



advice and support for older age

**Independent
Age**

Shining a light on care: helping people make better care home choices



Contents

Foreword by Professor Paul Burstow	3
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Executive summary	4
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Introduction	9
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1 What do older people and their families think?	13
---	----

2 Who collects and provides information and for what purpose?	29
--	----

3 What's missing?	42
– Basic indicators of safety	42
– Better information for families	45

4 A way forward: better information for families	47
---	----

Conclusions and recommendations	50
--	----

Final thoughts	55
-----------------------	----

Appendix	56
Acknowledgements	60

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*For the great work that's
done in care homes,
there are still dark
corners, and it's those
corners that a light
must be shone on.*

”

Former Care Minister,
Alistair Burt MP,
November 2016

Foreword

by Professor Paul Burstow

For most of us the thought of going into a care home is not a positive choice; instead it is seen as a last resort. Often the decision about when to enter a care home and which care home, is the result of a crisis, a bad fall or a hospital admission.

As this report demonstrates, the stress is heightened by the paucity of reliable information on which to base a decision. According to the polling commissioned by Independent Age, 1 in 3 of us is likely to hit Google to find out about care for our loved ones.

There is often a difference in people's perceptions of care homes and their views of the quality on offer depending on whether they have direct experience of them or not. Much of this is coloured by the deeply ingrained belief that abuse and neglect in care homes is commonplace, a belief fuelled by the media.

Choosing a care home is a life-changing decision; for many it will be their last home. But lack of knowledge and a shortage of reliable information can end in the wrong decision being made. When markets work well, the customer is king. But in the care market, the customer is often left in the dark unable to make an informed choice.

There is a need for a straightforward view of what good quality looks like, what to look for and what to ask for. Drawing on the insights of families who have gone through the process of finding a good home and the views of experts, this report offers a practical 'starter for 10' on the markers of quality.

Independent Age has turned the spotlight on a neglected area of public policy. With a growing number of very old people living with complex health and care needs, many more families will face the challenge of finding the right place for their loved ones. The government, the regulator and the industry all have a part to play in making that choice easier.

Paul Burstow served as the Minister of State for Care Services between May 2010 and September 2012.

Executive summary

“

Instead of thinking, 'Oh my God, I'm going to end up there,' I actually want to think, 'If I do have to go into care, I want to look forward to how fantastic it would be.' ”

Birmingham focus group participant

We rarely hear positive news stories about care homes and yet as more of us live for longer, many of us will live in one. The majority of care homes inspected by the Care Quality Commission (CQC) are rated 'good' or 'outstanding', but that still leaves large numbers of homes – nearly 4,000 – delivering substandard care or struggling to improve.

What's more, nearly half (45%) of British adults describe their overall perceptions of the quality of care in care homes for the elderly as bad¹.

We need to do better than this and aim for higher standards of quality in a market valued at £15.9 billion.

To get to a place where more of us can imagine positively choosing a care home, we believe what needs to change fundamentally, is the quality on offer.

This report highlights why we believe there is a worrying gap in the information currently available to people looking to choose a care home, and what can be done to fill that gap.

¹ Independent Age – Care Homes Poll. ComRes interviewed 2,030 GB adults aged 18+ online between 28th and 30th October 2016. Data were weighted by age, gender, region and socio-economic grade to be representative of all British adults aged 18+.

Main findings

There is a confused picture of safety and quality in care homes in England

- The CQC picture is of persistently variable quality – 2 in 5 (41%) of nursing homes are rated inadequate or require improvement, and a quarter (26%) of care homes are similarly below standard.
- There are big gaps in what the residential care sector knows about quality and how it communicates what it knows. The National Audit Office said it believes the CQC doesn't have access to routine information on adult social care good enough to trigger inspections.
- Public perceptions of care homes can be very negative, driven in part by concerns about the risk of abuse. Just over half (52%) of British adults believe that abuse and neglect in care homes is common².
- There were nearly 40,000 safeguarding risks relating to care homes reported and investigated in England in 2015/16. But this doesn't necessarily provide the full picture of the scale or types of abuse and neglect occurring in residential care.
- There is little hard data on the extent of abuse and neglect, which may lead to the public overestimating it.
- The care homes sector – unlike the NHS – doesn't even have a sector wide staff survey, meaning it misses opportunities to ask staff whether they would recommend the place they work as a place for relatives to receive care or whether they have witnessed abuse or neglect.
- Focus groups we ran highlight how people have very low awareness of existing sources of information on care homes – and when information is available, they often struggle to trust it.
- There are significant gaps in the information care homes directly provide about their own services, according to our mystery shopping survey results. From a sample of 100, 2 in 5 were unable to provide 'good' or 'satisfactory' answers to all of our six basic questions.
- Care rating sites have been criticised in recent years for providing inaccurate or misleading data. Earlier in 2016, an investigation by the Competition and Markets Authority (CMA) found that some rating sites risk distorting the picture presented to site users on care quality.

2 Independent Age – Care Homes Poll. ComRes interviewed 2,030 GB adults aged 18+ online between 28th and 30th October 2016. Data were weighted by age, gender, region and socio-economic grade to be representative of all British adults aged 18+.

- Our research with care professionals, older people and their families, unveiled almost 100 potential components of quality – ranging from how you are greeted on arrival to how many residents are being prescribed antipsychotic medication. Yet these are not routinely captured.
- In summary, we highlight three related issues that act as an obstacle to older people's and their families' efforts to choose a care home that matches all of their criteria for a good quality home:
 - 1** Too many interpretations or versions of quality
 - 2** Lack of consistent and standardised data collection in social care
 - 3** Lack of transparency and easily available information to support care home choice
- This shared view of quality could help the CQC with its own plans to promote a simpler, 'single' view of quality as part of its 2016-21 strategy.
- An improved, streamlined approach to capturing and reporting information on quality in care homes would be in the interests of both older people and care providers.
- This report identifies some basic indicators of safety, such as incidence of pressure ulcers, and details the use of such measures in the United States.
- Based on our research with older people and care experts, we have also developed 10 care home quality indicators to provide everyone looking for information on care homes with more reliable information. This includes whether a home has a registered manager in place, staff turnover, and how the home involves residents and the local community in social activities.
- To satisfy the demand from older people and their families for better guidance when looking for a care home, we are working to test these 10 new care home quality indicators.

A new approach

- What is missing is a shared view of quality that is not overwhelmingly complex, and that reflects not just experts' concerns, but also the concerns of older people, their families and friends.

Recommendations

- The Department of Health should demonstrate the same level of policy leadership on the issue of transparency and reporting performance in social care as it has for the NHS.
- The Care Quality Commission should work with the Department of Health and other stakeholders to agree a single, shared view of safety and quality in care homes and an agreed set of core indicators (a 'minimum data set') to be collected for all homes. This should form the basis of the data required by all commissioners of care home and nursing home services so as to minimise the data provided by homes and reduce duplication and overlap.
- The Competition and Markets Authority (CMA) should conduct a full market review of the care home sector to see whether it is a market that is working well and whether consumers are getting a fair deal, particularly in relation to information on quality and cost.
- The Department of Health should commission a Social Care Staff Survey similar to the NHS Staff Survey. By working with industry bodies, they should ensure the survey collects annual data on whether staff would recommend the provider they work for to a family member or friend and whether they have witnessed neglect or abuse.
- To reach a position where quality care is the norm for all, the overall care market needs to be sustainable. The government needs to respond to the recent challenge set by the CQC and avoid adult social care reaching a 'tipping point' where quality, funding and capacity continue to deteriorate.

Our research

We used a range of methods to gain a clear perspective of the problems and strengths of the current system for choosing a care home.

In addition to desk research, these included:

- **Interviews with 23 health and social care professionals** – ranging from care home providers, groups representing older people and families, researchers, representatives from local government and the CQC. We sought their views on the quantity and quality of information that people currently have to base decisions on when choosing a care home.
- **A seminar for health and social care professionals** – which drew together divergent opinions from the professional interviews and reflected on their insights.
- **Two focus groups with older people and their families – specifically on residential care:**
 - In Poole, we spoke to five Independent Age volunteers with no previous experience of choosing a care home, reflecting the situation that most people will find themselves in when faced with choosing a care home for the first time.
 - In Sutton, we spoke to a group of eight people, all of whom had experience of helping a relative or friend to choose a care home.
- **Two interviews with Anchor care home residents** – about how they chose the care home they did.

We commissioned QA Research to carry out a **telephone based mystery shopping exercise** with a sample of 100 care homes. In the calls, care homes were asked to answer six simple questions about the home, and were evaluated on their responses.

We ran a **further series of four focus groups** in London, Middlesex and Birmingham. These addressed issues affecting older people that they would like to see Independent Age take action on – care homes regularly came up as a topic.

We **commissioned ComRes to interview 2,030 British adults aged 18 plus**, online between 28 and 30 October 2016. Data was weighted by age, gender, region and socio-economic grade to be representative of all British adults aged 18 and over.

Introduction

There are currently more than 17,000 care and nursing homes across the UK and in 2014, it is estimated that these were home to around 405,000 people aged 65 and over³. However for the majority of people, for most of their lives, care homes⁴ exist in a parallel universe – out of sight and out of mind.

Yet sudden changes in life can make the necessity of moving into a care home an unexpected reality for many older people and their families. At this point, they need to absorb a lot of information rapidly – not just about the options available to them, and how to pay for care, but also about the kinds of things that distinguish a really excellent care home.

They may encounter various – sometimes conflicting – accounts of the quality of any one care home. These may come from the care home itself, from friends and neighbours, from the care regulator: the Care Quality Commission (CQC), or from feedback left on review sites. Their general perception of care homes may have been shaped by the infrequent but high-profile reports of abuse and neglect in the media.

Trying to get to the truth can feel like an impossible task for somebody thrust into the position of choosing a care home. It is no wonder that many of the people we spoke to in our research found themselves ‘playing detective’ to try and figure out what they could expect from the care homes they were looking at.

The personal challenges faced by older people and families trying to choose care homes reflect a bigger problem. Undoubtedly, there is a scarcity of reliable information about quality in care homes beyond basic comparisons relating to safety. This means people can struggle to make an informed choice about the right home and regulators and commissioners, likewise, can struggle to access the data they need to identify poor practice at an early enough stage to intervene.

A confused view of quality

In its strategy for 2016-21, the CQC noted that ‘multiple definitions of care quality are still being used’⁵ by the care sector, resulting in confusion and extra work for both providers and consumers of care.

3 Care of Elderly People Market Survey 2013/14, Laing and Buisson, 2014

4 Throughout the rest of the report we use the term ‘care homes’ to refer to all homes that provide care and support for older people, ranging from care homes without nursing, nursing homes, and homes for older people with dementia.

5 Care Quality Commission, 2016, Shaping the future: CQC’s strategy for 2016 to 2021, p. 11, http://www.cqc.org.uk/sites/default/files/20160523_strategy_16-21_strategy_final_web_01.pdf

The CQC has pledged to develop a single shared view of quality over the next five years, which it hopes will allow 'better access to consistent and clear information about what quality care looks like'⁶. We support this ambition, but argue that while the CQC is clearly a key player in achieving this, it will require active support from care homes, local authorities, clinical commissioning groups and other partners across health and social care.

The CQC must strive to help individuals and families make sense of a complex and currently opaque market. We also want to see the Department of Health playing a leadership role in this area, building on its work championing improved data in the NHS by setting out its own vision for improved quality and transparency in residential care.

Quality at a regulatory level across the care home sector remains persistently variable – an issue that has also been repeatedly highlighted by the CQC. As of 31 July 2016, the CQC had inspected 9,100 care homes (without nursing) and 3,649 nursing homes under its new inspection framework, awarding each of them a rating of 'outstanding', 'good', 'requires improvement' or 'inadequate'. Only 1% of care homes and a similar proportion of nursing homes were rated 'outstanding', while 41% of nursing homes and 26% of care homes were rated 'requires improvement' or 'inadequate'⁷.

Quality was adjudged to be a bigger issue in residential care than in other adult social care services such as home care, where under a quarter (23%) of domiciliary care agencies were rated by the CQC as 'inadequate' or 'poor'⁸.

While there is undoubtedly good care in many homes and innovative work taking place to improve provision, the former Care Minister, Alistair Burt MP, has recently used a parliamentary debate on regulation in care homes⁹ to declare there are "still dark corners" in the residential care market and that "it's those corners that a light must be shone on".

Care Quality Commission ratings

The Care Quality Commission is the independent regulator of health and social care services in England. It has powers to monitor, inspect and regulate services to ensure they meet fundamental standards of quality and safety. They publish what they find, based on key lines of enquiry they follow in their inspections and services, then issue one of four ratings to help people choose care.

These ratings are:

- Outstanding
- Good
- Requires improvement
- Inadequate

6 Care Quality Commission, 2016, Shaping the future: CQC's strategy for 2016 to 2021, p. 15, http://www.cqc.org.uk/sites/default/files/20160523_strategy_16-21_strategy_final_web_01.pdf

7 Care Quality Commission, 2016, The state of health care and adult social care in England 2015/16, http://www.cqc.org.uk/sites/default/files/20161013_stateofcare1516_web.pdf

8 Care Quality Commission, 2016, The state of health care and adult social care in England 2015/16, http://www.cqc.org.uk/sites/default/files/20161013_stateofcare1516_web.pdf

9 Adjournment Debate on Regulation of care homes for older people (3/11/16)

Negative perceptions

We know that our concerns about quality of care are shared by the public. In fact, public perceptions about residential care can be very negative and often stem from anxiety about the risk of abuse. The 2014 Demos Commission on Residential Care found that more than half of British adults who wouldn't move to a care home had been put off by a fear of abuse in the home¹⁰. In fact, new polling for this report reveals that more than half (52%) of British adults believe abuse and neglect in care homes for the elderly to be common. As many as 1 in 10 British people would say it is very common¹¹. Crucially, over a third of those (36%) who agree that abuse and neglect is common base their view – at least in part – on personal experience. Public fears are likely to overstate the likelihood of care home residents suffering abuse or neglect – but there is no current way of evidencing that because there is no reliable available measure of abuse and neglect.

The problem in context

There are currently some gaping holes in what is known about the care sector. These were highlighted in July 2015 by the National Audit Office (NAO) in a report looking at the capacity of the CQC to regulate health and social care.

Their report concluded that:

In contrast to the national datasets available for hospitals and GP services, the [Care Quality] Commission does not have access to routine information about adult social care good enough to monitor risk or trigger inspections¹².

This lack of routine data collection poses a double problem for the CQC – it means they cannot respond to a lapse in care standards as quickly as they can for services with better data, such as GPs and hospitals. It also means that when they do plan an inspection, in the absence of pre-existing data, inspectors are left reliant on manual data collection directly from care homes using forms which often come back only partially completed. In spite of CQC efforts to strengthen the data they are drawing on, including using technology to get real-time feedback on services, they still have some way to go before they can build a single picture of quality across different care and nursing care homes.

Funding pressures

And yet we currently see no evidence that these issues are registering at a political level. In fact, there is a sense that the political debate about the quality and standards of care homes has been overtaken by the issue of financial sustainability in the sector. A number of warnings have now been issued about the widening funding gap in adult social care.

10 Demos, Commission on Residential Care, 2014, http://www.demos.co.uk/files/Demos_CORC_report.pdf

11 Independent Age – Care Homes Poll. ComRes interviewed 2,030 GB adults aged 18+ online between 28th and 30th October 2016. Data were weighted by age, gender, region and socio-economic grade to be representative of all British adults aged 18+.

12 National Audit Office (July 2015), Care Quality Commission: capacity and capability to regulate the quality and safety of health and adult social care, <https://www.nao.org.uk/wp-content/uploads/2015/07/Capacity-and-capability-to-regulate-the-quality-and-safety-of-health-and-adult-social-care.pdf>

The King's Fund has suggested the gap could be as big as £3.5bn by 2020¹³. The CQC recently issued its own warning that social care is reaching a 'tipping point'¹⁴. Reductions in local authority funding and pressure on fees mean the care market is now very fragile, with nursing home capacity actually stalling since 2015. Just in residential and nursing care for the over-65s alone, the latest figures highlight a cash terms cut between 2014/15 and 2015/16¹⁵.

To reach a position where quality care is the norm for all, the overall care market needs to be sustainable. The government needs to respond to the recent challenge set by the CQC and avoid adult social care reaching a 'tipping point' where quality, funding and capacity continue to deteriorate.

The risk is that the battle to secure funding could be won without any noticeable impact on the quality of care in care homes. It is essential that care funding rises to a level where care providers can operate sustainably, and offer an acceptable level of pay and reward for staff that attracts people to work in care roles. Independent Age has been a vocal supporter of a cross-party government-backed commission that sets out how the NHS and social care will be funded in the long term, through our Care for Tomorrow campaign¹⁶.

However, funding alone – without a clear vision for the level of quality and choice we should be striving for in a modern care home system – will not be enough to raise standards. We need to streamline efforts to improve quality by encouraging all players to zone in on a core set of quality measures. Not only will this aid regulators, it will also help commissioners and the individuals who have to find a care home for themselves or a loved one. Put simply, it will help service users identify the best care. Without this knowledge, all purchasers operate, at least partially, in the dark and the market for care risks remaining distorted and ineffective.

We embarked on this research to try and better understand what is currently known about quality in care homes and how this is affecting the choices open to older people in need of residential care and their families. We found that both the care sector, as a whole, and older people and their families urgently need to know more about quality in care homes.

This report explores some of the impacts of *not knowing* what quality care looks like – both to help inform older people's choices and to improve residential care. We also recommend some ways in which the information gap in care homes and nursing homes could be filled.

13 The Spending Review: what does it mean for health and social care? The King's Fund, Nuffield Trust and The Health Foundation (December 2015)

14 The State of health care and adult social care in England 2015/16, Care Quality Commission (October 2016)

15 Personal social services expenditure and unit costs, NHS Digital (October 2016)

16 For more information on Independent Age's Care for Tomorrow campaign please visit <http://www.carefortomorrow.org.uk/>

1 What do older people and their families think?

The care information gap

Our 'Difficult Conversations' report¹⁷ from earlier in 2016 showed an unwillingness on the part of many of Britain's families to talk about the 'taboo' subject of residential care. Around 7 million people aged 65 and over have never had a conversation with family about who will care for them when they are older and where they would like to live if they could no longer live at home.

We wanted to understand whether older people and their families feel that they know enough about care homes when the time comes to choose one. We found that all too often, there is a huge gap between what people want to know about care homes, and what they are able to find out in the short timescales available to them.

Naturally, people's knowledge of care homes will, to a very large extent, be based on their personal experiences of visiting or choosing a home. However, only 15% of British adults have visited an elderly relative or friend in a care home in the past 12 months (see **Table 1**).

Table 1: Percentage of British adults who have visited an elderly relative or friend living in a care home in the past 12 months

	%
Yes	15%
Adults age 65+	21%
No	85%
Adults age 65+	79%

Although adults in the oldest age groups were most likely to have visited someone in a care home in the past year, 4 in 5 (79%) of over-65s had not. At any one time there are around three times as many people living in care homes in the UK as there are patients in a bed in hospital¹⁸. But our collective levels of knowledge and understanding about who these people are and the quality of care they receive lags way behind what we expect to know about how our hospitals are performing.

¹⁷ We need to talk about caring: dealing with difficult conversations, Independent Age (2016)

¹⁸ Overcoming the challenges to improve health and wellbeing in care homes, David Oliver, The King's Fund <https://www.kingsfund.org.uk/blog/2016/10/improve-health-and-wellbeing-care-homes>

The fundamental expectation: safety

The first, most basic expectation of a care home is that the individuals living there will be safe and will live a life free from abuse. Yet we know that the public harbours deep reservations about whether they or a loved one will be able to avoid what appears to them to be widespread neglect and abuse in care homes.

High-profile investigative reports of abuse and neglect affecting older people have been broadcast to millions in documentaries such as BBC's Panorama and Channel 4's Dispatches. A number of these reports have specifically highlighted cases of abuse in care homes, for example, through the use of hidden cameras. Some of these reports led to successful prosecutions of care workers, but it is hard to know whether these cases in fact hint at widespread levels of abuse and neglect. The CQC has produced guidance for care homes and families on the appropriate and proportionate use of cameras in care homes, but public perceptions about safety in care homes may be hard to shift.

The Demos Commission on Residential Care found that only 1 in 4 people surveyed would consider moving into a care home if they became frail later in life. As many as 43% said they would not move to a care home. The risk of neglect or abuse was the second most common reason among them – with an alarming 54% of their survey respondents citing this¹⁹.

52%

of our respondents feel that abuse and neglect in care homes for the elderly is common

New polling commissioned for this report suggests levels of public alarm may have grown even more acute since the Demos survey. Just over half (52%) of British adults would say that abuse and neglect in care homes for the elderly is common²⁰ (see **Table 2**). People who have visited a friend or a relative in the last year are less likely to say they think that abuse and neglect is common (45% say this). However, since 53% of people who have not visited a care home in the last year say they think that abuse and neglect is common, the differences in view are surprisingly and worryingly small.

Of the half (52%) of British adults who agreed that abuse and neglect is common, 71% said they had reached their views as a result of media coverage. Furthermore, 15% of those who would say that abuse and neglect is common know someone in a care home, and an additional 5% who believe this say one of their reasons is because they work in care²¹.

19 The Commission on Residential Care, Demos, 2014

20 Independent Age – Care Homes Poll. ComRes interviewed 2,030 GB adults aged 18+ online between 28th and 30th October 2016. Data were weighted by age, gender, region and socio-economic grade to be representative of all British adults aged 18+.

21 For more tables detailing these poll findings, please look at the appendix.

Table 2: Half of British adults say that abuse and neglect in care homes for the elderly is common (52%), while around a third (35%) say that it is not common

	%
NET: Common	52%
Very common	10%
Fairly common	42%
Not very common	33%
Not at all common	3%
NET: Not common	35%²²
Don't know	13%

Putting figures on abuse and neglect

The most frequently cited statistic on the prevalence of abuse is the number of 'safeguarding risks' which are referred to local authorities. Since the 2014 Care Act, they have had a statutory duty to run enquiries and investigate them²³.

Of the total number of safeguarding enquiries that took place in 2015-16, more than one third (36%) related to safeguarding issues in care homes. That amounts to just under 40,000²⁴.

The types of safeguarding concern varied from area to area, but last year acts of neglect and omission accounted for more investigations – or 'safeguarding enquiries' – than any other form of abuse.

Latest figures on alleged abuse and neglect in care homes reveal that 55% of the safeguarding incidents involved social care staff, whereas social care staff were involved in just under a quarter (23%) of safeguarding incidents in adults' own homes.

However, these figures record only the number of concerns that are actually identified and raised. One international study into abuse²⁵ indicates that it is significantly under-reported and is likely to be more widespread than official figures suggest. There has been work to examine the experience of older people and staff in care homes with attempts to also look at the prevalence of mistreatment.

One study revealed that 1 in 40 older people had been mistreated by someone they knew in a single year²⁶. What proves difficult to pinpoint is the extent to which older people may or may not be at greater risk of abuse or neglect in residential care.

22 Each of the percentages in the data tables (including the net percentages) take into account weighting to make the findings representative of the actual population – this explains the small discrepancy when calculating the net score of 35%.

23 Safeguarding enquiries are a statutory requirement local authorities are under a legal obligation to complete where a safeguarding risk is brought to their attention. This is a legal requirement (Section 42) under the Care Act 2014. Before conducting an enquiry, a local authority has to have reasonable cause to suspect that an adult in its area has needs for care and support, is at risk of or experiencing abuse or neglect and as a result of their care and support needs is unable to protect themselves against the risk of, or act of abuse or neglect.

24 Safeguarding Adults 2015 to 2016, Experimental statistics, NHS Digital (October 2016)

25 Interventions for preventing abuse in the elderly (Review), Cochrane Public Health Group, Baker PRA, Francis DP, Hairi NN, Othman S, Choo WY (2016)

26 Abuse and neglect of older people: Secondary analysis of UK prevalence study, King's College London & National Centre for Social Research (2013)

Another recent study in the United States found that nearly a quarter of relatives of older people in care homes said their relative had experienced physical abuse from a caregiver²⁷.

One way of identifying the current level of abuse and neglect in UK homes would be to ask staff, via a confidential survey, whether they had witnessed abusive or neglectful behaviour by other staff in the previous 12 months.

Currently, however, no such survey exists within social care, unlike the NHS Staff Survey which asks staff questions about whether they would recommend the provider they work for as a place relatives should get treatment and whether they have witnessed potentially harmful errors or incidents. We know that safeguarding referrals do not paint the full picture when it comes to abuse and neglect, or the wider workplace culture within care homes – so what is the full picture?

The Department of Health should commission a Social Care Staff Survey similar to the NHS Staff Survey, working with industry bodies to ensure the survey collects annual data on whether staff have witnessed abuse or neglect.

This should include whether they would recommend the provider they work for to a family member or friend who needs care. The survey would provide regular benchmarked information on the profession and key aspects of quality within residential care.

Finding good quality care

Most people, when faced with choosing a care home, will be venturing into unknown territory, with little or no experience of other care homes to draw on for comparison. For many, the decision will come at a time of crisis, possibly when there is pressure on an older person or their family to free up a hospital bed.

It is in these pressured circumstances that people will be looking – often in a rush – to search for information on care homes. We found that nearly double the number (29%) of British adults would search on Google or another search engine first before they would consider approaching their local council (16%) or obtaining information from the CQC (another 16%) (See **Table 3**).

A further fifth (22%) of all British adults say they wouldn't know where to look first if they needed to find information on a care home. Among the over-65s, 1 in 5 (19%) also say they wouldn't know where they would go to for information.

However, it is the so-called 'sandwich generation' who could struggle most were they placed in a position of needing to arrange care for an elderly parent. Nearly 1 in 3 (27%) of adults aged 45-54 simply wouldn't know what information to look for if they wanted to find a care home (see appendix for the full results). Not knowing where to start can increase the pressure even more at a time when other parts of the health and care system are expecting families to make a speedy decision.

27 Physical abuse of older adults in nursing homes: a random sample survey of adults with an elderly family member in a nursing home. Schiamberg LB, Oehmke J, Zhang Z, Barboza GE, Griffiore RJ, Von Heydrich L, Post LA, Weatherill RP, Mastin T (2012)

Table 3: Which websites or organisations, if any, British adults would look to first for information on care homes

	%
Google or other search engine	29%
Local council	16%
Care Quality Commission	16%
NHS Choices	14%
Other	2%
I don't know where I would go to for information	22%

Table 4: Overall perceptions of quality of care in care homes for the elderly

	%
NET: Good	39%
Very good	4%
Fairly good	35%
Fairly bad	37%
Very bad	8%
NET: Bad	45%
Don't know	16%

Mixed views on quality of care

In most markets when we look to choose a service, we generally begin with some basic assumptions about the choices on offer and what the overall quality of provision may be. These can act as a filter as we look to compare services and judge which service is most suitable or offers the best quality.

The problem is that more British adults believe overall the quality of care in care homes is bad (45%) than those who believe overall the quality of care on offer is good (39%) (see **Table 4**).

British adults are already likely to feel constrained by the range of options on offer if nearly half (45%) hold the view that the overall quality of care in care homes is substandard. This may mean many people already begin the process of choosing a care home feeling unconfident about the quality on offer. With 16% saying they simply don't know what quality to expect, the reality of weighing up quality is a very difficult judgement for people to make.

To understand people's expectations and actual experiences of choosing care homes, we ran two focus groups – one in Poole, Dorset, and one in the London borough of Sutton. The Poole group involved people who had never gone through the experience of choosing a home, while the Sutton group involved people who had.

The Poole group of care home 'beginners'

In Poole, we asked five of our volunteers to imagine that they were faced with the task of finding a care home on behalf of an older family member or friend. We asked them what would be the first thing they would do, and what questions they would have.

What we found from this group:

- Older people and their families can see care homes as unknown places.
- Levels of trust in care homes can be extremely low – participants were suspicious of care homes attempting to 'put on a good face' and talked about the difference between surface appearance and reality at length.

"If you go to look at a care home, obviously they are all going to be on their best behaviour, aren't they?"

Poole focus group participant

- There was very low awareness of existing sources of information.
- Our participants saw care homes as scary places – where the risk of poor care and abuse is real. Professionals and informal contacts would be most people's first port of call when trying to find out about care homes locally – GPs and social workers, in particular, were mentioned as trusted and knowledgeable sources of information.

There was little acknowledgement that cost would pose a serious obstacle to having a good choice of care homes.

In spite of this, when prompted, the people we spoke to did not have any trouble describing what a good quality care home should look like. They were clear about what they would ideally be looking for when choosing a care home, which is detailed in **Table 5**:



Table 5: Focus group expectations



THINGS I WOULD LOOK FOR:

- * A pleasant location (quiet, residential) and close to family and friends
- * A homely and welcoming atmosphere
- * Staff are well-presented and friendly
- * Rooms are comfortable, with en-suite facilities
- * Staff give the impression that they really care about residents, and treat them as individuals, with dignity and respect, catering to their individual needs and preferences
- * Staff are qualified
- * Familiar faces and staff are in post for a good length of time. Plenty of staff are available to see to residents' needs.
- * No set visiting hours
- * Access to a GP – either on-call or at regular surgeries in the care home
- * Residents being helped to get out and about and continue with everyday activities if they are able to (eg gardening, DIY, going out to the shops, or a café)
- * Pets in the home
- * Homes have a good choice of food including options for those with swallowing difficulties
- * Staff are able to communicate with residents effectively
- * Home is clean, tidy and well-presented

Weighing up information about a home

Families and friends of older people place a huge amount of emphasis on the 'softer' indicators of quality such as how the home looks and feels, and how people treat you within it. This makes perfect sense. When choosing a home where we are planning to live for a number of years, most of us would want to know that we will feel happy there, and that we will be able to live as we choose.

"You see, I'm a person who would be interested in what activities are going on. To keep my body and mind and spirit together I think... I would also like that there are very specific cultural or religious homes... I would be interested in that."

Birmingham focus group participant

However, the Poole group we spoke to also recognised that it was possible to find out about some of the things they were interested in advance – either by looking on the care home's own website, or information provided by the local authority. These included:

- number of staff
- how long staff had been in post
- staff qualifications
- visiting hours
- whether the home has regular access to a visiting GP.

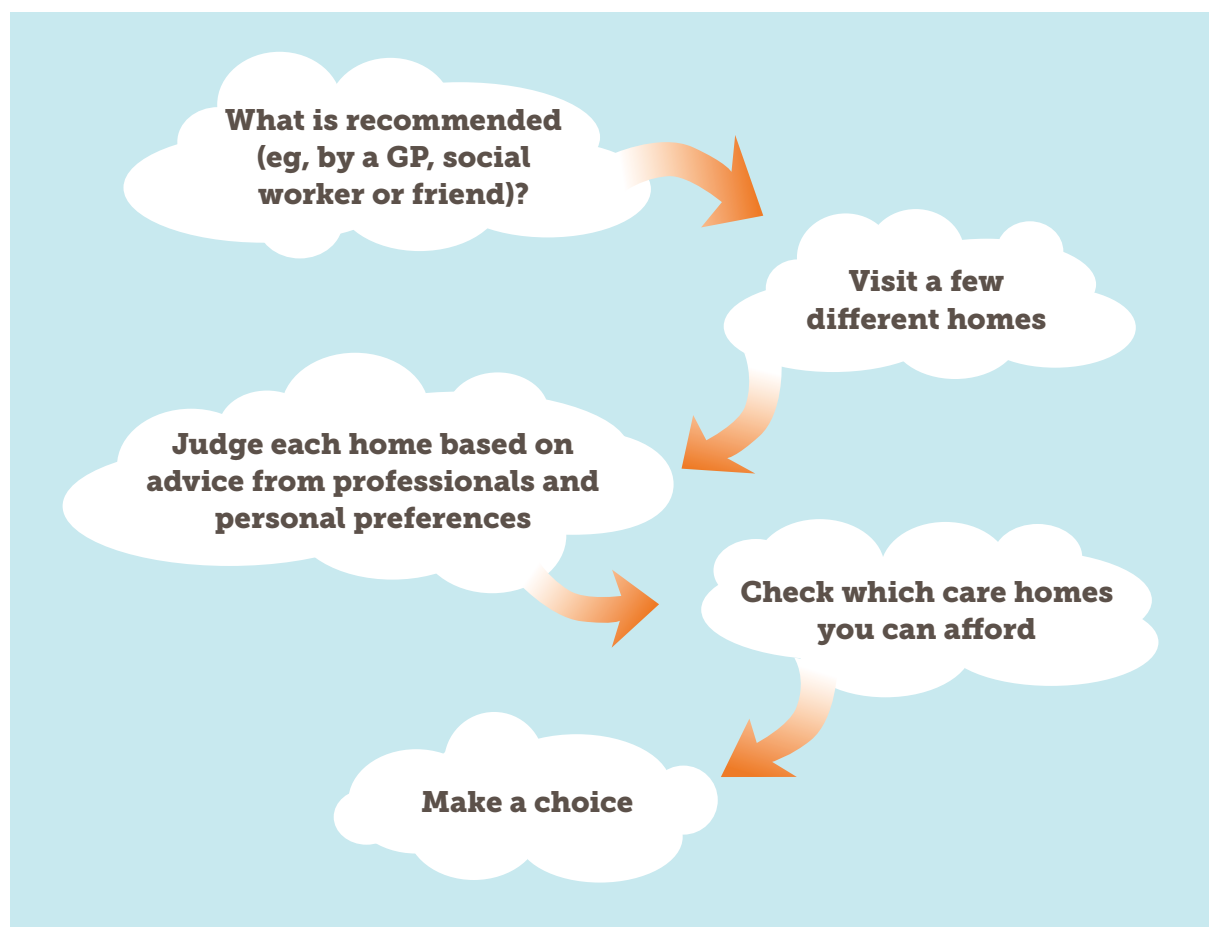
Expectations around decision-making

As with other major decisions in life, people approach choosing a care home with a set of expectations about what the process will look like. They generally expect:

- a reasonable number of affordable care homes to choose from
- quite a lot of support and advice from professionals – particularly GPs and social workers
- to have plenty of time to make a decision
- to be able to access the information they need to make an informed decision
- to gather most information face-to-face and through home visits.

Despite the mistrust that they had of care homes, people in our Poole focus group expected the process of choosing a home to be relatively straightforward, and to look something like **Chart 1** overleaf.

Chart 1: Decision-making process for group with no experience of choosing a home



What is the reality?

In contrast to this first group, who imagined what it might be like to choose a care home without the benefit of experience, a second group of people had recently been through the process of choosing a care home. They described a very different experience, characterised by stress, rushed decisions, little information or support and lack of choice.

In a recent polling by the CQC, 92% of Mumsnet users said that choosing care for a loved one was stressful – more so than getting married, buying or selling a home, or getting divorced²⁸.

Distance from family and friends, costs, availability and ability to meet specific health needs were all urgent and upfront concerns for our Sutton group. The kinds of things that people actually wanted from a care home (such as a friendly atmosphere, good staff retention or a varied activities programme for residents) came a distant second place in their decision-making process – if they featured in decision-making at all. We heard that by the time all local care homes had passed through this series of filters, people were often left with only one option.

28 CQC, Caring Across Generations: infographic, <http://www.cqc.org.uk/content/caring-across-generations-infographic>

Strikingly, those whose care is being paid for by their local council are guaranteed no choice at all: councils must currently only offer one home which meets a person's needs and does not require an additional 'top-up' payment by friends and families.

This sense that choice can be very limited was backed up by what health and social care experts told us:

"There are parts of rural England and there are certainly parts in Wales where your options of choice are limited by what's actually available if your relative has dementia... In some parts of the country, the options of which care home you could choose is so limited that actually you've only got a choice of one."

Independent Age interview with care experts

For people who don't qualify for local authority-funded care and must therefore pay for their own or their relative's care, choice can feel further obscured by a lack of decent information on cost and what represents good value for money when choosing a care home. Elsewhere in our research we heard from self-funders, who felt totally unsupported when they went through the process of identifying a suitable home:

"Getting my wife into a care home was not easy. Everything was fine until the social worker came along and said, 'if you've got more than £23,500, here is the book of homes', and practically said, 'you're on your own' and left."

Middlesex focus group participant

For the group in Sutton that had recently chosen a home, a typical decision-making process looked something like **Chart 2**.

Throughout this process, the risk of making 'the wrong choice' – particularly among people who were looking at care homes on behalf of a family member – loomed large, with people describing choosing a care home as a 'minefield'.

"You ask yourself: have I done the right thing – are they in the right one? But you don't [know] until they are in there."

Sutton focus group participant

In contrast to the group who had no experience of this kind of decision, those who were more familiar with the process reported a distinct lack of help from health and care professionals – particularly in hospitals:

"We rarely saw any nurses when we were there, let alone any advice where needed."

"That's been taken away with the cuts and everything."

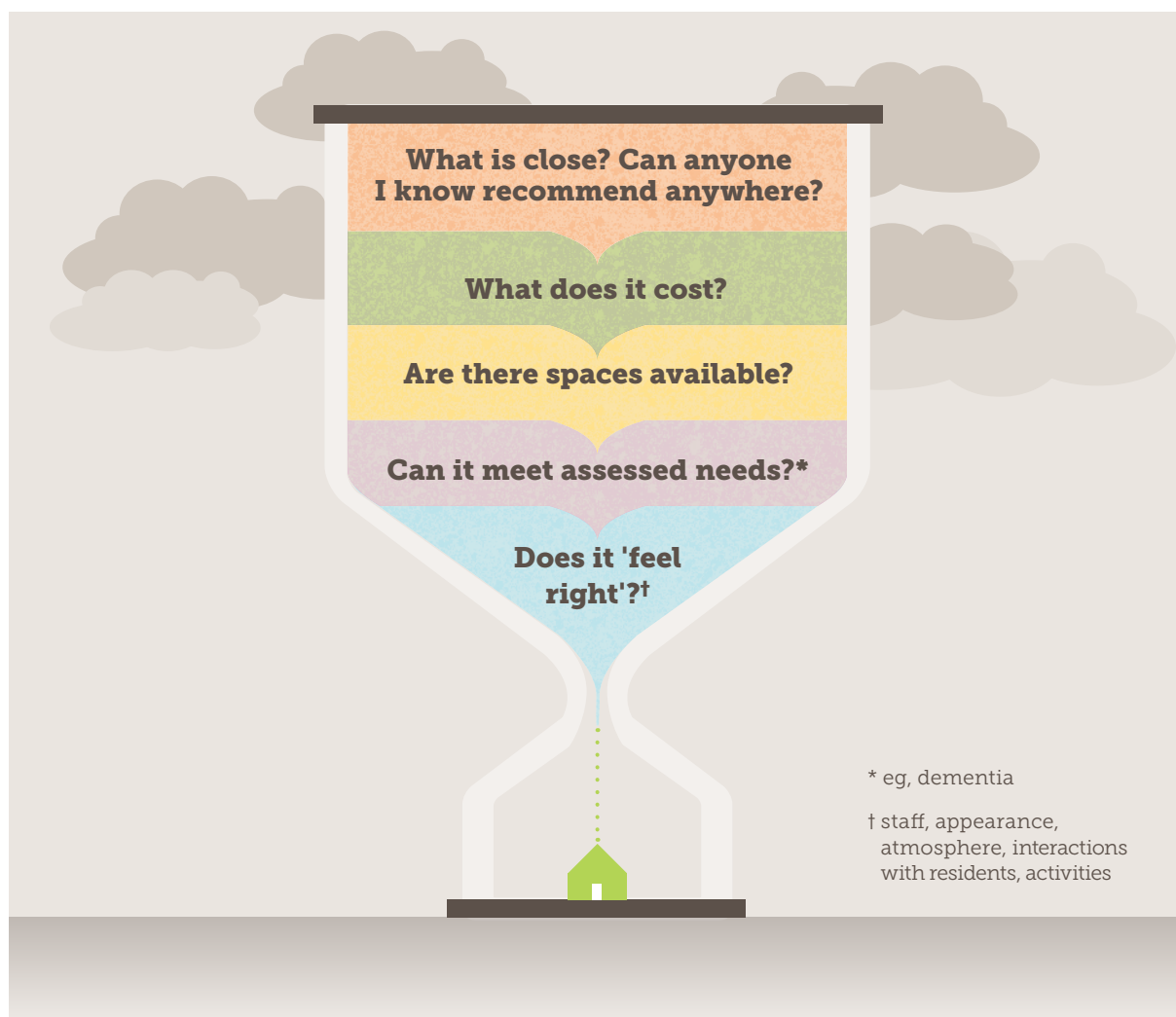
Sutton focus group participants

What the two groups shared was a lack of knowledge of current sources of information about individual care homes, and a deep mistrust of how care homes represent themselves. There was a strong suspicion that care homes are 'saying one thing and doing another'.

"I mean obviously if you look online to find homes, they are going to give a glowing account of their services and how do you really distinguish what is good and what is bad?"

Poole focus group participant

Chart 2: Decision-making process for people with experience of choosing a home



There was also a problem of lack of knowledge around what sources of information on care homes currently exist. Most people in both of our focus groups were simply not aware that such information was out there. When presented with information from the CQC, NHS Choices and a care home listings website carehome.co.uk, participants in our Poole focus group (with no experience of choosing a care home) had not even heard of any of these sources, let alone looked at them.

Even among people who had already been through the process of choosing a care home, nobody had known in advance what the CQC rating of the care home they chose was. One participant had only found out about the CQC's role in inspecting and rating care homes because she happened to be visiting her friend when an inspection was taking place.



A lack of knowledge, and a lack of support from health and care professionals or indeed trust in the available information, left people turning in desperation to more informal, sometimes chance methods. These included speaking to people who lived near to a care home they were considering, or 'driving by' at different times of day to see what was happening:

"We drove around and checked what they looked like and if they weren't nice we drove off."

"They [people who lived near the care home] threw a lot of light that you wouldn't expect, like their deliveries and things."

Sutton focus group participants

Word of mouth recommendations – either by friends, family and neighbours, or by a GP, nurse or social worker – was seen almost universally as a method that people would use to help them narrow down their options.

In fact, the two current Anchor care home residents we spoke to had only ever looked at one option, following a recommendation from a friend.

Another very clear message from our research was that information is no substitute for seeing a care home with your own eyes. We heard that visits carried out by older people, and on their behalf, will continue to play an important role in choosing a care home.

"I think the visits have to be very, very important... Until you walk over the threshold and meet somebody [in the care home], it's all a bit sterile, isn't it?"

Poole focus group participant

However, we also heard how laborious and time-consuming this process could be for relatives, who were often still working and had families of their own to look after. Members of our Sutton focus group estimated that it took six weeks, on average, to select a care home, during which time they were regularly leaving work early or taking time off.

Time to care

With more of us now responsible for both eldercare as well as childcare, many people are struggling to balance the multiple responsibilities of working and looking after family members. Previous research has shown that the UK is falling behind other countries when it comes to developing carer-friendly policies²⁹. Germany, for example has put in place a period of 10 days' leave for a relative of someone with care needs in the event of unexpected illness and a six-month unpaid period of 'long-term care leave'. A further policy of 'family caring time' provides employees with the option of reducing working hours to a minimum of 15 hours over a period of up to two years to care for a dependent relative.

Whilst not everyone we spoke to identified themselves as a carer or necessarily provided round-the-clock care, we did hear about the many adjustments relatives would need to put in place – especially in their working lives – around the time a care home choice needed to be made.

As our population continues to age, more and more adults will be helping their older relatives make decisions around care, whether that is in a care home, or at home.

There is a role for forward-thinking employers, and industry bodies like the Chartered Institute of Personnel and Development (CIPD), to look at their absence management policies. They could review processes for employees who are helping choose or arrange care for an older relative, and extend compassionate leave to staff in these circumstances.

More fundamentally, the government needs to consider a statutory right to care leave and look to international examples such as Germany where policies have been introduced to help working carers.

The government's forthcoming strategy on carers represents an ideal opportunity to strengthen the support available to unpaid carers, especially in helping them to manage both work and caring responsibilities.

Making the right decision

For some of our research participants, decisions on choosing a home were characterised by 'chance and instinct' in the absence of any real knowledge. However, many of those people who had chosen a care home in the past commented that they felt they would make a better decision second time around, with the benefit of hindsight.

29 The case for care leave, Carers UK (2013)

Some had simply become aware of sources of information that they could have used, such as CQC reports, or they had gained a better perspective on the things that can make or break a care home.

"[Would you use CQC ratings to help you choose?] "I would do now, in hindsight, and I didn't even know they existed."

Sutton focus group participant

Since their family member or friend had moved into the care home, people said that they had added to their knowledge of what makes a care home good or bad, and suggested the following additional things that they 'wished they had known' to look for the first time around, in **Table 6**:

Table 6: Additional things people wish they had known to look for in a care home



However often this knowledge comes too late, leaving too many older people and families to make the wrong decision before they make the right one. Independent Age regularly receives calls to our Helpline from people in exactly this situation, such as Alex, who helped his mother choose a care home:

Mrs Walker's story³⁰

Mrs Walker was diagnosed with dementia at 85, after her family noticed she was forgetting to eat and becoming increasingly frail. The council carried out a care needs assessment, and concluded that she could no longer live at home and would have to move into a care home.

Mrs Walker's son, Alex, was told that although his mother qualified for local authority care funding, he would have to find her a suitable care home himself.

He knew very little about care homes, and found it very difficult to understand what information was available and what he needed. He visited a number of care homes, only to be told that they were not accepting new residents. Finally, he settled on a home that was close, so that he could visit often and stay in touch with his mother as much as possible.

However, after Mrs Walker moved to the home, Alex noticed she was getting unhappier by the day, and more and more confused. When he tried to find out why, he realised her medication was being administered erratically, and that when his mother called for help, it took a long time for staff to answer.



There also seemed to be confused older people wandering down the halls of the home at all times of day and night, with very few staff around to take care of them.

After a number of complaints which went largely unanswered, Alex felt he had no choice but to search for a new home – despite the disruption this would cause to Mrs Walker's care, and the threat to her health.

This time, armed with a better understanding of what to look for in a care home, and what to avoid, he found a suitable home where Mrs Walker lived happily for 18 months. With access to better information, however, Alex is sure he could have avoided the confusion and health risks that his mother faced at the first home.

³⁰ All names have been changed to protect the identity of our case studies

What would help?

There are rarely second chances. So we want to see older people and their families empowered to get this crucial decision right first time. We asked people in our focus groups what they thought would help them to do this, and they had several suggestions. These included:

- the ability to speak to current residents and their families to ask them questions about life in the care home – or at the very least to see their feedback reflected in quality reporting (similar to the Friends and Family Test currently used in the NHS)
- a clear, succinct list of things to look out for when choosing a care home – possibly in the format of a checklist of questions to ask
- for sources of information to be clearly independent and trustworthy
- for all information to be presented in one place, on a dashboard that people could access quickly and easily (a ‘Tripadvisor for care homes’).

The sheer range of information currently captured on care homes, presents an overwhelming array of things that older people and their families could look at when choosing a care home. However there is very little clarity on what’s most important. This creates a care home quality landscape that is almost impossible to navigate – and not just for older people and their families.

2 Who collects and provides information and for what purpose?

Information on care homes does exist – for consumers, providers and regulators – but it has a tendency to create more questions than it answers, as it is not all attached to a single, shared framework for quality. Instead, different organisations collect different pieces of – sometimes conflicting – information.

And not all of these organisations are sharing the information they gather about care homes in the public domain where it can be picked up by older people and their families. The result is a huge amount of information swirling around ‘behind the scenes’, in stark contrast to the dearth of useful and good quality public information.

The many different sets of eyes on care

As part of our research, we interviewed 23 health and social care leaders and professionals about their perspectives on quality in care homes, including how it is measured and how it is reported. We also organised a seminar with a wide range of academics, charity representatives, commissioners, providers and care experts to identify gaps in information on quality and safety in care homes and to probe how information could be improved³¹

What we learned is that there are many different sets of eyes on care homes, and many organisations have a role in checking that quality of care in care homes is being maintained across a wide variety of measures.

It is not just individuals and families who need information about quality and safety in care homes and nursing homes. In fact, the majority of care is purchased by local authorities, who have a duty to meet the care needs of residents who cannot afford to buy care home places themselves. Councils therefore purchase large numbers of care homes places, often in block contracts.

Clinical Commissioning Groups also need information about quality in care homes. They fund registered nursing care and also commission ‘step down’ facilities when patients are medically fit to leave hospital, but may not be ready to return home or for end-of-life care. Trusts also have an interest in care home quality because many of the patients who arrive at their hard-pressed accident and emergency units have come from care homes and some of these emergencies might, with better care, have been prevented.

31 What do we know about quality and safety in care homes? Independent Age (October 2015)

Who regulates safety and quality?

The Care Quality Commission (CQC)

The Care Quality Commission (CQC) – the regulator for health and care services – is the main reference point for quality across every care home, and is used by a mix of audiences, from policymakers to researchers to members of the public. When talking about the quality of care homes, most people in policy and care circles refer back to the ratings awarded by the CQC.

The 13 fundamental standards that the CQC judges providers against are legislated on by parliament, and include standards around safety, the care environment, staffing, transparency and dignity and respect (see appendix for the full list)³². The CQC monitors routine data – particularly for hospitals and GPs – to identify risks of falling standards, and carries out inspections during which they ask five key questions: is the service safe, well-led, effective, caring and responsive?

CQC reports are skewed towards safety and ‘minimum standards’ rather than wider measures of quality. As participants in our expert seminar commented, this is the traditional role of regulators in other sectors, where there is also a clear separation between what the regulator needs to know and what the ‘customer’ needs to know (for example, an aeroplane passenger would not be expected to check the air pressure on the aeroplane tyres before take-off – they should be able to take for granted that somebody else has already checked this).

This separation has not happened in the care sector, where prospective consumers are largely reliant on the same information that policymakers, researchers and commissioners are using.

CQC reports are therefore much more effective at telling older people whether a potential care home is safe rather than telling them how sociable the home is, or indeed whether they would enjoy living there. The CQC has made efforts to expand the range of ‘soft’ information they gather and collect, but this work will take time and some of the care experts who participated in our research questioned whether it is even the role for a regulator like the CQC to make judgements on quality in this way.

Through its annual ‘State of Care’ and other reports, the CQC provides useful information about factors that correlate with good performance against its standards. The single biggest influence on performance, it says, is the presence of a registered manager in a care home. The information provided is generally of a high standard, but some of the care professionals we spoke to commented on the lack of routine quantitative data.

“There’s very little quantitative information in a CQC report it’s nearly all qualitative in a sense of the inspector’s impression or experience of what they saw... You might in the body of the text get someone saying ‘I was in the dining room and there were four members of staff’...but you won’t get anything that gives you a breakdown of what that care home practically looks like in terms of numbers.”

Interview with care professional

32 CQC, The fundamental standards, <http://www.cqc.org.uk/content/fundamental-standards>

A CQC inspection report is inevitably a 'snapshot' of a home's performance, with inspections scheduled over a short period of time and involving only limited engagement with staff, residents and relatives. In addition, the periods between inspections will vary depending upon the performance of the home in its last inspection, with better performing care homes being reviewed less regularly. In some circumstances, standards can change dramatically very quickly (caused by a change in management at a home, for example).

The most recent CQC State of Care report for 2015/16 reveals there is a particular issue with some care services which on re-inspection fail to improve or even get worse³³. Up to 57% of all social care services which had an initial rating "requires improvement" had in fact remained the same or deteriorated as at July 2016. In the absence of routine or up-to-date data on performance CQC decisions on which services to re-inspect will always be an inexact science. More worrying still, performance can be allowed to slide even further without any real public scrutiny or insight.

However the CQC is by no means the only body which attempts to measure the quality and safety of care homes. As we have seen, local authorities and the NHS are both major users of care and nursing home places. They also have other duties that may require them to understand care home performance. In the section below, we set out the other key players in the collection and provision of information about care homes.

Who else collects and provides information?

Local authorities

Most local authorities also collect additional information about the quality of care home provision, particularly those that they commission services from, as part of their contract management and quality assurance processes.

This reflects the fragmentation of available information and advice around care. Local authorities are required under the Care Act to provide information on the process of applying for care, the available financial support for service users, what local services are available and more. However they are not required to publish detailed information about individual care homes.

Care homes may be visited by multiple teams within the local authority, including those responsible for quality assurance and compliance, safeguarding, and social workers reviewing individual placements within the care home. Little of this potentially rich information is available to others who might need it however (including the CQC). Very few local authorities publish the additional information they collect about local care home standards. Even those that do release the information, like Birmingham, publish only the conclusions of their investigations, rather than the evidence that informed them.

³³ The state of health care and adult social care in England 2015/16, Care Quality Commission (October 2016)

Clinical Commissioning Groups (CCGs)

Similar to local authorities, local NHS commissioning bodies may carry out quality assurance in nursing homes, as well as reviewing the care of residents who are receiving funding from the NHS, such as continuing healthcare (CHC) funding.

Care home owners and managers

Care homes – particularly those that are part of larger chains – may also collect and report their own quality measures and seek feedback from residents, families and staff to help understand their own performance and identify areas for improvement. They may have their own governance processes for reporting quality in line with the CQC Fundamental Standards. Many care homes also collect and report data to the industry training body, Skills for Care, which then provides those homes that do participate with a measure of their own performance against the industry aggregate in areas such as staff turnover. Once again, however, the data on individual homes is not available to others in the sector or to the public.

Department of Health

Some social care data is collected on behalf of the Department of Health (DH) by NHS Digital and others. However, the majority of these are collected and reported at local authority level, rather than provider level, meaning that their usefulness for judging the quality of individual care homes (or other types of provider) is extremely limited.

One exception to this is the National Minimum Dataset for Social Care (NMDS-SC). The NMDS-SC – run by Skills for Care on behalf of DH – collects workforce data from participating social care providers (including care homes) covering 23,000 locations and around 730,000 staff. The database holds information on numbers of staff, working patterns, length of time in the role, turnover, vacancy rates, pay, qualifications and workforce demographics.

The NMDS-SC also acts as a workforce planning tool for social care providers, allowing them to review their own staffing and training, and compare this with other similar organisations. The data it contains is also useful to policymakers, commissioners, researchers and (where providers agree to share the information) the CQC and people choosing care homes via NHS Choices³⁴. However it does not provide a clear enough picture of quality care as experienced by service users, unlike the National Minimum Dataset in the US.

It is only voluntary for registered care providers to participate and return information on their employees. Although it covers the majority of care homes, the data cannot provide a comprehensive profile of the entire care workforce.

NHS Choices

NHS Choices is the main public platform for people to find out information about health and care services, including care homes and nursing homes. It pulls in data, mainly from sources such as the CQC and NHS Digital and displays it as a dashboard that – in theory at least – members of the public can use to compare and choose between different care providers.

³⁴ <https://www.nmds-sc-online.org.uk/>

However, data sharing for the purposes of understanding and benchmarking quality of social care particularly remains ad hoc.

Information is often incomplete but even where it is more comprehensive, it suffers from a consumer perspective as being merely the data that is available to NHS Choices rather than the data which is the best indicator of quality.

The original vision in the Government's 2012 Care and Support White Paper was for the public to be able to access independent quality ratings that are easy to understand and continually updated but far from achieving this, large numbers of care homes don't have public ratings of any kind provided on NHS Choices. There is a Friends and Family Test which provides people with satisfaction ratings to help choose between local health services, but resident or relatives' feedback on the quality of care homes on the website is comparably lacking.

In addition to these many pairs of eyes, care homes themselves must follow the guidance and quality standards issued by the National Institute for Health and Care Excellence (NICE), NHS England and others.

As well as the very large gaps in quantitative measures of quality in care homes, what is often also missing from this data is any real sense of how residents experience the care home in which they live, or the difference that the care provided there is making to their lives, in terms of health and happiness.

As one care professional who we spoke to pointed out:

"The current standards, for example, say nothing about social interaction. They say nothing about ever leaving the premises."

Interview with care professional

To fill this gap, new approaches have emerged that focus on resident outcomes and experience – two of the most well-recognised of which are the Your Care Rating survey of care home residents: and ASCOT (Adult Social Care Outcomes Toolkit)

Your Care Rating

Your Care Rating is a survey of care home residents that asks questions about life in the home in a standardised way that allows different care homes to be compared. Each home is awarded an overall rating out of 1,000, as well as further scores across four themes – staff and care, home and comforts, choice and having a say, and quality of life. The survey is repeated annually – in 2015, 20,520 residents from around 1,000 care homes completed the survey³⁵.

Many care professionals we spoke to were enthusiastic about the Your Care Rating survey – and the possibility it offers of benchmarking care homes and understanding people's experience of living in care homes.

35 Your Care Rating 2015 – Technical Note, http://www.yourcarerating.org/creo_files/upload/default/YCR%202015%20-%20Technical%20Note%20for%20Public-facing%20Website_100216.pdf



"The great thing about the Your Care Rating is that the survey is independently taken from the care providers and Ipsos MORI is the organisation that undertakes that work, so it's a very reputable organisation."

Interview with care professional

However, they also cautioned against placing too much weight on it. Given the prevalence of dementia and other health conditions, only a handful of residents in each care home are able to take part in the survey. Also, no attempt has been made to see whether Your Care Rating feedback correlates with other measures, such as CQC ratings, or whether the feedback can itself act as an early indicator of homes experiencing falls in quality.

ASCOT

ASCOT is a measurement system, developed by the Personal Social Services Research Unit (PSSRU), for capturing information about an individual's social care-related quality of life. The ASCOT measurement tools cover a range of domains from food and drink, personal cleanliness and comfort to control over daily life and social participation – all of which have been robustly researched to ensure they reflect the things that matter to care service users. Data is collected through a combination of interviews with residents, relatives and staff, and observation, and reflects the difference that social care makes to the different aspects of a person's quality of life.

It represents a new attempt to evaluate the more experiential aspects of life in care homes that other data doesn't always address, but at this stage it is primarily used by academics and a limited group of professionals.

36 <http://www.carehomeopenday.org.uk/>

A question tracking changes in social care-related quality of life is contained in the annual Adult Social Care Survey. There have been some attempts to apply the model internationally but, in common with other initiatives, it hasn't dramatically altered public access to or use of information on quality in residential care.

Other initiatives that seek to positively promote and improve public understanding of life in the UK's care homes are My Home Life and National Care Home Open Day³⁶. Thousands of care homes take part to create stronger links between care homes and the community they are located in.

Rating and review websites

Over a number of years, a range of independent review websites have been set up, some with more success than others. Sites include carehome.co.uk, Which? Elderly Care and the Good Care Guide and for a large number of these the ambition is to provide a space for user-led reviews. They also typically contain standard information on the facilities in a care home and details of the home's most recent CQC inspection or rating.

Depending on the site, users can leave reviews on a care home's quality of care and staff, facilities and cleanliness, value for money and food and drink. Some have attempted to invite user feedback on other areas, for example the activities on offer. Unfortunately what many struggle with is achieving the critical mass of user feedback that could genuinely help other customers confidently choose between homes.

Some care rating sites have been criticised in recent years for providing inaccurate or misleading data. Earlier this year (2016), an investigation carried out by the Competition and Markets Authority (CMA) found that:

- some processes and policies used by care rating sites have the effect of preventing or delaying negative reviews from being published, or otherwise distorting the picture presented to site users
- some sites' checks of reviews were not sufficiently rigorous given the risk of fake reviews; and
- some sites did not clearly and prominently explain to site users how they collect, check or publish reviews³⁷.

While a number of care ratings sites³⁸ have entered into an agreement with the CMA to improve their practices, many people will be left unsure of the quality of information care rating sites provide in general.

"I think one has to be careful online that it isn't a commercial proposition rather than an independent assessment and with the way people name their websites these days, you are never quite sure whether it is independent."

Poole focus group participant

37 CMA, Summaries of the five agreements, 2016: https://assets.publishing.service.gov.uk/media/56bc816440f0b617db000012/Summaries_of_the_five_agreements_v2.pdf

38 Checkatrade, Trustatrade, Carehome.co.uk, Care Opinion, and Most Recommended Care, for example.

Mystery shopping

Care homes themselves are often the first port of call for older people and families who may be unaware of official and independent sources. In fact, initially speaking to the care home manager or staff, was the most common approach taken by Independent Age campaigners who we asked to share their experiences of choosing a care home.

To evaluate the quality of information available directly from care homes, we undertook a mystery shopping exercise with 100 care homes in England. We used the following sample breakdown³⁹:

CQC rating	Number of care homes in sample
Outstanding	10
Good	60
Requires improvement	20
Inadequate	10
Total	100

We then phoned each care home to enquire about a (fictional) 85-year-old grandmother looking for a care home place. She would be paying for her own care, and had been assessed as not needing nursing care.

We asked the following basic questions, and scored the quality of the care home's response as 'good', 'satisfactory' or 'bad':

- How much do you charge per week (single room, without nursing)?

- Can you tell me a little bit about what life is like for people living in the home?
- Who is the manager?
- What training do you give your staff?
- What is your most recent CQC rating?
- How do you know that you are delivering a good service?

Those care homes that were unable to answer the question asked, or provide any additional detail, were rated 'bad', while those that gave a full answer were rated 'satisfactory' and those who provided additional helpful information were rated 'good'.

The results from the analysis revealed significant gaps in the information available directly from care homes about their own services:

- 2 in 5 (40%) of the care homes we spoke to were unable to provide a 'satisfactory' or 'good' answer to all six simple questions.
- Only 1 in 25 (4%) of the care homes we spoke to were able to provide good answers to every question, and none of those care homes had the top CQC rating of 'outstanding'.
- 1 in 15 (7%) of the care homes we spoke to were unable to provide a 'good' answer to any of the questions we asked, including five care homes rated 'good' by CQC and one rated 'outstanding'.

³⁹ This broadly reflected the national distribution of care home quality, but with an increase in size for outstanding care homes (only 0.5% of rated care homes received the outstanding rating by the time of publication of the 2014/15 State of Care report) and inadequate care homes (only 6% of care homes had received the inadequate rating by the same point). As a result, our sample is likely to include a slightly higher quality of care homes than the broad market.

In more detail:

- Almost 1 in 5 (19%) of the care homes were unable to provide a satisfactory or good answer about the training they provided to staff.
- 1 in 6 (17%) care homes were unable to provide a satisfactory or good answer about their latest CQC rating, and what it meant; and
- 1 in 8 (12%) care homes were unable to provide a satisfactory or good answer about how they knew they were delivering a good service.

This demonstrates that too often older people and their families cannot access the information they need to make an informed decision about a care home, even when they are speaking directly to the care home itself.

Complex care market

In addition to this mystery shopping exercise, a number of older people we speak to through our Helpline tell us they are not always clear about the care home contract they or their relatives are being asked to sign. This is a market place in which consumers can feel very disempowered with issues regularly being raised with us around sudden or arbitrary fee increases, unclear notice periods and pressure to pay top-up fees to maintain a standard level of care.

As a next step, we believe the Competition and Markets Authority should conduct a full market review of the care home sector to see whether it is a market that is working well and whether consumers are getting a fair deal, particularly in relation to information on quality and cost.

Mr Jones's story*

Mr Jones's mother-in-law has dementia. She had been living in a care home for over three years, with the local authority making a contribution and Mr Jones paying an additional fee to completely cover the costs of her care.

Mr Jones received a letter from the care home explaining that in addition to the standard fees, the weekly 'top-up' fee that he pays for his mother-in-law's care would triple due to the National Living Wage being introduced for care staff.

When Mr Jones challenged this, the care home said that they had not increased his 'top-up' fee for over three years, and had permission from the local authority to increase it. Mr Jones wasn't aware they had a right to do this. The care home responded by sending Mr Jones a new agreement to sign, but he remains unclear about why he is personally responsible for covering these extra costs.

*All names have been changed to protect the identity of our case studies

The challenges of capturing care home quality in data

The professionals we interviewed as part of this project, highlighted some of the conceptual difficulties involved in measuring quality in care homes, including:

Capturing the experience of residents, staff, families and visitors

Current quality measures tend to focus on features of the care home itself (eg, is it clean, does it have enough staff, does it keep people safe?), rather than reflecting how people feel about living in, working in or visiting the home. Capturing the views of residents in particular can be methodologically challenging due to the level of disability and capacity of some residents, and concerns about whether their responses will get back to the manager or staff and cause offence:

“When you have got a very frail and older population, 80% of whom have dementia, filling in questionnaires is hard.”

Independent Age interview with care professional

“I think when you are asking someone where they are living 24 hours a day if they like it, chances are they generally say they do, whatever their feelings, because they are not free agents and they don’t generally think that what they are saying is not known by the person running the home.”

Independent Age interview with care professional

Recognising that quality is subjective

People will always have different views of what makes a quality care home, and no single list of quality measures will be able to satisfy everyone.

Setting a benchmark to see whether providers are meeting the standards

Some potential quality indicators (such as the number of falls in a care home) need to be compared to what would be an acceptable level. How many falls is too many falls? How many pressure ulcers is too many ulcers?

Some indicators are meaningless without knowing exactly who is living in the care home

Certain indicators make more sense when you know more about the residents living in the home – are they slightly younger and more fit and active, or elderly and ill? How many have dementia? For instance, looking at the number of falls again, you might expect more falls if a home goes out of its way to keep its residents active, rather than leaving them to spend most of their time sitting.

In addition, the nature of the social care system poses significant challenges for data collection.



The social care sector lacks a culture of data collection comparable to that of the NHS.

The NHS was recognised by those we interviewed as being further advanced in data collection practices, with better information systems, and dedicated departments and budgets – a situation that has been partially driven by health commissioning practices. Given the huge variation in size of providers in the adult social care sector, it may not always be reasonable to expect the same amount of data to be collected across the board.

People's relationship with social care is very different from the one they have with the NHS

With the NHS, it tends to be short-term, episodic and focused on clinical outcomes. In contrast, social care services – including care homes – support people over periods of months if not years. During this time, their aim is not to treat health conditions, but to allow people to live full, happy and meaningful lives in spite of their health conditions and disabilities. This requires a very different set of measures, which will be far more focused on softer, qualitative outcomes.

Social care is delivered in more than 20,000 locations, ranging from small family-run care homes to chains with hundreds of homes across the country. This makes consistent data collection much more challenging than in, for example, a hospital context.

Different ambitions for transparency in health and care

The Secretary of State for Health has made a series of speeches calling for more transparency and “patient power” in health services and for the NHS to become the world’s “largest learning organisation”⁴⁰. Driven by a number of high-profile failings in hospital safety, the government has talked about the need for the NHS to become more “human-centred”, not just “system-centred”⁴¹ in terms of targets and the information it gathers and reports.

This higher set of expectations for health care is perhaps best reflected in the wide range of quality measures the public can look at when comparing performance in GP surgeries, available from Public Health England⁴². Its National General Practice Profiles makes public a huge range of information, from the percentage of patients who saw or spoke to a nurse or GP on the same day through to those reporting a good overall experience when making appointments”.

More information is also publicly available about hospitals than care homes. A typical hospital profile on NHS Choices might contain seven metrics, including whether the hospital concerned has a good approach to reporting safety incidents and information on infection control and cleanliness. There are also far more user ratings than is typically the case for care

homes. This increases the likelihood members of the public will act on this information to assist with their own decision-making process.

Unfortunately, the Department of Health hasn’t shown the same level of ambition or vision for improved reporting or transparency in residential care. Where NHS Choices really can help the public most is by reporting how many members of the public would recommend a service. For example, for GP services this data is taken from the GP Patient Survey. The hospital profiles provided on NHS Choices share handy details about the percentage of staff who work for the hospital that would recommend the service to a friend or relative if they needed treatment. Care services simply can’t report on any of these benchmarks around service user or staff satisfaction, which a range of health services are expected to routinely report against.

Healthcare in care homes

Six areas in England – ‘care vanguards’ – have been looking to offer older people more joined-up care with a particular focus on enhanced health for residents in care homes. However, the new model framework for enhanced health⁴³ acknowledges that for many care home residents, quality is being held back by a number of barriers which include “a narrow focus on medical rather than holistic needs” and “variable access for care home residents to NHS services”.

40 Making healthcare more human-centred and not system-centred’, Speech by Rt Hon Jeremy Hunt MP to The King’s Fund, July 2015

41 Making healthcare more human-centred and not system-centred’, Speech by Rt Hon Jeremy Hunt MP to The King’s Fund, July 2015

42 <https://fingertips.phe.org.uk/profile/general-practice/data>”

43 The framework for enhanced health in care homes’, NHS England, September 2016

Whatever the improvements being made NHS England still believes many people are not having their needs properly assessed and addressed in care homes. As a result, they say, care home residents “often experience unnecessary, unplanned and avoidable admissions to hospital, and sub-optimal medication”.

The NHS Safety Thermometer contains detailed information on pressure ulcers and falls, including falls that lead to harm but the results are only available for a random selection of homes, possibly homes which provide NHS-funded care to residents with nursing or continuing healthcare needs who may have to report against such measures as part of contracts with clinical commissioners.

‘Care confusion’

We have seen how different organisations have varying views of quality – this results in a muddled view of what quality looks like, which impacts on older people, their families and on care homes themselves.

The Department of Health has been looking at the burdens on care home providers and how these might be reduced as part of its ‘Red Tape Challenge’⁴⁴. An action plan with a range of local authority and care sector partners is now progressing with one key driver a need to rationalise the volume of information requested from providers and simplify data requests and returns.

However, as part of our research, care homes managers told us they struggle with fulfilling multiple reporting requirements that can leave them feeling pushed and pulled in all directions. A care home enquiry for the Joseph Rowntree Foundation (JRF) found that care homes are typically required to complete over 100 separate pieces of paperwork on a regular basis – and some care home managers estimate spending 20% of their time filling in forms⁴⁵.

Managers complain that there is no co-ordination of the different sets of data they are required to provide to the CQC, and to different bodies within local authorities and the NHS.

“You’ve got to think about how it’s collected and how much work it takes people to collect it and analyse it, because there’s no extra capacity – so everything that people do in a care home takes you away from dealing with the residents.”

Independent Age interview with care professional

However, this array of data has been largely unsuccessful in supporting older people and their families to feel well-informed about care. In spite of all of this existing information, participants in our research reported feeling that care homes remained almost ‘unknowable’, that the array of information available was confusing and contradictory, and that they didn’t know which sources of information were trustworthy. These are the challenges that remain unaddressed.

44 Cutting Red Tape – Response to the Review of Adult Social Care Residential and Nursing Home Sector, Department of Health (February 2016)

45 Warmington, J., Afridi, A. and Foreman, W. (February 2014), Is excessive paperwork in care homes undermining care for older people?, Joseph Rowntree Foundation, <https://www.jrf.org.uk/report/excessive-paperwork-care-homes-undermining-care-older-people>

3

What's missing?

Both professionals and the wider public need far better data and information about care homes and nursing homes than the market currently provides.

We propose that this information can be categorised roughly into two groups. Harder, often quantitative data about safety could be used by commissioners, regulators and others to measure the performance of homes and provide an alert if things appear to be going wrong. Some of this data may also be useful to the public.

Secondly, a set of softer measures could be used by individuals and their families to help them make a finer judgement about which care homes provide the best quality experience. As an older people's charity focusing on providing information to the public, in this section we concentrate mainly on the second area. However, by working with sector experts, and looking at international experience, we have also been able to identify a number of the quantitative measures that could be used to provide the first set of indicators.

Basic indicators of safety

Sector experts – including providers, commissioners, regulators and academics – highlighted a number of quantitative measures that could be important indicators of safety and quality in care homes. Perhaps the most frequent was the incidence of pressure ulcers.

Pressure ulcers (often known as pressure sores or bed sores) typically occur in people who are confined to a bed or a chair, as many people in care homes often are. They are graded from one (the least serious) to four. They are painful, costly to treat, and life-threatening at their most extreme. Crucially, up to 95% of them may be preventable so their prevalence in a care home may act as a 'smoking gun', indicating a problem with quality⁴⁶.

Care homes are only currently required to report grade three and four pressure ulcers to the CQC, and this information is not routinely shared with Clinical Commissioning Groups or, of course, with the public. Experts we spoke to felt that there was scope for much greater use of data on pressure ulcers.

⁴⁶ Pressure ulcer prevention: making a difference across a health authority, British Journal of Nursing, 2013, Volume 22, No 12 <http://nhs.stopthepressure.co.uk/docs/BJN-Article-2013.pdf>

In addition, the following indicators were often suggested:

- existence of a registered manager (and time in post)
- staff turnover
- ratios of staff to residents, daytime and night-time
- safeguarding alerts and number of death notifications
- indicators of malnutrition and/or dehydration
- prescriptions of antipsychotic and/or anti-depressant medications
- number of falls
- other indicators of skin integrity (e.g. bruises)
- number and type of complaints received
- ambulance call-outs.

Of course, we recognise that quality will be too complex and personal to be able to crack in just 10 indicators, and there will be many, many more important pieces of information.

Indeed, in the course of our research with care professionals, families and older people, almost 100 potential components of quality were suggested to us – ranging from how you are greeted when you walk through the front door of the care home to how many residents are being prescribed anti-psychotic medication.

The use of antipsychotic medication was singled out however as a particularly important marker of how a home is ‘managing’ its residents.

One recent study, based on experts examining prescribing data from more than 600 care homes, found no significant decline in antipsychotic prescribing rates over a four-year period⁴⁷ and highlighted how prescription levels still remain too high.

Such a list of indicators could and should form the basis of a Minimum Data Set for social care in England.

Forming the basis of a Minimum Data Set for social care in England

In contrast to the fragmented system currently in place in England and other parts of the UK, countries elsewhere have streamlined their data collection processes into a single multi-purpose assessment framework, known as a National Minimum Data Set.

What is a National Minimum Data Set?

A National Minimum Data Set (NMDS) is – as the name implies – a minimum set of measures that have been agreed for mandatory collection and reporting at a national level. It uses a single assessment process for people receiving long-term care, whether this is in a care or nursing home, or in the community. For a NMDS to exist, there needs to be a national agreement between all organisations involved about what will be collected, by whom and in what format.

47 Szczepura A, Wild D, Khan AJ, et al. Antipsychotic prescribing in care homes before and after launch of a national dementia strategy: an observational study in English institutions over a 4-year period. *BMJ Open* 2016

It is only a minimum data set – which means that organisations may collect additional data to suit their own requirements.

There have already been a number of ongoing attempts to address some of the deficiencies in current care home quality data, either by collecting additional measures or through better co-ordination of existing information, bringing it all together in one place where it can be useful.

However, implementing a true NMDS for care home quality could have a number of advantages over simply joining up existing sources of data.

It would reduce the amount of duplication, by introducing standard measures, as opposed to the current situation where care homes are required to report similar things in slightly different formats to different bodies.

The US Minimum Data Set (MDS)

The US Minimum Data Set (MDS) is one of the longest established National Minimum Data Sets in the world. It was introduced by the Centers for Medicare and Medicaid Services during the 1990s, following a series of high-profile failures of care in long-term nursing establishments.

The MDS collects data from the clinical assessment of all residents in Medicare and Medicaid certified nursing homes. As such, data is collected at resident level and expressed in terms of resident outcomes (for example, whether the resident has a pressure ulcer, or has received the flu vaccine). These can be aggregated to show the proportion of residents in any given nursing home who are experiencing that outcome, and allow comparison between different homes, with state averages.

The assessment is carried out when a person enters a nursing home, and is repeated regularly.

It covers a huge range of outcomes including:

- daily routines
- ability to communicate
- indications of depression or anxiety
- ability to move around and perform tasks such as eating and dressing independently
- quality of social relationships and sense of social identity
- involvement in activities
- nutritional status
- medications
- skin conditions (eg, pressure ulcers, bruises, other wounds, foot conditions).

Taken together, this information charts residents' progress from the time when they move into a nursing home, and reflects the impact that care is having on their health and wellbeing. Have they become more sociable? Less anxious? Are they eating more?



Implementing an NMDS could also help satisfy the demand for better public information to help people choose care homes, as covered in the first part of this report.

In the US, the Medicare Nursing Home Compare website represents the 'front end' of the Minimum Data Set – it allows members of the public to access a dashboard of quality indicators for all nursing homes.

There is now a strong case for policymakers to consider whether there should be a similar minimum data set for care homes here in England.

The Care Quality Commission should work with the Department of Health and other stakeholders to agree a single, shared view of safety and quality in care homes and an agreed set of core indicators (a 'minimum data set') to be collected for all homes. This should form the basis of the data required by all commissioners of care home and nursing home services so as to minimise the data provided by homes and reduce duplication and overlap.

Better information for families

Such a data set should also be available to families, though it would be important to allow providers the opportunity to add context and narrative around the raw data. In addition, what we – and many experts we spoke to – felt was missing was a view of quality that is not overwhelmingly complex, and that reflects not just experts' concerns, but also the concerns of older people, their families and friends.

This would satisfy the demand from older people and their families for some 'starters for ten' when looking for a care home.

We looked at the areas of quality of most interest to three different groups of people: family members of care home residents; older people who have never had to choose a care home before; and professionals working across health and social care.

As a result, we have a better sense of what constitutes quality and what the most important expectations are when looking to choose a care home. **Table 7** overleaf highlights the areas where agreement overlapped across the groups in terms of which areas of quality should be prioritised.

Table 7: Areas of quality that different research participants agreed were important



Overlap	Area of quality
Flagged up by health and social care professionals, older people and families with or without direct experience of care homes	<ul style="list-style-type: none"> • Home has a nice atmosphere, is homely, welcoming • Home is clean and hygienic with low infection rates • Staffing levels – day and night, enough staff on shift to help people promptly and flexibly with things like eating, dressing and going to the toilet • Staff treat residents as individuals, with warmth, respect and dignity • Staff turnover is low • Staff are well qualified and ongoing training needs are met • Staff speak good English/are able to communicate with residents in their preferred language • There are no set visiting hours • A wide range of activities are on offer – both inside and outside of the home, and these are tailored to the tastes and preferences of individual residents • Good links with the local community – residents are helped to go out and about if they are able, the home is well known and used locally • Residents and relatives would recommend the home
Flagged up by those with more direct experience of care homes only	<ul style="list-style-type: none"> • Staff morale is high, staff enjoy their jobs • Home is able to meet the changing needs of residents (eg, developing dementia, increasing physical frailty) • Home is open to comments and complaints, these are handled well, willing to answers questions, 'nothing to hide' approach • Home is well managed – manager is present on site, provides good support to staff and management is stable • Residents have regular access to a GP • Residents' specific cultural and spiritual needs are met
Flagged up by older people and families but not professionals	<ul style="list-style-type: none"> • Food is tasty and tailored to residents who have trouble chewing or swallowing • Residents have a sense of purpose, are able to continue with familiar routines (eg, cooking, cleaning, gardening, DIY)

4 A way forward: better information for families

Reflecting on these insights and the desire to see a single, coherent view of quality, we have drawn together a list of 10 quality care home indicators (see **Table 8** overleaf). We believe these indicators serve as a useful basis for:

- older people and family members or carers looking for information to help them choose a care home.

They draw on some of the data we have recommended to help commissioners, regulators and the wider care sector make better judgements about care home quality.



Table 8 'A good care quality home should':
Independent Age's Care Home Quality Indicators

1 Have a registered manager in post.

The registered manager is the most important staff member in a care home – and the one responsible for ensuring quality standards and residents' needs are met. They should be visible within the care home, provide good leadership to staff, have relevant experience of the health and care system and qualifications to help them do their job.

2 Have a stable workforce. Care homes with knowledgeable, experienced staff who get to know residents can make the difference between an institution and a home. Where turnover of staff is very high, these qualities can be lost. It may also be a sign that staff are not happy working in the home.

3 Have staff who have the right skills to do their jobs. Well-informed, skilled staff who are valued and developed as employees are vital to a smooth-running care home. All care homes should have a clear, comprehensive training scheme to ensure staff have the knowledge they need.

4 Have enough staff on duty during the day and night. Many homes have a lower proportion of staff on during the night, but if the ratio falls too low – at any time of day – response times can be too slow.

5 Be clear about how they will be able to meet residents' needs both now and in the future. Many residents will develop more care needs as they get older – particularly if they have a condition like dementia. It is vital that homes can spot changes to their health and respond appropriately – consulting other health professionals where necessary – in order to provide the right level of care, and prevent residents from having to move again.

6 Actively involve residents, family, friends and the local community in the life of the home. Homes should have a clear way for residents, relatives and friends to get involved in decision-making in the home, if they choose to, such as a residents and relatives committee. Homes should not have set visiting hours, or any other arrangements that makes them feel more like a hospital than a home. They should have good links with the local community, for example by arranging visits from local schools.

7 Offer meaningful activity and enjoyment to suit all tastes.

Care homes should not be boring places – they should offer an interesting range of activities and entertainment that match the tastes and preferences of their residents, including individual activities. Homes should take steps to stop residents from becoming isolated or lonely while respecting their privacy and choice.

8 Enable residents to see a GP or other health professionals like a dentist, optician or chiropodist, whenever they need to.

Residents should have the same expectation to be able to promptly see a health professional as they would have when living in their own home. Care homes should be able to explain the relationship they have with their local NHS services – does a GP visit regularly? Can they call a GP out in an emergency? How easy is it for residents to see a dentist, optician, chiropodist or physiotherapist, either for a check-up or in an emergency?

9 Accommodate residents' cultural and lifestyle needs.

Care homes should be set up to meet residents' varied cultural and lifestyle needs as well as their care needs, and shouldn't make people feel uncomfortable if they do things differently to other residents. They should also be proactive in finding out what an individual's needs are, so they can accommodate them.

10 Show that they're always looking to improve.

People choosing a care home should be able to find out what current residents, their families and friends think about the home. The care home should be happy to help people do this – for example, by putting someone in touch with a residents and relatives group, or allowing someone to speak to residents and visitors in private. They should also have support in place for people who wish to make a complaint at any time, and there should be a healthy culture of challenge and feedback among residents, relatives and staff.

Conclusions and recommendations

In this report, we have highlighted three related issues that act as an obstacle to older people's and their families' efforts to choose a care home that matches all of their criteria for a good quality home:

- 1 Too many interpretations or versions of quality**
- 2 Lack of consistent and standardised data collection in social care**
- 3 Lack of transparency and easily available information to support care home choice**

We believe there are a number of actions all of us concerned with improving quality in care homes can take, some of which can be taken now and some over the longer-term:

For government bodies

- 1** The Competition and Markets Authority should conduct a full market review of the care home sector to see whether it is a market that is working well and whether consumers are getting a fair deal, particularly in relation to information on quality and cost.
- 2** The Care Quality Commission should work with the Department of Health and other stakeholders to agree a single, shared view of safety and quality in care homes and an agreed set of core indicators (a 'minimum data set') to be collected for all homes. This should form the basis of the data required by all commissioners of care home and nursing home services so as to minimise the data provided by homes and reduce duplication and overlap.

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- 3** The Department of Health should demonstrate the same level of policy leadership on the issue of transparency and reporting performance in social care as it has for the NHS.
 - 4** To reach a position where quality care is the norm for all, the overall care market needs to be sustainable. The government needs to respond to the recent challenge set by the CQC, and avoid adult social care reaching a 'tipping point' where quality, funding and capacity continue to deteriorate.
 - 5** More fundamentally, the government needs to consider a statutory right to care leave and look to international examples, such as Germany, where policies have been introduced to help working carers.
 - 6** The Department of Health should commission a Social Care Staff Survey similar to the NHS Staff Survey. By working with industry bodies, they should ensure the survey collects annual data on whether staff would recommend the provider they work for to a family member or friend and whether they have witnessed abuse or neglect.

Older people/their carers or families

- 1** Older people, their families or carers can take the stress out of conversations about care and make them easier conversations to have by discussing the subject ahead of time, before their care needs get worse.
- 2** Older people, their families or carers can prepare for making care home visits by using our care home quality indicators so that quality is the focal-point of their decision-making about choosing the right home. Independent Age's new 'Choosing a Care Home' guide could be a useful tool for people to use.

For care providers

- 1** Care home providers need to improve the quality and accessibility of the information available to older people and their families. They need to be more aware that families are often making decisions under emotional and time pressure.
- 2** Industry bodies, such as Care England, the National Care Association and National Care Forum, should develop resources for care homes of all shapes and sizes, emphasising transparency and trustworthiness – key issues in an industry plagued with fear and suspicion from its target market.

For employers

- 1 Given the importance that seeing a care home with your own eyes will continue to play in the decision-making process, forward-looking employers should be offering compassionate leave to employees who need to take time off to help an older relative or friend to search for care. We call on the Chartered Institute of Personnel and Development (CIPD) to develop guidance for HR professionals on absence management for employees who are helping choose or arrange care for an older relative.

Independent Age plans

Now:

- 1 **Work with Healthwatch Camden to pilot an approach to assessing local care homes on each of our suggested 10 quality care home indicators.**

Longer term:

- 2 **Continue to widen and strengthen the information and guidance we offer to people choosing care homes.**
- 3 **Continue to actively promote Care Home Open Day as an opportunity for people to go and see for themselves the good care choices that are available to them, and help them prepare for choosing care in the future.**

Piloting the 10 quality standards with Healthwatch Camden

Between 2001 and 2011, the number of people over the age of 65 living in a care home in Camden rose by more than 60%. This is an extreme example of a trend occurring across London, and the third highest increase in London⁴³.

Independent Age has partnered with Healthwatch Camden to gather information from Camden care homes on each of the quality indicators through a series of “Enter and View” visits. Through a series of focus groups, we will then test how useful this information is to members of the public trying to find out more about care homes. This will help us refine the quality indicators and add weight to our calls for them to be adopted at a national level.

Between October 2016 and January 2017, Healthwatch Camden will be carrying out “Enter and View” visits of all seven of Camden’s care homes, using our 10 quality indicators.

Following this pilot, we are keen to work with other local Healthwatch organisations looking to develop an “Enter and View” process for care homes in their area. We encourage any interested organisations to get in touch with us at policy@independentage.org.

⁴³ Reported in Independent Age, 2016, *Moved to care: the impact of migration on the adult social care workforce*

Final thoughts

What's clear from our work with older people and their families is that decisions on choosing a care home are being made against a backdrop of extreme and damaging pressure on the health and social care system. Good quality options can feel few and far between, particularly for people whose care is being paid for by the local authority. People are coming under pressure to make decisions about care quickly, and overstretched staff often lack the time to stop and help explain the system to people.

The social care system is under extreme financial pressure. This adds to an environment where choice is limited, and time pressures on decision making are substantial. Between 2009/10 and 2015/16, social care services in England faced a funding reduction of £4.6bn made up of cuts, demand increases and inflationary price rises⁴⁸.

These pressures have severely limited the amount of choice older people and their families have when choosing a care home. For those relying on local authority funding, choice has become far more restricted.

The number of residential care homes has fallen by 12% since 2010, with a corresponding fall of 8% in the total number of beds – meaning there are almost 20,000 fewer beds to choose from⁴⁹.

Due to the squeeze on local authority funding for care home places, the CQC expects that those receiving support from their local authority will be most affected⁵⁰. Even for those who can fund their own care, choice is beginning to decline⁵¹.

There is growing recognition of the need for an honest national debate about the future of health and social care – and politicians from across the political spectrum have come together to call for this to take place.

We believe that this national debate is fundamentally necessary, so that the NHS and social care can stop struggling for survival and focus its attention on achieving world class standards of quality and choice for older people, now and well into the future.

48 ADASS budget survey, 2015

49 The State of Health Care and Adult Social Care in England, 2015/16, Care Quality Commission (October 2016)

50 Care Quality Commission, Market Oversight presentation to Community Care Live 2016: https://s3-eu-west-1.amazonaws.com/cjp-rbi-comcare/wp-content/uploads/sites/7/2015/04/bullring_wed_1400_Stuart-Dean-The-role-of-the-Care-Quality-Commission-CQC-in-market-oversight.pdf

51 Residential care home fees have risen faster than inflation for 17 of the past 24 years: Laing & Buisson, 2015, Care of Older People, UK Market Report, 27th Edition

Appendix:

The Care Quality Commission (CQC) fundamental standards⁵²

The fundamental standards that the CQC expects all health and care providers to comply with were agreed by Parliament in 2014⁵³. These are:

- 1 **Person-centred care** – care or treatment is tailored to meet people's needs and preferences.
- 2 **Dignity and respect** – people are treated with dignity and respect at all times while receiving care and treatment, including having privacy when they need and want it, receiving equal treatment and being given any support they need to help them remain independent and involved in their local community.
- 3 **Consent** – people must give consent before any care or treatment is given to them.
- 4 **Safety** – people must not be given unsafe care or treatment or be put at risk of harm that could be avoided. Providers must assess risks to people's health and safety during any care or treatment and make sure their staff have the qualifications, competence, skills and experience to keep people safe.
- 5 **Safeguarding from abuse** – people must not suffer any form of abuse or improper treatment while receiving care, including neglect, degrading treatment, unnecessary or disproportionate restraint or inappropriate limits on their freedom.
- 6 **Food and drink** – people must have enough to eat and drink to keep them in good health while they receive care and treatment.
- 7 **Premises and equipment** – must be clean, suitable and well-maintained; equipment must be used properly.
- 8 **Complaints** – people must have the ability to complain about the care they receive, and providers must respond appropriately by investigating the complaint and taking action to resolve any problems.
- 9 **Good governance** – providers must have plans in place for how they will meet these standards, and monitor and improve their own performance around quality and safety.
- 10 **Staffing** – there must be enough staff. They must be qualified, competent and experienced, and have the training and support they need to do their jobs.
- 11 **Fit and proper staff** – robust recruitment procedures should screen out people who are not able to provide care and treatment.
- 12 **Duty of candour** – the culture of openness and transparency, admitting to and apologising for mistakes.
- 13 **Display of ratings** – the most recent CQC rating must be on display on the premises, and on the provider website.

52 CQC, The fundamental standards, <http://www.cqc.org.uk/content/fundamental-standards>

53 The Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, <http://www.legislation.gov.uk/ukxi/2014/2936/contents/made>

Appendix:

Independent Age Poll – Care Homes (October 2016)

Half of British adults say that abuse and neglect in care homes for the elderly is common (52%), while around a third (35%) say that it is not common.

7 in 10 British adults (71%), who think that abuse and neglect is common in elderly care homes, say that they think this is because of media coverage, while more than a third (36%) say personal experience.

	%
Media coverage	71%
NET: Personal Experience ⁵⁴	36%
	<ul style="list-style-type: none">• I have heard anecdotal evidence – (e.g. from friends) – 25%• I know someone in an elderly care home – 15%• I work in care – 5%
Gut instinct	34%
National statistics (e.g. CQC inspection results)	26%
Other	6%
None of the above	2%

⁵⁴ This was a multi-code question which is why the net figure totals 36% - it is the figure for anyone who responded to at least one of the options provided on 'personal experience'.

More than half (53%) of British adults, who think that abuse and neglect is common in elderly care homes, have not visited an elderly relative or friend in a care home in the past 12 months, but just under half (45%) who think that it is common did make a visit to see an elderly relative or friend in the past year.

	Visited a care home in the past 12 months	Has not visited a care home in the past 12 months
NET: Common	45%	53%
Very common	9%	10%
Fairly common	36%	43%
NET: Not Common	46%	33%
Not very common	42%	31%
Not at all common	4%	2%
Don't know	8%	14%

Responses by age group for British adults who stated they wouldn't know where to go to for information on care homes if they were choosing one for an elderly relative or friend.

Total, all ages	22%
18-24	24%
25-34	20%
35-44	24%
45-54	27%
55-64	21%
65+	19%

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Qa Research carried out the mystery shopping exercise of 100 care homes in June 2016.



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