

What the public want from social care

A summary of Healthwatch England's research and insight - July 2018

About us

Healthwatch is the independent champion for people who use health and social care services. We exist to ensure that people are at the heart of care.

There is a local Healthwatch in every area of England with a remit to research and report on what local people want from health and social care services, and advocate for the change they want to see. Last year they identified social care as one of their key priority areas for the year ahead. This is a critical time for social care, the government's ongoing review and forthcoming green paper offers a chance to reform, improve and develop the capacity of the sector so that it is fit to meet the current and future needs of our population.

Our research and insight

Every year Healthwatch England pulls together a list of top priority areas within health and social care based on the work of the 152 local Healthwatch. Between 2015 and 2017 social care moved from fifth to second place on the list overtaking a whole range of issues on the way, including access to GPs.

Local Healthwatch also provide advice and information about local services. Last year they provided assistance and impartial guidance to 173,000 people. Analysis of these requests revealed that social care is the number one topic people contact us about, accounting for around a quarter (26.7%) of all queries. The key social care issues people contact us about include; accessing care assessments, signposting to care services and support to plan for current and future care needs.

It is clear that social care is an important and growing issue for the public. Reacting to this, in the summer of 2017 Healthwatch published two baseline reports to provide an overview of current user experience of social care:

- What's it like to live in a care home? Findings from the Healthwatch network¹
- Homecare: What people told us about their experiences²

In early 2018 we undertook further qualitative and quantitative research to understand what can be done to help people plan better for their future care needs.

- Two deliberative research sessions in March 2018, one in Watford and one in Leeds
- A representative poll of 2,106 adults in England.
- Analysis of a Freedom of Information request, submitted to every council in England requesting information on waiting times for assessments and care services.

The purpose of this short briefing is to summarise our research findings to help the government to ensure that the forthcoming Social Care Green Paper focuses on what matters most to those who are currently using or will need to use services in the future.

¹ <https://www.healthwatch.co.uk/resource/whats-it-live-care-home-findings-healthwatch-network>

² <https://www.healthwatch.co.uk/resource/home-care-services-what-people-told-healthwatch-about-their-experiences>

What people told us through the research

- Respondents to the national poll and those who took part in the deliberative research highlighted huge uncertainty over how care is funded; with those in the focus groups also expressing a clear sense of resentment about the lack of clarity around current funding mechanisms.
- There is a lack of understanding among the public about where to go for reliable information and advice about social care. Our polling showed that GPs are often seen as the most reliable and trusted source of information, with 78% respondents reporting high levels of trust in GPs. The deliberative research confirmed this, though for the purpose of this briefing we should bear in mind that when the public refer to a ‘GP’ they tend to mean the practice as a whole, not an individual medical professional;
- People are clear on what they would want from social care. The most important factors are the ability of the service to meet individual needs (65%) and the safety of the service (66%). The ability to compare cost of service between local providers was equally important (66%);
- However, people are reluctant to think about or plan for potential future care needs. Only 5% of survey respondents said they were fully prepared to meet their future or urgent care needs, while 27% said they did not think people should plan at any particular time, and should just ‘wait and see’;
- As people get older they are less likely to think that they should plan for their future care needs, the over 55 years of age group were most likely to say that people should just ‘wait and see’ what happens (38%);
- Attendees at our deliberative events suggested that the best way to encourage more people to plan and consider their care needs earlier in life would be to simplify and streamline current advice. They wanted to see the development of an independent, single point of contact, like an online portal or dedicated telephone service, which could advise and guide people through the current system. In order for this to succeed people said it would be vital to have a well-resourced and prolonged awareness-raising campaign.
- Our deliberative events have led us to conclude that the information and advice needs of the public stem from two key questions that for the most part people do not know the answer to: how is care funded and what is the standard of care?
- Finally, it was clear from speaking to people that while they spoke of a single point of contact for information, equivalent to NHS 111, they also want localised guidance to explain what care options are available in their area.

Waiting times for social care services and assessments; what councils told us.

In April 2018 we submitted a Freedom of Information request to every council in England, asking questions about assessments for social care services and care package reviews.

Availability of data

The responses to our request revealed that many councils do not hold or track this data in a way in which they can report.

- 31% of councils were able to provide data on how long people have to wait to receive a social care assessment.
- Only 22% held data on how long people wait to receive care and support after they have had an assessment.
- We also asked about waiting times for services by route of access, only 22% of councils record this data.

The remaining councils either did not respond to us, or told us they did not hold the data. This is a matter of concern; people tell us that waiting times for assessments is a big issue. However, if councils are not able to track and monitor data on this problem, it will be much harder to resolve.

Waiting times for assessments and support

Data from the councils who did respond showed that:

- Average waiting time between requesting an assessment and a care package starting in 2016/17 was 57 days.
- The longest waits recorded were for people being referred from the community (60 days) - the shortest waits for people being discharged from hospital (34 days). People in need of services designed to prevent a hospital admission on average waited 38 days.
- In our view, the data we collected shows that councils are being pressured into prioritising people awaiting discharge, to reduce delayed transfers of care, at the expense of people in the community. This, we believe, is not an efficient way to manage patient flow, and should be reviewed.

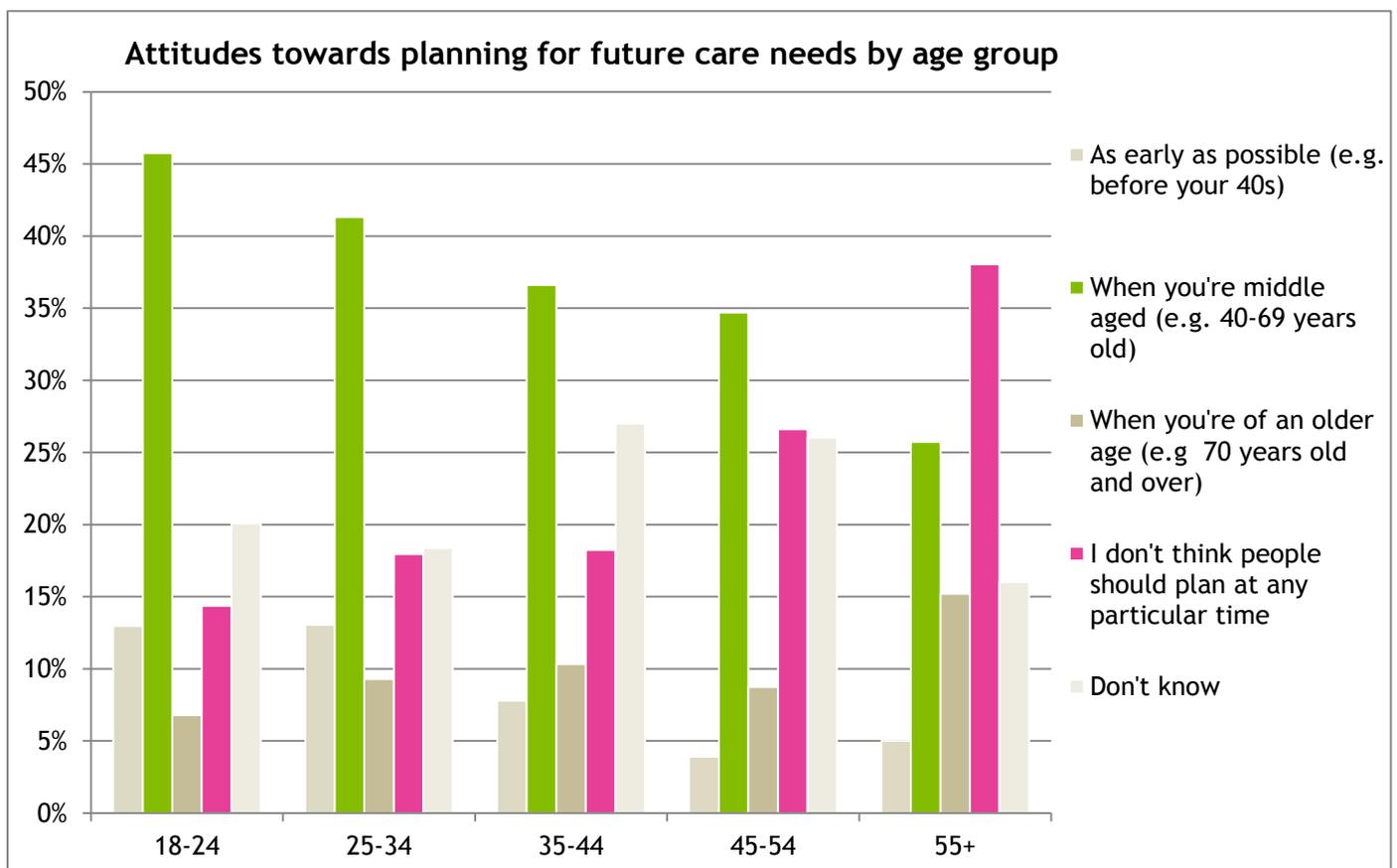
Planning for our future social care needs

Our research found that very few people have thought about or planned for their potential future social care needs, as shown in the table below, which shows a breakdown by age groups of responses to the question “How much thought have you given to your future social care needs?”:

	18-24	25-34	35-44	45-54	55+
A lot	0%	0%	0%	0%	0%
A little	3%	14%	15%	15%	33%
Not a lot	23%	23%	28%	35%	33%
None at all	64%	57%	52%	47%	33%
Don't know	9%	6%	5%	3%	0.2%

These relatively low levels of consideration across the age groups is seen in the very low levels of actual preparedness for future social care needs uncovered by our survey. 5% of people consider themselves to be ‘fully prepared’; this figure increases to 9% for the 55 years of age and over group.

We also asked about when people thought the best time in life was to start planning for their future social care needs. The responses to this question, broken down by age group, are displayed in the graph below:



Interestingly the younger age groups have a greater propensity toward stating that people should either plan for care as early as possible or in middle age. The older age groups have the greatest propensity towards a ‘wait and see’ attitude toward social care, 38% of over 55s said this compared to just 14% of the 18-24 years age group.

This suggests that at certain points in life people are more amenable to considering future social care needs and planning. We believe that further research should be undertaken to investigate this disparity between age groups, and to establish how best to target information and advice at these different groups.

Primarily the data here suggests that there are significant barriers and disincentives that keep people from planning for their future care needs.

This is borne out in the findings of our deliberative research. The key barriers people discussed included:

- People do not know where or how to start planning for their future care needs, it is too difficult therefore they choose not to address it.
 - Fear of the costs involved, for many people the topic is too difficult or overwhelming to consider, as such some people prefer to take a ‘wait and see approach’.
 - People’s care needs are unpredictable, or they may never develop any. Something so uncertain and variable is almost impossible to effectively plan for.
 - For many people, saving for their potential care needs is not affordable and there is widespread resentment. Some people said that there is a disincentive to save money, on the grounds that if you don’t have the means to pay you won’t have to.
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“Would you phone up the council for advice? I’m not so sure I would...”

Deliberative research participant, Watford.

“What are we meant to be planning for? I could get hit by a bus tomorrow, or I may never need to go into a care home.”

Deliberative research participant, Leeds.

“Historically we haven’t had to plan for how we fund care because years ago it was all funded by the state and it’s only the last few years that has changed.”

“There was going to be a contribution cap wasn’t there? I don’t know whether it’s been quietly dropped from the government’s agenda or whether it’s been implemented and actually enforced now.”

Deliberative research participants, Watford.

“How can you ask someone to plan ‘just in case’. It’s like an insurance policy.”

Deliberative research participant, Leeds.

In terms of incentivising and encouraging people to plan, information and advice needs to be made clearly available. Participants in the deliberative sessions suggested the following:

- A single source of information and advice (website and/or helpline) which covers all aspects of social care.
 - An ‘NHS 222’ service was suggested, equivalent to the NHS 111 service, but focussed solely on social care.
 - It was suggested that any information should be widely advertised.
 - Planning should be incentivised by focussing on securing people’s dignity and wellbeing in older age. Issues of financial security were secondary.
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“I think for me, based on a personal experience with parents, I’d want information around the risk factors of how you’re going to be treated after you’ve had the fluffy handshake and introductions on day one.”

Deliberative research participant, Watford.

“TripAdvisor for carers and care homes, now there’s an idea!”

Deliberative research participant, Leeds.

“I suppose there could be a national phone line, like NHS 111, that could answer all your questions.”

Deliberative research participant, Leeds.

However, people were clear that these are not stand alone solutions, they should be complemented by face-to-face support and guidance from a trusted professional, like a GP or dedicated social care ‘caseworker’.

“You’d need support from everyone including medical staff - but I think I’d be lost in that situation.”

Deliberative research participant, Leeds.

The information and advice gap

There is a clear demand for independent information and advice, to support people to understand and think about social care. People are unclear on where to look or ask for support, so often defer to their GP.

While GPs are often seen as ‘gatekeepers’, people are aware of other information sources,³ however they do not hold them in the same esteem as they do GPs, as shown in the table below:

	Very likely	Fairly likely	Net likely	Trust a lot	Trust a little	Net trust
GP	23%	39%	62%	41%	37%	78%
NHS Choices	21%	40%	61%	34%	41%	75%
Council	21%	34%	54%	17%	42%	59%
Charity	15%	37%	53%	37%	37%	74%
Private provider	9%	29%	38%	8%	37%	46%

These findings were confirmed and reiterated at our deliberative events. Participants expressed a demand for a trusted, independent advice service to provide guidance on key aspects of planning and preparing for social care, choosing a care provider as well as the financial aspects.

“People want a familiar and friendly face, that’s why I think that the GP should always be involved.”

Deliberative research participant, Watford.

“I don’t think there is one place or person that can sort all this out. You need to gather information from various sources.”

Deliberative research participant, Leeds.

“Is there a rating system out there where you (a care provider) can get a 2 star or 5 star?”

Deliberative research participant, Leeds.

³ There is comparative awareness of NHS Choices but this services is not held in the same regard as GPs, this was evident in the deliberative events

The fact that such a service is not widely available or known of, means that many people will defer to primary care professionals for social care information.

Looking specifically at the care home market, the Competition and Markets Authority also observed a lack of reliable information to help people plan for their care effectively. This formed part of a wider issue around a lack of consumer protection.⁴

The CMA observed that people are often unwilling to plan ahead for potential social care needs, so frequently have to plan under duress and with urgency when a sudden illness has necessitated social care provision.

In our complex social care system, adequate advice and support is not always available to ensure that people in this situation make the right decisions about their care provision.

We agree with the CMA's recommendation that more should be done to encourage earlier planning. More information on social care eligibility, options and what can be expected from social care should be widely disseminated to address the fear and stigma associated with social care that is often a barrier to early planning.

We note that the government has accepted the CMA's recommendation in full, and is committed to ensuring that the public are informed and empowered social care consumers.⁵ This is a very welcome commitment, and we offer our assistance to the government to make this aspiration a reality.

What people want from social care; personalisation and quality

The table below shows a breakdown, by age group, of responses to our survey question on what types of information people would want and find useful when beginning the process of thinking about their future social care needs.

There is a clear variation in priorities between age groups, with older age groups desiring a wider range of information, while younger adults are more likely to be unsure of what information they want, or not to want any at all.

Across the age groups surveyed it is clear that the most important and most demanded topics of information are:

- The ability of services to meet individual needs, providing person-centred care;
- The quality of services, in terms of its CQC inspection rating but also in terms of the services overall safety, cleanliness and staffing; and
- The relative cost of a service in comparison to other local providers.

⁴ CMA, *Care Homes Market Study*, June 2017. Available at: <https://www.gov.uk/cma-cases/care-homes-market-study#final-report>

⁵ DHSC, *Government response to the Competition and Markets Authority's 'Care homes market study, final report*. Consumer Protection (recs 4-11). Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/685315/cma-care-homes-market-study-final-report-government-response.pdf

	18-24	25-34	35-44	45-54	55+	All ages
The cost of different services	55%	62%	60%	63%	74%	66%
The ability to meet my individual needs	54%	60%	60%	63%	75%	65%
Cleanliness and safety	49%	54%	53%	65%	77%	64%
Quality of staff	50%	56%	55%	64%	74%	63%
Care Quality Commission rating	49%	58%	57%	62%	71%	63%
Reviews from people who use the service	48%	52%	50%	57%	66%	58%
The activities/services available	42%	53%	50%	58%	69%	58%
Proximity to family and friends	40%	48%	49%	55%	65%	55%

Participants at our deliberative events expressed similar preferences about the kind of care they would want, and what makes ‘good’ social care.

“You’d want a similar standard to your own home, or maybe better.”

Deliberative research participant, Leeds.

“Consistent and routine. Not someone different every time.”

Deliberative research participant, Watford.

“All I’d want is to be treated with dignity and respect.”

Deliberative research participant, Leeds.

The expectations, preferences and wants expressed by participants at our deliberative events and respondents to our survey confirm the range of themes on quality and experiences of social care reported by the Healthwatch Network.

The Healthwatch network regularly hears from members of the public, and carries out statutory ‘Enter and View’ visits in care homes across England. The evidence from these exercises bears out the findings of our survey research.

Three key themes emerged from our ‘Enter and View’ visits, that we believe are essential to delivering the quality of care people want:

1. The best care homes recognise that they are people’s home, residents should be supported to live as full and independent a life as possible, to do this support and activities should be tailored to individual preferences.
2. Good care homes meet people’s health and care needs in a joined up way.

3. Quality of care varies between homes and within homes. Too few of the homes local Healthwatch visited got every aspect of care right, often this is about meeting people's individual needs. This does not require large amounts of money to be resolved; rather it is about changing the attitudes of care homes and shifting individual care homes' culture.⁶

Similarly, the views we collected about home care services highlighted a range of key themes around quality and what's important to people who use home care services:

1. Care planning is key, it is important to set realistic expectations, and to ensure that care plans are regularly reviewed to reflect changing support needs.
2. The quality and skill level of staff is vital to ensuring that care at home is delivered effectively and that quality is consistent.
3. People and their families must be involved in the assessment process helps people to take control over their care, and to be an active partner within the planning process.
4. Providers should use feedback to identify and address shortcomings within their service.⁷

Conclusion and next steps

Funding and personal financial liabilities for social care will be the key, headline issues for the Social Care Green Paper. They are of course vitally important; however money alone is not the answer to social care's current problems.

We believe that our research highlights the need for an accessible, trusted and independent source of information and advice, to guide people through the social care system so that they are better enabled to plan and prepare for their future social care.

There is a clear lack of public understanding or awareness of how to and indeed when to plan for potential future care needs, choose between providers and manage their finances.

In their analysis of the care home market, the CMA identified and addressed this issue; suggesting that work should be undertaken to disseminate information and advice about social care to incentivise early care planning.⁸

We agree with the CMA's recommendation, our research concurs with theirs and also shows that attitudes to planning for social care vary considerably between age groups.

We suggest that further research is undertaken in this area, so that information about social care is more effectively targeted in the future.

⁶ Healthwatch England, *What's it like to live in a care home? Findings from the Healthwatch network*. Available at: <https://www.healthwatch.co.uk/resource/whats-it-live-care-home-findings-healthwatch-network>

⁷ Healthwatch England, *Homecare: What people told us about their experiences*. August 2017. Available at: <https://www.healthwatch.co.uk/resource/home-care-services-what-people-told-healthwatch-about-their-experiences>

⁸ CMA, *Care homes market study*, June 2017. Available at: <https://www.gov.uk/cma-cases/care-homes-market-study#final-report>

Further to this, we suggest that, on a national level, new information and advice services are developed to proactively support and signpost people to effectively plan and consider their present or future social care needs.

Over one quarter of the 176,000 requests for information and advice that Healthwatch England received last year were in relation to social care. There is a considerable public appetite for services like this.

A good information and advice service should improve the transparency of the social care sector, enable people to take greater control of their social care and importantly support more people to proactively plan for their potential future care needs. However, it needs to be effectively resourced and delivered consistently over time in order to sufficiently penetrate public thinking.

These issues should be addressed as a matter of priority, and the forthcoming Social Care Green Paper should be used as the means by which to consult on and develop solutions.

About us

We are the independent consumer champion for health and care. Our job is to make sure that those who run local health and care services understand and act on what really matters to people.

A local Healthwatch exists in every area of England. We support them to find out what people want from health and care services and to advocate for services that work for local communities. Local Healthwatch also act as our eyes and ears on the ground, telling us what people think about local health and social care services. We use the information the network shares with us and our statutory powers to ensure the voice of the public is strengthened and heard by those who design, commission, deliver and regulate health and care services.



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