Clinic	Cognitive Stimulation Therapy (memory)	n/a	19 wte		09:00 - 17:00 Mon - Fri
	Memory Liaison	n/a			09:00 - 17:00 Mon - Fri
	Memory service	n/a			09:00 - 17:00 Mon - Fri
Admiral Nurses	Admiral nurses	n/a	5.6 wte	09:00 - 17:00 Mon - Fri	

Following the CQC inspection July 2019 the decision was made to close Shackleton due to workforce vacancies and safety concerns. As of September 2019 inpatient provision for people with dementia with complex need is provided off island

Out of hour admissions and the length of stay had reduced for Shackleton, but this service is now closed

Annual Admission to Shackleton

Count

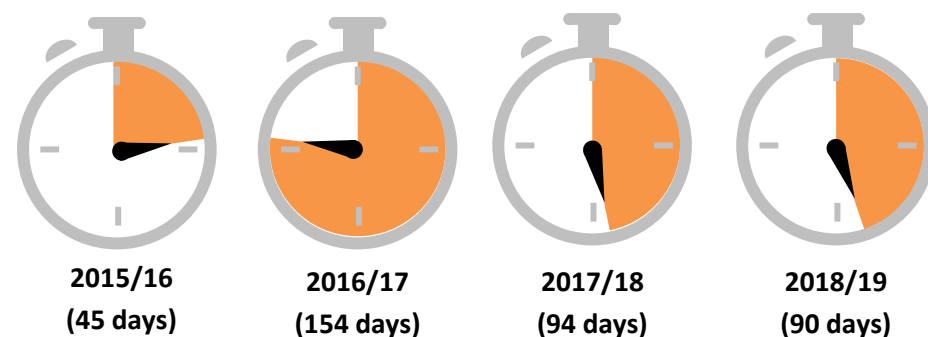


The annual number of admissions to (the now closed) Shackleton ward were low ranging from 11-20 people per year

Although the number of admissions fluctuated each year, there was a loose **decreasing** trend in admissions from 2015/16 to 2018/19. When looking at the months across 2015/16 to 2018/19, there appears to be an increase in admissions during the June – October period

Average length of stay for Shackleton

Days



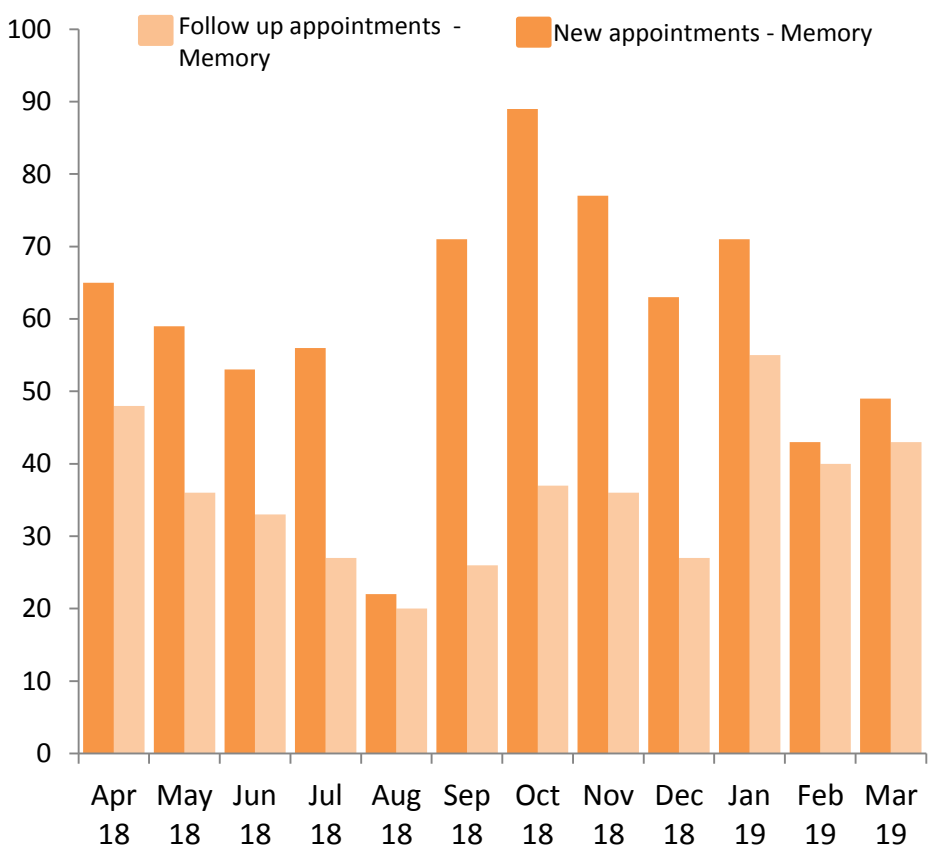
In 2015/16 there was a higher number of admissions (20 people) with a shorter length of stay suggesting a higher turnover rate of beds. However, in 2016/17 there were fewer admissions (11) with a longer length of stay (154 days)

The average length of stay over the past two years has been relatively stable at 90-94 days in 2018/19

Source: IW Trust data, Sep 2019

The memory service provides support for all old age psychiatry services

Memory Service Outpatient Appointments - Memory Count



Source: IW Trust data, Sep 2019

There were **718** new Memory Appointments and **107** new functional appointments (as the department conducts the administration for the old age psychiatry) in the memory service during 2018/19

The service is designed to be supported by 19wte nursing and professional staff, and accesses shared psychiatrists for the department.

The Memory Service primarily (80%) consists of new and follow up appointments for patients attending for memory and 32% of new memory appointments occur in Q3

“Until a formal diagnosis they and their carers seem neglected”

Informal consultation 2019

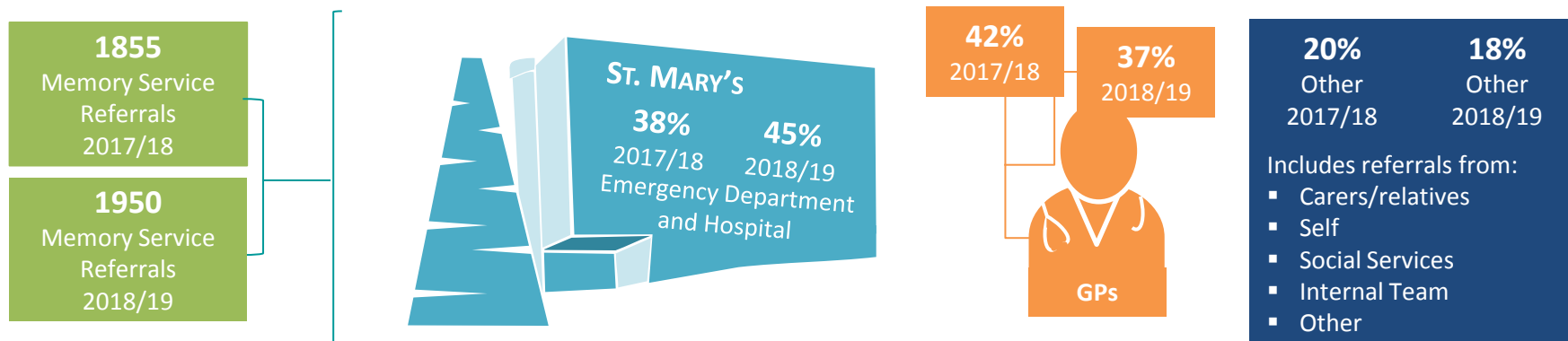
“No constructive help was given at the point of diagnosis, I didn’t know what to do next and I remember crying and feeling helpless”

Alzheimer’s Café Focus Group August 2019

The majority of referrals for the memory service come from the hospital services or primary care

Referral sources to the Memory Service

Count and %



“When we got the diagnosis I felt like I was put in a boat without any oars”

Alzheimer's Café Focus Group August 2019

“She was left with a diagnosis but told there was no treatment, there was no support”

“Little information was given at the time of diagnosis. The family did not know where to go to get support or what support was even available”

Informal consultation 2019

The number of referrals to the Memory Service has increased by 5% - which partially mirrors the estimated 8% increase in the number of people thought to have dementia on the Isle of Wight

The majority of referrals to the team either come from the hospital services or from GPs and appear to be linked e.g. where hospital referrals increased from 2017/18 to 2018/19, the number of GP referrals inversely mirrored this activity

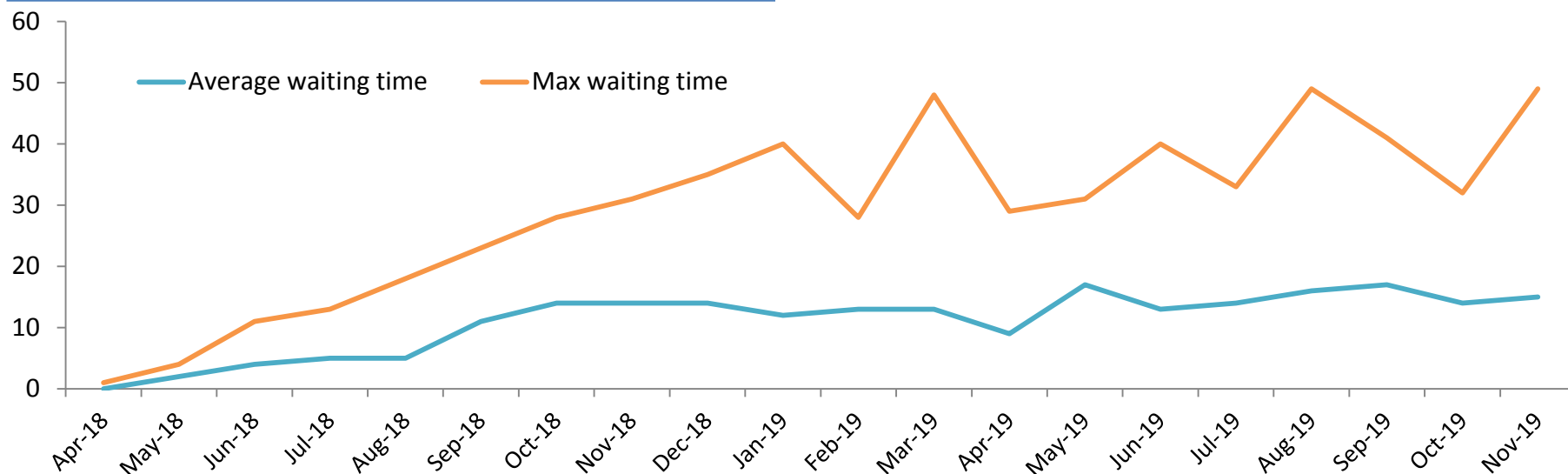
The majority of ‘Other’ referrals were made by a Memory Service team member in 2017/18 and 18/19. Very few, only 68, referrals over the two year period came from non clinical routes.

Source: IW Trust data, Sep 2019

Memory service waiting time from referral to new appointment has been steadily increasing since April 2018

Memory Service – Referral to new appointment waiting times

Weeks



New appointments for the Memory Service have been steadily increasing since April 2018, with the average waiting time being 15 weeks as of November 19.

The longest waiting time for a new appointment following a referral was 49 weeks.

“I felt fobbed off , [it] took 4 months to get an appointment”

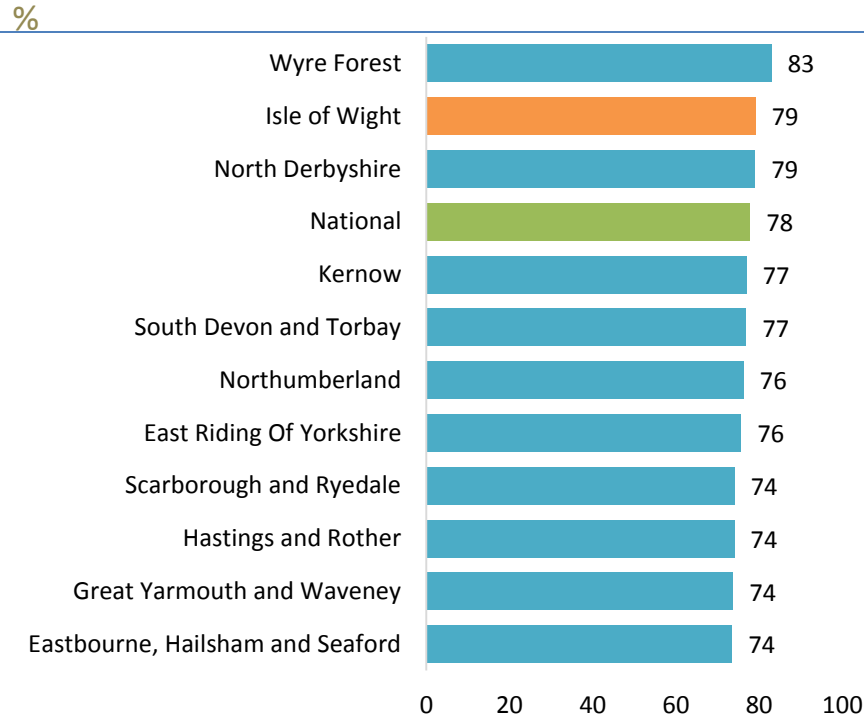
“Diagnosis could have been faster. Waited 7 months. More initial support at time of diagnosis would have been useful”

Informal consultation 2019

Source: IW Trust data, Dec 2019

Primary care is meeting national targets for face to face review for people with dementia

Face to face review of people who are on the dementia register during 2017/18



Although the Isle of Wight primary care is meeting national targets for yearly face to face review for people with a diagnosis of dementia, it is not clear what is included as part of this review and whether this is being delivered consistently across all practices

Dementia: Short stay emergency admissions (aged 65 years and over)

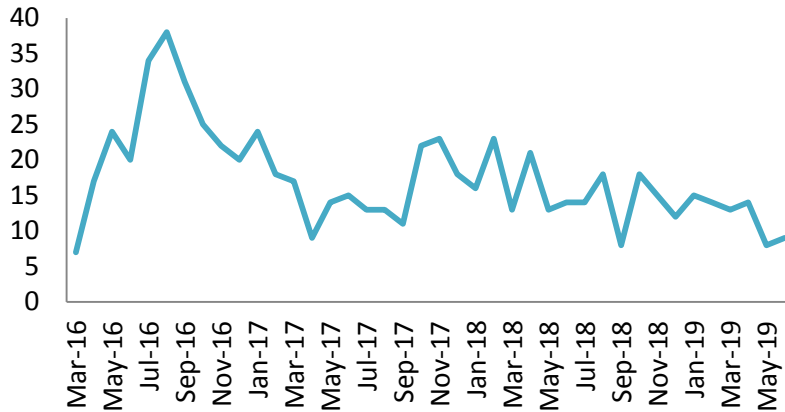


The dementia short stay emergency admissions refers to the percentage of emergency inpatient admissions for people (aged 65+) with a mention of dementia that are short stays (1 night or less).

Source: PHE QOF data, CF analysis

Referrals to Admiral nurses have reduced, but the service is not meeting assessment targets

Number of new referrals the admiral nursing services

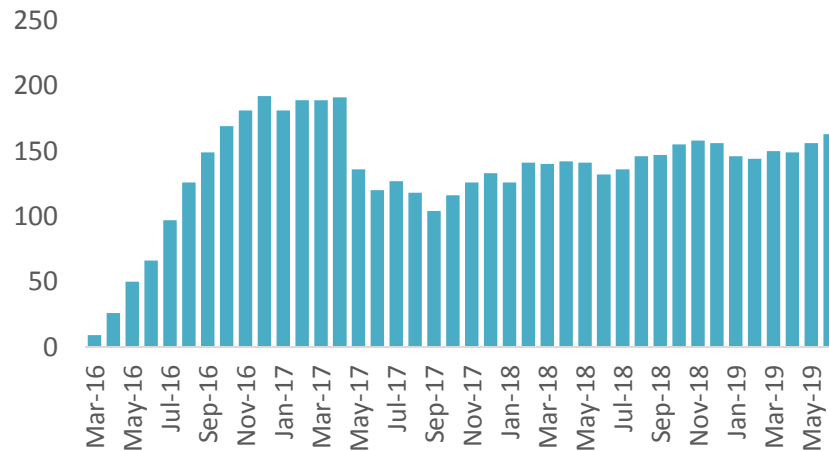


The number of new referrals to the admiral nursing service has dropped, with 163 new referrals June 2018 – May 2019 compared to 201 in the previous in the previous year

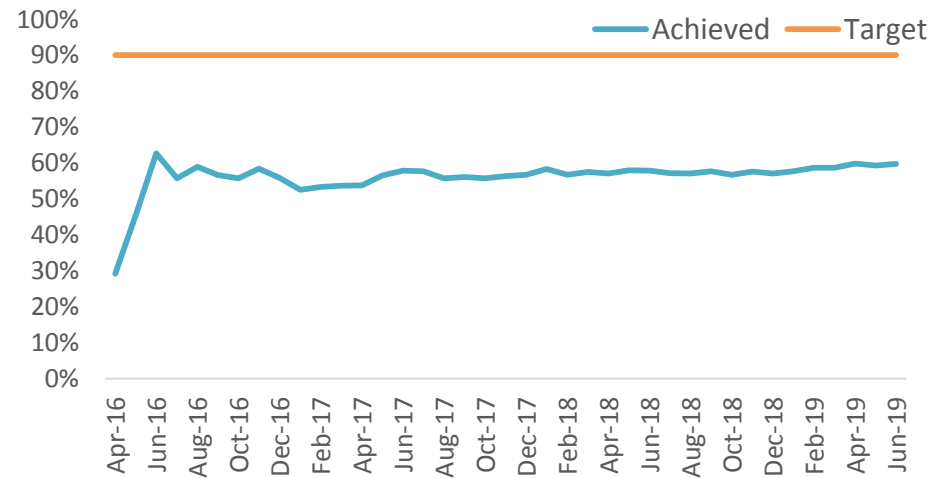
The total open case load has increased in the last year, with an average of 150 people being treated June 2018 – May 2019 compared to 128 in the previous year

Although there have been improvements in the number of people contacts immediately after referral (within 10 days by phone call/ letter), the % of clients assessed within 6 weeks is well below target

Total case load for the admiral nursing services (dementia)



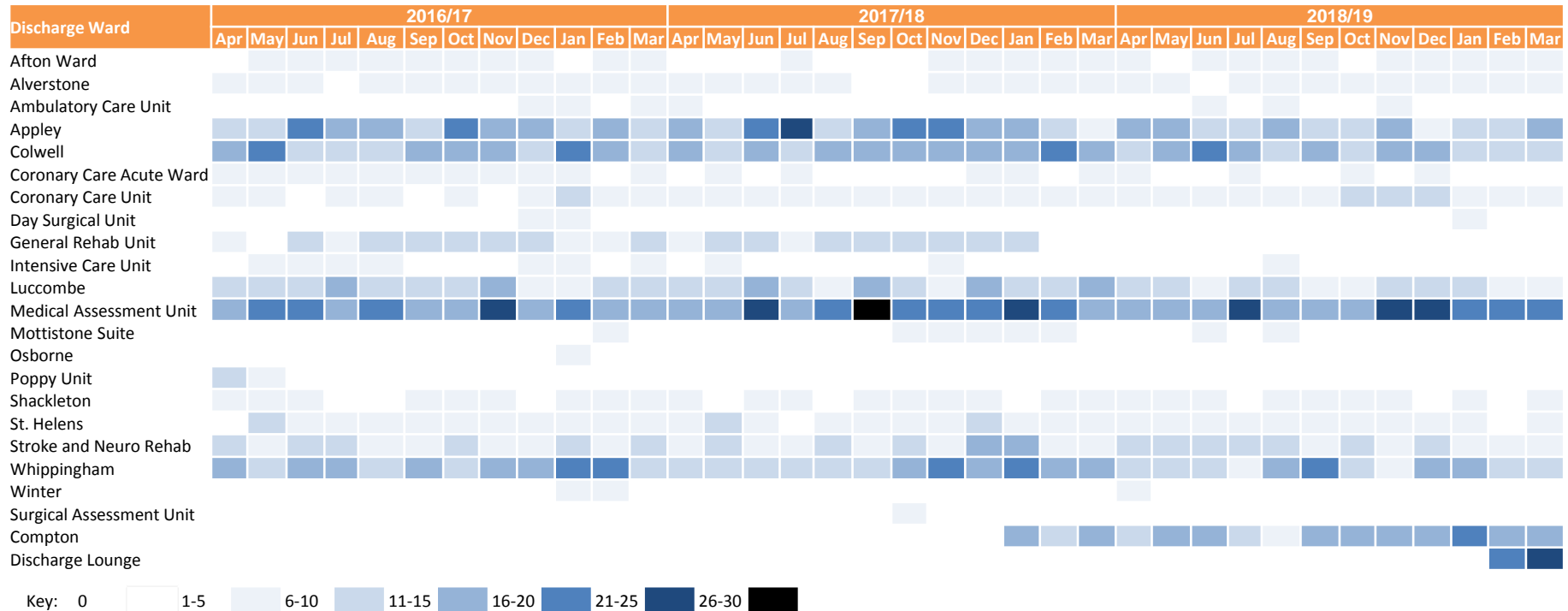
% of clients given assessment within 6 weeks (42 days)



Source: Admiral nurse data; CF analysis 2019

Every ward across the hospital has admitted people with a diagnosis of dementia

Inpatient Non Elective Discharges with a Diagnosis of Dementia



There were **1016 in 2016/17**, **1080 in 2017/18** and **1037 in 2019/20** non elective discharges of people with a diagnosis of dementia. There has been little fluctuation over the past three years in the number of episodes at the hospital where people have a diagnosis of dementia

The majority of people with dementia who attend the hospital are discharged from the Medical Assessment Unit, after this Appley and Colwell see the most activity; this pattern has been fairly consistent over all three years

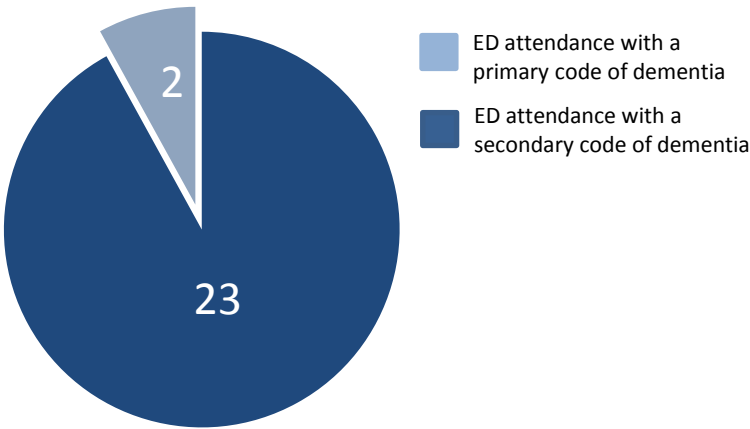
N.B Non elective discharge refers to the discharge of a patient whose admission to hospital was unplanned

Source: IW Trust data, Sep 2019

In 2018/19 people with dementia used over 16% of acute bed weeks compared to the population where 1.2% have a diagnosis of dementia

Proportion of Emergency Department Attendance where there is a diagnosis of dementia 2018/19

Count



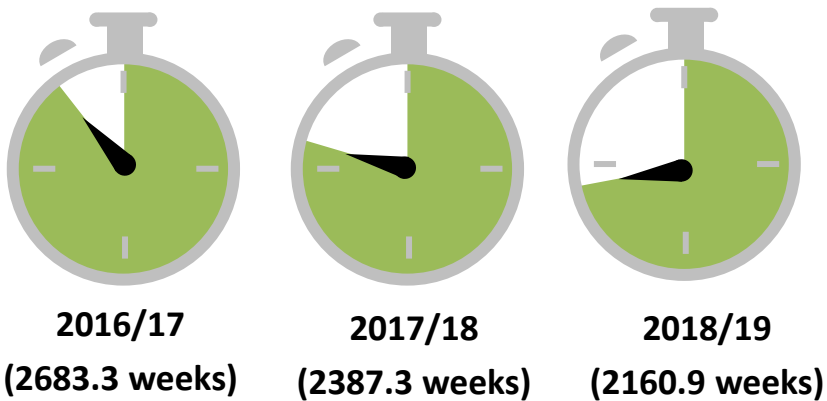
Only 25 attendances were recorded in the NHS Isle of Wight Trust Emergency Department as involving an individual with a diagnosis of dementia.

Previous CSU data analysis showed that admissions from the Emergency Department of people were much higher. This is a significant discrepancy in activity volume.

	ED att with Primary Code of dementia	ED att with Secondary Code of dementia
2015/16	29	794
2016/17	48	896

Sum of length of stay of admissions for people with dementia 2018/19

Weeks

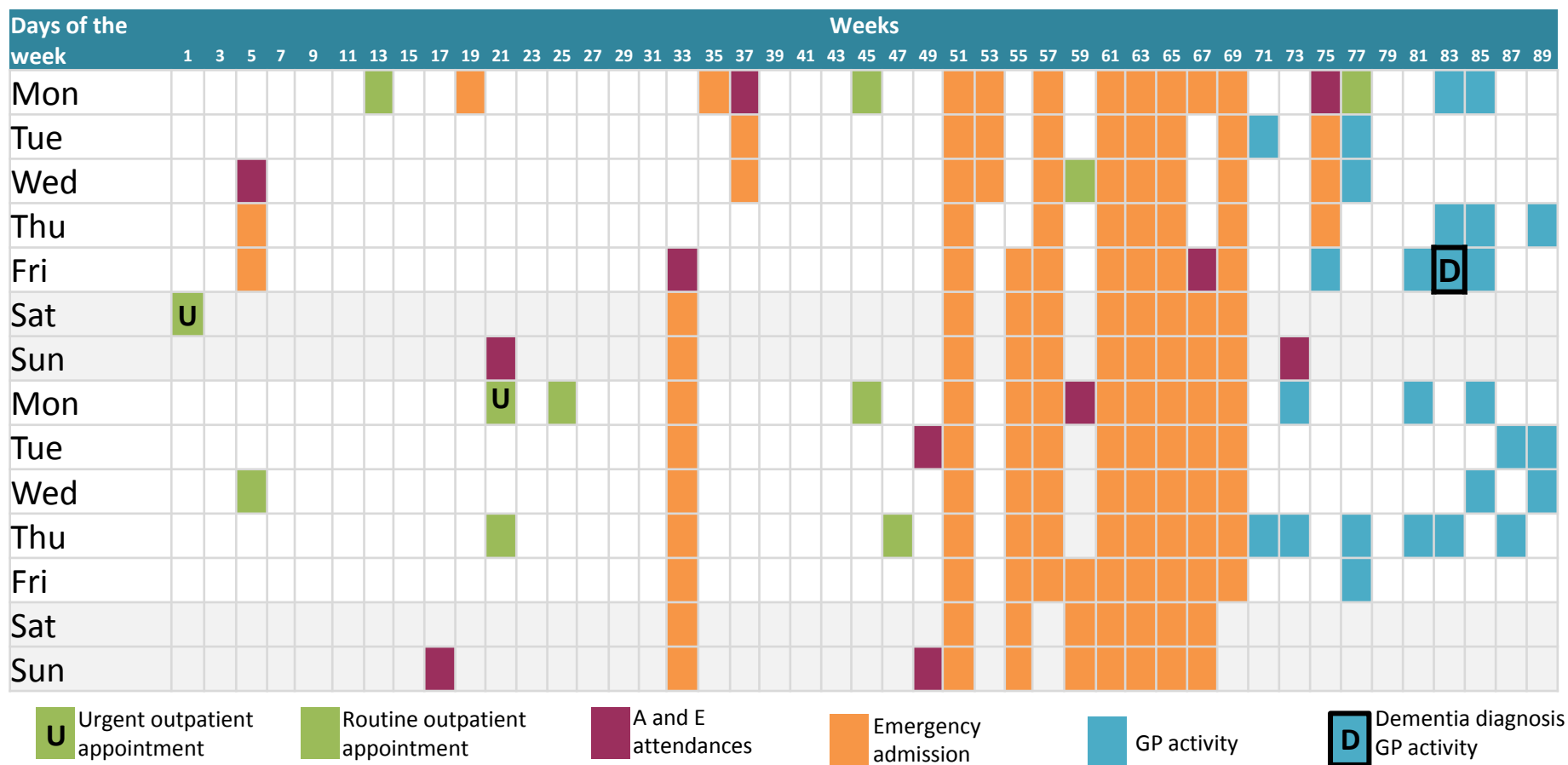


The cumulative length of stay for admissions for people with a diagnosis of dementia has been decreasing over the past three years.

Currently as of September 2019 there were 246 available beds which equates to 12,792 bed weeks available, however this number will have fluctuated over the period with beds opening and closing. Based on these bed numbers **16.89% of available bed weeks were used for a patient with a diagnosis of dementia, in comparison to the island where 1.2% of the population has dementia.**

Source: IW Trust data, Sep 2019

CASE STUDY: A person with dementia's 90 week activity across health services

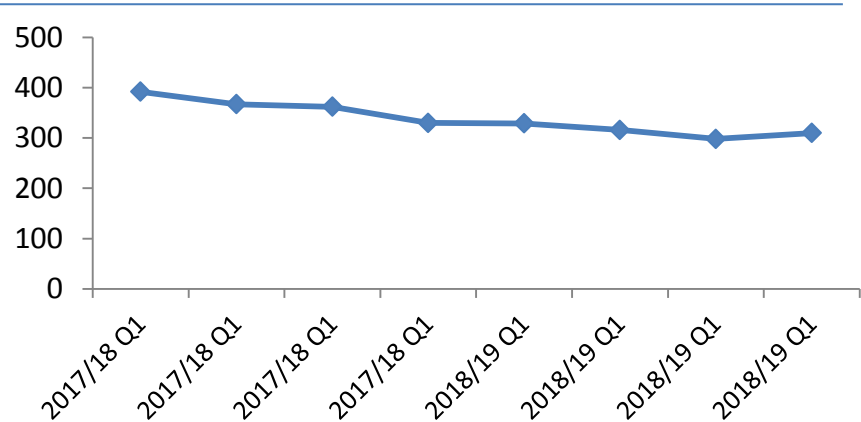


This diagram shows the patient receiving a diagnosis in week 83 leading up to this period there were 11 A and E attendances, 12 outpatient appointments and 124 days in hospital, during the hospital stay a UTI was noted in week 62, delirium was noted in week 63 and unspecified dementia was noted in week 69, diagnosis of dementia was added to the patient record in week 83

Source: CSU analysis

Adult Social Care has seen a decrease in the number of open dementia cases

Open ASC cases with support reason of Memory and Cognition
Count



Adult Social Care operate a locality based team structure with each team undertaking assessments for individuals with a range of needs including those with a diagnosis of dementia. There is also a specialist Mental Health Team who are able to support when cases are complex or in crisis.

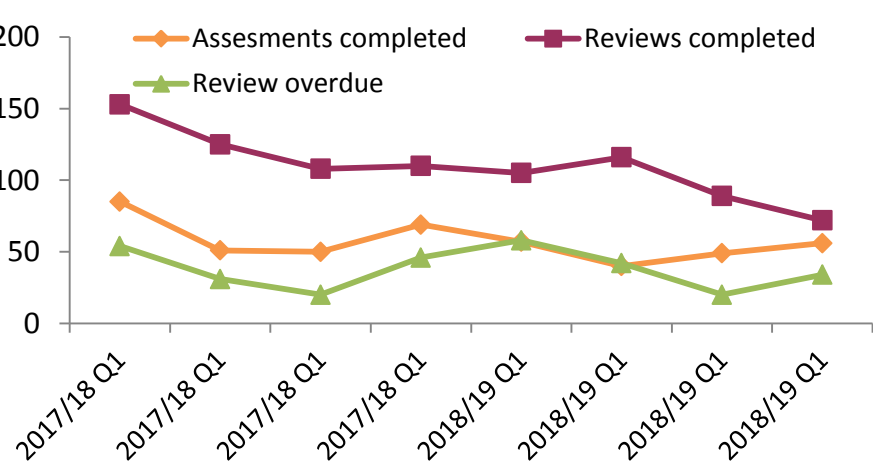
“I am for the most part trapped in the house. I cannot leave mum who has dementia alone as she cannot do anything for herself and is scared and anxious”

“The statutory services are fragmented and overloaded”

“There appears to be no positive approach to this particular condition, and either not enough knowledge amongst those responsible for discussing care, or no provision for the very many different forms this disease can present”

Informal consultation 2019

Reviews and assessments for ASC cases with support reason of Memory and Cognition
Count

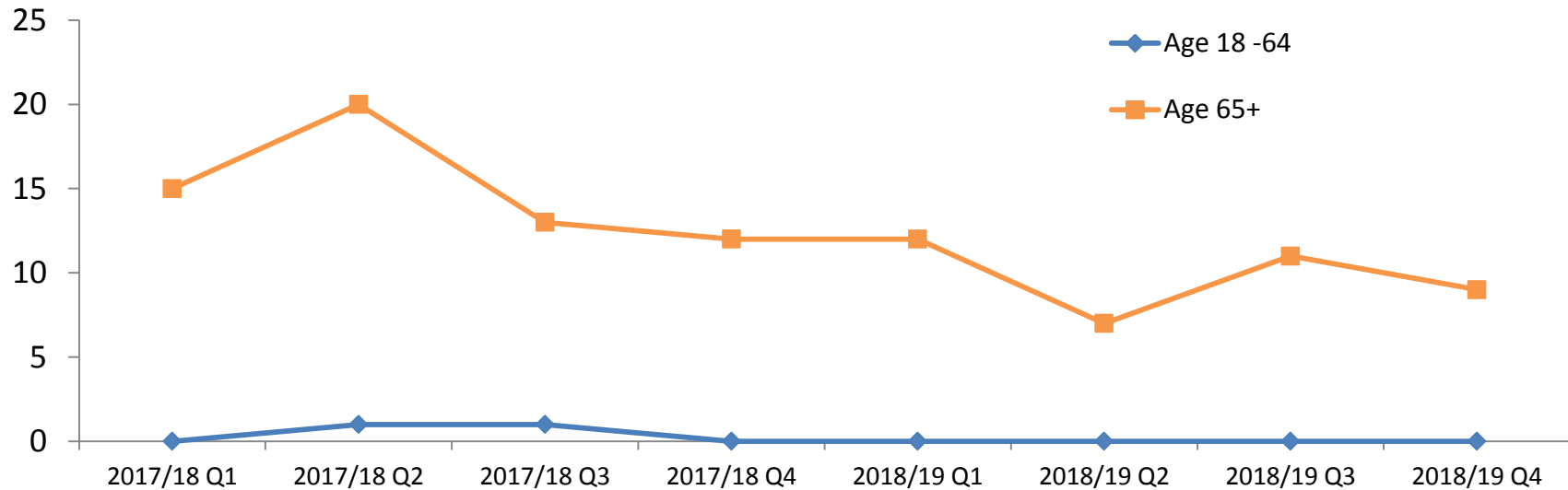


Adult Social Care has maintained a relatively steady number of open dementia cases over the two year period 2017 to 2019. While the number of initial Your Needs Assessments completed has varied little over this period, there has been a decrease in the number of case reviews undertaken resulting in an increase in the number of overdue reviews

Source: IW Council ASC analysis, Sep 19

Long term residential placements have been declining in line with the Care Closer to Home strategy

Number of long term residential placements per quarter



One of the main aims of the Adult Social Care “Care Close to Home” Strategy is to enable people to live their lives as they wish, safely and with dignity, in their own homes wherever possible.

The strategy seeks to develop alternative options which prevent, delay or reduce people’s need for care and support and enable people to access the support they need in their own homes where possible.

This change of focus and different way of working has resulted in a decline in the number of long term care placements for people with dementia.

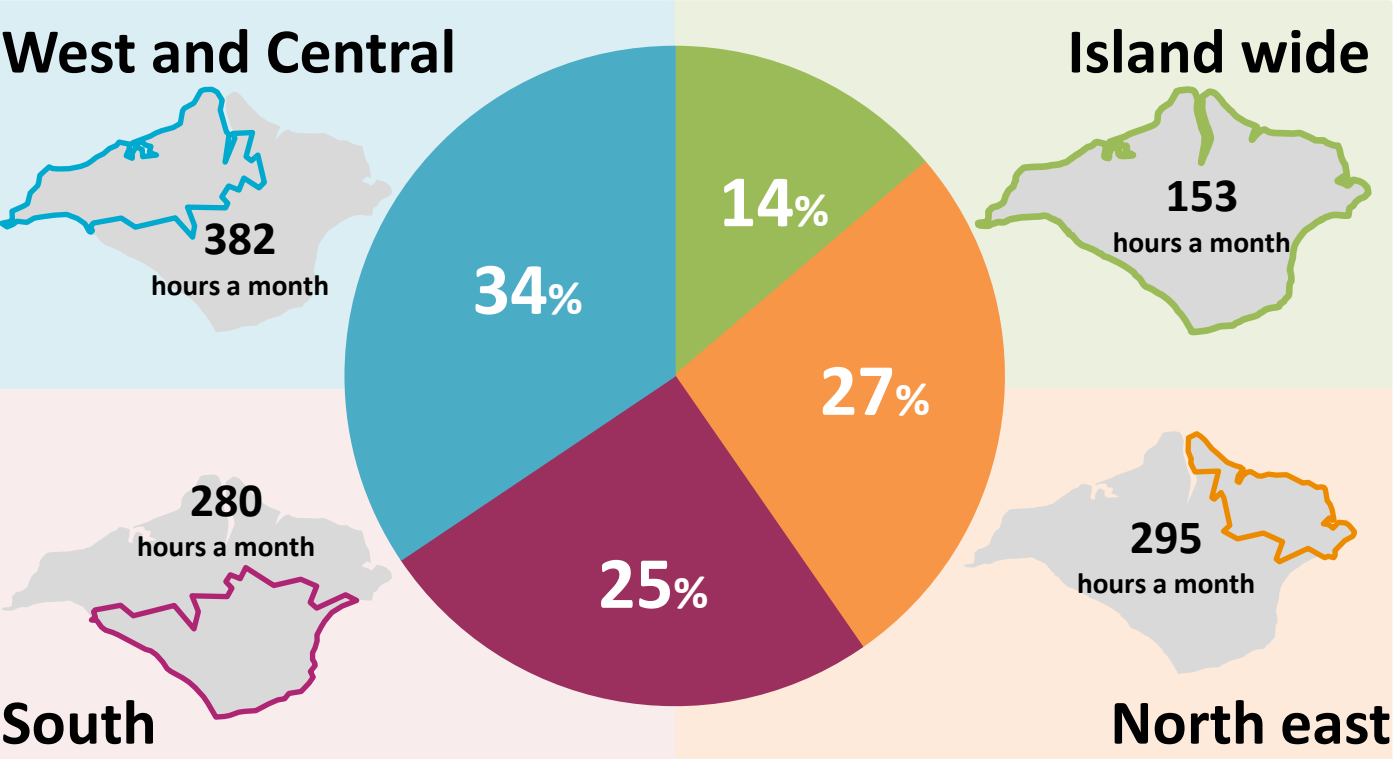
“Its sad he ended up in residential care sooner than he had to – so many different carers (5 agencies) turned up at different times of day an could not get to know him, which led to him getting agitated and aggressive”

Informal consultation 2019

Source: IW Council ASC analysis, Sep 19

The islands voluntary and community sector provides 1,110 hours of services for people with dementia their family and carers every month

Proportion of VCS support by locality base on hours per month
Hours and percentage



Across the island there is 1,110 service hours listed on the Isle Find It Dementia Directory in the community and voluntary sector for people with dementia their family and carers.

West and Central has the highest proportion with 382 hours equalling 34% of all listed activity. This supports the split in prevalence across localities/ PCN's.

It is likely that there is more activity that is not listed on the Dementia Directory

"The West Wight community is excellent, everyone is supportive and understanding"
Informal consultation 2019

Source: Age UK analysis of Isle Find It, Dementia Directory, Oct 19

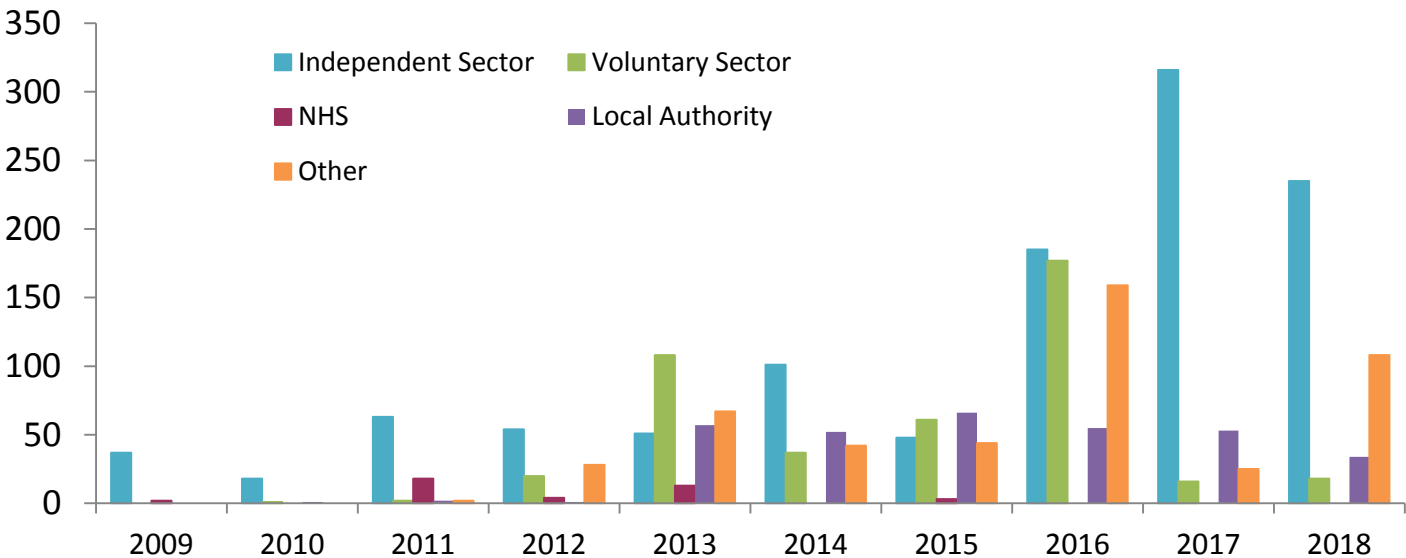
Three key charities supporting people with dementia their family and carers offered significant support in 2018/19

Organisa tion	Service	No. staff	No. volunteers	Service Hours	Total Activity 2018/19	Dementia specific activity 2018/19
Carers IW (Dementia support only recorded)	Dementia Drop In	6.2 FTE	11	Mon – Fri 9am to 4pm	34	34 (100%)
	Specific Emotional Support				38	22 (58%)
	Take a Break Group			Though some services are offered at evenings and weekend to support working carers	22	22 (100%)
	Dementia Training				53 carers 18 professionals	53 (100%)
	Ring Round Support				850 (71 carers)	542 (64%)
	Carers Lounge				35	14 (4%)
	Former Carer Support				44	29 (66%)
	Key Worker Support Visits				2340	1512 (65%)
Age UK IW	Digital Inclusion	1	5	Mon – Fri 9am to 5pm	49	10 (20.4%)
	Good Neighbour Scheme	3	220		291	145 (49.8%)
	Information and Advice	3	10		1064	266 (25%)
	Living Well Team (inc Care Nav)	9	20		1661	415 (25%)
	Hospital Discharge	3			516	199 (38.6%)
	Men in Sheds	1			121	12 (9.9%)
	Memory Group	6	4		43	43 (100%)
Alzheimer's Café	Alzheimer's cafes operating in Ventnor, Ryde, Cowes, Totland, The Bay, Newport and ACE7	1	59	Varying times during the week days including evenings	2609	100%

Over the last 9 years the voluntary sector have trained over 2500 individuals in Dementia Awareness Training

Individuals who have received 1 to 4 day Dementia Awareness Training by sector

Count



“All hospital and care staff to have Dementia training. So many nurses and staff especially agency have no idea how to deal with Dementia patients”

Informal consultation 2019

Over the last 9 years the Alzheimer’s Cafes and Dementia Awareness Partnership have delivered over 2,500 training courses from 1 day to 4 day courses. Training has been delivered to individuals across the system, but the majority of individuals trained have worked in the independent sector.

The breakdown of total number trained by sector over the 9 year period can be seen in the table below:

	Ind Sec	Vol Sec	NHS	LA	Other
Total number of people trained from 2009 -18	1113	439	40	321	475

The Isle of Wight Trust does provide their own in house training and all staff are expected to have Tier 1 which is a 2 hour session. There are also other providers of dementia training on the island such as the hospice.

Source: Alzheimer’s Café Training Data, Oct 19

Voluntary sector campaigning through the Age Friendly Island work has impacted how the wider community support people with dementia



Nine Town and Parish Councils have produced Age Friendly Action Plans. Alongside the action plans Town and Parish Councils have also signed an Age Friendly Charter which includes general commitments to older people's rights around inclusion, participation, health and wellbeing, as well as specific commitments for that council.

Age Friendly Island is creating cultural change through working with private organisations that provide services. Working with Southern Vectis the local bus company Age UK IW has rolled out Age Friendly training to all staff which has included how to better support people with dementia, helping the organisations' understanding of the needs of their customers.



In 2017 the Age Friendly Challenge award was won by Mike, who has Alzheimer's disease and dementia. Mike found it hard to find the right words when conversing, and so, designed a card he could use when out and about. Carers IW helped Mike to share the cards with others, and subsequently, GP surgeries have requested cards for patients encountering similar difficulties.

Source: Moyes and Shepherd evaluation of Age Friendly Island, 2019

“There is an awful lot that can be done by encouraging local businesses and groups to be included those with dementia, and offer them an opportunity to be valued” Informal consultation 2019

6) Quality, Issues and Challenges

CQC inspections of the IW Trust have seen wards for older people deteriorate since 2014

CQC ratings for older peoples mental health services – June 2014, November 2016, January 2018 and April 2019

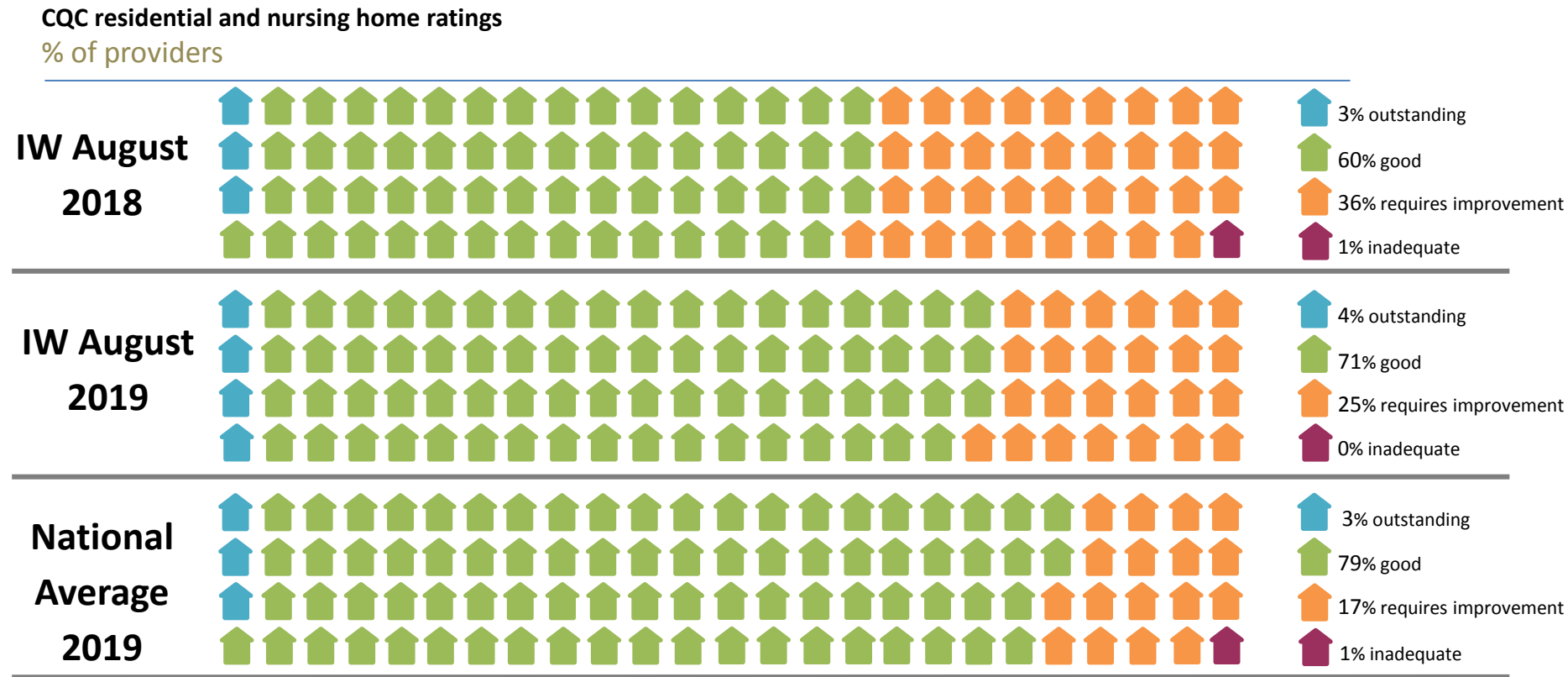
Rating

Service Area	Safe	Effective	Caring	Responsive	Well-led	Overall
Wards for older people with mental health problems 2019	Inadequate →←	Inadequate ↓	Requires improvement →←	Good ↑	Inadequate →←	Inadequate →←
Wards for older people with mental health problems 2018	Inadequate	Requires improvement	Requires improvement	Requires improvement	Inadequate	Inadequate
Wards for older people with mental health problems 2016	Inadequate	Inadequate	Good	Inadequate	Inadequate	Inadequate
Services for older people 2014	Good	Good	Good	Good	Good	Good

The IW Trust has seen its wards for older people receive a deterioration in rating since 2014. Looking at the analysis of the reports this is mainly linked to the dementia (organic) inpatient ward (Shackleton) rather than the functional mental health ward (Afton).

SOURCE: CQC June 2014, November 2016, January 2018 and April 2019

A review of care home ratings shows that there has been an improvement in ratings from CQC



As of August 2019 there were 79 residential and nursing homes on the Isle of Wight. The Raising Standards Initiative, funded through the iBCF, provides training for independent providers of residential and nursing care.

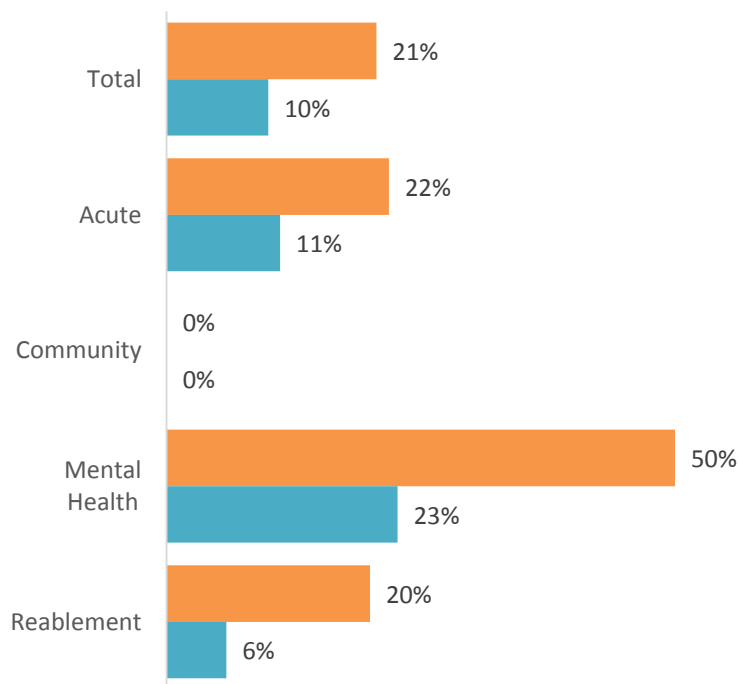
The training aims to improve the quality of care within these settings by working with their management teams to develop a consistent approach to achieving the standards required by the CQC. In August 19 evidence showed that 90% of providers who had attended the training and subsequently been inspected by the CQC had attained a good or outstanding rating.

SOURCE: IW council residential and nursing home analysis , Aug 19

A bed audit of all acute beds suggested there is a lack of coordinated care for people with dementia

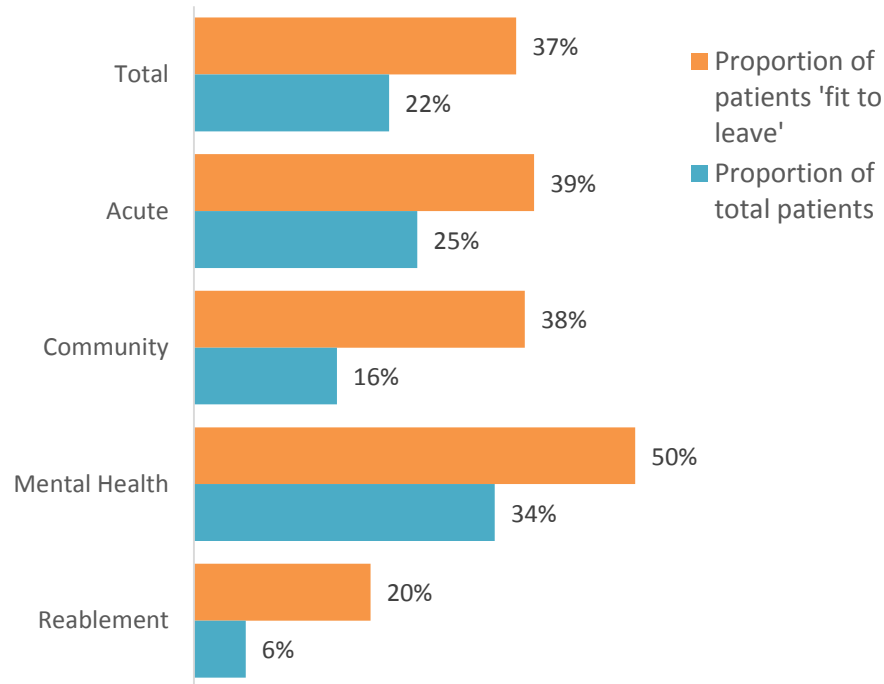
People with dementia

% of all patients and 'fit to leave' patients



People with cognitive impairment

% of all patients and 'fit to leave' patients



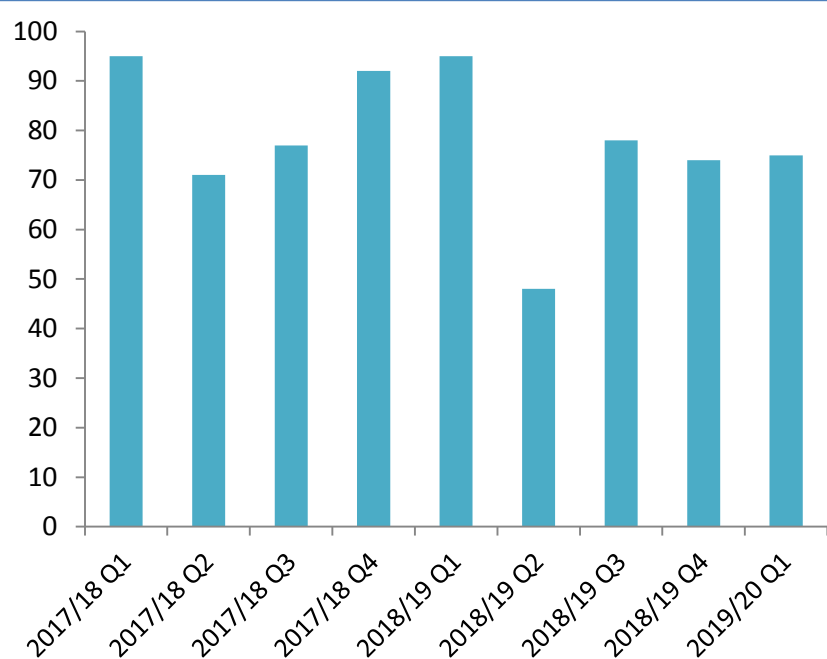
An average of 21% of 'fit to leave' patients had dementia, compared to 10% of all patients in beds, these were patients that clinicians confirmed had a formal diagnosis of dementia

An average of 37% of 'fit to leave' patients had cognitive impairment, compared to 22% of all patients in beds, these were patients that clinicians confirmed had a cognitive impairment

Source: Bed audit return, CF analysis

The IW council has improved its national targets for safeguarding conversion from concerns to enquiries for people with dementia

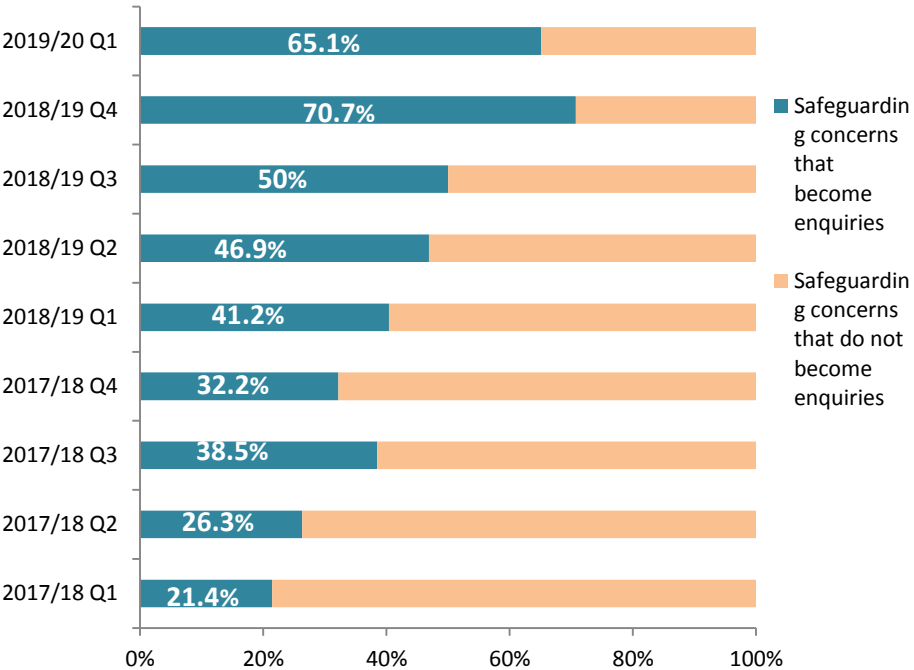
Number of safeguarding referrals received for people with dementia
Count



The IW council has seen a decline in the number of dementia related safeguarding referrals it has received, with over 50% of these referrals coming from residential and nursing homes every quarter. The conversion rate for dementia related safeguarding concerns to enquiries has also improved over the period.

This is due to the work that Adult Social Care and the Isle of Wight Safeguarding Adults Board have led on with development of a threshold criteria and training and workshops to support making informed decisions about safeguarding.

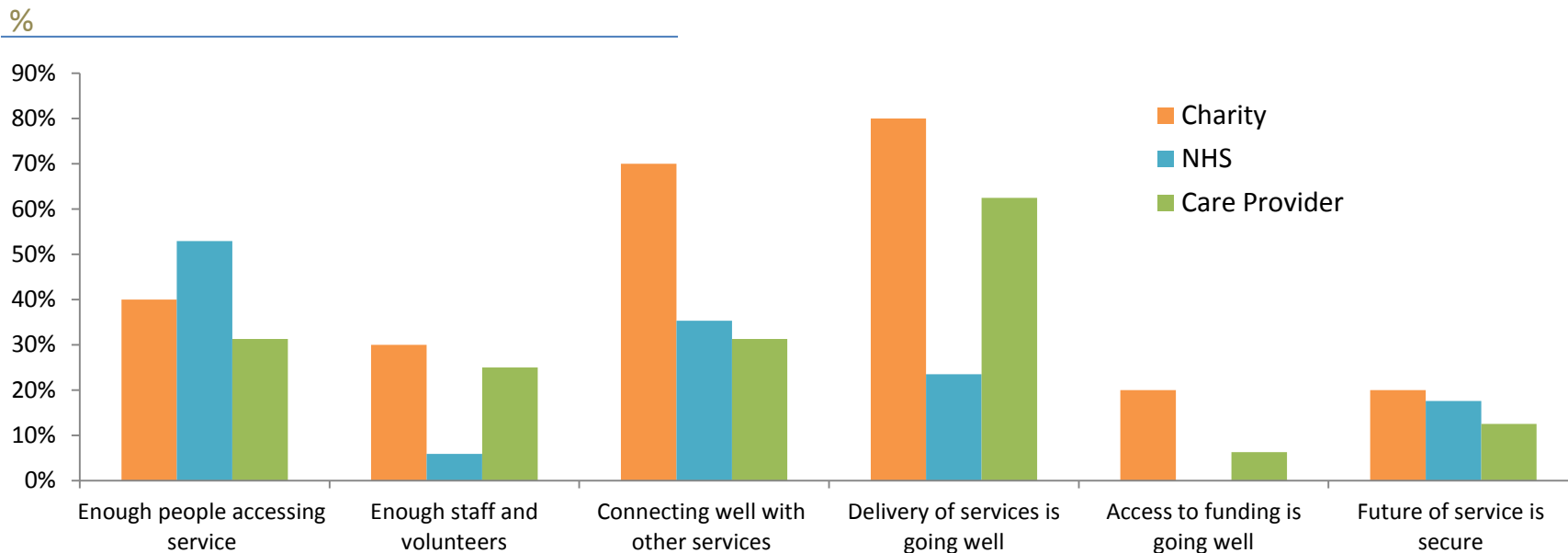
Conversion rate for safeguarding concerns converted to enquiries for people with dementia
% of safeguarding concerns converted to enquiries



SOURCE: IW council ASC data analysis , Sep 19

Provider survey responses show concerns about funding and sustainability across all sectors

Provider responses agreeing with statements by sector



A provider survey was sent out in July 2019 which received over 50 responses of which 10 were from the charity sector, 17 were the NHS and 16 were from the independent sector. The survey asked providers to say whether they agreed with statements in relation to their services.

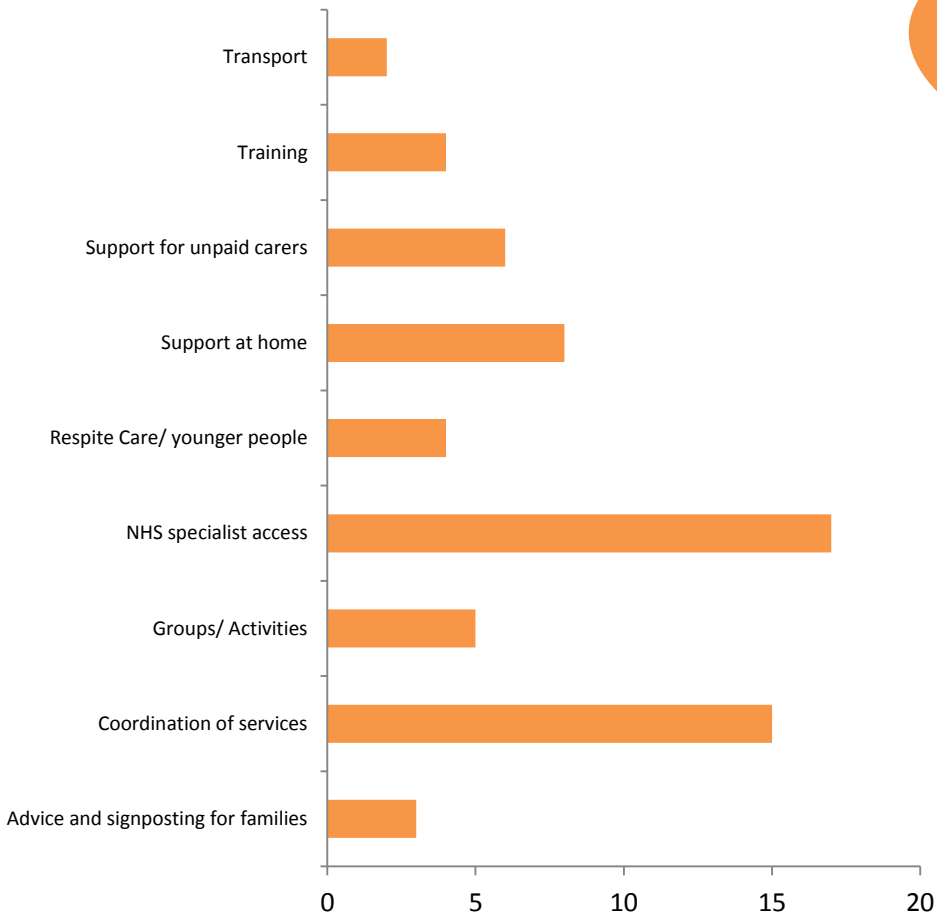
- When looking at the results **voluntary sector organisations a high percentage agreed that their services are connecting well with other services (70%) and that the delivery of services are going well (80%)**, compared to NHS providers with only 35.3% and 23.5% agreeing with the statements.
- All sector had a low response rate to agreeing with having enough staff and volunteers, but the **lowest was from NHS responses with only 5.9% agreeing that they had enough staff and volunteers**.
- This was similar in the responses to access to funding is going well and future of service is secure with **only 17.6% of NHS providers agreeing that the future of their service is secure**.

SOURCE: Provider survey responses, Sep 19

Provider survey responses identified that coordination of services and NHS specialist access are the biggest gaps in dementia service provision

Provider responses to current gaps in service by theme

Count



“Unpaid carers find [it] to understand NHS ‘route’ before and after diagnosis”

“It take so long to get a diagnosis once problems with memory have been identified”

“There is no current dementia inpatient ward on the island, and this I believe is essential”

“[There is a] disconnect between health and social care”

“[There are gaps in] respite care for short term respite”

“Coordination could be improved of all involved parties and organisations”

“Services don’t seem at all joined up”

“Lack of community support for individuals with Dementia in terms of crisis”

SOURCE: Provider Survey responses , Sep 19

A positive outcome

- This is Marie who is 93 years old
- Marie was living at home alone and was admitted to hospital when she became unwell due to dementia and self-neglect
- Marie went from hospital to a step-down dementia service and then successfully went home again, with a package of day-care, for almost a year
- Marie now lives in the care home where she went for day-care as she was so lonely at home and needed more support



7) Finance, System Costs

The majority of resources are used for those with complex needs which includes people with dementia and early onset dementia

	Mostly Healthy	Long term chronic conditions						Complex needs							
		1 LTC		2+LTC		Cancer		SEMI		Dementia		High needs			
Children 0-15	Mostly healthy children £873	Children with 1 chronic condition £1,471		Children with 2+ chronic conditions £3,387		Children with cancer £16,722		CAMHS £8,371		-		Children with LD/PD £15,427		Vulnerable/looked after children £48,245	
	20.1 £17.6	1.3 £1.9	0.0 £0.1	0.0 £0.3	0.2 £1.3	0.0 £0.0	0.1 £2.1	0.2 £9.8							
Adults 16-69	Mostly healthy adults £617	Adults with 1 chronic condition £1,393		Adults with 2+ chronic conditions £2,531		Adults with cancer £2,883		Adults with SEMI £7,192		Adults with dementia £10,679		Adults with learning disability £25,716		Adults with physical disability £17,190	
	58.3 £36.0	19.9 £27.8	8.1 £20.4	2.5 £7.1	1.0 £7.5	0.1 £1.6	0.7 £19.0	0.5 £8.4							
Elderly 70+	Mostly healthy elderly £2,223	Elderly with 1 chronic condition £2,260		Elderly with 2+ chronic conditions £4,101		Elderly with cancer £4,093		Elderly with SEMI £10,506		Elderly with dementia £10,037		Elderly with dementia £22,808		Elderly with physical disability £24,851	
	5.0 £11.2	6.9 £15.6	8.1 £33.4	0.2 £2.4	0.2 £2.4	2.2 £22.4	0.1 £1.8	1.2 £30.5							

Segment

Spend per head

Population (m)

Total spend (£m)

SOURCE: IOW CCG data return, QOF data 2015/16, ONS population data, KID data, CF analysis

It is estimated that the proportional cost for patients with dementia is higher than the population proportion of people with dementia

Island practice dementia data example for 65+
Numbers, costs and percentages

Aged 65+	With Dementia	Without Dementia	Total
Number of people	89	2,317	2,406
Proportion of population	3.7%	96.3%	
Total costs	£321,957	£5,240,481	£5,562,438
Proportion of costs	5.8%	94.2%	
Average cost per individual	£3,617	£2,262	

Looking at patients over 65 in a sample GP practice on the Isle of Wight, the proportional cost of patients with dementia is higher than the proportion of the practice population (over 65) that has dementia

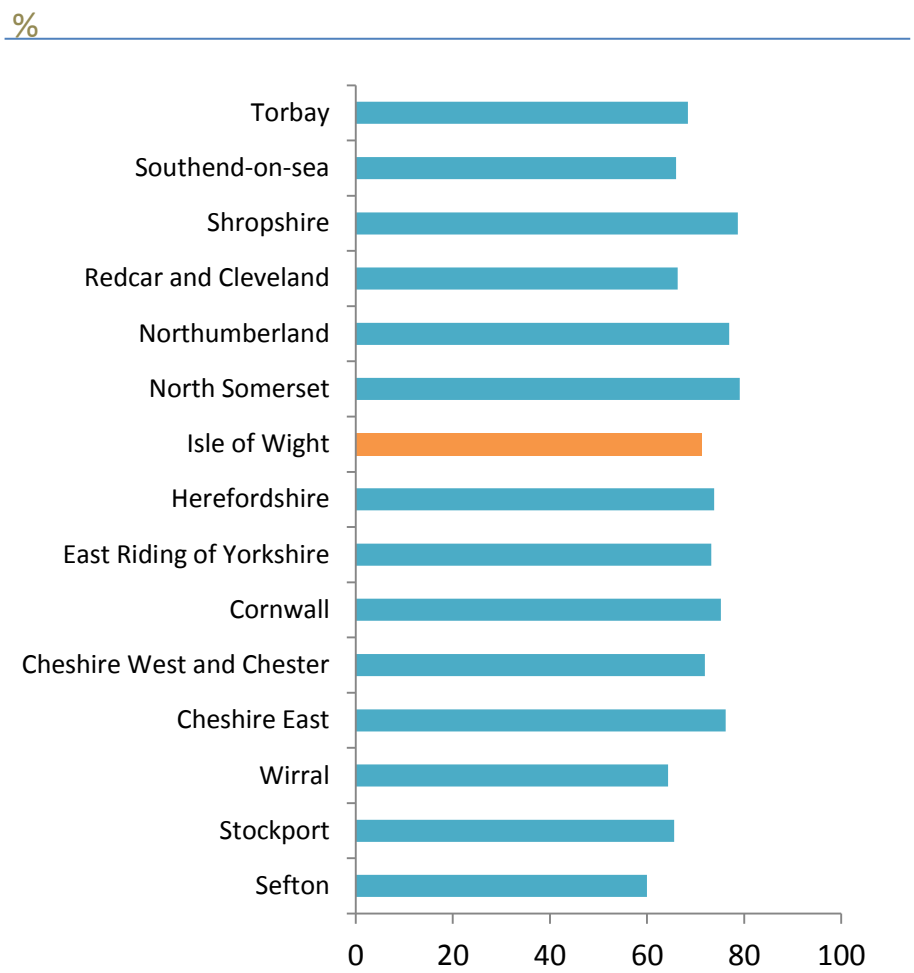
There are 89 people aged 65 and over with a dementia diagnosis. This amounts to 3.7% of the population aged 65 and over with a dementia diagnosis accounts for 5.8% of the total costs for this age group.

In 2017/18 there were 1,785 patients with a diagnosis of dementia registered across island practices. If we use the example average cost above for these individuals then this would equate to £6,456,345

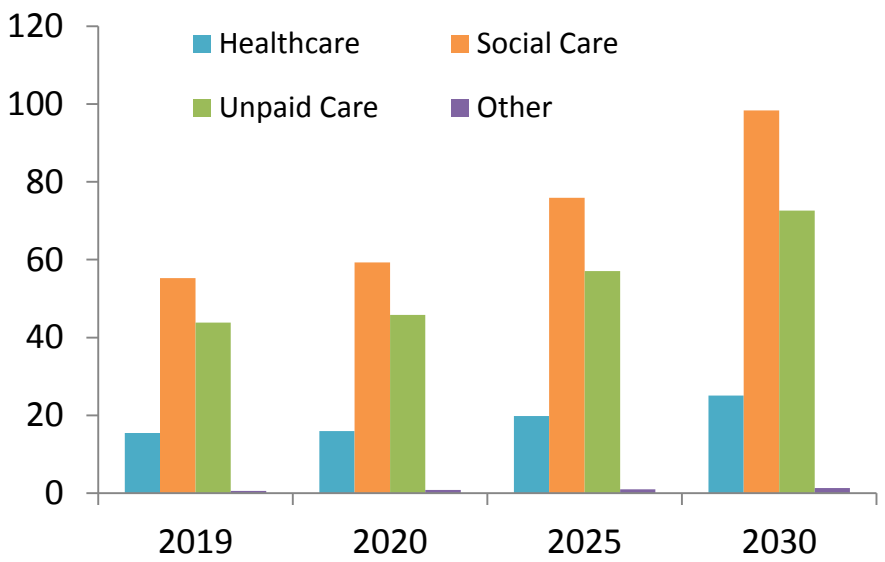
SOURCE: CSU IPA Tool, EDC Code NUR24, 1 Practice. Primary care, pharmacy, outpatient, inpatient and A&E costs are included.

There is projected to be a large increase in the cost of dementia care for the Island but this is no different than peers

Projected growth of costs of dementia against Local Authority peers from 2019 to 2030



Isle of Wight projected costs of Dementia by type of care
£millions



The cost of care for people living with dementia is expected to increase for the Isle of Wight.

The biggest increase is predicted to be in social care with costs rising from £55.3m in 2019 to £98.4m in 2030.

SOURCE: Projections of older people with dementia and cost of dementia care in the United Kingdom, London School of Economics : Care Policy and Evaluation Centre (November 2019)

The majority of adult social care finances for memory and cognition is spent on residential placements and over 65s

Summary Gross Spend by service	2018/19
Homecare	£549,979
Nursing Care	£1,466,942
Residential Care	£5,262,273
Total	£7,279,194

Summary Gross Spend by age	2018/19
65+	£7,005,967
18 -64	£273,228
Total	£7,279,194

Proportionally more money is spent on Nursing and Residential Care placements than Home care, with 72% being spent on Residential Care and 20% being spent on Nursing Care.

The majority of local authority spend for memory and cognition is on 65+ in line with prevalence and diagnosis rates on the Isle of Wight.

SOURCE: Adult Social Care cost of memory and Cognition 2016/17 – 2018/19

The Isle of Wight Trust budget is higher than the allocation from the CCG it receives for dementia services run by secondary care

Service	CCG Allocation 2019/20	Trust Budget * 2019/20
Inpatient service (Shackleton)	£1,526,448	£1,239,873
Memory Service	£178,787	£664,318
Admiral Nurses	£258,295	£164,340
TOTAL	£1,963,530	£2,068,531

* Trust budget exclude the cost for 3x Consultant psychiatrists which is in excess of £350k full time however these roles cover both dementia and older peoples mental health

The Isle of Wight Trust secondary care budget for dementia services is higher than the received allocation from the CCG by more than £100,000, and the split between the allocation differ specifically the memory service budget is £485,000 higher than the received allocation

Currently YTD figures show that the trust is already overspent across these budgets by over £90,000

SOURCE: Trust and IW CCG allocation and budget 2019/20



8) Opportunities and Next Steps

Next steps following on from the Isle of Wight Dementia Stocktake

Following on from the completion of the IW Dementia Stocktake, the next steps of the project will be to develop the strategy and implementation plan. To develop the strategy the following next steps will be taken:

- Results from an informal consultation with the public will be analysed against themes and trends
- Evidence of best practice from across the country will be gathered
- Engagement with professional and carers to co-design the first draft of the strategy chapters
- Draft strategy will be tested with people with dementia their family and carers

The strategy and implementation plan will be developed against key stages in people experience of having dementia as identified below with a chapter on each:

1) Preventing Well

2) Diagnosing Well

3) Living Well

4) Supporting Well

5) Dying Well

Dementia Strategy Programme Timeline

