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Care Inspectorate
Wales

National review of care homes for people living with dementia

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Foreword

I am pleased to be publishing our national overview report arising from our inspection work in care homes. This report focused on the experiences of people living with dementia and the care homes who provide care and support.

I am pleased to be publishing our national overview report arising from our inspection work in care homes. This report focused on the experiences of people living with dementia and the care homes who provide care and support.

This was a commitment in our strategic plan 2017-2020 and, whilst we completed the fieldwork and analysis earlier this year, we delayed publication due to the COVID-19 pandemic. I made this decision because at the height of the pandemic it would have been difficult for the important issues highlighted in the report to be heard, and addressed with the vigour necessary to improve the well-being and outcomes for people living with dementia.

It is important to acknowledge older people, and people from black, Asian and minority ethnic (BAME) communities, have been most affected by COVID-19. None more so than people living with dementia in care homes for whom the experience of social distancing, personal protective equipment (PPE) and isolation has been particularly distressing.

As we begin to recover from the pandemic, I have reflected on what we have learned and one thing that stands out is the importance of social care and healthcare services working seamlessly together to promote the well-being of older people living in care homes in Wales. The findings in this report highlight much positive practice but also areas where improvements are still needed. Many of these are practice improvements that do not require additional resources.

That said, the landscape of social care and healthcare services has changed as a result of the pandemic and may not be the same as it was when we carried out our inspections for this report. We know many providers have faced unprecedented challenges that will affect their sustainability. Working together, we have an opportunity to build on the learning from the crisis and the innovative responses to it, to ensure we work together in the interests of older people living with dementia.

I expect Regional Partnership Boards will want to take account of the findings of this report as they reflect on the pandemic and plan future integrated service delivery for people living with dementia and those who care for them. I trust this work will also support the wider context of Welsh Government's Dementia Action Plan for Wales and the work of Social Care Wales.

We did not do this work alone and I would like to thank the people who joined our stakeholder group. Their input was invaluable, especially their expertise and constructive challenge.

I should also like to thank the people living in the care homes we visited and the staff working there who shared their experiences with us.

Finally, I cannot end without recognising the exceptional dedication of all those working in care homes during the pandemic. On behalf of everyone in CIW, I should like to express our admiration and thanks.

Gillian Baranski, Chief Inspector, Care Inspectorate Wales

Introduction

Our review considered the care received by people living with dementia in care homes in Wales and how they are supported in this important stage of their lives. The aim of the review was to make recommendations that bring about improvements in people's lives.

Method

We conducted 164 inspections in a range of care homes using tools specifically designed for the review alongside our usual inspection framework. We spoke with people living with dementia and their families and we observed the care they received.

We also issued surveys to service providers and commissioners.

- ### Care home service providers survey

  In August and September 2019, we sent a survey to the 1,004 adult care homes in Wales. We received 316 responses. The survey considered the current provision; the quality of care; and how well care homes achieved good outcomes. Providers described the challenges they faced in providing good quality dementia care.

- ### Commissioners survey

  In December 2019, we undertook an online survey looking at the commissioning practices of health boards and local health authorities. We had a 100% response rate from all local authorities and all but two local health boards.

Stakeholder group

We established and consulted with a range of people and organisations involved in promoting positive outcomes for people living with dementia. [1] Their contributions informed how we carried out the review and the findings. We refer to their work throughout the report.

Rights-based approach

CIW take a rights-based approach to its work and our stakeholders also stressed the importance of this to our review. We consider people's rights to have choice and control, to be safe, be treated with respect, to have a voice and to develop their full potential.

To uphold the rights of an individual living with dementia in a care home requires a person-centred approach that recognises the uniqueness of each individual. This includes following the correct processes to safeguard the welfare of people, with adherence to the principles of the Mental Capacity Act 2005 and the Deprivation of Liberty Safeguards (DoLS). It also includes ensuring that people's right to access a service in Welsh is upheld and that Welsh-speaking staff support people living with dementia who speak Welsh.

1. See appendix – members of stakeholder reference group

Summary of Key Findings

We found 97% of care homes followed the correct processes regarding DoLS but less than half (42%) had received a response from the Supervisory Body (local authority). This is a serious infringement of people's human rights. There will be changes to this process as the new Liberty Protection Safeguards come into force that should improve practice.

We saw Welsh-speaking people in homes where there were no Welsh-speaking staff and no Welsh language activities or resources. Less than half of care homes provide a bilingual service and it would appear many care homes do not identify people who are Welsh-speaking. This could be harmful for people whose preference is to communicate in Welsh and an infringement of their individual rights.

People living with dementia told us the care they received was good, they felt happy and safe. Some people said more staff were needed and that at times they felt bored.

Overall we observed people were happy, content, comfortable and relaxed.

Our main findings

- People living with dementia are cared for by staff who are warm, respectful, and provide care in line with personal plans.
- In a small proportion of homes, care is rushed.
- Staff received dementia training but this did not always result in person-centred care.
- People's well-being and care could be more effective with improvements to the environment in which they live. As the complexity of people's needs and the numbers of people living with dementia increase, this is a growing problem. This will have an increasingly negative effect on outcomes for people in the coming decades.
- In general, families were very positive about the care, staffing and management in the care homes. They described staff as caring and welcoming and praised the food. Families told us improvements were needed in the range of activities available for people, staffing levels and the environment.
- People living with dementia had access to healthcare but frequently did not receive a timely diagnosis of their dementia.
- Multi-disciplinary working could be improved, particularly hospital discharge practice.
- People's medication had been reviewed in consultation with a GP or pharmacist in about 90% of care homes and there is monitoring of the effect of medication.
- Providers said one in four people living with dementia are prescribed antipsychotic medication. In about three quarters (78%) of cases, there had been a multi-disciplinary meeting to review the use of antipsychotic medication. Further work to determine the frequency of review is required.
- People living with dementia were supported to access specialist mental health support.
- More effective admission and discharge from hospital would support care homes.
- We saw care homes embracing technology, developing links with communities and undertaking a range of creative activities that improved the well-being of people living with dementia.
- Providers told us that the key challenges facing care homes for people living with dementia are the retention of staff, the complexity of dementia and the impact on the home of people needing one-to-one care. Finance was a challenge consistently identified by providers.

As illustrated in this diagram, it is essential that our findings are not considered in isolation. In order to improve the well-being of people living with dementia, we must consider how these factors affect each other and the actions needed as a whole to improve people's lives.

Quality of Care - People have choice and control

Control

People told us:

- "The carers are nice and come when I ask them"
- "I can't fault it. Staff treat us as equals, we're the same"
- "I can leave when I want to, staff do not stop us"
- "It's lovely here, staff are great and it's very close to my family"

During our inspections, people told us they receive care and support as they choose. One person said *"It's brilliant here, anything I want I have, love it."* We saw care and support delivered in line with personal plans and staff provided personalised responses when people were distressed.

At busy times during the day there are increased pressures on staff and managing the periods of high and low demand is one of the challenges faced by all care homes. The pressure on staff time affects the quality of care people receive. In a small number of care homes the staffing levels or the deployment arrangements needed to be improved. In some cases, staffing arrangements focused on inflexible rostering arrangements rather than adapting in response to changing needs of people living at the service.

At times we saw staff were rushed in their care; in some cases, people were not supported to eat their food at mealtimes or people had to wait for personal care. When we saw this, we informed the provider of the improvements required.

Providers described the pressures on staff time. They said the need for constant supervision and one-to-one staff time is higher for people living with dementia, but this is currently not funded. One care home provider described the changing pressures over time: *"Twenty years ago 25% of the occupancy of the home were [people] living with dementia. However, today 75% of residents are now living with dementia. This increase puts high demands upon staff."*

In two out of the three services subject to high-level enforcement action, we identified ensuring sufficient numbers of staff as an area requiring improvement. Care was rushed and resulted in distress and poor outcomes for people having to wait for care.

People were safe and treated with warmth but person-centred care could be developed further. In 88% of our inspections, we saw service providers ensure that the service is responsive and proactive in identifying and mitigating risks, and positive risk-taking is supported.

We found the majority of services with strong leadership and management achieved the best outcomes for people living with dementia. In 44% of our inspections, we saw the provider promoted a positive strengths-based use of language in day-to-day practice. Social Care Wales' Good Work framework *"A Dementia Learning and Development Framework for Wales"* highlights the importance of the role that leaders in developing the culture, learning, staff support and systems to ensure people receive the best support possible. One commissioner told us: *"Where training is occurring it is not resulting in changes to care practices. The change in practice is not being driven through with quality assurance processes and dementia champions in the work place. The staff provide care but are not delivering the person-centred care that is needed by the individuals."* The provision of training alone is not enough: it must be translated into everyday practice through the development of a learning culture.

Choice

The number of care homes in Wales has not increased over the past seven years. There are just over 1,000 care homes providing care for just over 26,000 people [2].

During this period, there has been a growing number of people living with dementia with increasingly complex needs. It is estimated [3] that there are 48,100 people living with dementia in Wales. This will increase by a third to 64,200 by 2030. From the information providers gave us, 64% of people living in adult care homes are living with dementia. The unsuitability of the premises is a growing problem.

Families describe huge difficulties in choosing a care home. They often have little understanding of dementia and no experience of care homes. We found in 77% of care homes there was a guide to service in a suitable format for people living with dementia or their representative. Guides are important in provding a description of the service and assisting people to choose the right home. Families said local authorities gave them little or no information. They found places for their relatives based on their proximity to their home using internet searches.

We found that people requiring residential care are generally able to find a care home close to where they live. There is less availability and less choice of care homes for people living with dementia who require nursing care. This was echoed by commissioners. This means that in some parts of the country people live considerable distances from their families and communities. Commissioners also described gaps in care for people who present a risk to themselves or others. We found disparity in people's ability to access the right care in the right place across Wales.

The profile of the people living with dementia is in the appendix to this report [4].

Welsh language

Most Welsh-speaking people who live in areas with high levels of the use of the language receive their care in Welsh. This is a particularly important issue for people living with dementia where there is a loss of language ability. However, in Wales more than half of care homes provide services in English only and do not identify people who are Welsh-speaking. We found that only one in five people who were Welsh-speaking received all their care in Welsh, with many living in care homes where there are no Welsh-speaking staff. Only a quarter (24%) of the next of kin we spoke to whose relative's main language was Welsh said they received their care in Welsh. For the Welsh-speaking people living with dementia who do not receive their care in Welsh, this is harmful and an infringement of their rights.

We also saw some homes manage people's language needs well with systems in place to ensure the service could meet the needs of people before they moved into the home. We heard staff speaking with people in English and Welsh as needed and ensuring Welsh-speaking staff were on the daily rota. Some care homes went to lengths to meet the Welsh language needs of people but this was not routinely the case.

Stakeholders and providers were clear in their view that improving the Welsh language skills of the workforce to achieve optimum services for people should be a joint responsibility for partners, rather than focused solely on providers.

People should be placed in a care home that meets their Welsh language needs. Commissioners need to align commissioning plans with the predicted need for Welsh language placements and work with providers to ensure service planning includes focus on future population needs. In addition, providers, commissioners and Social Care Wales should support the education and improvement of the Welsh language skills of care staff.

2. See appendix Care Home services and places regulated by CIW as at 31st March

3. Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040 Alzheimer's Society https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

4. See appendix - People living with dementia by gender and age group

People are safe and protected from harm

Safeguarding

People told us they felt safe living in their care home. We found there were effective safeguarding systems in place in nearly all care homes [5].

People told us:

- "I feel safe", "I am looked after", "food is excellent"
- "It's comfortable living here; I'm happy"
- "I love living here, I feel very safe" and "it's a lovely place to live, staff are excellent"
- "They've never done anything wrong to me"
- "Here it's like an extended family" , "they're incredibly patient" , "I don't have any complaints"
- "They look after me well. We have no complaints. The staff work very hard and are always busy. I am happy here. I feel safe here. We need more staff"
- "This is a wonderful place to be. People are good"

Liberty

The Deprivation of Liberty Safeguards (DoLS) aim to uphold people's rights and ensure any deprivation of liberty is in the person's best interest. The way in which the process has been designed has resulted in significant delays in applications by providers for deprivations of liberty to be authorised by local authorities. These delays are a breach of people's human rights. The law is currently being amended and, when introduced, the Liberty Protection Safeguards aim to improve these arrangements.

Our provider survey indicated approximately 60% of people living with dementia in care homes are subject to a DoLS. Our inspections found the majority of care homes followed the correct processes (97%) but less than half (42%) had received a response from the local authority as the supervisory body.

Stakeholders told us there is a lack of understanding about mental capacity legislation and there is a need to upskill staff about rights-based approaches. People living with dementia told us that the effect of deprivation of liberty on them and the people they lived with was profound. It affected freedom and created frustration and distress, which in turn has a negative effect on other people living at the home.

To effectively manage risk and promote people's liberty, people living with dementia need to be understood and trusted. Families should take an active part in the assessment and the management of risks. People living with dementia described their concerns that people are free to walk down the road to get the paper one day, but the following day because they are living in a different setting they are no longer free to walk outside.

5. See appendix safeguarding

It is important for people living with dementia that attention is given to this area, and scrutiny is given to the performance of local authorities. CIW will continue to monitor this and the impact of new legislation when introduced.

Medication

There is concern that antipsychotic medication is used to manage the behaviour of people living with dementia instead of more person-centred approaches. This is an infringement of people's rights and can increase the risks of heart attack and stroke. These matters were considered in the National Assembly for Wales' Health, Social Care and Sport Committee's report, "Use of antipsychotic medication in care homes", May 2018. This review aimed to consider the use of antipsychotic medication in care homes, including arrangements for medication review and staff training.

There is significant and growing use of antipsychotic medication with providers reporting that one in four people living with dementia are prescribed antipsychotic medication. As the complexity of needs of the people living in care homes increases, the use of antipsychotic medication also increases.

We found in about 90% of care homes, people's medication had been reviewed in the last six months, although responses from providers demonstrated a lack of awareness of the requirements to review antipsychotic medications. There had been liaison with the GP/pharmacy regarding high-risk medicines including antipsychotics in 95% of cases, but the frequency of this did not follow national guidance. We saw in 92% of cases the effect of the antipsychotic medication was monitored. In 78% of cases there had been multi-disciplinary team meetings to determine the continuing appropriateness of antipsychotic medication.

The management of antipsychotic medication in care homes would be greatly improved by the dissemination of specific guidance, education and clarity regarding the responsibilities of the service and other professionals.

We saw covert medication administered in 37% of our inspections. In these services 87% was given in line with current best practice guidance. In 78% of the services, staff received training regarding the administration of covert medication.

To contribute to improvement in the management of antipsychotic medication, CIW will:

- consider capacity and rights of people in the use of antipsychotic medication at inspection;
- consider practices in homes to see if there are lessons to be learnt in the use of alternative approaches; and
- work with the Dementia Oversight of Implementation and Impact Group (DOIIG) contributing to the 'alternative to medication' work stream.

People are treated with respect

Care

People living with dementia said to us:

"They treat the people here with so much respect."

"It's first rate care here."

People and their families told us the care they receive is respectful and kind. During our inspections we saw positive relationships between people living with dementia and staff, and staff were warm and caring.

We saw high quality care being provided, as one inspector wrote: *"I felt the care and support being provided was to a very high standard. All my observations throughout the two-day inspection found that staff were very natural in all their interactions with people living at the home. The staff "really got dementia" and how best to support people living with dementia."*

Carer's story

During the review one carer spoke to us about her father who had moved to live in a care home. He was living with vascular dementia. This is what she told us:

"In a few weeks of living in a care home, his health deteriorated significantly. Following a fall and a hospital admission, he was then admitted to a different care home. In the second home, the interaction with staff was totally different, they seemed to talk to and interact with people a lot more; if somebody was having difficulties staff would calm them and soothe them." The daughter was surprised that some care homes were not set up to meet the needs of people like her father.

Experiences like this show that the variation in quality of care for people living with dementia in care homes is dependent on staff understanding the needs of people with dementia, and having the knowledge and skills to provide person-centred care.

Most families were very positive about the care, staffing and management in the care homes. They described the staff as caring and welcoming and praised the food. The areas for improvement identified by families were regarding activities, staffing levels and the environment. Families told us they felt their relatives were safe and well cared for.

People told us:

- "They look after you. They'll do anything for you"
- "Food is excellent", staff are "good"
- "It's a nice place but it is not home", "they tell me where to sit"
- "Good all round care"
- "It's a wonderful home"
- "I do not know where I would be without the staff"
- "I've lived here a long time and I like it very much"
- "Fabulous staff"
- "I enjoy living here". "It's wonderful here, the staff are lovely"

We identified common themes in the provision of care and support that achieved the best outcomes for people. These included care staff providing respectful care with a detailed understanding of each person, based on personal information provided by people living with dementia and their families. This was detailed in personal plans and resulted in activities tailored for the individual, and enabled managed risks to be taken to achieve personal outcomes. This could have been improved by including accurate information about personal linguistic and communication needs.

Good practice

Describing one home, an inspector said: *"The home excels in its provision of social and recreational activities. There is such a choice available that meets all interests. The home is not risk averse and following robust risk assessments enables residents to achieve their goals. A few residents living with dementia had, over recent months, been skating, indoor rock climbing, swimming and sailing. One resident with dementia had been supported by staff to attend his granddaughter's wedding in North Wales. The home also provides high quality food, with sweet and savoury snacks being available between meals. The chef arranges a buffet style "Breakfast Club" for residents and staff twice a week, which was very popular. We saw people enjoying a wide range of food including fresh fruits, cheeses, breads, pastries and yoghurts, as well as traditional cooked breakfast options."*

We saw examples of people maintaining links with the community, attending community activities, services, and going to the pub as well as activities being brought in to the home. When one man could not attend the Eisteddfod to receive an honorary award, a ceremony was arranged for him to receive the award in the home. At inspections carried out during the Christmas period we saw many inspiring celebrations with donkeys, pigeons and geese contributing to nativity scenes played out by staff. There were numerous choirs, brass bands and musical recitals.

Leadership

Services with strong leadership and management achieved the best outcomes for people living with dementia. The factors that contributed positively were the manager's knowledge in supporting people living with dementia and the people living in the home, and a good supportive relationship with staff. Other factors included the Responsible Individual being present and visible; effective quality assurance activity; listening to the people and families; and staff training.

Providers described the difficulties they faced in providing good quality dementia care particularly in maintaining a skilled team of staff. Staff training is important in ensuring person-centred care, but we saw the important role that leaders have in ensuring person-centred care is delivered. Where this has not happened, services have failed to treat people with respect. Contributing factors include insufficient oversight of the care of people who are distressed; the use of antipsychotic medication; inappropriate language in describing people living with dementia; and limited use of the Welsh language.

Learning and development

In 75% of our inspections, staff were supported to undertake learning and development to enable them to deliver person-centred care for people living with dementia. Providers said 88% of staff understood dementia well or very well; in services specialising in dementia care, this rose to 95%. We saw services where the Responsible Individuals and managers led and ensured the provision of person-centred care. The majority of relatives told us they thought staff had the necessary training and skills to support their relative.

There is a huge variety of training materials available. Providers reported the most popular training resource was Dementia Friends, followed by the Butterfly Approach developed by Dementia Care Matters. All care homes said they use a mix of several different learning techniques to better understand dementia. Training provided by the local authority and health board was appreciated but scarce, and providers made their own arrangements. Providers said training staff in dementia care was one of the challenges they faced and we found training to support care homes could be better arranged and coordinated. People could not access services of their choice in Welsh and there should be training to improve Welsh language skills and greater appreciation of the importance of the More than Just Words Framework. [6] Just over one third of care homes were aware of the Social Care Wales Good Work framework and this figure rose slightly in services offering dementia care (38%).

6. More than Just Words: Strategic Framework for Welsh Language Services in Health, Social Services and Social Care, Welsh Government, 2012

Healthcare support

Providers described how having effective teams around the person, including community support services, can hugely improve the quality of care for people. Getting a timely diagnosis for people is important in enabling care homes to access additional support services and activities for people, but providers told us it was a challenge to access the relevant services to achieve this. Lack of, or delay in, diagnosis can make it difficult to get the right help and medication for an individual.

One provider said: *"It can be challenging when a person is showing strong signs of having dementia but nothing is diagnosed when they come to us. Sometimes reasonably advanced dementia is categorised simply as 'short term memory loss' or 'cognitive impairment'. This can make getting the right help or medication that may help someone more difficult, as getting a diagnosis can be a long process. In addition, some people move to the home with no dementia but develop it, again getting [a] diagnosis can be difficult but also it can quickly change their assessed needs."*

In all our inspections, we saw that people living with dementia were supported to access healthcare and other services to maintain their ongoing health and well-being.

The most widely used resources were district nurses, general practitioners, social workers, community psychiatric nurses (CPNs), speech and language therapists, pharmacists and dieticians. Many care homes also accessed palliative care teams, dentists, chiropodists and opticians. Less widely available were psychiatrists, occupational therapists and sensory loss support services. Providers also stressed the lack of physiotherapy support in some areas. Inspectors recorded the quality of the support provided to care homes [7].

Good practice

We saw one home where a physiotherapist was employed by the home to start physiotherapy upon admission; the home has developed a good relationship with local hospitals.

There was particular difficulty accessing CPNs which left care homes trying to support people and manage difficult situations on their own, when expert advice was needed.

Providers shared concerns that people's health and well-being can deteriorate if they are admitted to hospital. This was the result of insufficient attention by hospital staff to important needs such as continence and mobility, and ensuring people had their false teeth, hearing aids and glasses.

Effective multi-disciplinary team work to support care homes is essential in achieving good outcomes for people living with dementia. Mental health support services and hospital discharge are areas for improvement.

7. See appendix Inspection diagrams Healthcare.

People have a voice

Listening

Providers told us that they carry out a range of activities to seek the views of people living with dementia and their families. Significant use was made of 'house' meetings, reviews and questionnaires. Some providers supported this by having an open door approach and ensuring they learned from complaints.

One provider described:

"We carry out our own interval reviews called "My Care Review". These are carried out bi-monthly in order to gain the views of the people living in our home to ensure they are happy with the care and treatment they are having.

We have documentation [called] "What Matters to Me" which is reviewed monthly. Family are encouraged to become involved in their loved ones care as little or as much as they would like."

Effective person-centred care can only be provided if people are listened to. To do this well, people need supportive relationships with staff. This in turn requires good leadership to develop and instil this culture. The Responsible Individual must actively listen to people, their families and to care staff to ensure care is person-centred.

Advocacy is an important way of ensuring people's voices are heard. In 81% of inspections, we saw evidence of effective advocacy for people living with dementia. The majority of commissioners (93%) said they had sufficient arrangements in place to ensure advocacy was available. Some local authorities were in the middle of procurement processes to ensure these services were in place. Considerable progress has been made by some regional partnership boards in progressing the development of advocacy services in partnership with the third sector, for example Gwent has a vision for Gwent citizens. [8] Other commissioners said arrangements are made as required but general advocacy was not sufficiently available to support families.

8. https://www.blaenau-gwent.gov.uk/story/news/adult-advocacy-a-vision-for-gwent-citizens/

Observation

We use an observation tool in our inspections known as SOFI (Short Observational Framework for Inspection). It is an evidence-based inspection tool used by inspectors to make a judgment about what life is like for people using services, based on observing staff interactions with people and the impact this has on their mood. Sometimes people cannot tell us how they are feeling and SOFI gives us a way of gaining a view on their well-being.

During this review, we saw that the mood of people living in care homes was largely positive or neutral. Overall the people we observed were not distressed. We did see some people in poor mood states and some poor interactions by staff, and we brought this to the attention of the care provider for action.

One daughter's story

"Mum could no longer manage at home, and came into the care home. She was withdrawn and did not talk to me very much and no longer recognised me. I felt guilty and felt Mum was unhappy.

Mum had led a very active life, backpacking in Asia well into her seventies. This changed when there was an episode where Mum was admitted to hospital. She was very anxious and would not settle in hospital, not eating or drinking. However as soon as Mum returned to the care home she completely relaxed and even chatted to staff.

This is when I realised Mum was happy in the home with staff who knew her well and who Mum liked. I felt so much better."

Recording

We saw that having detailed information about the person in their personal plan led to person-centred care. In 86% of cases, we found the plan focused on what mattered to the person. These person-centred plans and life stories were completed with people, their families and care professionals recording personal family histories, memory photographs, likes and dislikes. The plans note what is important to the person, what makes them happy and their wishes for the future. Plans also record changes in physical/emotional states and enabled activities to be tailored to each person. Good plans included detailed assessments and managed risks to enable people to achieve their personal outcomes.

The personal plan is important in recording the wishes of the person because it gives staff direction and information in how to provide personal care. In 89% of the plans we looked at, they had been co-produced with the person living with dementia, and their representative. We also found that when the plans were reviewed, consideration was given to changes in communication (92%), sensory loss (88%) and mobility (94%).

Linda Marsh, a Cardiff care service resident with her HUG™, a comforting object developed by Cardiff Metropolitan University's LAUGH project. Image used with permission.

People develop their full potential

What matters to people

We found 87% of people are supported to fulfil their potential and do things that mattered to them and make them happy. We saw examples of individuals maintaining links with the community, for example attending community activities and going to the pub. Staff also brought activities into the home.

Good practice

Some people living with dementia may live in a home that does not specialise in looking after people with dementia.

We inspected a small care home for people with learning disabilities/mental health issues where one person had developed dementia. As a result, some staff attended a three-day dementia awareness course to ensure they had a comprehensive awareness of the issues associated with dementia care.

The service had put in place a comprehensive and personalised dementia care plan, addressing all aspects of daily living and detailing the impact of the person's dementia on their life. It provided staff with clear advice and guidance about how they should support the person, focusing on strengths and maintaining independence.

Activities

Providers told us about how they had developed creative opportunities for people to promote their well-being.

- Therapy through electronic pets/dolls/toys - several examples were given of people engaging very well with robotic pets and dolls. Their use has a positive impact on the person's well-being by improving mood and focus (see image on page 14).
- Animal/pet therapy - some care homes have access to pets that residents enjoyed feeding and looking after. Some care homes invited animal charities into the home for people to spend time with a range of different animals such as puppies, kittens, hamsters, frogs, snakes etc. One care home had chickens which people were very attached to and eager to help look after, cleaning out their hutches and collecting the eggs.
- Dementia friendly spaces - this included the use of colour-coded facilities within specific areas of a home to enable people to easily recognise them if they have sensory loss, for example coloured facilities used within wet rooms. Outdoor spaces and sensory gardens were used in some care homes. In one care home, a greenhouse/summerhouse was erected for people to grow and nurture plants, and to enjoy the good weather and views.
- Encouraging independence through activity - these includes polishing brass, housekeeping, gardening, arts and crafts or going to local shops. People were supported to take part in external events and to try something new like writing or singing, with achievements recognised through certificates and showcases.
- Embracing new technologies - although quite a new area, a lot of care homes responded to our survey describing how they were trialling digital tablets and virtual assistants. In some examples Skype/video messaging was being used to enable residents to stay in touch with loved ones who lived further afield.

In some cases people told us there was "not much to do" in their care home, and a lack of activities prevented them from fully engaging in the world around them. There may be low participation in activities because of communication barriers and a lack of interest or ability to participate in activities. Some people do not want to participate in activities and prefer to be by themselves. Tailoring activities to suit each person can be difficult and highlights the need for resourcing activities to provide person-centred care. In 88% of inspections, we saw providers ensure the service was responsive and proactive in identifying and mitigating risks as appropriate, to enable people to take part in activities that promoted independence and may involve positive risk-taking.

The environment

The environment of a care home is important in enabling people to achieve their potential and to remain as independent as possible. In 77% of our inspections we found people's surroundings promoted well-being with appropriate lighting, décor, plants and outdoor spaces. We found there was room for improvement in some care homes.

We found that less than 10% of care homes had environments specifically designed to achieve good outcomes for people living with dementia. Over half of care homes have buildings over 50 years old. The absence of dementia-friendly environments was one of the major challenges for providers and had a direct impact on people's well-being, freedom and choice.

In recent years, few purpose-built care homes designed to meet the needs of people living with dementia have been opened. One provider told us they would not do so again under the current funding arrangements. This means that people live in premises that do not optimise their well-being and it is harder to provide good quality care.

In 75% of our inspections, we found the environment helped to promote meaningful and purposeful activity. For example, a welcoming environment with living spaces arranged with small clusters of chairs to encourage conversations, and with spaces for group activity and engagement in daily living activities such as laundry.

In 83% of inspections, we found the environment promoted people's mobility through use of handrails, colour, texture and contrast along with small seating areas for resting. Points of interest inside and outside were also valued and we saw positive examples of circular and returning pathways.

Overall we found half of care home environments had a supportive design for people living with dementia. In these homes the environment promoted orientation with consideration of matters such as visual cues and prompts, personalised bedrooms and clocks and calendars specifically developed for people living with dementia. Such items provide reassurance and help to promote independence. In 81% of inspections we also saw environments that encouraged people to access food and drinks independently. In 74% of inspections we found the environment supported people's continence and personal hygiene with suitable toilet facilities.

The design of the environment is also important in promoting people's safety and well-being. The behaviours of people living with dementia can lead to challenging incidents that may be infrequent but are significant. In 85% of our inspections, we found the environment promoted calm by reducing noise, clutter, and being least restrictive while maintaining people's safety. Providers described the difficulty of safeguarding people from the actions of other vulnerable adults, where ensuring sufficient safe personal space can sometimes be difficult. This means safeguarding people in care homes becomes increasingly difficult as people's needs become more complex in environments that do not facilitate avoidance and management of these situations.

Good practice

An inspector described a care home that focused on the needs of people living with dementia: *"The environment has an excellent range of facilities for residents to enjoy either on their own, with fellow residents, with staff or with visiting family members. This includes:*

- *a large cafe area with sofas and comfortable chairs where residents and their visitors can help themselves to coffee and cakes;*
- *a farmhouse kitchen where people with dementia are encouraged to make snacks or simple meals for themselves under supervision;*
- *a fitness room, a large cinema room, an indoor garden with pets, a sensory room; and*
- *an attractive garden where residents are able to tend to plants and grow vegetables.*

The home is innovative and was trialling an aroma diffusion system in one of the dementia communities. This released appetite-stimulating food smells into the atmosphere before mealtimes (apple and cinnamon pie at the time of my visit) and was proving to be effective in drawing residents with poor appetites into the dining room to eat."

Engaging families

Engaging families in planning care, reviews and having on-going involvement is important in providing person-centred care. Families need to understand the changes associated with living with dementia and the importance of sharing information about their relative, to help staff to understand their life story and enable them to provide personalised care.

One provider referred to the need for a proactive partnership between the care home and families to better support people living at the home. When a family does not engage with the service, this negatively affects the quality of care that can be provided. One provider said: *"We hold a meeting on a three monthly basis. I do feel we lack support from some families when care plan reviews are needed, often they are invited to attend but do not, we have some very limited visits to the home from some families - this is often because the families work or live far away."*

Key Recommendations

1. **Choice –** people need clearer information about the location and types of service available. Commissioners need to address gaps in care home provision.
2. **Training –** providers of care services and commissioners need to ensure that training supports the delivery of person-centred care. Training should involve people living with dementia who can describe their experience of care.
3. **Environment –** providers and commissioners should work together to ensure new homes are designed and built to improve outcomes and enable effective care, informed by evidence.
4. **Welsh language –** providers and commissioners must gather better information about the Welsh language skills of the workforce; educators should work to upskill the current workforce.
5. **Antipsychotic medication –** all partners in care should work together to ensure improved practice in administration and review of antipsychotic medication.
6. **Rights –** there is a lack of understanding about mental capacity with a need to upskill staff in the context of rights-based approaches to care and support.
7. **Multi-disciplinary support –** there is a need to improve support from mental health services and effective admission and discharge from hospital.

Appendix

Stakeholder reference group

The stakeholder reference group included the following people and organisations:

- People living with dementia
- The carers and families of people living with dementia
- The providers of care home services
- Care Forum Wales
- Alzheimer's Society Cymru
- Age Cymru
- Bangor Unviersity
- Aberystwyth University
- Older People's Commissioner for Wales
- Welsh Language Commissioner
- Social Care Wales
- NHS
- Senior Medical Officer Welsh Government
- Welsh Government Chief Pharmaceutical Officer

Table 1. People living with dementia by gender and age group[1]

	Age Groups						
Gender	18-24	25-44	45-64	65-74	75-84	85 and over	All ages
Male							
Number of services	0	2	39	88	161	170	
Number of people	0	2	59	204	619	679	1,563
Female							
Number of services	0	0	34	89	181	205	
Number of people	0	0	42	214	1,035	2,075	3,366
Total number of people	0	2	101	418	1,658	2,754	**4,929**

[1] CIW Care Home Service Providers Survey (2019)

Chart 1.

The percentage of people living with dementia by gender and age group

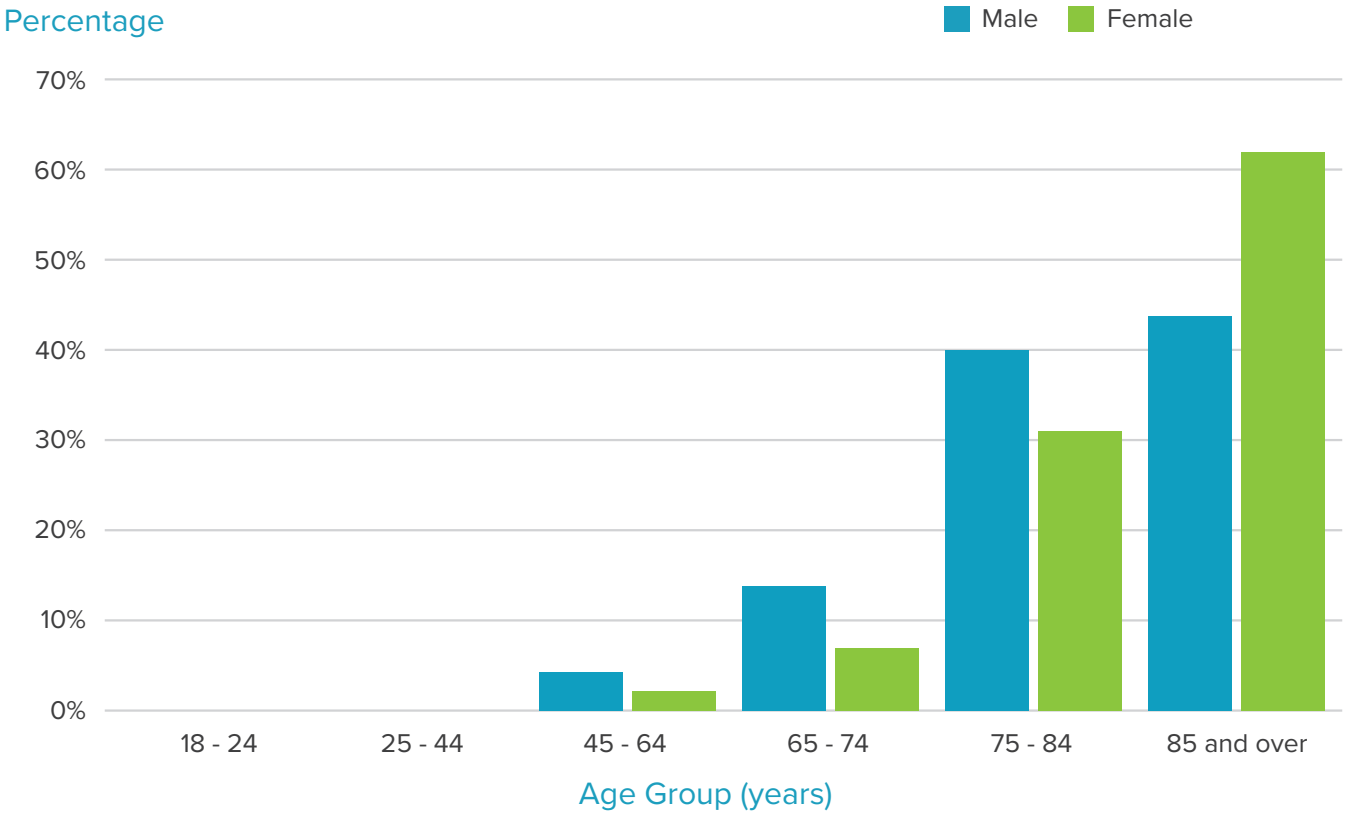


Chart 2.

The number of people living with dementia by gender and age group

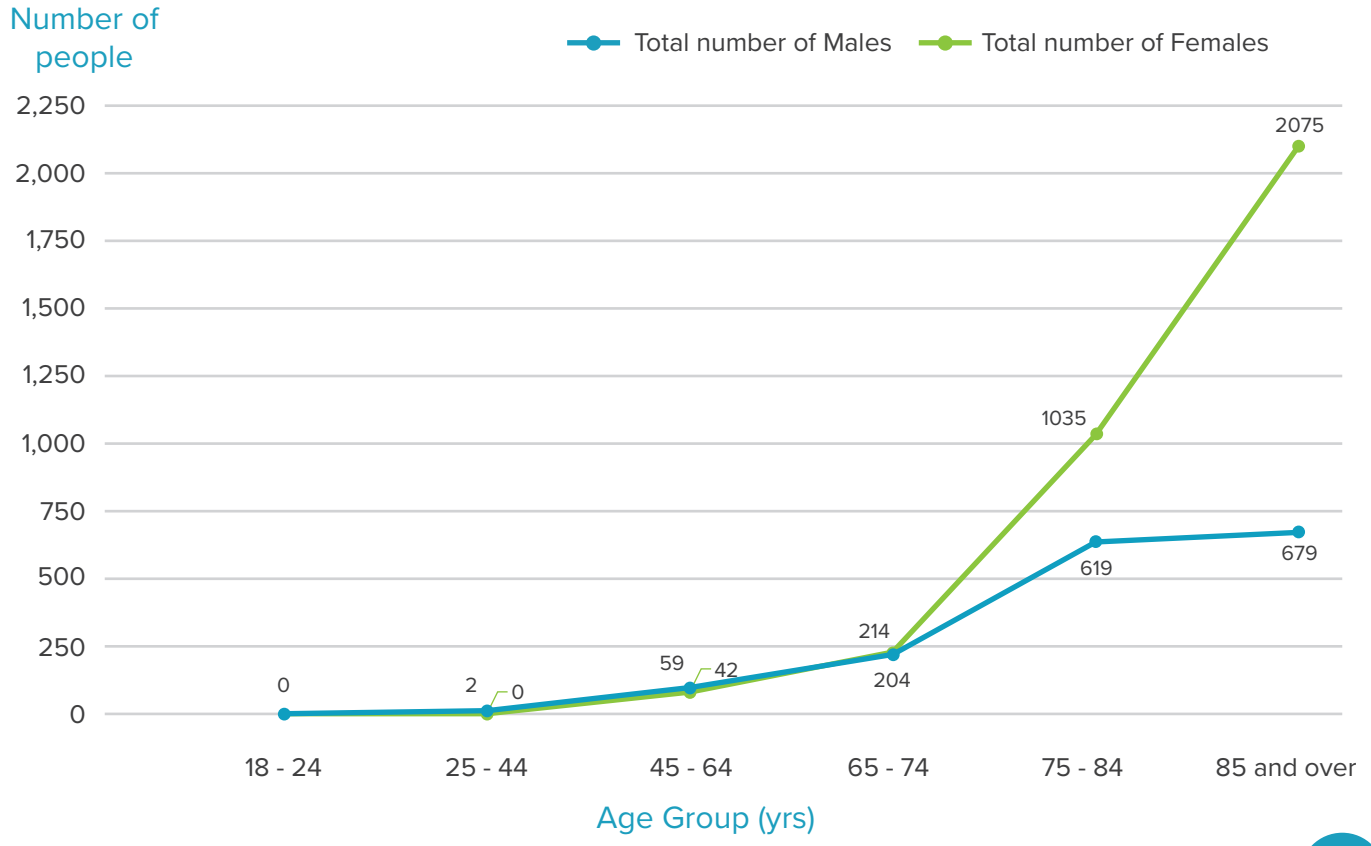


Table 2.

People living with dementia by specific diagnosis[2]

	Specific dementia diagnosis							
	ARBD[3]	Alzheimers	With Lewy Bodies	Frontotem-poral	MCI[4]	Vascular	Young-on-set[5]	Other/ Rare
Number of services	79	194	80	66	115	206	22	58
Average number of people per service	2.0	7.3	1.8	2.2	4.6	7.2	1.3	4.4
Total number of people	155	1,425	143	145	527	1,479	29	256

[2] CIW Care Home Service Providers Survey (2019)

[3] ARBD – Alcohol related brain damage

[4] MCI – Mild Cognitive Impairment

[5] Young onset or Familial dementia

Chart 3.

The percentage of people living with a specific diagnosis in care homes

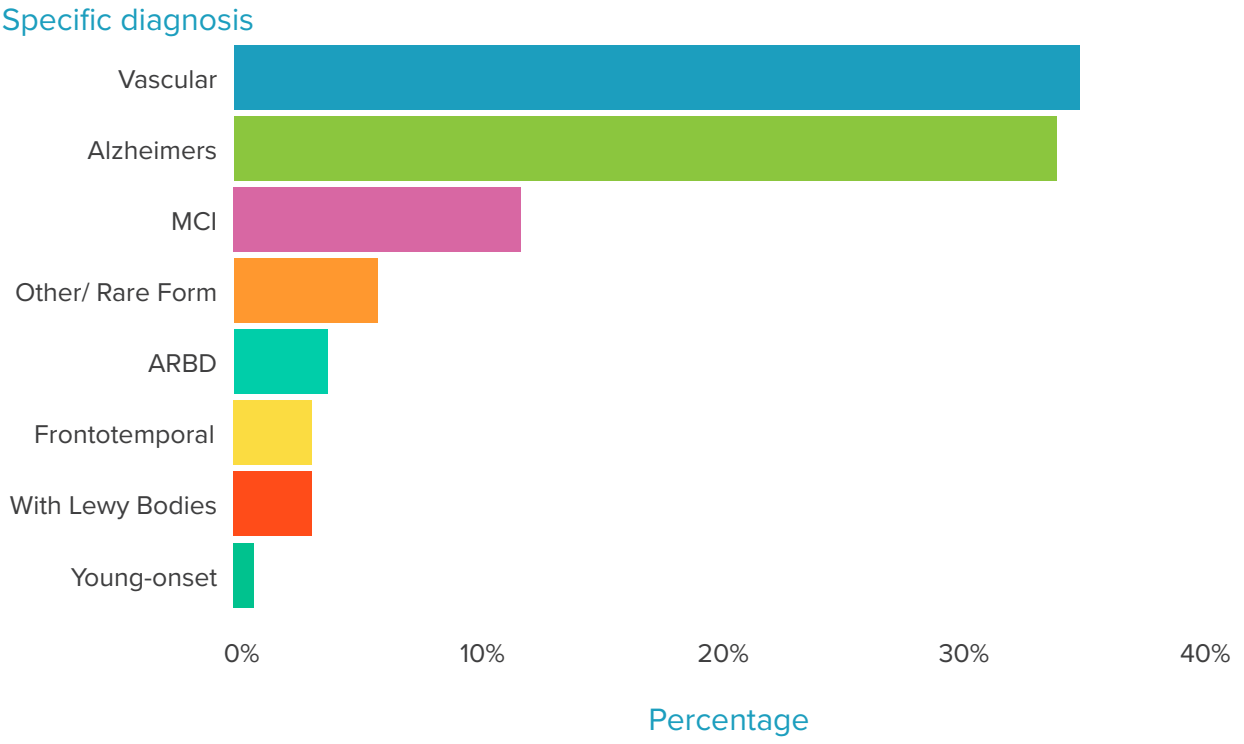


Table 3.

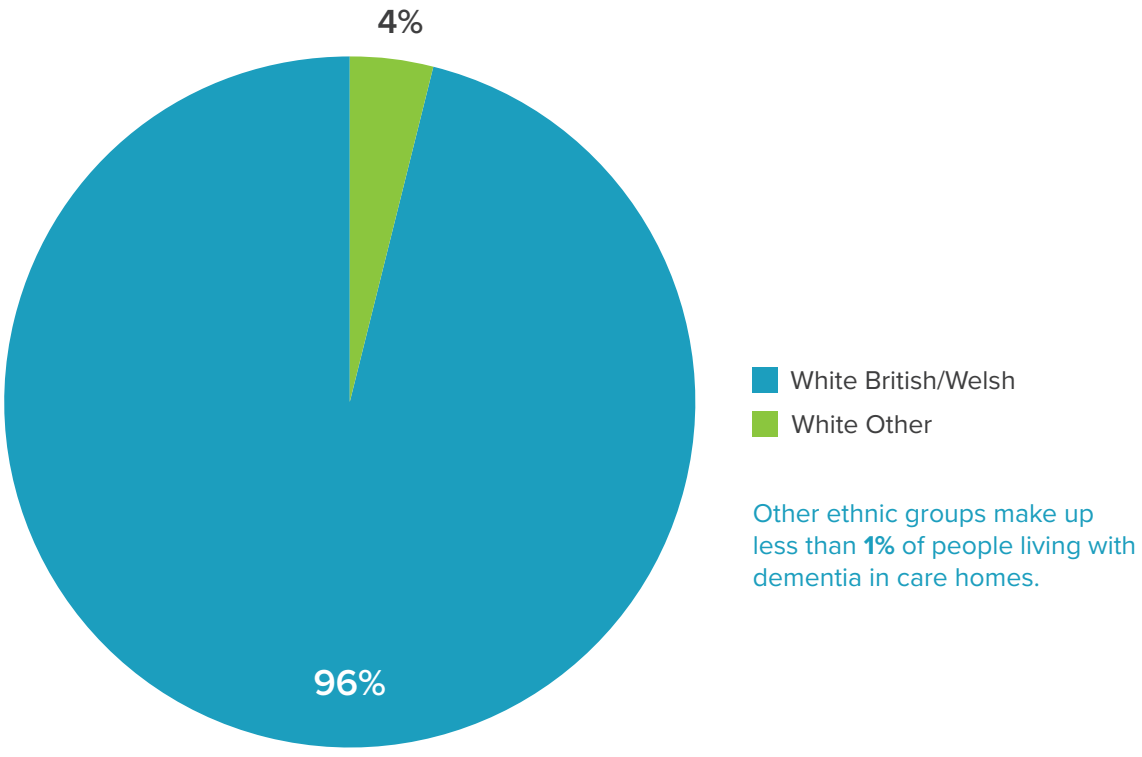
People living with dementia (diagnosed/undiagnosed) by ethnic group[6]

	Ethnic Group					
	White British/Welsh	White Other	Mixed/ Multiple Ethnicity	Asian/Asian British	Black/Black British	Other Ethnicity
Number of services	237	29	5	9	11	1
Number of people	4,813	182	9	9	15	1
Percentage by ethnic group	96%	4%	0.2%	0.2%	0.3%	0.0%

[6] CIW Care Home Service Providers Survey (2019)

Chart 4.

The percentage of people living with dementia by ethnic group



Other ethnic groups make up less than **1%** of people living with dementia in care homes.

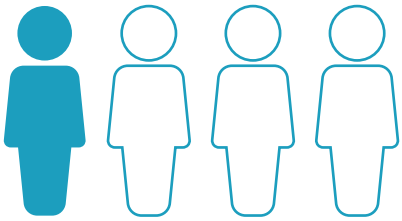
Table 4.

The number of people living with dementia in care homes (diagnosed/ undiagnosed) that are prescribed antipsychotic medication[7]

	Antipsychotic prescribing		
	Number prescribed	Number not prescribed	Total
Total Services	189	64	253
Total People	1,454	3,965	5,419

[7] CIW Care Home Service Providers Survey (2019)

Proportion of people being prescribed antipsychotic medication in care homes



1 in 4

Our provider survey identified that 1 in 4 people (27%) living with dementia were being prescribed antipsychotic medication.

Chart 5.

Care homes with people living with dementia and the levels of prescribing

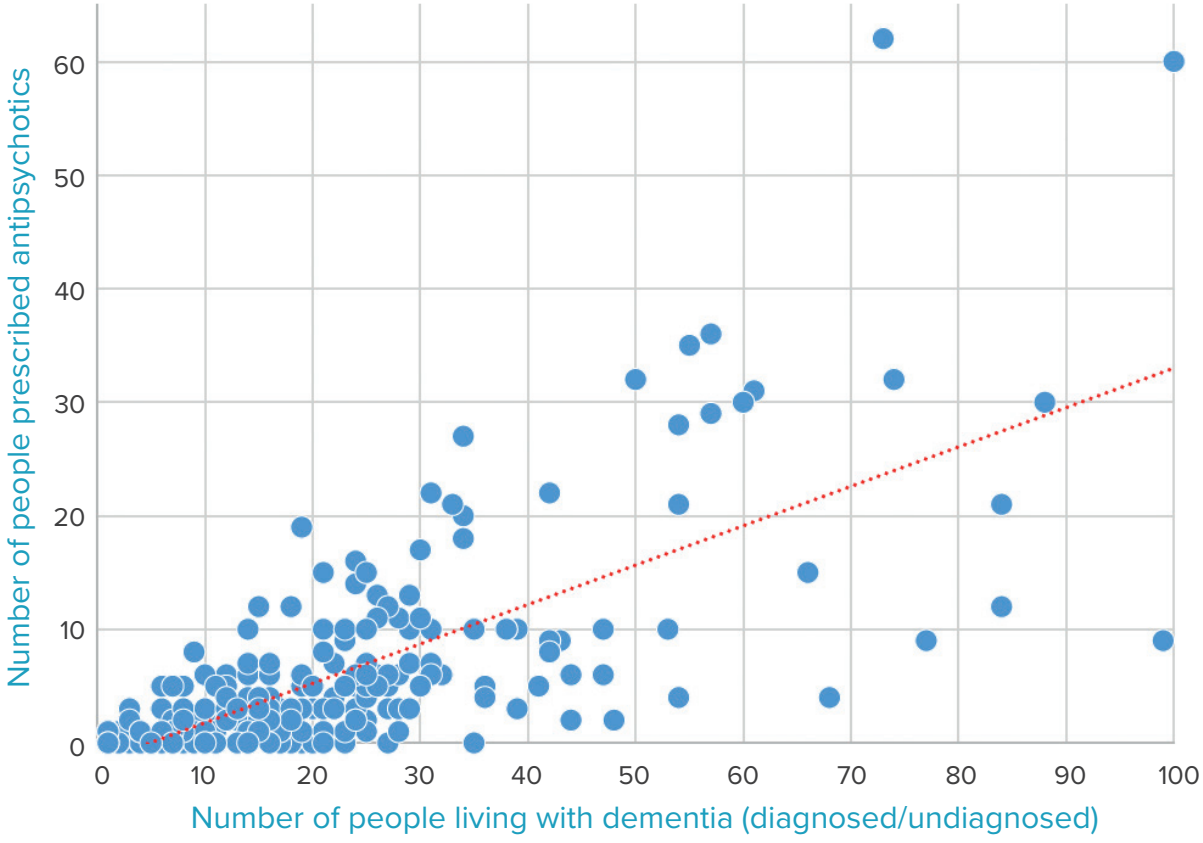


Chart 6.

The percentage of care homes where staff understand dementia

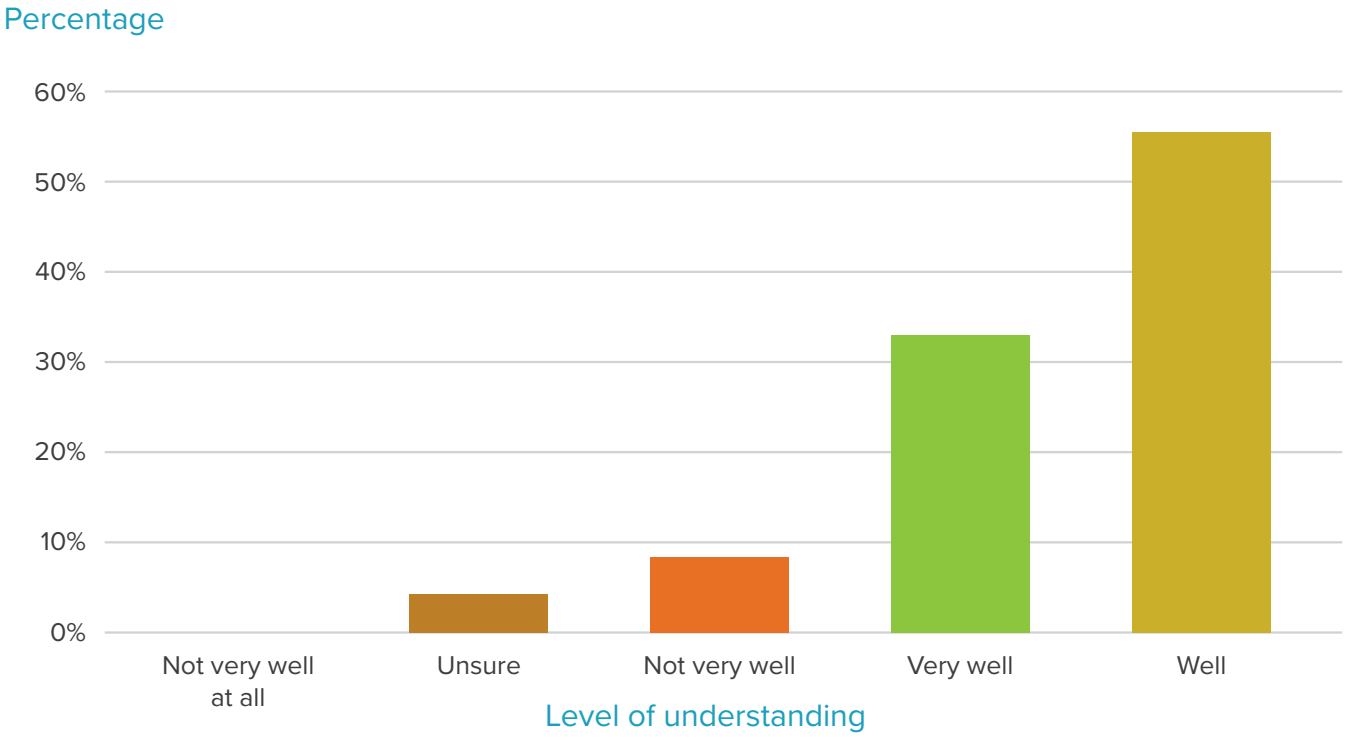


Chart 7.

The percentage of care homes that are aware of the Social Care Wales 'Good Work Framework'

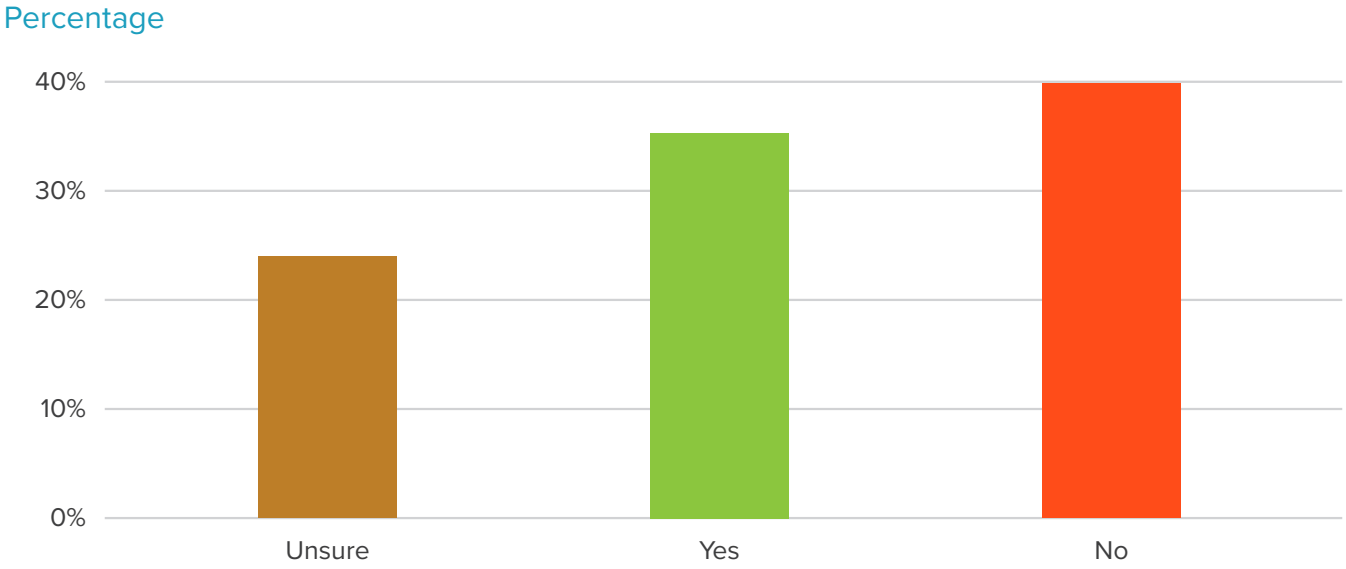


Table 5.

The service operational language used in care homes where people are living with dementia (diagnosed/undiagnosed)[8]

	Service language				
	Welsh only	Bilingual Welsh and English	English only	Bilingual English and other languages	**Total**
Number of services	0	123	120	10	**253**
Number of people	0	2,586	2,528	305	**5,419**

[8] CIW Care Home Service Providers Survey (2019)

Chart 8.

The percentage of operational language used in care homes for people living with dementia

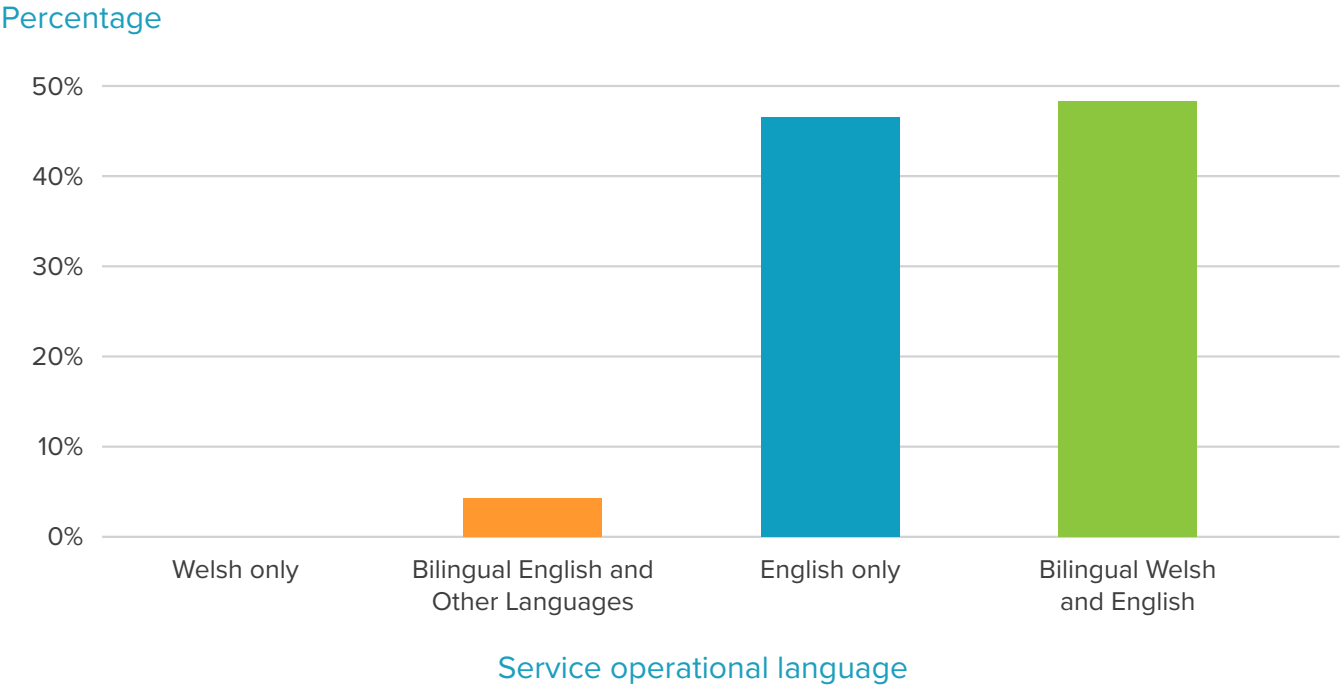
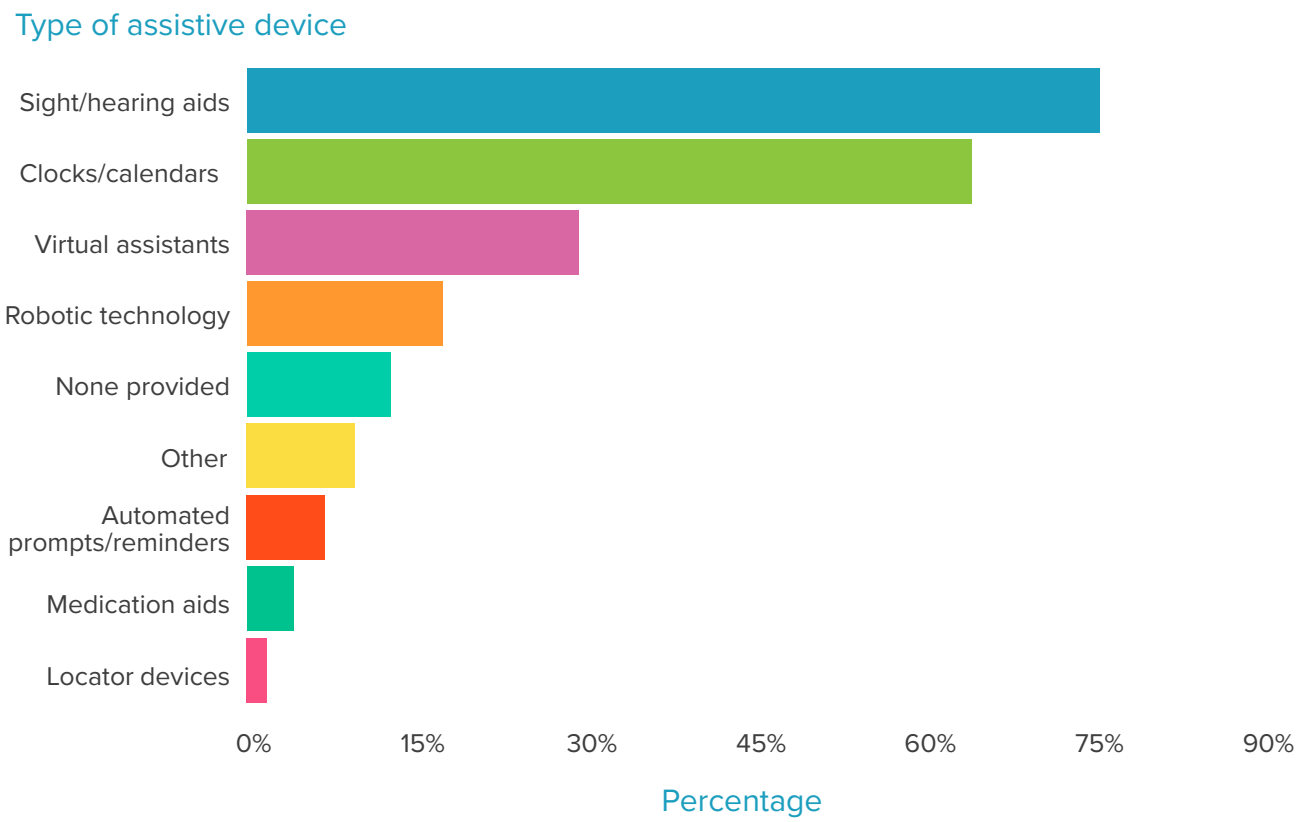


Chart 9.

The percentage of care homes using assistive devices to support people with dementia



Inspection diagrams

(from CIW dementia inspections 2019-20)

Healthcare

Chart 10.

The GP support for adults living in dementia care homes

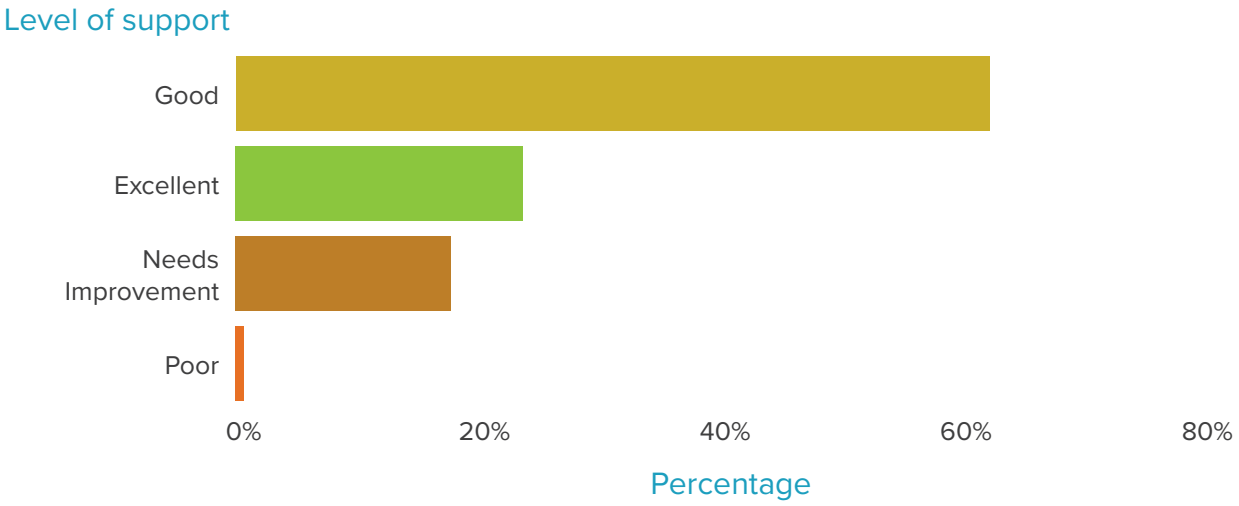


Chart 11.

The Commuity District Nursing support for adults living in dementia care homes

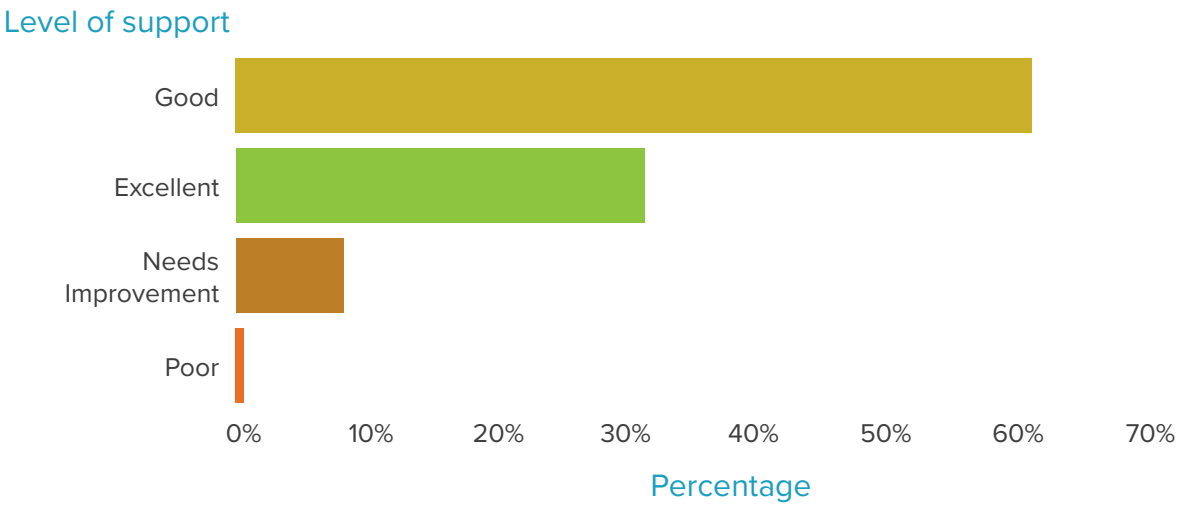


Chart 12.

The mental health support for adults living in dementia care homes

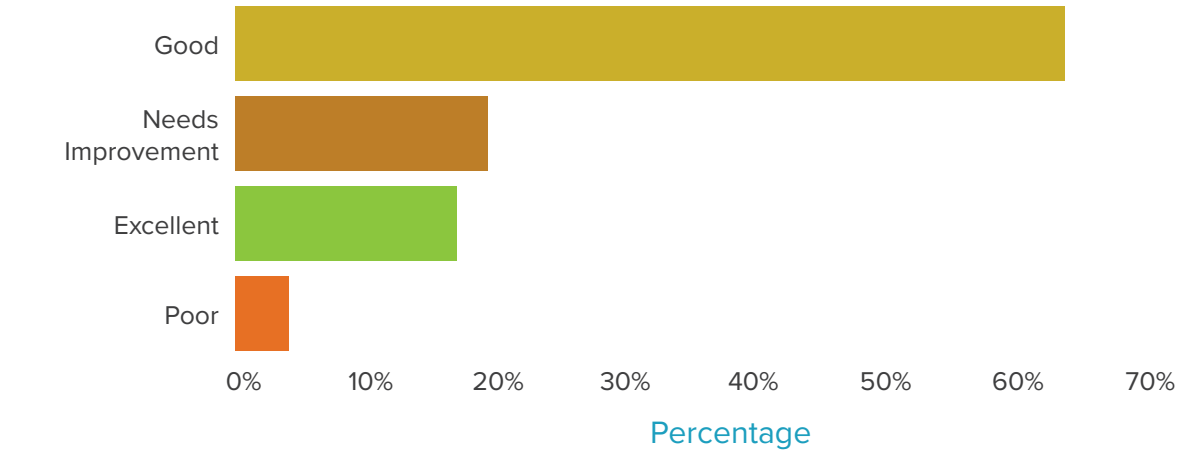


Chart 13.

Hospital discharge support for adults living in dementia care homes

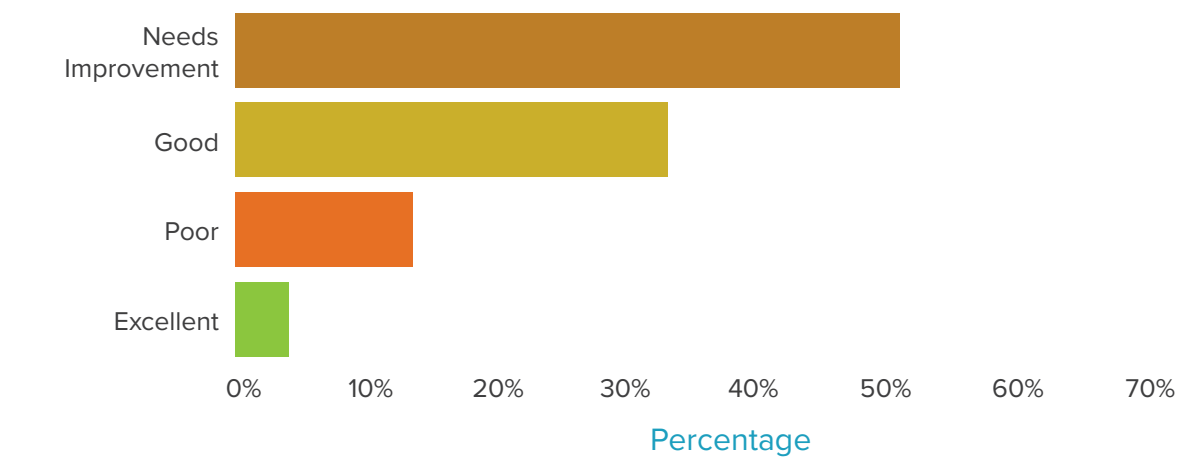
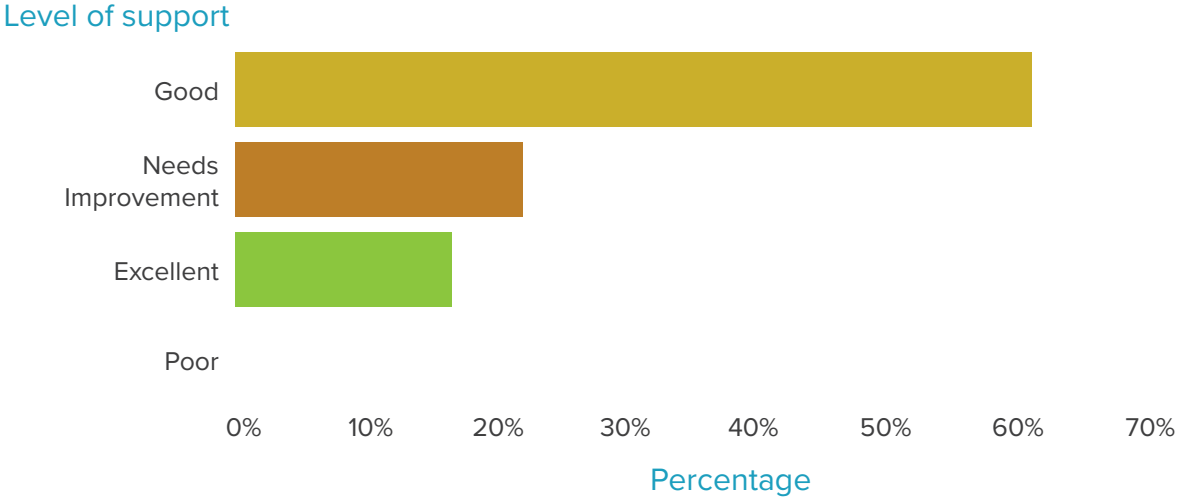


Chart 14.

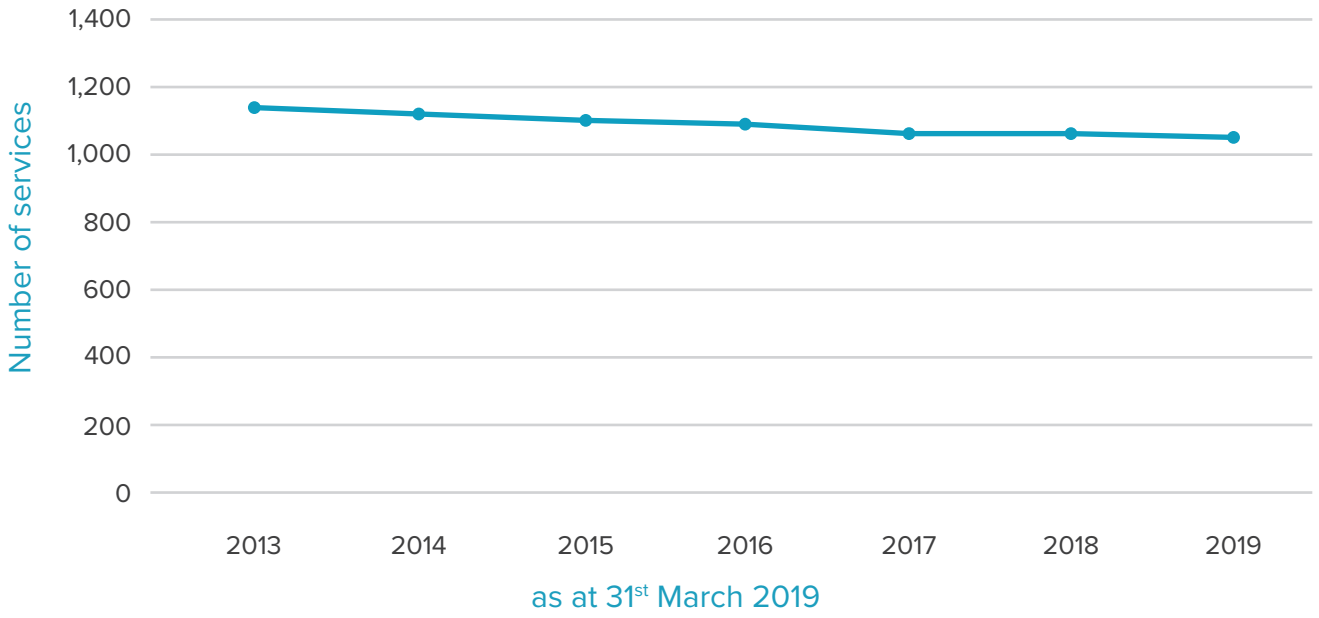
Practice Development Team support for adults living in dementia care homes



Care home services and places regulated by CIW as at 31st March

	2013	2014	2015	2016	2017	2018	2019	Change (b) Level	Change (b) Percentage
Adult Care Home Services (a)									
services	1,143	1,132	1,114	1,106	1,081	1,082	1,080	63	-6%
places	26,460	26,240	26,191	25,642	25,753	25,993	26,035	425	-2%

(a) Adult care services before the Regulation and Inspection of Social Care (Wales) Act or 2019 are the combined counts for older and younger adult care homes
(b) Change in services and places comparing 2013 and 2019



Safeguarding

93% individuals living with dementia and their representatives were given information about safeguarding, how to raise a concern and are they supported to do so.

96% of staff received training relevant to their role to enable them to understand their responsibility to safeguard and protect vulnerable individuals.

99% of staff were aware of their individual responsibilities for raising concerns to ensure the safety and well-being of individuals.

SOFI observations

All observations	X. What are the staff interactions with the person living with dementia?			
Y. What is the mood state observed of the person living with dementia?	Positive	Neutral	Poor	*Total*
Positive	243	8	0	*251*
Neutral	123	48	15	*186*
Poor	24	7	4	*35*
Total	*390*	*63*	*19*	*472*