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## Social Care Deliberative Events

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Report prepared for:

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# The research findings...

This presentation provides key insights into the findings from two deliberative events, conducted in February – March 2018, exploring public needs, perceptions and behaviours in relation to social care

The Healthwatch logo is displayed on a white rectangular card tilted at an angle. The word "healthwatch" is written in a bold, lowercase, sans-serif font. The letters "h", "e", "a", "l", "t", "h", "w", "a", "t", "c", "h" are in blue, while the letter "o" is in green.The djs research logo is displayed on a white rectangular card tilted at an angle. The letters "djs" are in a large, bold, lowercase, sans-serif font, with a small pink dot above the "i". Below "djs", the word "research" is written in a smaller, lowercase, sans-serif font in pink.

## Structure

**Background, objectives & methodology**

**Summary & conclusions**

**Social care wants and needs**

**Planning for the future**



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**Background,  
objectives &  
methodology**





# Background & context

## Background

**The combination of a growing and ageing population, more people with long-term conditions, and a challenging financial environment has placed significant pressure on social care services in recent years.**

In its 2016 'State of Care' report CQC raised concerns that the fragility of the adult social care market is beginning to impact both on the people who rely on these services and on the performance of NHS care. In response, the spring 2017 Budget announced an additional £2 billion to councils in England over the next three years to spend on adult social care services.



## The need for research

**The purpose of Healthwatch's focus on adult social care is to share the experiences that are heard from people to help inform the wider understanding around what people need from future services and how they expect the system to operate.**

This strand of research forms part of a wider evidence base that Healthwatch has been collating. The deliberative events were focused on understanding (future) needs and expectations in terms of care, and information and advice about social care.



# Research objectives

## Overarching objective

For Healthwatch to continue to **build evidence** to assist its stakeholders and support the government in their decision making around the future of adult social care and to continue to **fill known and identified gaps in service evaluation data** on adult social care services and **refresh its contribution to this subject area**.

## Through this research Healthwatch are looking to:

- Engage the public in discussing how they would like their social care needs to be met in the future (including the provision of care, and also needs in relation to information and advice)
- Explore behaviours, attitudes and needs in relation to planning for social care
- Produce evidence that can be presented in conjunction with existing Healthwatch insight data to influence service change. This will be done via stakeholder events and a roundtable.



# Methodology



- 2 deliberative events lasting approx. 2.5 hours
- We agreed a profile for each group to ensure representation from a range of demographic groups – it was agreed to weight profiles slightly towards 'empty nesters' as this was a group of particular interest (see table).
- DJS then arranged the events and recruited participants face-to-face, screening to ensure they were outgoing, and met certain agreed (demographic) criteria.
- We designed a topic guide to steer the discussions – it included a range of questions, prompts and interactive exercises to elicit views.
- Three moderators from DJS Research attended to facilitate discussions, and various colleagues from Healthwatch also attended..
- Discussions were audio recorded for analysis.



	Male	Female
<b>Pre-family</b> (no kids, aged 18 to 30)	2-3 (including at least 1 from BME ethnic group)	2-3 (including at least 1 from BME ethnic group)
<b>Family</b> (with kids at home, aged 30 to 55)	4-5 (including at least 1 from BME ethnic group)	4-5 (including at least 1 from BME ethnic group)
<b>Empty nesters</b> (no kids/kids left home, aged 55+)	7-8 (including at least 1 from BME ethnic group)	7-8 (including at least 1 from BME ethnic group)

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# Summary & Conclusions



## Summary & Conclusions

**There are a broad range of wants and needs, most of which stem from the standard of care and individualised *quality of life* on offer...**

People expect safety, comfort, a friendly face, cleanliness, to be treated with respect, consistency in staff (not a different carer everyday), and the right medical advice/treatment.

Many of these might be regarded as hygiene factors, but based on media coverage (and in several cases, experience), there are real concerns about quality and consistency of social care and whether even these basic needs will be met.

As a result, there is appetite for an independent and trusted source of advice to help people assess and choose the right care (people aren't generally aware of such a source existing, with many suggesting their GP as the first port of call for advice).

Individualised care is important and this goes beyond the basic needs discussed above. People want (but in the current climate do not necessarily expect) to have a choice over their quality of life. This encompasses highly individual issues such as music, pets, food and social activity. Given how important these factors appear to be, it is interesting that people are so reluctant to plan their care in advance.



# Summary & Conclusions

## **There is uncertainty (and resentment) over how care is funded...**

Many participants were quick to admit they are uncertain about how social care is, or can be funded. Common questions that came in discussion included:

- What options are available for funding? Government vs self?
- Are there price plans?
- Does it depend on location/council?
- What do I get for my money?
- What does my national insurance pay for?

Some participants appeared somewhat displeased with the idea that after paying National Insurance all of their life, they may still have to contribute towards the cost of social care.

Several took this further – suggesting that you may actually be penalised for planning the financial aspects of care – the suggestion here is that when the time comes that someone needs care, if they haven't made the provision to pay for it, someone else will have to pay!



# Summary & Conclusions

## **There is a gap in the market for a trusted information source...**

This research has validated that family GP's are still in many cases seen as the gatekeeper to accessing information about health & social care services.

A number of other channels were discussed (Local council, CQC, Citizens Advice, Charities such as Age UK), but there was no consensus about an existing, comprehensive and trusted source of independent information and advice.

There is a real appetite for an independent website and helpline that provide assessments of care options/quality, and advice on key aspects such as planning/choosing care, individualised care and financial aspects. This was often referred to as either 'Trip Advisor for Social Care' or 'NHS 222'.

Such an information source may not meet all need however. Face-to-face access to medical professionals is seen as important for assessment and monitoring, and many people also desire a single 'caseworker' who will coordinate and monitor care.



# Summary & Conclusions

## **People are very reluctant to put much thought into their care needs until there is actually an (urgent) need...**

Many felt that it is impossible to pin down when someone would need care and what they will need - for some it could occur earlier in their life, others may be able to live independently until they are much older. This uncertainty makes planning difficult.

Some are reluctant to plan for the financial aspects as they resent having to pay at all (and are unsure whether they will have to) and may feel that they will actually be penalised for making provision for the financial aspects of care.

Ultimately, one of the main reasons why many have not put thought into planning for their social care needs is – they just don't want to think about it!

## **There are a number of methods that could help people start thinking and planning earlier**

Making it easy is one aspect – again a single 'NHS 222' source for advice on planning would be welcome, as well as a campaign to raise awareness of the importance of giving thought to future care needs.

In terms of motivating people to plan, people clearly hope to have individualised care that goes beyond meeting basic needs and also meets their social and 'quality of life' needs (respect and dignity, social activities, food, music etc). Leaving the planning of such things to someone else is putting their future happiness at risk.

# Key messages for Healthwatch...



Participants were invited to provide their one key message to Healthwatch surrounding social care services at the end of each session

## Funding

*"Make it free"*

*"Make it affordable"*

*"More funding"*

*"Make health and social care available for everyone, regardless of financial circumstances"*

*"Keep funding to the rate of inflation"*

## Information

*"One-stop shop for social care"*

*"Clear, concise information about options"*

*"More public information on planning for social care"*

*"Develop one freephone number where every type of help, advice and information about care is available"*

*"Offer precise information about entitlements and benefits"*

## Standard of care

*"Treat people as individuals, not as numbers"*

*"Look after us when we need it!"*

*"Living through old age with dignity"*

A close-up photograph of a healthcare worker in blue scrubs holding the hand of an elderly person. The worker's stethoscope is visible around their neck. The elderly person's hand is wrinkled and appears to be resting on the worker's arm. The background is slightly blurred, showing another person in a dark jacket.

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**Social care wants  
and needs**

# Clear & transparent information...

**Scenario 1:** Someone is in need of care at home

**Scenario 2:** Someone is in need of going into a care home

- Participants were provided with **2 scenarios** and were asked to think about what their wants & needs would be in this situation
- Generally participants focussed on the **quality of care as the primary theme**
- When discussing quality of care, the notion of **consistency** was commonly used and many felt there were **gaps in what is available** (in terms of quality & provision of carers and care homes) - this often was put down to individual councils
- When asked to drill into the information and advice needs, participants felt that there needed to be **greater transparency on the quality of care offered** and this should be delivered via an **independent organisation** (not connected to local government)



*I suppose there is a general expectation that the council will point you in the right direction*  
**(Leeds)**

*You'd need support from everyone, including medical staff – but I think I'd be lost in that situation*  
**(Leeds)**

*Would you phone up the council for advice? I'm not so sure I would..*  
**(Watford)**

# Wants & needs stem from the quality of care (and quality of life) on offer...

Participants naturally revert to the quality of care on offer as a key factor and often cited stories of poor care that have been reported in the media

## People want...

- Safety, comfort & a friendly face
- Good food
- Cleanliness
- To be treated with respect
- Independence aligned to their needs
- Companionship
- Consistency in staff (not a different carer everyday)

## People need...

- Professional staff who are trustworthy
- Carers who are empowered and knowledgeable
- General reassurance that their loved one is in good hands - DBS, 'ratemy care' (explored later)



*You'd want a similar standard to your own home, or maybe even better*  
**(Leeds)**

*Consistent and routine. Not someone different every time*  
**(Watford)**

*All I'd want is to be treated with dignity and respect*  
**(Leeds)**

**Ultimately before people can consider what care they need and where they need it, they need reassurance and confidence in the services available – this is a key information need...**

# Quality of care is paramount...

## Participant exercise output: care at home

Scenario: New needs for support & care in own home

**I want.....**

- Respect
- Flexibility + fit with lifestyle
- On-call support from familiar care workers
- Company
- A good relationship with my GP/hospital/careers

**I need.....**

- Consistency in care routine
- Good relationship with carers
- Multi-skilled support with financial, health needs (DBS checked)
- Help with cooking, shopping etc, maintenance jobs
- Access to car - (bring driver)
- option for 24-hr care.
- Company
- Options | info re private | social care

### Wants...

- Respect
- Flexibility
- On-call support (familiar face)
- Company
- Good relationship

### Needs...

- Consistency & routine
- Multi-skilled support
- Access to transport
- Option for 24hr care
- Options & info on private care

# There are various information needs...

## Participant exercise output: care home

Scenario: Relative going to a care home

**I want.....**

- KNOW HOW PEOPLE TREATED? KIND?
- TALK TO FRIENDS FAMILY SIMILAR
- .GOV / ONLINE
- FACEBOOK GROUP
- GP / MEDICAL ADVICE
- 'WHAT'S INVOLVED / COST / TIME
- HOW LOCAL? / VISITING HOURS.

**I need.....**

- AM I ELIGIBLE? / WHAT CRITERIA?
- PRICE PLAN.
- LENGTH OF TIME
- PERSONAL BELONGINGS?
- COMMUNAL? / VISITORS? / TRIP?
- INDEPENDENCE
- LICENCE
- MEDICATION.
- COST IMPLICATIONS.
- SUBSIDISED CARE.

**Additional notes:**

- MONITORING / NO ABUSE
- DBS / CRB CHECK.

### Wants...

- How are they going to be treated?
- Online info (.gov)
- Role of social media
- Cost & time information
- Locality of homes

### Needs...

- Eligibility criteria
- Info on price plans
- Subsidies available
- Advice from GPs & medical professionals



# Information needs stem from two questions...

## How is the care funded?

- Many participants were quick to admit that they are in **the dark over how social care is, or can be funded**
- Some were aware of the care needs assessment, but there were clear gaps in knowledge on the **eligibility** of care
- Common questions that came up in discussion included:
  - *What options are available for funding? Government vs self?*
  - *Are there price plans?*
  - *Does it depend on location/council?*
  - *What do I get for my money?*
  - *What does my national insurance pay for?*

## What is the standard of care?

- Information on the standard of care available is key
- Some participants discussed their own **personal experiences** of social care, some positive, some negative
- Participants conceded that concerns in this area stem from an influx of media reports where there has been a **mistreatment of people in care** and as a result, there has never been a bigger spotlight on both carers and care homes
- People want **transparent information** on the standard of carers & care homes
- Many felt this should come from an **independent body**, removed from local government

**On the subsequent slides, we'll explore how people currently access this information surrounding these questions, and what the ideal process would be**

# Communication channels vary...



## Where would you go first?

- There are clearly a **number of routes** people would take in the scenario of needing access to social care services
- This research has validated that **family GP's are still in many cases seen as the gatekeeper** to accessing information about health & social care services
- However, a number of other channels were discussed:
  - **Local council:** calling up to seek advice or searching the council website
  - **CQC:** only a minority were aware of the CQC, some felt it only related to private services
  - **Citizens Advice:** people felt the CAB could provide general advice and would refer to the appropriate bodies
  - **Charities (Age UK):** many felt charities such as Age UK would be able to provide a certain level of advice and guidance
- There is a caveat in that many people **have not thought about their social care needs**, which we will explore later

*There was going to be a contribution cap to lifetime care wasn't there? I don't know whether it's been quietly dropped from the governments agenda or whether it's been implemented and actually enforced now*  
**(Watford)**

*In terms of funding, someone like Citizens Advice would be able to let you know about this. For care within the home, I suppose I'd got to my GP*  
**(Leeds)**

# FAQs focus on the standard of care...



Is there a one-stop shop that can answer some, or all of these questions?

*If it was a carers agency, I would like a website where they have to post all the reviews of their services, which can be left anonymously. This should help as people are reluctant to post negative reviews if they think it might lead to their relative being penalised*  
**(Watford)**

*I suppose there could be a national phone line, like NHS 111, that could answer all of your questions*  
**(Leeds)**

## What is the standard of care?

- Participants were asked to write a number of 'FAQs' relating to a social care scenario
- Many of these focussed on the **standard of care**
- FAQs included:
  - 'Are the carers reliable?'
  - 'Are they honest?'
  - 'Will they turn up?'
  - 'How will they get access to my home?'
  - 'Will my relative be safe?' (safeguarding)
  - How personalised will care be?
  - What is the access to emergency care if needed?
- Many people also want access to information on the **quality of life** of someone going into care
  - FAQs included:
    - Will I be able to maintain a social life?
    - What activities / entertainment is on offer?
    - Are pets allowed? (notion that companionship is important)
    - What amenities are available and can I still maintain a level of independence ?

# Information needs:

## Standard of care



*I don't think there is one place or person that can sort all this out. You need to gather information from various sources*  
**(Leeds)**

*If families of people in care homes could do a review and rate them, that would be totally independent wouldn't it. You could review and rate them so other people can see it's open and honest*  
**(Watford)**

*TripAdvisor for carers and care homes, now there's an idea*  
**(Leeds)**

*The first thing I'd do in the situation is head to the Care Quality Commission and start looking at rating & reviews of care homes*  
**(Watford)**

*Is there a rating system out there where you can get 2 star or 5 star?*  
**(Leeds)**

*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*  
**(Watford)**



# The ideal process...

The ideal process will vary depending on the needs of the person going into care / having care at home...



*Having social care in the home ranges depending on age, background, mental and physical capabilities. It's very difficult to have a one size fits all*  
**(Leeds)**

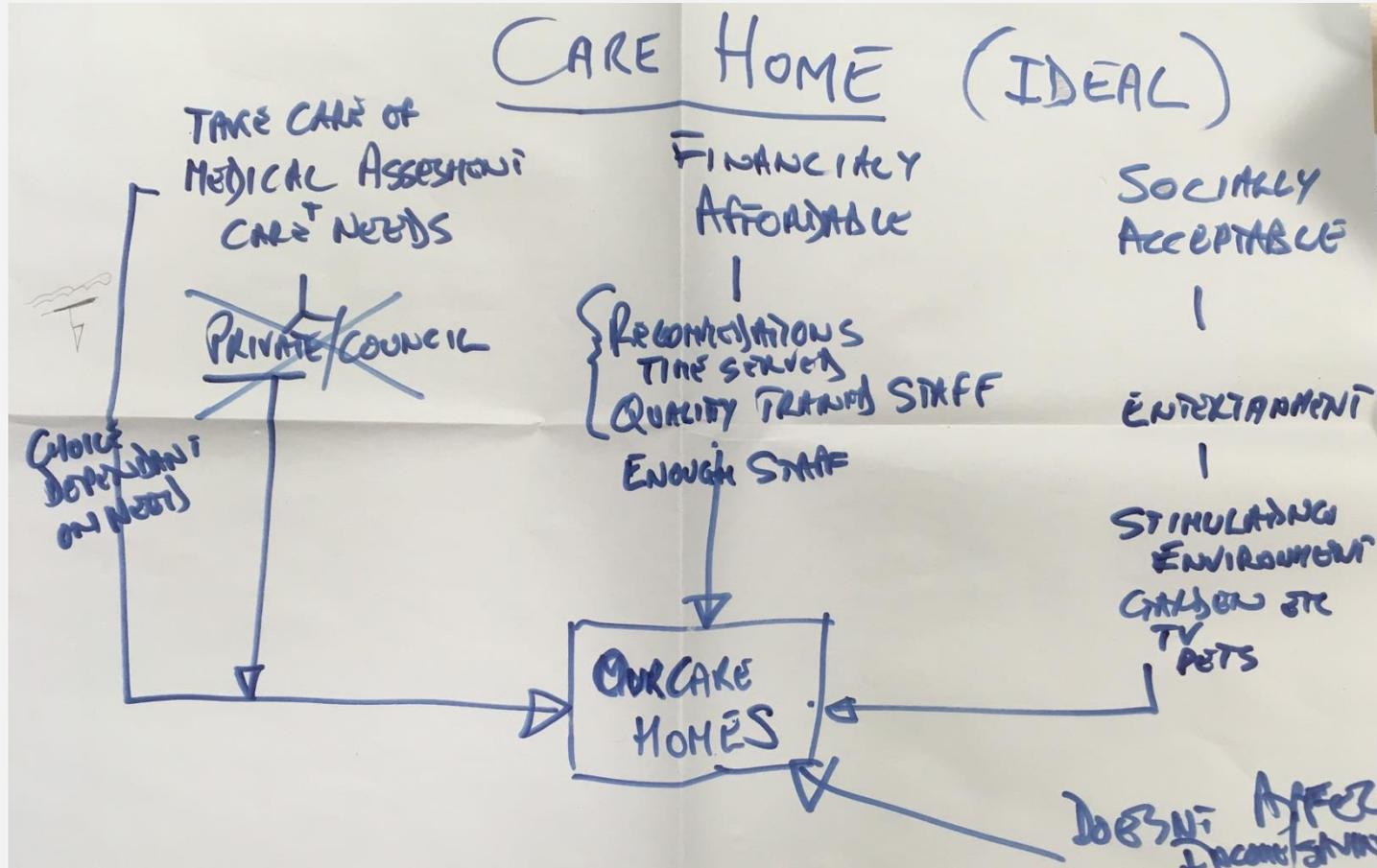
*The person who needs care is able to get their point of view across. I think some people forget that*  
**(Leeds)**

*People want a familiar and friendly face, that's why I think the GP should always be involved.*  
**(Watford)**

- People will have **individual needs** and the ideal process involves being treated as such
- People also recognised that in reality, a 'one-stop shop' could deliver some, but not necessarily all of a persons information needs
- The first port of call still for many **will be their GP** to gather initial information on the first steps needed
- Supplementary, more detailed information could then come from a '**NHS 111**' style service and '**independent review websites**', however some felt they would still want face-to-face contact with a **medical professional** (and possibly a **caseworker** who coordinates and monitors care)
- This F2F contact would ideally be someone within social services, who would also conduct an assessment to determine the individuals needs
- Whilst professional advice is sought, **the family and individual also want a say** – this is very important
- Finally, all participants agreed that all social care should be **state funded** and their should be no burden of cost to the family

# The ideal...

## Participant exercise output: care home

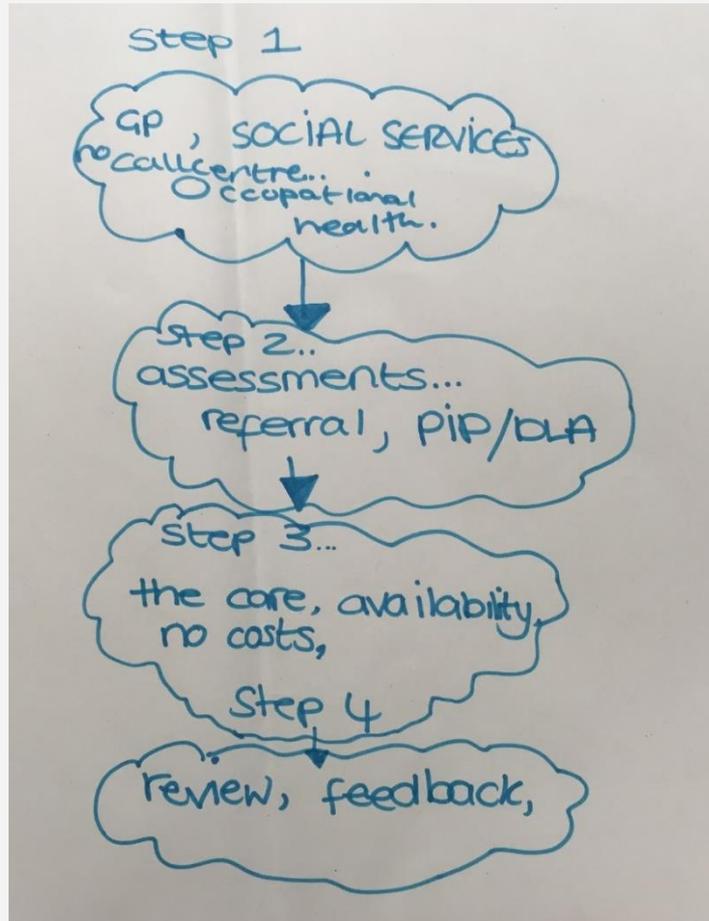


This group focussed on 3 strands, that care should be:

- Financially affordable;
- Socially acceptable (quality of life); and
- Takes care of the medical assessment & care needs

# The ideal...

## Participant exercise output: care at home



- This group focussed on a 4 step process and considered that the individual may still be working
- **Step 1** involves **obtaining information** from a GP, Social Services and an occupational therapist
- **Step 2** is an **assessment, referral** and information on and help with costs i.e. Personal Independence Payment (PIP)
- **Step 3** is the care itself – there should be **good availability** and no cost to the individual (ideally)
- **Step 4** involves **reviews and feedback**, monitoring the quality of care and the individual's care needs

There was a consensus that the ideal would be a single **case manager to coordinate care**

*There is a need for a more tailored, joined up approach. I think you should be able to talk to one central person throughout the process*  
**(Watford)**



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**Planning for the  
future**

# Planning for your care needs...

The overall consensus is that generally people do not put much thought into their care needs until there is actually an (often urgent) need, there are a number of reasons for this

## 1. You can't predict when you may need care

- Many felt that it is impossible to pin down when someone would need care, for some it could occur earlier in their life, others may be able to live independently until they are much older
- This ultimately comes down to the behaviour that, if you can't predict something, how can you plan for it (in contrast, it was highlighted that people might plan their funeral as this is a 'certainty')?
- Many did recognise that this behaviour isn't necessarily the right way to think, but often with people living busy lives, many admitted that it's just something they push to the back of their mind until the need actually arises - an element of denial?

*How can you ask some to plan 'just in case'. It's like an insurance policy*  
**(Leeds)**

*You don't know at what point you are going to deteriorate to the point where you cannot look after yourself. It's the unknown*  
**(Leeds)**

# Planning for your care needs...

The overall consensus is that generally people do not put much thought into their care needs until there is actually a need, there are a number of reasons for this

## 2. Circumstances could vary dramatically

- This is not too dissimilar to point 1, in the notion that, if you can't predict for something, it's very difficult to plan for
- However, there is also the idea that an individual's needs could vary dramatically – for example an individual may just need minimal care from a relative in home, or there may be a more urgent need for nursing care
- Again, people just don't know and this is one of the major barriers towards getting people to think about their care needs in the future

*I wouldn't know whether it would be a care home or a nursing home, or how old I would be*  
**(Leeds)**

*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*  
**(Leeds)**

# Planning for your care needs...

The overall consensus is that generally people do not put much thought into their care needs until there is actually a need, there are a number of reasons for this

## 3. Is it financially viable?

- For many the interpretation of planning for your care isn't just putting thought into it, it's making a financial decision to save as well
- For a lot of people, saving for your potential care needs is just not financially affordable, and there is some resentment about payment ("*isn't this what I pay my national insurance for?*"). Some even felt it might be better not to plan – if they don't have the means to pay they won't have to
- People don't put saving for social care in the same bracket as a pension scheme, or even a funeral plan
- Participants described retiring and death as inevitable. Whilst you don't want to think about it, people are prepared to plan financially for their funeral, but very few share the same behaviour when it comes to social care

*What happens if you can't afford it? People can barely afford to live now. We live in the present*  
**(Leeds)**

*If you spend all your money thinking you are going to go into care, then you haven't got any money to be assessed against your care when the time comes*  
**(Watford)**

# Planning for your care needs...

The overall consensus is that generally people do not put much thought into their care needs until there is actually a need, there are a number of reasons for this

## 4. We don't want to think about it!

- Ultimately, one of the main reasons why many have not put thought into planning for their social care needs is that they just don't want to think about it!
- Some participants admitted to a selfish assumption that 'everything will be ok' and 'my family will look after me' (although others were keen not to burden their family)
- Some older participants even stated the older (and closer to needing care) they get, the less they want to think about it!

*People have a funeral plan, but they don't have any sort of care plan. We don't think it will happen to us*  
**(Leeds)**

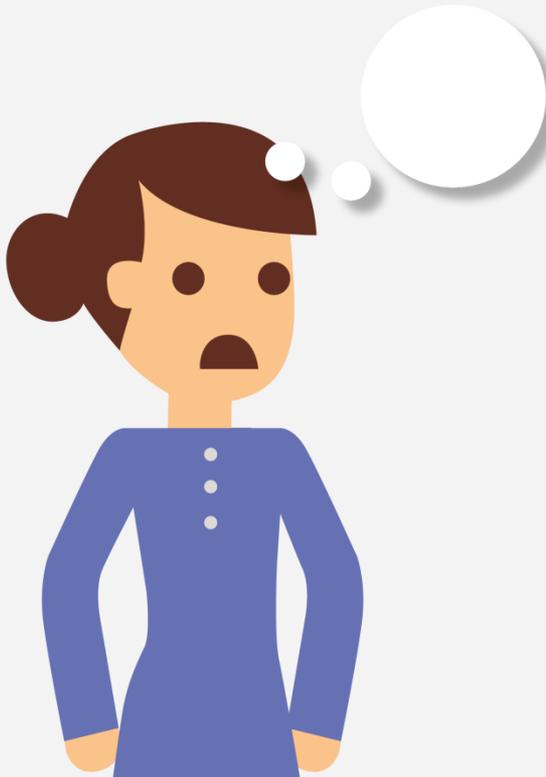
*None of us want to think that we are going to need care, so I think it is not necessarily a conscious decision, but never the less, it is there*  
**(Watford)**

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## Fear of the cost involved...

There is clearly a genuine fear in the cost involved with modern social care. Unless someone has had a personal experience, most are unsure what is funded by the state and what is self-funded. Some felt that as a result of this changing landscape, people are putting more thought into their care needs for the future (or should)...



*"Historically we haven't had to plan for how we are going to fund care because years ago it was all funded by the state and it is only in the last few years that has changed. So it has been that as a society haven't thought about needing to plan and now we do. People are putting advanced care plans in place and people are thinking about how they would like to be cared for. I think it is important because I lost somebody who didn't have the capacity to think about these things - what time they like to get up? how they actually like their breakfast? do they have a cup of coffee? do they have a cup of tea? All those things are really important in care so having that written down in advance so that people know how you like things is really key."*

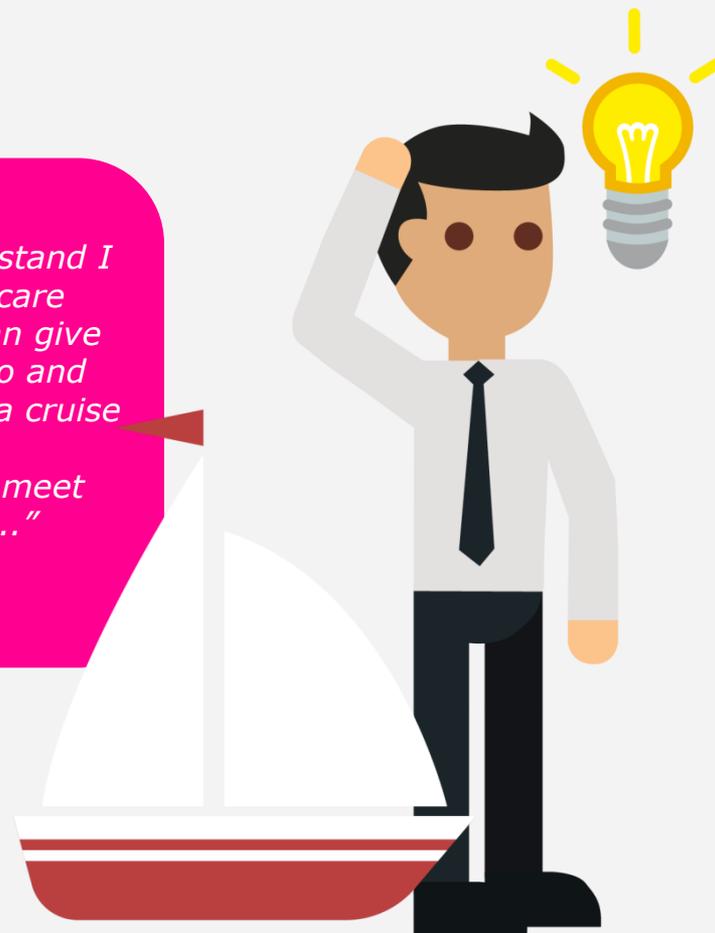
**(Watford)**



## Fear of the cost involved...

In both sessions, participants commented on the 'cruise ship' analogy: it has been reported that it is cheaper to live on a cruise ship for your retirement years than in the care system in England...

*"It is semi-serious, half joke but from what I understand I could get similar care on a cruise ship than in a care home. It's cheaper, they have got doctors, they can give you all your medication on board, if you wanted to and they can do dialysis if that is what you needed. On a cruise ship and you get looked after a lot better... you get all the entertainment that you want, you meet people every week, you get your laundry done.."*  
**(Watford)**





# Changing behaviours...

Encouraging people to think about and plan for their care needs in the future is a challenge – it needs to be made as easy as possible with information, support and guidance

## How can you encourage people to plan for their social care needs...

*Why isn't there something that you can opt in and pay a % of your wage? Isn't that what national insurance was meant to be?*  
**(Watford)**

- People don't know where to start in terms of planning care (both in terms of the care itself, and the financial aspects)
- The ideal is to have an independent single source of information and advice (website and helpline) which covers all aspects of social care – planning care, choosing the right care and financing it
- NHS 222 was suggested by a number of participants.
- A need for advertising to raise awareness of the need to plan was also highlighted

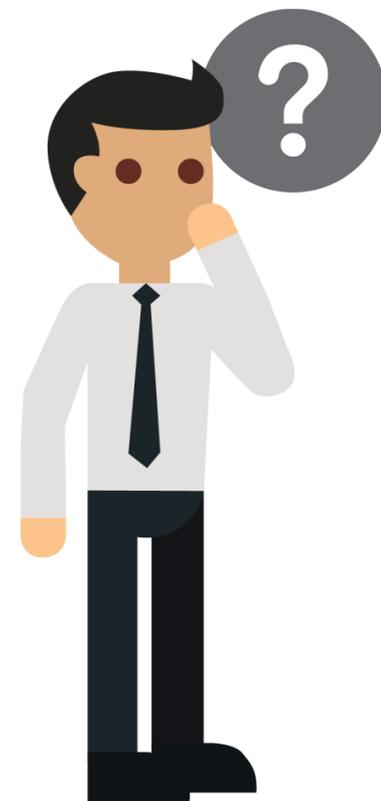




# Changing behaviours...

**We asked participants to create an advert which could encourage people like them to start thinking about and plan for their social care. This is a technique we often use in behaviour change research, as it can be effective in uncovering the less rational, more subconscious motivators and drivers of behaviour**

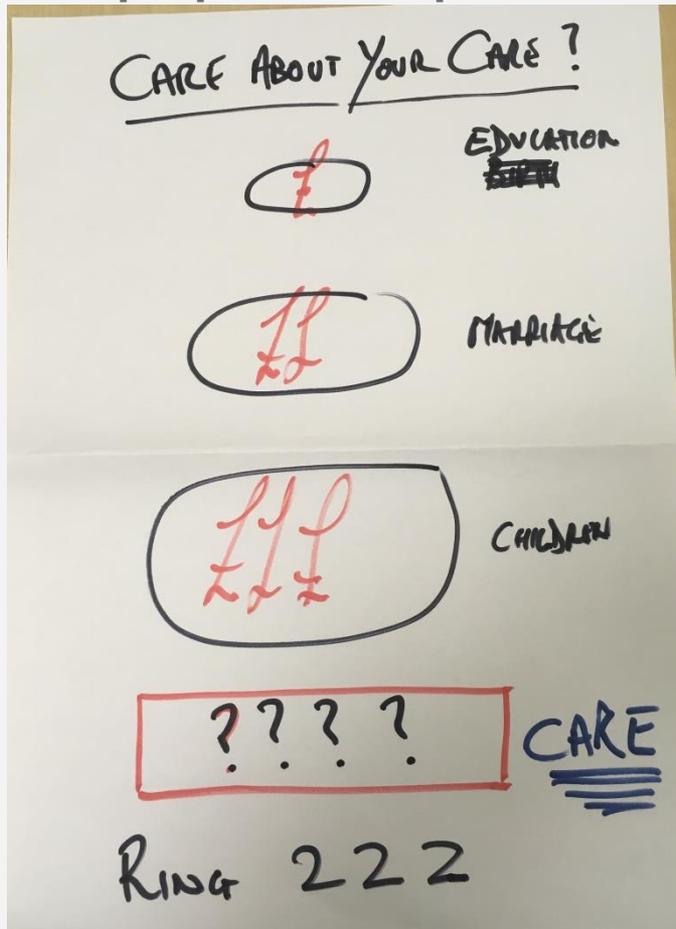
- Interestingly, although much of the discussion about planning kept coming back to financial aspects, only a minority chose this as the focus for their advert (although it was recognised that this could be a powerful message)
- Most of the adverts created actually focused on future quality of life, and these types of messages were felt to be particularly powerful:
  - You are planning for your future dignity and quality of life.
  - The emphasis was often on the social aspects of quality of life (as opposed to quality of care) – and the conversation revealed how individual these needs are - listening to Mozart, allowing pets in my bed (not everyone liked this idea!) the right food and social activities.
  - It is your choice, and if you don't plan, someone else might be taking these decisions for you.



# Changing behaviours...

## Participant exercise output: design an advert

Focus on the financial aspect, put in perspective by other significant costs people tend to plan for



Focus on the fact you are planning your future quality of life, which is individual to you and your choice





# Changing behaviours...

## The recurring theme of a trusted information source

- Throughout discussions, it was clear that people are unsure where to go for information and advice about social care, with most suggesting they would start with their GP
- There is a real appetite for a single, trusted, independent source of information and advice about social care – which would ideally comprise of a website and helpline.
- This source would ideally provide independent advice and independent assessments of care quality (a Trip advisor style rating system was suggested several times).
- It would also provide more information about planning the financial aspects and planning individual care needs.

Ring 222



# If you have any questions please contact...

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