



Ipsos MORI  
Social Research Institute

August 2017

# Care Homes: Consumer Research

Ipsos MORI report for the CMA



# Contents

## Contents

Executive summary .....	6
1 Introduction and methodology .....	12
Background .....	12
Research Objectives .....	12
Glossary of terms .....	13
Methodology .....	14
Interpreting findings .....	17
Structure of the report .....	17
Acknowledgements .....	18
2 The context for moving into a care home .....	20
The circumstances leading to full time care .....	21
A care home was considered when it was the only practical option .....	23
The timing of the decision .....	24
Experiences of care assessments .....	26
3 Information and support when finding a home .....	30
Types of information used .....	31
Information on the care home system .....	33
The role of social workers and care managers .....	34
Improvements to information and support .....	36
4 The process of finding a care home .....	39
The steps taken to find a home .....	40
The number of homes considered .....	42
Deciding on a home .....	45
Preferences for a care home .....	46
Constraints on choice .....	48
Perceptions of choice .....	50
5 Funding Care .....	54
Different types of funding .....	55
Navigating the funding system .....	56
Experiences of applying for funding .....	59
Financial assessments .....	62
Paying top-up fees .....	63

Information and support available .....	65
Planning for care in the future when financial circumstances have changed .....	66
Measures to improve the support available .....	67
<b>6 Moving into a care home .....</b>	<b>70</b>
Priorities during the moving process .....	71
A lack of engagement with contracts and terms and conditions .....	73
<b>7 Paying for care .....</b>	<b>77</b>
Setting up payments for care .....	78
Deferred loans on residents' property .....	80
Billing and extra charges .....	81
Fee increases .....	83
<b>8 Raising concerns and making complaints .....</b>	<b>86</b>
Concerns and providing feedback in general .....	87
Types of complaints raised .....	89
Escalating complaints or raising complaints externally .....	92
<b>9 Moving between care homes .....</b>	<b>95</b>
Perceptions of moving between care homes change over time .....	96
Reasons for moving between care homes .....	96
Difficulties with moving between care homes .....	97
Experiences of moving between care homes .....	100
<b>10 Participants' ideas for improvement .....</b>	<b>103</b>
Early planning .....	103
More support and guidance .....	103
Better information provision .....	104
Simplifying administrative aspects .....	104
<b>11 Appendix .....</b>	<b>107</b>
1: Advanced letter to representatives .....	107
2: Information sheet for representatives .....	109
3: Information sheet for residents .....	113
4: Discussion guide for representatives .....	116
5: Discussion guide for residents .....	123
6: Discussion guide for social workers .....	129
7: Quota table for care home placements .....	135

# Executive Summary

# Executive summary

## Overview

1. Ipsos MORI was commissioned by the Competition and Markets Authority (CMA) to undertake a qualitative research study exploring how people navigate the care home sector across the UK. This was in support of a wider market study the CMA is carrying out into care homes for the elderly, to review how well the market works, and whether people are treated fairly. As part of the study the CMA wanted to commission research to understand the experiences of residents and their representatives (i.e. family and friends) who have been through the process of choosing a care home.
2. The study was designed primarily to explore the customer journey when choosing a care home, as well as experiences within the care home. Specifically, it looked at the background to the decision to enter a care home; the process of choosing a home, including preferences, perceptions of choice and the ability to access information and support; experiences of navigating the system for funding; the ability to understand contract terms, the billing process and experiences of unexpected fees; the process of moving care homes; and mechanisms for resolving issues in the care home, including experiences of providing feedback and making complaints.
3. A qualitative research approach was used, comprising in-depth interviews in England, Scotland, Wales, and Northern Ireland with representatives of people living in care homes, residents of care homes, and social workers. Fieldwork took place from March to May 2017. In total, 102 representatives (family member or friends of a resident), 16 residents (someone living in a care home), and five social workers were interviewed.

## Key themes emerging from the research

4. This executive summary synthesises the key themes that emerged across the research:
  - there was often limited time to make decisions about which care home to choose;
  - there was limited engagement with the details of the 'system';
  - there was a perceived lack of information and support when choosing a care home;
  - there was a perception that options were limited – the availability of spaces generally and availability of a space in the *right* home;
  - people felt powerless to control the situation.

## Limited time to decide

5. A move into a home was commonly triggered by an event, such as a fall or stroke that made it clear that a resident was no longer safe to live in their own home. Consequently, the family or friends had to begin considering a 24-hour programme of care. However, pressure from hospitals to free bed space, from care homes because of competition for limited spaces, and the need to settle the resident quickly meant the **search for a care home was often urgent**, and participants said they felt **rushed into making their decisions**.

6. The ease of conducting an online search allowed people to get a quick sense of what care homes existed within a given area. Establishing a broad array of potential options was, therefore, relatively straightforward. Yet other, more physical constraints subsequently narrowed these options.
7. Because of this limited timeframe, people often said they only visited a small number of homes, and felt they had limited time to seek more detailed information on the care sector, care homes in general, or other things such as funding.
8. Typically, representatives visited 3-4 homes in their desired location, depending on availability. Participants described how this felt like a small number of homes to visit, considering the magnitude of the decision they were making. However, a combination of a perceived lack of options – due to available space or due to geographical limitations – and the time pressure they felt they were being put under meant that visiting more than three or four homes was rarely a practical possibility. Participants expressed the view that more detail about the different care homes on offer, available before they visited them, would have helped.
9. Their final choice felt forced, and once it had been made, **moving into a care home happened rapidly** as the priority was to get their relative into a safe environment as quickly as possible.

#### Limited engagement with the details of the 'system'

10. An **absence of engagement with the different parts of the care system** was clear. For example, a lack of planning or engagement with care homes before a trigger event occurred was common, even if families had been aware of a longer deterioration in their relative's health. One of the reasons the decision was not contemplated earlier was due to resistance from residents, who wanted to maintain their independence for as long as possible. Additionally, families felt guilty admitting they were not able to cope with their relative alone anymore.
11. When representatives were looking for a home, they had **limited time to engage with the information sources** available and few sought them out. Furthermore, choosing a home was a highly personal experience – decision-makers prioritised their own gut instinct over more objective information and performance measures, e.g. their own perception of the care home being clean, friendly, and homely affected their decision more than the quality inspector reports, (the Care Quality Commission (CQC) in England, the Care and Social Services Inspectorate Wales (CSSIW) in Wales, The Care Inspectorate in Scotland and The Regulation and Quality Improvement Authority (RQIA) in Northern Ireland). Awareness of these quality inspector reports was also low.
12. Participants did not feel a need to engage with funding as they were not able to influence it – as one representative said, funding 'is what it is'. Awareness of top-up fees was low, particularly when it came to the detail of what the top-up fee was for and how they were used.
13. Once they had decided on a home, the paperwork involved in moving the resident in was generally straightforward. However, this time was rushed and overshadowed by the priority to settle the resident as quickly as possible. Participants had **little recall of the detail within the contracts** they had signed, suggesting they were not engaging with them before moving the resident in – and there was the assumption that contracts were regulated across the sector. When the resident was in the home, representatives rarely scrutinised the care home bills in any detail, and often weren't clear on the reasons for extra charges. They had also done little research to understand the different mechanisms to feedback beyond speaking to care home staff. Overall, they were happy to provide ad-hoc feedback,

but were hesitant about taking anything beyond the care home manager – though there was little discussion of what might happen in the event of serious and persistent concerns.

14. Participants in each nation were also relatively disengaged with the payment process, describing it as a “formality”. Those who were funded by the local authority were particularly disengaged from the details of paying, and said that the local authority paid the care home directly without their input. Those who were self-funded or mixed-funded – even though they believed they were paying in part or in full for their care – also exhibited low levels of engagement with the payment process.

#### A perceived lack of information and support

15. Participants said that **information and support was lacking on issues such as what kind of care home was appropriate** for a resident, regardless of funding type. Representatives relied on advice from family and friends or neighbours, health professionals such as doctors, or talking to staff in a respite home. Yet representatives felt like they had to **act alone and had little support offered to help them navigate the system** or understand the complexities of the sector. For example, people wanted an expert to talk them through their options and make recommendations about the suitability of different care homes, but did not feel like they received this support. Participants said that more guidance from someone who knew the system and could pass judgement on care homes would have helped them feel more confident in making a choice. Representatives also gave examples of not knowing that there was a difference between nursing and residential care until this was explained to them by a care home they were considering.
16. A considerable challenge faced was understanding what care home would best cater for their relative, and having to judge between a residential home, nursing home, Elderly Mentally Infirm (EMI) care and so on. Those who were self-funding found this particularly difficult, as they had less input from social worker beyond receiving a list of care homes
17. In Scotland and Northern Ireland, social workers and care managers were commonly – though not always – involved from the outset compared to elsewhere, and were also more involved in helping self-funders find a suitable care home. Participants said that more guidance from someone who knew the system and could pass judgement on care homes would have helped them feel more confident in making a choice and establish what care home would best meet their requirements.
18. Furthermore, information on funding was described as opaque and complex (including by professionals), and so residents and representatives only briefly considered it. There was therefore low awareness of funding options (for example, continuing healthcare), and information about options typically did not appear to be offered proactively by the relevant authorities. Furthermore, prices were rarely quoted by care homes upon first contact, nor did they seem to remain consistent between first being mentioned and the eventual signing of a contract. There was a sense that local authorities could do more to explain how needs assessments, financial assessments, and funding systems worked and why and when they were required. Residents and representatives alike found these aspects complex and confusing – they acted as significant barriers to engaging with the system and feeling informed about their choices.
19. Because of the perceived absence of much support or a lack of faith in the information sources they could find, **participants relied heavily on their own experiences of care homes** when deciding. Those who were aware of sources like the quality inspector reports initially found them useful to back-up their search – for example, as extra data or as a guide for where to start. However, they soon found these to be unreliable guides, with the reports frequently failing to match their own experiences of the homes they visited. Representatives engaged with the more tangible qualities of



the individual care homes that they visited – what they could see, smell and hear. Aside from location – which tended to be their primary priority – they wanted a home that was bright, friendly, and clean. Consequently, visiting care homes was the most important aspect of how they judged the quality of a home. Representatives felt there was a lack of information that was easily accessible and easy to understand about the sector and individual homes and suggested a facility to compare and contrast care homes would be helpful to them.

20. Similarly, the complaints or feedback representatives gave tended to focus on things that they felt able to see and judge (e.g. dirty clothes or unwashed hair) rather than more technical or less visible aspects of care. They suggested that they did not know what goes on 'behind closed doors' so can only complain about what they see. Furthermore, limited understanding on what to expect from a home, and how to assess that, meant they felt **ill qualified to judge a care home**.
21. There were specific challenges around the support provided by social services to people with local authority funding. Representatives described difficulties persuading social workers that a relative or friend needed to move into a care home.

#### Perception of limited options

22. Care at home was considered as an alternative to moving into a care home, but this was often rejected as inadequate because of the severity of the resident's needs. Therefore, 24-hour care in a home was seen as preferable. However, participants described several **constraints on their choice of care home**, regardless of funding type. These constraints included: availability of a home in the right location, affordability of the home, ability for the home to take care of a resident's needs, and the perceived quality of the home.
23. Cost of the care home was a consideration for those who were self funding. Furthermore, representatives of those who were publicly funded typically described how they could not afford to pay top-up fees, designed to give this group greater choice. Instead, the high prevalence of care homes charging top-up fees had a limiting influence on the choices available. Availability of the right kind of home – but also available capacity in *any* home – was a significant constraint. As was the perception that there are many poor-quality homes that people could end up in. Consequently, participants said they opted for a home that was 'good enough', as they were unable to find their ideal home or their ideal home was not available.
24. As a result of these constraints, representatives said that their overwhelming feeling was one of **relief to have found a home** for the resident. They said they felt lucky to have found a space because of the lack of availability, and the low quality of the other homes they had seen. This sense of relief and of opting for the 'good enough' option was also influenced by the low expectations residents and representatives expressed.
25. **Moving homes was typically considered as an option when first moving** – representatives opted for what could be described as the 'good enough' option and tried to put the resident on a waiting list for their first choice as they could 'always move later' – though few described getting a place in their 'first choice' home. However, moving homes became less realistic once the resident was settled – both residents and their representatives were reluctant to go through the upheaval of moving homes. Participants also said that because there was limited choice, homes were likely to be the same or worse than the home the resident was already in, so there was no point moving.

## Feeling powerless

26. Throughout the interviews there was the sense that **representatives and residents were powerless to take control of their situation**. This manifested itself in two ways: a lack of control when making the initial choice and moving in, and then a lack of control once in a home.
27. The absence of planning meant decisions were rarely driven by families or the resident themselves. Rather, they were reacting to an urgent requirement to get the resident into a home.
28. Participants were not engaging with contracts. There were examples of representatives being **unaware of notice periods** or powerless to change them when they wanted to move or a resident died. Furthermore, once the resident was in the home, participants felt powerless to change fee increases, and faced anxiety about covering these increases.
29. Participants said they were willing to provide feedback on issues around care and hygiene (for example, laundry), and care homes appeared to be open to this kind of feedback. However, they were more **reluctant to complain about contractual aspects like fees and notice periods** – possibly because there was little understanding of these issues. They had limited awareness of how to escalate concerns beyond talking to staff within the home. The reluctance to move to a different care home made residents and representatives alike feel helpless to change things. People also felt disempowered to challenge or negotiate fee increases. These were taken as inevitable due to a general sense that care homes' costs were increasing and care homes were under pressure financially.
30. These themes are explored in depth through the rest of this report.

# 1. Introduction and methodology

# 1 Introduction and methodology

## Background

- 1.1 The CMA is currently carrying out a market study into care homes for the elderly, to review how well the market works and whether people are treated fairly. Ipsos MORI was commissioned by the Competition and Markets Authority (CMA) to undertake a qualitative research study exploring how people navigate the care home sector.
- 1.2 The study covers the provision of adult residential care for older people (65 years +) in care homes and care homes with nursing ('nursing homes') in the United Kingdom. The market study examines how people choose appropriate care, whether the current regulation and complaints system gives residents adequate protection, and examines how well care homes are complying with their obligations under consumer law. Further information is available at: <https://www.gov.uk/government/news/cma-launches-review-of-uk-care-and-nursing-homes>
- 1.3 As part of this study the CMA asked Ipsos MORI to conduct research with residents and their representatives (i.e. family and friends), as well as social workers, to explore perceptions of how well the sector is currently working. This report details the findings of this research.

## Research Objectives

- 1.4 The study was designed to explore customer experiences of choosing a care home, covering:
  - The background to the decision to enter a care home, including the decision making around whether moving into a care home is appropriate for an individual.
  - The process of choosing a care home, the amount of choice available and which factors were important when choosing a care home.
  - Navigating the system for funding and sources of advice.
  - Ability to understand contract terms, the billing process and experiences of unexpected fees.
  - Experiences of moving care homes, including whether moving care home has been considered, the obstacles to moving and experiences of moving.
  - Mechanisms for providing feedback about issues and experiences of making complaints.
- 1.5 The research was designed to explore how these experiences relate to the characteristics of the care home resident – both those who are self-funded and those who are publicly-funded – the type, and location of the care home in question.

## Glossary of terms used in this report

Term	Definition
Continuing healthcare (CHC)	Package of care that is arranged and funded solely by the NHS for individuals who are not in hospital but have been assessed as having a 'primary health need'
Elderly Mentally Infirm (EMI) home	Care homes providing provision of care for older people with mental frailty
Care Inspectorate	Regulates and inspects care services in Scotland.
Care Quality Commission (CQC)	The independent regulator of health and adult social care in England.
Care and Social Services Inspectorate Wales (CSSIW)	Regulates and inspects adult care, childcare and social services for people in Wales
Mixed funding	Cost of care home is financed by both a publicly managed fund as well as the resident or their family. This could be as the resident's savings are above a certain threshold but below the threshold to be self-funded.
Nursing home	Homes that provide day-to-day care, but the care is supervised by registered nurses, who provide medical supervision.
Publicly-funded	Cost of care home is financed completely by a publicly managed fund, for example the local authority or the NHS (including CHC – see below)
Regulation and Quality Improvement Authority (RQIA)	Regulates and inspects health and social care services in Northern Ireland
Representatives	Friends or family members involved in the decision to find a care home
Residential home	Care homes providing personal care such as help with getting dressed, washing and other day-to-day tasks
Residents	Individuals living in a care home
Self-funded	Those paying for all their care home costs. In Northern Ireland, this includes individuals who are assessed as able, or declare themselves able, to meet the full cost of their care, but whose care is arranged and managed by their Health and Social Care (HSC) Trust. It also includes those categorised 'private funders' who arrange and pay for their own care under a private contract, with no involvement of an HSC Trust..
Social workers (and care managers)	People working for social services helping people find care homes
Top-up fees	The resident is publicly-funded or mixed-funded but a third party pays top-up fees to pay for a higher level of service, e.g. a better room in a care home, or to fund the difference

	between what the local authority is willing to pay and what a care home charges
--	---

## Methodology

- 1.6 A qualitative approach was adopted to provide in-depth insight into the views and experiences of those taking part. Three different audiences were included in the research to gain a broader understanding of the journey people go through:
- 102 representatives of people living in care homes, relating to 80 individual placements in a care home (that is, in several cases we talked to more than one person involved in the decision);
  - 16 residents in care homes; and
  - five social workers.
- 1.7 We focussed on representatives for two reasons. Firstly, they were most likely to have been the key decision makers when choosing a care home and so would offer the greatest insight into how people find the process. Secondly, they were better able to take part in the research than residents, being typically younger, more lucid, and in better health – those residents who took part were, for that population, relatively in better health and able to better recall the events surrounding the move into a care home.
- 1.8 Fieldwork took place between March and May 2017. Interviews were conducted by trained Ipsos MORI qualitative researchers. Interviews with representatives were largely completed by telephone, while interviews with residents were conducted face-to-face in the care homes. Further detail on how participants were selected and recruited are given below.

## Sampling and recruitment

- 1.9 A two-stage sampling approach was taken to identify participants for the research:
- Selecting the care homes (carried out by the CMA)
  - Selecting individual cases within the care homes (carried out by Ipsos MORI)

### Selecting care homes

- 1.10 Care Homes serving older people (those aged 65+) and dementia patients across the UK were categorised into residential and nursing homes based on their primary client type. These care homes were then further divided into those which were part of a larger chain ('chain') and those which were part of a smaller chain or were individual care homes not owned by a larger company ('other'). Care homes which were part of an organisation with more than the median number of beds held by organisations across the UK were defined as being part of a 'chain' whilst those with less were defined as 'other'. Using these two categorisations, the care homes were then categorised into four strata, i.e. residential care homes in a chain, nursing homes in a chain, residential homes 'other' and nursing homes 'other'..

1.11 Twenty-five care homes were selected, ensuring that the sample was distributed evenly by the four strata identified above, across a mixture of urban and rural locations and across the nations.

1.12 The care homes selected to take part had the following characteristics:

- 13 care homes in England, four care homes in Wales, four care homes in Scotland, and four care homes in Northern Ireland.
- 13 residential homes, and 12 nursing homes.
- 13 homes that were part of a chain (and 12 which were not).

#### Selection of individual cases

1.13 The CMA sought contact details for all residents and their main contacts from the selected care homes, to provide Ipsos MORI with suitable data from which to select research participants. Of the twenty-five care homes selected for the research, twenty-four provided usable contact details for all their residents and their main contacts.

1.14 The next step of the sampling process was to select individual placements (residents) within each care home, with quotas (or target numbers of interviews) set around each of the following:

- **Type of care home:** placements were selected in order to achieve a minimum number of placements in each of the 24 care homes.
- **Care needs:** whether the home provided nursing care; whether the home provided dementia care.
- **Funding arrangements:** a mix of residents who were self-funded, publicly-funded and received mixed funding (including top-up fees).
- **Time elapsed since entering the care home:** a mix of those who have moved into the care home relatively recently and those who had already been living there for some time.
- **Demographics:** a range of demographics, including both men and women and representatives and residents of different ethnic backgrounds.

Details of the exact quotas can be found in the appendix.

1.15 **Recruiting residents' representatives for telephone interviews:** The CMA sent an advance letter to all contacts provided by the care homes, with an information sheet appended (a copy of both can be found in the appendix). The letter provided an outline of the research and what was required from participants, giving them the choice of opting out from the study. Following one week in which participants could opt out from the study and having their contact details passed onto Ipsos MORI, the CMA securely provided the sample to Ipsos MORI with those who had opted out removed. Ipsos MORI recruiters then called potential participants to discuss willingness and availability for a telephone interview. Recruiters and interviewers also asked the original contact to identify other friends and family members involved in the decision making process for a particular resident. Residents' representatives were given £30 as a thank you for participating in the research.

- 1.16 **Recruiting residents for face-to-face interviews:** Residents were recruited through the representatives and the care homes directly. Residents with a main contact (a family member, friend or social worker) who were capable and would likely be willing to participate were identified through the interviews with representatives. An information sheet was provided to representatives, so that they could discuss the research with the resident. Residents without a main contact were recruited through the care homes directly. The CMA sent an advance letter to residents without a main contact, which was distributed by care homes based on their assessment of the resident's physical and/or mental capacity. Ipsos MORI recruiters then called the care homes to discuss the feasibility of residents taking part – focussing in particular on their mental capacity to take part in an interview. The interviewer obtained informed consent from the resident at the beginning of the interview. All residents who took part in face-to-face interviews received £40 as a thank you for participating in the research.
- 1.17 **Recruiting social workers for telephone interviews:** Social workers were recruited via the CMA supplied sample (where a main contact for a resident was a social worker). These participants talked more generally about their experiences, rather than specific resident, due to ethical constraints. The Ipsos MORI core team also identified social workers to take part in the research by calling local authorities to discuss the research. Participants were given £30 as a thank you for participating in the research, with the option to donate this to charity.

## Profile of participants

1.18 The following table provides more details about the participants in this research:

	Representatives	Residents
<b>Location</b>	54 interviews (42 placements), England, 17 (12) Northern Ireland, 17 (14) Scotland, 14 (12) Wales	12 England, 1 Scotland, 3 Wales
<b>Type of funding<sup>1</sup></b>	48 (37 placements) Self-funding, 17 (15) Publicly-Funded, 37 (28) Mixed funding	3 Self-funding, 6 Publicly-Funded, 1 Mixed funding <sup>2</sup>
<b>Type of home</b>	44 (33 placements) Nursing home, 58 (47) Residential home	7 Nursing home, 9 Residential home
<b>Care needs</b>	57 (44 placements) with dementia, of whom 43 (34) were receiving nursing care 21 (14) receiving only nursing care	At least 2 with early stages of dementia and receiving nursing care At least 2 receiving only nursing care <sup>3</sup>
<b>Length of residency</b>	38 (29 placements) moved in before 2016, 64 (51) since 2016	8 moved in before 2016, 8 since 2016
<b>Total</b>	<b>102 (80)</b>	<b>16</b>

<sup>1</sup> These were based on representative and resident self-description. There was confusion from residents and representatives as to what was considered fully publicly-funded and what was considered mixed-funding.

<sup>2</sup> This information is not available for all residents; for example, those who were recruited without a main contact and did not know how they pay for their care..

<sup>3</sup> This information is not available for all residents; for example, those who were recruited without a main contact and did not know details of whether they were receiving residential or nursing care.



**5 interviews with social services:** 2 based in England, 2 based in Wales, and 1 based in Northern Ireland.

## Designing the interviews

1.19 The interviews followed a discussion guide designed in collaboration with the CMA (a copy can be found in the appendix). The interviews with representatives focused on the overall journey experienced and the decision-making process. Interviews with social workers did not focus on specific cases, but rather explored general experiences of navigating the care sector. The discussion guide acted as a guide only for the depth interviews; researchers adapted the conversation to suit the participant, considering their unique situation and the sensitivity of the subject matter. Participants were assured of anonymity, and were given the freedom to opt out of the research at any time.

## Interpreting findings

- 1.20 Qualitative research is illustrative, detailed and exploratory. It offers insight into the perceptions, feelings, and behaviours of people rather than quantifiable conclusions from a statistically representative sample. Owing to the small sample size and the purposive nature with which it was drawn, findings from this research cannot be considered representative of the views of all people navigating the care home sector.
- 1.21 Much of the evidence in this report is based on participants' perceptions. It is important to remember that even though some perceptions may not be factually accurate, they represent 'the truth' to the participants and as such, are vital in understanding their attitudes and views.
- 1.22 Illustrative quotes are used throughout to demonstrate the points made by participants in their own language.

## Structure of the report

- 1.23 This report starts by looking at the context for moving into a care home, exploring what events lead up to the decision, including experiences of care assessments.
- 1.24 The next two chapters discuss the process of finding a care home. The first chapter explores the steps taken to find a home, including the number of homes considered, participants' preferences for a home and their perceptions of choice. The second chapter looks specifically at the information and support people used, and how this can be improved.
- 1.25 The report next presents the considerations around funding, including how people understood their options around funding and the information people used or would have liked around funding. We then turn to the process of moving into a care home, including how people understood contracts.
- 1.26 The next three chapters focus on experiences once a resident has moved into a home. The first explores experiences of providing feedback and complaints, including the barriers people face when providing feedback. We then turn to experiences of paying for care, before looking at perceptions and experiences of moving care homes.
- 1.27 Finally, we provide some conclusions and implications in the final chapter.
- 1.28 Throughout the report short case studies of individual experiences are included to illustrate the findings. Please note that the names used in these case studies have been changed.

1.29 The appendix of the report contains the discussion guides used for this research.

## Acknowledgements

1.30 Ipsos MORI would like to thank all the participants who gave up their time to speak to us. We would like to thank the care homes for agreeing to participate in the research. Finally, we would also like to thank the CMA core team for their help identifying and accessing care homes, and their advice and support throughout the project.

## **2. The context for moving into a care home**

## 2 The context for moving into a care home

- 2.1 This chapter looks at the events leading up to a resident's move into a care home. It explores what prompted residents and/or their representatives to begin looking for a home, and the reasons why a care home was considered the best practical option. It then looks at the reasons why the decisions to move into care happened when it did and what instigated the search for a care home. The chapter finally looks at how experiences of care assessments related to the need to find a care home.

### Chapter summary

The main reason representatives began looking for a care home was in response to a trigger event, such as a fall, that forced a family to make a decision about care. Typically, these decisions were not considered over a prolonged period.

Often a care home was the only practical option for the resident because of how pronounced their care needs had become. Only in rare cases had families begun planning ahead and considering the need for a home, whether or not representatives were aware that a care home might be required for the resident at some point in the future. The emotional distress played a part in this, including feelings of guilt, as well as resistance from the resident themselves. As a result, it was only when moving into a care home was imminent that representatives generally began to research.

Residents did not feel involved in the decision to look for a home – whether they were unable to be involved due to their health or because their family made the decision without consulting them.

Finally, experiences of care assessments varied, and participants had limited recall of what was involved. From the information provided, they appear to take place inconsistently, variously undertaken by care home staff, hospital staff, social workers or GPs.

### Key challenges

The decision to move into a care home was rarely driven by representatives or residents themselves, and a **lack of planning** characterised the experience of deciding to move into a care home.

The time leading up to a resident moving into a care home was filled with **anxiety that puts strain on families and friends**, as the resident struggled to live independently.

Representatives sometimes **struggled to convince the resident** to move into a home, **or convince the relevant professionals** that the resident needed more care.

Representatives often experienced **emotional distress** around moving the resident into a home.

### Key supports

Discussing care needs with a **professional**, particularly with doctors at a hospital, helped residents and representatives reach the decision that a care home was needed.

A stay in **respite care** was effective in demonstrating to representatives that a resident would benefit from full-time care. A care home offered families and friends **a relief** from the strain and worry they experienced when the resident wasn't coping well in their own home.

## The circumstances leading to full time care

2.2 Despite residents' diverse circumstances, there were two main routes that led to residents moving into a care home. First – and most commonly – representatives described an event that meant they had to quickly begin looking for a care home, for example in response to a resident having a fall, with little warning to help them prepare for this. Secondly – and less typically – they took a more considered approach by planning ahead, exploring their options, attempting to understand funding, and seeking advice from friends, relatives or experts. This process of planning took place over a series of months, typically. Yet even in these cases, there was often a trigger event which suddenly created a sense of urgency.

2.3 Across the interviews, representatives or residents had typically **begun looking for a home following a trigger event**, such as a fall at home, a stroke, or the recommendation of a health professional that now was the time to consider a care home. This forced representatives to seek full time care for the resident. There were cases where the family and friends had been aware that the health of the resident was deteriorating and the trigger happened as part of a series of events that were increasing in severity. Yet it was not until a moment of crisis had taken place that meant a resident had to be admitted to hospital, or move into respite care, that the decision was made to look for a care home.

*"My mother's health had been deteriorating. She was living on her own and she collapsed at home. She'd been on her own lying on the floor for probably 24 hours and ended up in hospital, and the outcome of that process was that it was recommended that she should go into a home."* Representative (England, Residential home, Self-funded)

2.4 It was therefore relatively **rare for representatives to initiate the process proactively**. Instead, they felt that the decision to move into a care home came at a critical point when other options were no longer practical. Moving into a care home was therefore a decision made in response to an event that took the decision out of their hands rather than something that was planned in advance.

*"That incident really just brought everything to a head. Maybe it wasn't that much of a shock to us. But it wasn't a matter of making that decision and then sitting back and looking for somewhere and then having the conversation with her about what was the right thing to do."* Representative (England, Residential home, Self-funded)

2.5 Talking to hospital staff about the resident's care was an important factor in the decision, and participants often said that it was on a **doctor's recommendation that they began looking into full time care** for the resident, whether the resident was still at home at the time, or had been admitted to hospital.

*"He ended up in hospital for close to seven months because of the various problems he had, that they wouldn't release him. And then the one doctor did finally turn round and say, look you've been like a yoyo in and out of here, you're not going back home again, you're going to care."* Representative (Wales, Residential home, Mixed funding)

- 2.6 A stay in respite care also influenced representatives' decision to keep the resident in full-time care. This was largely because the experience of full-time care helped the representative see that staying at home was no longer a viable option – as case study 2.1 demonstrates.

### **Case study 2.1: staying on in respite home after a fall**

Representative (Northern Ireland, Public-funding)

David's father, George, was getting increasingly immobile and had a few falls so went into a home for respite care to recover. George already had a care package in place at home organised through the local authority, with carers visiting him four times a day. However, there was a long break in these visits over night during which he was left alone and this was when accidents or difficulties (e.g. with his medical equipment) were occurring.

The longer George was in the respite home, the greater security it gave him having people close at hand if something happened. This made the family realise that having carers visiting at home was no longer enough to keep him safe from harm. Eventually, after a month and half of respite care they decided that George would stay in full-time care rather than going back home. David said this was not an easy decision to make as he felt a sense of failure because he was not able to care for his father himself, as well as one of relief that his father would now have adequate care in place.

*"My second feeling was relief...the position that he had been in for the previous six months to a year had placed a lot of strain on me and the rest of my family, on my wife in that we were constantly trying to get back and forwards to him just to check that he was alright."*

- 2.7 In other cases, representatives took a more considered approach to moving the resident into a care home, although these cases were much less common – few people we spoke to were comfortable contemplating the prospect of entering a care home, whether for themselves or a loved one. There was little evidence for (or against) the notion that those planning ahead got better outcomes.
- 2.8 For example, one representative said that their mother had been deteriorating for a long time but was also becoming increasingly lonely and isolated staying at home. Together, they made the decision that she should move to a care home, and in this case it was the social benefits of a care home that convinced them both that a care home would be suitable. In another case, a mother and her son had discussed the possibility of moving into a care home for a number of years although they had not done anything to investigate the options for finding a home.

*"Well Mum was really quite happy about it, she was really up for it, she's quite a sociable person, so she was quite ready to interact with other people and she thought it would be quite nice, because being in the flat she didn't see many people."* Representative (England, Residential home, Self-funded)

## A care home was considered when it was the only practical option

- 2.9 Concern for a **resident's safety was a significant factor in any decision** about moving into a care home. Representatives were faced with the reality that their elderly family member or friend was at risk by staying at home. As a result, a care home was seen as the only option available once it became apparent that other solutions were not enough to ensure their wellbeing.
- 2.10 Other **practical options had either been exhausted or dismissed** by the representatives. For representatives who already had a care package in place at the resident's home, they felt it would no longer be suitable as accidents were still happening – as illustrated in case study 2.1. Alternatively, participants felt that the situation with their family member had become so concerning that the only way to keep them safe was to ensure they had 24-hour supervision and care.
- 2.11 A lack of confidence on the part of the residents themselves was also a significant factor driving the decision to seek full-time care, when the resident was no longer comfortable staying at home alone. Consequently, in these cases the decision was driven by the resident themselves.

*"Mum didn't feel safe at home any more. The decision was hers. She felt that she couldn't cope at home, even though social services had put in the highest level of help that they could." Representative (Scotland, Nursing home, Mixed funding)*

- 2.12 Moving into a care home was generally seen as preferable to having a care package at home – despite there being a general perception that staying at home was best for residents' wellbeing. This rejection of staying at home was driven by a pronounced **resistance from residents to having carers coming into the home**. They felt this was intrusive and an invasion of their privacy. There were also concerns that care provided at home would be inadequate, particularly if someone had experienced poor care at home themselves or heard about peers' experiences, or if they had a general attitude that care in the community is under resourced and insufficient.

*"We were offered carers to come in and look after mum. They said that they would have carers come in here three or four times a day to look after mum and to do her needs but I said 'this is our home', it really would be an invasion of privacy really." Representative (Northern Ireland, Self-funded)*

- 2.13 Because of the nature of the trigger event, finding out they would be moving into a care home was normally unexpected for residents too. Regardless of whether they agreed or disagreed with the decision that they needed care, residents felt the decision had been made around them with little of their input.

*"I didn't like it at all, but they told me I couldn't go home. They didn't think I'd be able to look after myself." Resident (Nursing home)*

- 2.14 That said, the decision was normally made at a point where the resident was particularly unwell or vulnerable. Consequently, it was difficult for them to proactively engage with – or be engaged by others in – the process of finding a care home.

*"The decision really was made for me because of what happened, and it was only really when I was in [hospital] that I realised that I wouldn't be able to go back on my own."* Resident (Residential home)

- 2.15 Representatives therefore felt that moving into a care home was **the only practical option to keep the resident safe**. Subsequently, when the resident did move into a care home, representatives reported an overwhelming feeling of relief that they were safe, as case study 2.1 illustrates. This contrasted with the strain and worry that had characterised the weeks, months or years leading up to the decision.

*"You would be sitting having a gin and tonic with friends on a Friday night and the phone would ring because she had locked herself out of the house or some domestic crisis. It never went away...so my overwhelming reaction to her going in to a nursing home was a huge relief."* Representative (England, Nursing home, Self-funded)

- 2.16 This **sense of relief was something representatives felt strongly** across the research. It is unclear whether representatives would have been encouraged to look into care earlier if they had known it might ease the strain of worrying about a relative or friend. However, it is an area worth exploring further; a potential incentive for families to begin considering care earlier than they tend to do at the moment.

## The timing of the decision

- 2.17 Though representatives were often aware that their family member or friend's health was deteriorating, **only very rarely did they begin looking a care home before a crisis point** forced them to. Instead they were struggling to manage at home for as long as possible. A lack of preparation therefore characterised participants' experiences of finding a care home.

- 2.18 The emotional distress involved in deciding to send a loved one to a care home was an important factor in this. Representatives described **the decision to send the resident to a care home as a very difficult one to make**, and thus it was unlikely that they would opt to make it unless circumstances made it essential.

*"Well, it's just on a par with putting a child in to live with somebody that she doesn't know, when people are so elderly, and they're so vulnerable. It's just a horrible experience."* Representative (Northern Ireland, Self-funded)

- 2.19 The experience was also associated with **feelings of guilt**, because representatives felt they had failed to look after the resident. They would, therefore, put off confronting the issue for as long as possible – trying to do everything they could to prevent their loved one from needing to enter a home.

*"We probably delayed it longer than we should have, because of guilt. I couldn't bear the thought of him being in a nursing home and not knowing where he was, and wanting to come home and all the upset around that."* Representative (Wales, Nursing home, Publicly-funded)

- 2.20 Representatives also widely discussed the **resistance they got from residents who wanted to maintain their independence** for as long as possible. A particular challenge representatives faced was therefore coping with this opposition and trying to convince the resident to move into a care home, which added to their feelings of guilt. Representatives described their inability to control the situation and convince the resident that they needed more assistance and support.



*"She was not coping, she was a liability, I needed to go and see her every day and sweep up the mess, she was leaving gas on, she would lose things, have medical procedures she didn't really need...she was out of control and there was nothing I could do about it."* Representative (England, Nursing home, Self-funded)

- 2.21 In these cases, it was only once the crisis point was reached that the residents were finally convinced that things had to change. Crucially this crisis point also involved **professionals such as doctors, who were able to help the family come to the realisation that a care home was needed** to keep the resident safe, as described above. As other Ipsos MORI research has shown, health professionals such as doctors and nurses remain the most trusted professions, especially among older people<sup>4</sup>, and, in this research, were listened to readily by residents who were otherwise reluctant to move into care homes.
- 2.22 For residents whose care was being funded – at least in part – by social services, some representatives discussed challenges around convincing social workers that the resident needed a care home rather than a care package at home. These participants felt that social services could be obstructive when they did not agree with the representative that someone needed full-time care, as highlighted in the case study below. Other times, there was a sense that social services only stepped in to help them once a doctor had agreed with the representative that a care home was needed – and so the resident was considered to be 'bed blocking'. These participants were concerned that social services stalled on decisions or recommended care at home in order to delay the need to fund expensive care.

*"We'd been trying to persuade her to go into a residential care home for a few years, and social services didn't want anything to do with it. They told us she was fine at home so they wouldn't assess her as needing a home, although as far as I'm concerned, she definitely did."* Representative (England, Nursing home, Self-funded)

---

<sup>4</sup> <https://www.ipsos.com/ipsos-mori/en-uk/trust-professions>

**Case study 2.2: dispute with social services over need for a home**

Representative (England, Nursing home, Mixed funding)

After a stay in hospital for a few months following a fall, Jenny felt that her father, Rodney, needed to move into a care home to ensure he got 24-hour care. Her father was in his 90s at the time, and frightened of going home and having another fall.

However, social services disputed the need for 24-hour care and wanted Rodney to go home and have regular care visits instead. Jenny said she had regular calls and meetings with the hospital and social services to convince them that Rodney was not able to go home. It was a stressful time for Jenny; she remembers feeling sleep deprived as she was worried that her father would be sent home and be unable to look after himself. Around this time social services made a number of visits to Rodney in hospital to arrange his discharge. Against Jenny's wishes, these visits took place without her there to supervise. Rodney was given a discharge date which was not discussed with her, which she managed to delay.

*"I was sat on the edge of the chair, teetering on the edge, thinking surely to God, they're not going to send this man home because he'll die."*

Eventually, with the support of a doctor and ward nurse from the hospital, a multi-disciplinary team meeting was set up with nurses, physiotherapists, the doctor and social worker to discuss the case. It was decided that Rodney was not fit to go home and they should start looking into care homes.

- 2.23 Social workers talked about the importance of the meetings following the care assessment involving the multi-disciplinary team in deciding on the most appropriate form of care, rather than it being an individual decision made by them. They further described this as a decision led by the family, rather than by any professionals. They also mentioned the potential for difficulties to arise between medical and social models of care assessments in ensuring that a resident's full needs were met. This was particularly the case when looking at funding, where a resident might not meet the specific health markers for nursing care, for example, but a nursing home may be more appropriate for other reasons, such as mental health problems.
- 2.24 Other factors that could contribute to the wider reluctance to countenance care homes included the cost of care deterring representatives from making a decision until the last minute, and high profile stories in the media of abuse and neglect. However, although participants mentioned these in the research, they did not raise these as significant factors in their decision-making – it is not clear from this research whether these factors influenced a lack of planning ahead.

**Experiences of care assessments**

- 2.25 Recollection of care assessments was limited, and it appeared that they happen in a variety of settings and mean different things to different people. Representatives largely recalled them happening in hospitals, particularly when the resident was confined to their bed and unable to return home. When the resident was well enough to return home, assessments took place there – as the below examples illustrate.
- 2.26 In most cases, care assessments happened before a resident moved into a care home in order to confirm the need for a care home and what the resident's care needs would be. However, this was not happening consistently and there were rare occasions where the care assessments happened once the resident had moved in. For example, if the

resident needed to move in urgently then the care assessment might happen retrospectively, alternatively if the family were self-funding then they did not necessarily wait for a care assessment before moving a resident in.

*"We chose the home before we went through all those processes in a way. I chose it and then we got the social workers involved and they came round and assessed her after that really so it was almost, it was a temporary measure to begin with but then they got involved and assessed her and it seemed a suitable place I guess."*

Representative (England, Nursing home, Self-funded)

- 2.27 However, on the whole, representatives had a limited recall of when care assessments were taking place and what they covered. They were not able to discuss in detail what constituted a care assessment – overall, they did not appear to be happening in a consistent way, as the below examples demonstrate.

### Examples of different types of care assessments

- 2.28 This section provides examples of the wide range of different care assessments participants described, for example in a care home, by a multi-disciplinary team (MDT), or in the hospital. Representatives were not able to provide much detail on what the assessments involved, but positive experiences tended to be when the care home staff visited the resident and the representatives could ask questions and find out more about the type of care they would receive in the home. There were instances where representatives also described more than one care assessment – for example, a care assessment at the hospital to decide whether a care home was appropriate for the resident, and then an assessment by the care home to check they could meet the residents' needs.

- 2.29 **Assessed by the care home:** The resident was at home when two members of the care home's team came to assess her. The resident's daughters were also involved and could ask questions; one of the daughters who was not convinced her mother needed a care home found this very reassuring and was convinced of the need for a care home as a result.

*"Two team leaders came to my mum's house and my sister was on the other end of the phone and my sister had a lot of questions, I had a load of questions, and they were, and they answered all of them and they answered them all satisfactorily."* Representative (England, Residential home, Mixed funding)

- 2.30 **Assessed by social services:** When the representative's father had to go into hospital, his wife was also assessed by social services as her dementia was getting worse, and it was decided that she needed to go into a home.

*"Social services, they were really very good. When my dad came into the hospital, they assessed mum as well and they decided that she would need a care home that provided the type of service for Alzheimer's basically."*

Representative (Scotland, Residential home, Self-funded)

- 2.31 **Assessment by hospital staff** to determine whether the resident required fast track nursing care: The resident had been suffering from cancer and was in respite care following an operation. A team of nurses assessed her in hospital and decided that she needed to go into a nursing home.

*"The initial assessment was when she was in the hospital. They have district nurses, you know people who know medically what they are talking about to go in to do the assessments and I think it is kind of just a tick box exercise, and life expectancy and a few other bits are thrown in."* Representative (England, Residential home, Mixed funding)

- 2.32 **Assessment by a GP:** the representative's father had been in hospital for a year following a stroke. The hospital wanted to discharge him and so various meetings were set up with care professionals to discuss the options, such as having a care package at home or going into a care home. The hospital consultant was not in favour of sending him home so they decided to look for a care home. A GP undertook the assessment of his needs.

*"Well they had a GP come out and the GP assessed his mobility and he has cognitive impairment, so they were doing assessments on that and his level of understanding of what was going on, and his physical ability."* Representative (Northern Ireland, Mixed funding)

- 2.33 **Assessed by an MDT:** the representative's father stayed in a respite home after going into hospital. The council was initially paying for this care before he sold his house, and a multi-disciplinary team met to discuss what his care needs would be.

*"There was a multi-disciplinary meeting in the hospital including him before we were discharged, so we went through a folder which was about two inches thick of how he was at that time, but of course people change daily as, obviously, they're getting older."* Representative (Wales, Residential home, Mixed funding)

- 2.34 **Assessed in hospital and at home:** The resident was in hospital after a fall when she had her first assessment by hospital doctors. They decided that she could go home but would need carers to come in and help her. Social workers then came to her property to carry out another assessment and they agreed with the hospital's assessment, and carers were consequently set up to come in the mornings and evenings to dress and wash her. However, it became clear very soon after that her mother was going to be confined to the lounge and would not be able to manage the stairs. The hospital and social workers therefore carried out another assessment and decided that the resident would need to move into a home.

*"The hospital and the social people did a thorough check and examination and they decided on reflection that no, we think that she should go into a home."* Representative (England, Residential home, Self-funded)

### **3. Information and support when finding a home**

## 3 Information and support when finding a home

- 3.1. This chapter looks at the support and information families used to help them find a care home. It begins by exploring the types of information representatives used, and the role of social workers in finding a care home. It then looks at the types of information and support representatives said they would have benefitted from.

### Chapter summary

Representatives used internet search engines, care home websites and brochures, calling and visiting the care home to understand factors such as availability, and the price of homes. Resources such as quality inspector reports were rarely used and were not an important factor in making decisions about care. Very few had used charities to help them understand the sector or care homes on offer, and few spent time seeking out this information. Overall, participants felt that there was limited support and information available to help them decide about a care home.

Participants felt that they were left alone to find a home, and they could have benefitted from more support with navigating their options. This could take the form of information that is well-signposted and easy to find, as well as having one-to-one advice from a neutral expert. In Scotland and Northern Ireland, social workers and care managers were commonly – though not always – involved from the outset compared to elsewhere, and were also more involved in helping self-funders find a suitable care home. Participants who had a social worker or care manager on board from the outset of their search found this beneficial as they felt more supported through the process of finding a home.

### Key challenges

There was **limited time to seek information** and become more informed on care homes or the wider sector.

More informed representatives were aware of, and referred to, quality inspector reports when choosing which homes to visit, but **lacked confidence in their usefulness** because they were either out of date, or did not match their experience of visiting homes.

Care home websites and brochures were considered **'glossy'** and **'misleading'**, in the sense that they were trying to sell the home to consumers, and did not reflect experiences when visiting the home.

A considerable challenge faced was **understanding what care home would best cater for their relative**, and having to judge between a residential home, nursing home, EMI care and so on. Those who were self-funding found this particularly difficult, as they had less input from social worker beyond receiving a list of care homes. Self-funders expected **more support from social services**, and those who were fully funded felt social workers could sometimes offer an inappropriate home or push an "agenda".

Representatives said they felt **alone making their decision**, with no one to guide them through the various options.

## Key supports

Lists of care homes provided by social workers were **helpful to identify homes** in the right location, but provided limited support beyond this. Where they did take the time to explain the system representatives found this useful.

Care homes and care home staff also provided key support into the structure of the care home sector and what might be available. Representatives gave examples of not knowing that there was a difference between nursing and residential care until this was explained to them by a care home they were considering

Resources such as quality inspector websites were useful to get **an overview of the types of homes** on offer in the area, despite making little difference to representative's ultimate choices. Other websites such as care sector specific websites were seldom mentioned.

Representatives would have liked more detail about local care homes (e.g. a comprehensive list), and a **tool to compare and contrast** their options.

Reviews and feedback from friends were helpful and representatives suggested that a way of speaking to other friends and family, **'users' of the home, to get feedback** could be beneficial.

Families wanted **more guidance from someone with expertise** about the sector to help them navigate their options. In Scotland and Northern Ireland, social workers and care managers were commonly – though not always – involved from the outset compared to elsewhere, and were also more involved in helping self-funders find a suitable care home. Participants who had a social worker or care manager on board from the outset of their search found this beneficial as they felt more supported through the process of finding a home.

## Types of information used

3.2. Participants sought information on what care homes were in the area, availability, price, and feedback on the homes – both formal feedback and word of mouth. They then visited care homes home to understand what they looked like, view the facilities, meet the staff, and assess the 'feel' of the home. Few sought information on how the care sector worked and how to navigate it.

3.3. Only the better informed representatives were aware of resources, particularly quality inspector reports, and used these as part of their search. However, even in these cases, they were a **useful starting reference for a search, rather than driving decisions**. For example, representatives looked at the quality inspector report at a glance before visiting a home. What was more important to them was their own experience of the home when they visited it.

*"I probably would have checked it out just in case, but it wasn't necessarily uppermost in my mind, I think I would have gone for a home that my dad liked first and then checked how it was rated, and did it that way."*

Representative (Wales, Residential home, Self-funded)

3.4. On the whole, **participants therefore did not place much emphasis on** the quality inspector reports, even if they had at the beginning of their search, as in the case study below. An issue with quality inspection reports was that representatives found that they didn't match their own experiences of a home, and so lost faith in them. For example, they saw a home rated 'good' or 'outstanding' but observed unhappy residents and disengaged staff when they visited. They found that report might also be a few years out of date which reduced trust further. There were

examples of representatives choosing homes that had no quality inspector reports, or a poor report, because they were satisfied that they had found the right home from their own visits.

*"I did actually quite quickly come to realise that from my point of view that they actually meant nothing. I went to see one that had a high rating. But it was awful. I would not have put a dog in there."* Representative (Scotland, Residential home, Self-funded)

### **Case study 3.1: importance of the 'feel' of a home over the ratings**

Representative (England, Nursing home, Mixed funding)

Miranda wanted to find a home for her father, Sidney, that took the 'Dementia Care Matters' approach to caring for people with dementia. It has won a lot of awards and she had had a good experience with it during her father in law's stay in a care home. She also reviewed CQC reports.

She visited some homes to 'put the ratings into context'. She saw a couple of homes with an 'outstanding' CQC rating but was disappointed with the care she observed at these homes – for example residents calling out for help and being ignored. Overall, she visited over ten homes. Throughout the course of her search she increasingly felt that the feel of the home was the most important factor, and as a result stopped looking at care home ratings.

*"I'd let go of the Dementia Care Matters bit really because I just felt that it was just finding somewhere that felt alright. After I was just going and looking around to just get a feel of what it felt like really."*

During her search Sidney's needs changed and she had to start looking for a home that would be able to offer nursing care in the future. She hadn't been aware of the different levels of care available for people with dementia until she started visiting the homes. She discovered that a few of the homes she visited would not be able to accommodate her father's care needs.

She finally settled on a home that was originally written off because the CQC report had been poor. However, she was encouraged by her husband to visit it because it was local. When she visited she was impressed with the staff who were welcoming and knowledgeable, and appeared to care about her father and his needs. She also realised that the home might be appropriate for her mother as well – both parents now live at the home.

*"It was very welcoming and I think that their staff are well trained, they've got heart and soul. And that shone to us more and more. They were personal and seemed to enjoy their jobs."*

- 3.5. Care home brochures were used by representatives. However, they did not find them particularly helpful, because they did not reflect their experience of the homes when they visited. Representatives had similar experiences of care home websites and brochures which, though useful to get an idea of location and facilities, were described as unrealistic 'sales pitches' and participants therefore preferred to go and visit the home instead.

*"I'm rather suspicious of websites because commercially slick operators can write down fantastic things and they can sound out of this world, but when you go along it seems to be the attitude of the staff and the owner which makes a really big difference and that's very difficult to capture on a website."* Representative (Wales, Nursing home, Self-funded)



- 3.6. Very **few representatives used charities or other organisations** to help them find a care home, and participants were largely unaware of the range of information and support that they could draw on. Information from Age Concern and Age UK had been used in a few cases, for example to get advice on how to choose a home.

*"I went on the [website] to see recommendations for choosing a care home, because it was the first time I'd had anything to do with that. One of them said, 'be a bit suspicious if they say you have to turn up at such and such a time on such and such a day'." Representative (Wales, Residential home, Mixed funding)*

- 3.7. However, as discussed, participants were looking for homes under pressured circumstances so the time to seek information and digest it was limited. They may have sought additional information if they had not been under so much pressure to find a home quickly.

*"I imagine the Alzheimer's Society and Age UK have a wealth of information, but it's just when you're in the middle of that situation, I felt personally I had social services breathing down my neck for a decision that I just don't feel that I had any time to breathe." Representative (England, Residential home, Mixed funding)*

- 3.8. Residents expressed a desire for more information before they needed to move into a care home. It was felt that because of the urgency of the decision, they struggled to make sure everything they wanted was provided by a home and to find out what else they would like or need. Being encouraged to think about it earlier, and provisions of lists of what to expect and think about at that stage, would have been helpful.

*"You haven't ever really thought about it and suddenly you realise that you can't do what you want to do...it's something that doctors or something should start saying to people to think about." Resident (Residential home)*

## Information on the care home system

- 3.9. Representatives felt **particularly ill-informed about the care home system in general**. This included the different types of care that homes provided, how funding worked and what funding might be available to them, and what they should expect or look for from a care home. These were the areas that participants felt unable to start researching, as they weren't sure **where to go or what they needed to know**. This was particularly the case with funding, as will be discussed in Chapter 5. Where there was urgency, it was also felt that it was more important to start the search and see homes as quickly as possible, rather than being able to take the time to find out how the system worked.
- 3.10. Representatives gave examples of not knowing that there was a difference between nursing and residential care until this was explained to them by a care home they were considering. This was particularly concerning as it could mean that they had wasted time during an urgent search on care homes that were not an option for them.

*"There was a bewildering range of care options that we didn't know existed...and it seemed there were no hard and fast rules as to how they were treated. The final yay or nay was up to the home manager, which is understandable." Representative (Wales, nursing home, publicly-funded)*

- 3.11. They also talked about not knowing what they needed to know to make an informed decision. This meant they worried that they had made a wrong choice, because there was something key about the process they might be missing.

*"I think we were very lucky to stumble upon a nice place ... I didn't know what I was doing - clutching at straws and grasping around in the dark, groping about in the dark."* Representative (England, nursing home, self-funded)

- 3.12. Where social workers or care managers had taken the time to explain the system and what they should look for to representatives at the beginning of the search, representatives really appreciated this and felt more comfortable knowing what they were looking for.

### The role of social workers and care managers

- 3.13. Experience of social workers and care managers was mixed. Representatives had good experiences when they felt supported in their decision, but overall there was an expectation that social workers and care managers would be more involved throughout the process than they were in reality.
- 3.14. Participants had positive experiences of social workers and care managers when they could help them understand the range of care homes on offer; offered advice and recommendations on the different homes the representative was considering; offered specialist local knowledge, such as which homes might have more Welsh language speakers of staff; or advised on what kind of care home was needed to take care of their relative's needs. However, making recommendations was not common, and social workers taking part in the interviews also said that they would not typically provide recommendations, and instead provide a list that met their standards from which families could choose.

*"[The social worker] was quite honest...she would say 'I wouldn't have recommended this one, I wouldn't recommend that one'. That was the biggest help I got"*. Representative (Scotland, Nursing home, Self-funded)

- 3.15. The **list representatives got from social workers or care managers was helpful**, and some felt able to work with the social worker or care manager to identify the right home in the right location.

*"We said we just wanted the centre of town...and she phoned me back with two options. I thought, no...then she came back and says, 'there's a space in [a central care home]' and she could move there so that was all done. It didn't feel it was out of my hands, no."* Representative (Scotland, Residential home, Mixed funding)

- 3.16. In some cases, beds in care homes were found entirely by the social services, as in the case study below, with limited input from the representatives.

**Case Study 3.2: social services identifying a home**

Representative (England, Residential home, Self-funded)

Elaine's mother's health had been deteriorating for a long time, and she already had a programme of care in place with adult social services. However, after a fall at home that led to a hospital admission she was admitted to a respite home. The home was identified by social services. Elaine felt like finding this home was a continuation of the care that was already in place as it was organised through social services who were already administering care for her mother.

The care home wasn't a permanent plan and only a stepping stone between hospital and going back home. However, it became increasingly clear to the family that she would not be able to return home and it was decided that she would stay permanently. The family is not completely happy with the home – for example, the rooms are small. Yet they are concerned that mistreatment and neglect can happen elsewhere and they are confident this doesn't happen at her home. They are always aware that choice is limited in the area so the best decision is to leave her where she is.

*"Initially it wasn't talked about as being a permanent plan. So, at that point we weren't looking at that as being selecting a place for her to spend the next number of years, for example."*

- 3.17. In Scotland and Northern Ireland, social workers and care managers were commonly – though not always – involved from the outset compared to elsewhere, and were also more involved in helping self-funders find a suitable care home. Participants who had a social worker or care manager on board from the outset of their search found this beneficial as they felt more supported through the process of finding a home. For example, one participant in Scotland had a social worker involved once her mother went to hospital. The social worker was instrumental in convincing her mother and relevant professionals of the need for a home, helping the representative locate a home, and providing reassurance throughout the process.

*"My mother and I had a meeting with the social worker. The social worker did a fantastic job...she said, 'that went a lot better than I thought it would, it went a lot better than some similar meetings that I've had, I think what we now need to do is just press ahead and find a care home for your mother to go into'."* Representative (Scotland, Nursing home, Self-funded)

- 3.18. Nevertheless, across all four nations there was a general expectation that **social services and care managers could have provided more support than they did**. For example, those who were self-funding felt that social services or care managers often disengaged once a list had been provided, and the list was not sufficient in helping them find a home. Representatives also reported problems with the list – for example not all homes being appropriate to look after a relative's needs, prices not being included, or availability not being up-to-date.

*"I got a list from social services. The classifications were wrong on it half the time, I must have found fifty care homes and, of those, I only had about 10 that were suitable. The list was not up-to-date at all."* Representative (Wales, Nursing home, Publicly-funded)

- 3.19. Representatives of residents whose care was being funded by social services also regularly reported that **social workers had offered homes that were too far away**, for example a 20 or 30-mile drive in rural areas or on the far side of London. This was distressing for representatives and residents alike, as they feared their families would be separated. However, these participants felt that they could push back and ask for a home closer to where they lived.

This was more noticeably an issue for those with nursing care needs or complex dementia, due to the lack of availability at specialist homes.

*"People are actually being sent out of the local area, they can be miles away. The social worker told my dad and I went absolutely mad, he frightened my dad to death. I fought tooth and nail to get him where I did."*

Representative (England, Residential home, Mixed funding)

- 3.20. Representatives also raised suspicions that it felt to them like **social services and care managers had an agenda that influenced the advice they were offering**. Participants felt that social workers wanted their relative to go home, first and foremost, or alternatively find a space in any care home regardless of the families' preferences. They also felt that social services and care managers had a certain type of care home in mind – for example, one participant felt that her social worker would only consider a particular provider's homes in the area – or that they were trying to 'smooth things over' with the care home.

*"The social worker would try to push what suited them as opposed to what suited us as a family and my brother. Our priorities were to meet his needs and to keep him in an area where it was convenient for us to visit, as opposed to just wherever had a room."* Representative (Northern Ireland, Mixed funding)

## Improvements to information and support

- 3.21. Participants' decisions were largely based on their experiences visiting a home. However, it was also a stressful and daunting experience making that choice, and one that they felt underprepared for. They also felt that they were **left alone to make the decision**. Representatives said that there was not enough information available to help them feel confident in the choices they were making, and that they could have benefitted from more support throughout the process.

### Improving information provision

- 3.22. Reflecting on their experiences, representatives across the research said that they would have found the following information helpful:
- 3.23. More **detail about the different care homes on offer**, available before they visited them. For example, a more comprehensive list of care homes with pricing, the care they offer, and staff turnover, plus more information on care home's websites, such as activities offered and food menus.

*"It would have been nice, with hindsight, to have a list of all the care homes in front of you with details of everything they provide and their prices all in black and white so that you can just tick or cross the boxes appropriately."* Representative (England, Residential home, Self-funded)

- 3.24. Access to **reviews of the care home from other residents and representatives**, or the ability to talk to other representatives face-to-face, so they can understand from peers what experiences have been like.

*"It really would have been helpful to have had reviews or just the ability to chat to other people whose loved ones were already there. I don't know what sort of system could do that."* Representative (Northern Ireland, Self-funded)

3.25. A tool to compare different care homes on a range of different features.

*"I would like would be some sort of website, almost like a holiday booking website where you can check off the facilities, check the fees, compare them with each other, look at reviews". Representative (Wales, Residential home, Self-funded)*

3.26. However, looking for information on care homes – for example on websites – was not the priority, and people's personal requirements, assessed via the visits, were a far more important aspect of their search. Choosing a care home was felt to be a highly subjective issue, and participants acknowledged that it would be **challenging to provide the same information to all as people's preferences were so different**. Representatives were making decisions based on look and feel, rather than facts and figures pertaining to a particular home, and pointed out that they would always need to visit homes and meet people before making a decision. What was more important to them was to have support in place to help them make their individual decisions more confidently.

*"I don't know whether information really influenced my decision. I think the decision was based on who we met personally. I've said to people since, be sure you go and present yourself personally to meet people...You have to satisfy yourself." Representative (Northern Ireland, Self-funded)*

## Improving support

3.27. Finding a home was described as an ordeal by representatives. Participants said that **more guidance from someone who knew the system and could pass judgement on care homes** would have helped them feel more confident in making a choice. It would be important for this person to be informed, independent, and able to tailor their advice to individual cases to make sure it is relevant.

*"I want an independent view: 'these are the right steps to take'. Because I don't know whether I've done the right thing. Looking back on it, I don't know if I've gone through all the right checks, I've absolutely no idea." Representative (Scotland, Nursing home, Self-funded)*

3.28. Participants wanted someone who can help families navigate the system and look out for the resident's needs. This person was described as **a care navigator or champion**, who would be able support families through the process, and keep them involved in each step of the way. Most importantly, they would be experts in care system so that representatives would feel reassured that they are making the best decision for their relative.

*"I would want some sort of residents or families champion to say 'I am your contact and everything that you will need on a basic level to help you make that decision and I will help you through the process'." Representative (Wales, Nursing home, Self-funded)*

3.29. A considerable challenge they faced was **understanding what care home would best cater for their relative**, and having to judge between a residential home, nursing home, EMI care and so on. Those who were self-funding found this particularly difficult, as they had less input from social worker beyond receiving a list of care homes.

*"We weren't really guided on whether he should have an EMI home or a general nursing home, so it was kind of 'well, go and look and see what you think'. It was very difficult. At one stage, you think, well maybe a residential EMI because he was mobile and wandering, and then another week down the line and he was immobile and being very resistant to nursing." Representative (Wales, Nursing home, publicly-funded)*

## **4. The process of finding a care home**

## 4 The process of finding a care home

- 4.1. This chapter explores the process of finding a care home. It first looks at the steps people took to find a home, and the number of homes they considered. It then explores the process of deciding on a home, and how representatives and residents make their choice, including what constraints they felt there were on their ultimate decision.

### Chapter summary

Representatives typically started their search for a care home by looking for local homes online, via online search engines and then visiting care home websites. They also spoke to family, friends and neighbours, or if they had a social worker, used lists supplied by social services to identify homes in the local area. The next step was to visit a shortlist of homes they thought might be appropriate, to see if they would be comfortable with their relative living there. The number of homes representatives visited varied but they generally looked at a narrow selection of homes, typically a maximum of three or four options depending on availability, before finding one they considered acceptable and not looking any further.

When choosing a home, representatives considered a range of factors. They were looking for a home that was local, had the right look and feel, and that was clean, welcoming, with good facilities and friendly staff. However, these choices were constrained by factors including the availability of a room, whether they could afford the care home, and whether the care home could cater for the resident's care needs. These limiting factors meant that, overall, representatives felt they had few homes to choose from, regardless of whether they were funding the care themselves or it was publicly funded.

Residents were little involved and struggled to stay engaged with the process.

Families who felt they had time took a more considered approach to finding a home, by visiting a variety and then deciding which best met their needs of the options available to them, but these cases were rare and it was more common for families to be making their decisions in a short period.

### Key challenges

Representatives felt **time pressured**, meaning they were unable to conduct extensive research prior to their decision, or investigate what additional information they 'should' know or ask about when visiting.

More tangible qualities like **look and feel of the home were important** aspects in representatives' decisions – their own direct experiences visiting care homes was the most trusted aspect of the search.

Capacity within the homes posed a significant **constraint on choice** and meant representatives were often unable to move into their first choice of home.

### Key supports

Talking to **friends, family, and neighbours** to identify good homes in the area was helpful and influential. This was felt to be more trustworthy than any information online or provided by the care home.

An essential part of the process was **visiting care homes** to meet with care staff, observe other residents, and get an idea of the look and feel of the home.

The internet was central to finding local homes – typically originating with an online search engine rather than specific online tools for the care home sector.

## The steps taken to find a home

- 4.2. There were two main stages in the process of finding a care home. The first involved scoping the available homes in the area, for example on the internet, using a list provided by social services, or calling the homes for more information. They typically asked for basic information such as the care provided, location, and price. The second – and more important – stage was visiting the homes. These two stages are described below.

### Stage 1: identifying appropriate care homes

- 4.3. Once it had been decided that a care home was necessary, the first stage of finding a care home was to **identify what care homes existed in the local area**. Representatives used the following methods to find homes:

- internet searches (typically via an online search engine);
- care home websites;
- lists from social services;
- local telephone book or newspapers; or
- talking to friends or local people.

- 4.4. Using **online search engines and care home websites were most commonly used as it was convenient** – it was helpful to understand what homes there were in the local area. Care home websites allowed representatives to learn a little about the home, but representatives did not particularly trust them – as discussed in Chapter 3. Any information that was not available online, for example availability and prices, would be gathered by calling the care homes or asked about on the visit. Specific online tools for the care home sector were used rarely. If used, this was to find out what homes were in the local area rather than finding out more detail about homes or about the care sector. Only those who did not have access to the internet used telephone books or newspapers.

*“Just looking on their websites I’d say, on the internet, there’s various sites you can say where you live and it tells you what homes there are in the vicinity, and then it tells you what they specialise in. I can’t remember exact websites now.” Representative (England, Nursing home, Self-funded)*

- 4.5. Representatives who had a social worker to assist them were provided with a **list from social services** summarising details of care homes in the area. Both self-funded and publicly-funded representatives had sometimes received a list from social services. However, the latter typically had a far more limited range of homes to choose from – for example they were given the choice of three homes from which to rank their preferences. Those who were self-funded, on the other hand, were simply provided with a long list to start their search and then, apart from a few exceptions, left to make their decision alone.



*"They gave us leaflets...they basically said, there's three. Could we pick a top three, and we'll take it from there? The top one, we'll see if he can get in there, if not your second one, if not, your third one."* Representative (Scotland, Nursing home, Self-funded)

- 4.6. In Northern Ireland, representatives got this list from the local Health and Social Care Trust or a care manager, who would provide them with a choice of care homes selected from a list. Representatives – including those who were self-funding – were asked to provide their top choices for homes from a short list, from which the Trust would make a decision based on needs and availability.

*"We were given a list from the Health Trust in the area and we had to give the health service our top three choices and then out of those choices then the decision would be where had a bed, where had a room for him, somewhere that was most suited to his needs."* Representative (Northern Ireland, Self-funded)

- 4.7. Representatives would then shortlist these homes, based on the information they were able to gather such as the care they provided, location, price and feedback they were aware of. Feedback from trusted sources was found to be very helpful for representatives. This was largely through friends, family and neighbours in the local area. In many cases this was preferable to looking on the internet as they were able to get more detailed 'insider information' that they trusted on what care homes would be suitable. This seemed more likely where there were small, close knit communities – particularly in rural areas.

*"We just asked any of our friends who had family members in care homes and asked them what their opinions of them were, and then I rang round the ones that had got good feedback."* Representative (Northern Ireland, Self-funded)

- 4.8. As discussed in the previous chapter, access to other forms of feedback was limited, apart from quality inspector reports, which helped representatives who were aware of them eliminate homes that had poor reports.

## Stage 2: Visiting the care homes

- 4.9. Once representatives had identified a short list they would then go and visit the care homes. **Visiting the care home was the most important part of the search** for representatives whatever their funding type. It was on the visit that representatives felt able to assess the elements of the home they liked. They typically prioritised the 'softer' aspects of the home at this point, such as the look and feel of the home, rather than ratings, number of staff and other quantifiable features. Representatives frequently described judging whether the care home felt homely, and whether they would be happy for the resident to live there.

*"We were looking for not just is it grand and beautiful, but is it homely because it's going to be her home, and we're not going to be there 24/7, either."* Representative (England, Nursing home, Mixed funding)

- 4.10. On their visits, representatives were looking to see if the rooms were satisfactory; they wanted a room that was spacious, clean, and bright. They were interested in the attitude of the staff, and whether they were friendly, caring, and well-informed. Representatives generally felt able to do this, particularly staff attitude and friendliness. However, they usually had little experience to compare how well-informed staff should be and some described care homes showing their best side during a visit. The facilities were also of interest, for example whether there was a garden, and a living room for residents to sit in. Representatives were also looking at other residents to try to assess whether they appeared happy and well looked after, and at the quality of the building itself (for example, whether it was well-kept

or dilapidated). The smell was also an important factor, indicating to representatives how clean the home was and how well looked after the residents were. Food or menus were not typically part of the discussion at this stage of the process.

*"What was important was the attitude of the staff, to see the rooms, smell is very important to me, does it smell like the old-fashioned hospital? Was there laughter, was there a smile somewhere? The ambience of the people sitting, they're all in rows not interacting."* Representative (Scotland, Residential home, Self-funded)

- 4.11. Representatives found it easy to organise visits, and said that care homes were generally accommodating and helpful. Representatives also visited care homes unannounced as they had heard from friends that this would be a good way to test whether the homes were just putting on a show for visitors. In other instances, they would arrange an appointment with the home manager.
- 4.12. Due to the context discussed above, residents typically struggled to stay involved in the choice. They were rarely able to be proactive in finding what was available, if the home was not somewhere they were already aware of. Where residents had been able to visit, they then felt they had some say over whether the home was the one they wanted. But these instances appeared to be rare – typically, residents put their trust in family members or representatives to pick the right place for them.

*"Two places I wouldn't have gone to and they saw this place, and recommended it. They're my family so I accepted it. I knew I still have the house to go back to."* Resident (Residential home)

#### **Case study 4.1: residents struggling to stay informed in finding process**

Resident (Nursing home)

Claire moved into a care home as she was told there were two vacancies across two different homes, so she had to choose between the two. She picked her favourite of the two but was unhappy this was far away from her family and friends.

She recently mentioned to her social worker that she would have preferred to be in a location closer to where she had lived previously, and the social worker asked why she hadn't put her name down for care homes in that location.

Until then, Claire hadn't realised she could have had more choice than the original two options.

- 4.13. The number of homes on a short list varied. The time representatives had to visit the homes was an important factor in determining how many they visited; this is explored in more depth in the next section.

### **The number of homes considered**

- 4.14. The number of homes representatives considered varied. The **individual circumstances, preferences and ease of finding an appropriate home, and the time available for searching all played a role in determining how many homes representatives looked at.** Those who only looked at one home did this because they managed to find a home they liked at the beginning of their search, particularly if there was a tight time constraint, or did not have a choice of homes. Typically, representatives looked to get as much choice as possible in the limited time they had. In rare cases

representatives looked at a wide variety of homes, as they had more time to find the right home. However, overall representatives felt rushed into a decision and were not able to take their time to consider their options.

- 4.15. The time people had to find a home also limited the number of care homes they could visit. Representatives reported a **sense of urgency when making the decision about what care home to send the resident to** – experienced by both self-funded and mixed or publicly-funded representatives. This time pressure was due to factors including pressure from a hospital or respite home to free up a bed, or pressure from the care home to take an available space quickly, or fear about the resident's safety if they were still living alone. Representatives also wanted to settle the resident as soon as possible, and therefore wanted to make the decision quickly. This **time pressure had a substantial impact on representatives' experiences of finding a home**, as they felt rushed to find somewhere or risk the resident being discharged from hospital prematurely or being in a situation where they were unsafe. They therefore lacked the time to consider their options carefully.

*"The hospital said, you've got two days to find her a care home. I'm an only child and I've got no father on the scene so it was me or social services. I ended up going round five care homes in two days trying to find one."*  
Representative (Wales, Residential home, Publicly-funded)

- 4.16. Where a social worker helped representatives find a home, participants said that they got a sense of urgency from them, particularly if a hospital said it needed to discharge a patient. Social workers also reported that families are not given enough time once they have been notified of discharge to find appropriate care, as illustrated in case study 3.2<sup>5</sup>. This time pressure was experienced consistently by participants in all four nations.

*"We needed to get something quite urgently, I suppose that I didn't waste any time. I probably could have visited a lot more, but we wanted somewhere fairly quickly and it seemed to fit the bill. Perhaps we were lucky that they had a vacancy and we've been happy with it really."* Representative (England, Nursing home, Self-funded)

## Visiting one home

- 4.17. The reasons representatives cited for only looking at one home were mixed. For example, if a resident was in respite care and the care was satisfactory, no choice was necessary. Representatives who had taken a word of mouth recommendation felt that that negated the need to search for more. If a representative was satisfied with a home early on in a search, only had a limited number of homes to choose from (in rural areas, for example, or because of limited capacity in local homes), or because social services had a limited range they could offer, then they only visited one home. Those who only looked at one home did not necessarily feel unhappy with their choice if the home was ultimately suitable for the resident.

*"The social worker helped with the short list. I think there were about three care homes that were potential but my uncle and I really only visited the one just because it's so close and we knew it had a good reputation."*  
Representative (Scotland, Nursing home, Self-funded)

<sup>5</sup> The challenges the sector faces around delayed discharges and the pressure this puts on hospital services are well known. For example, a [recent report from the NHS Confederation](#) looks at how the independent sector is working with the NHS to reduce delayed discharges of care.

## Visiting a small number of homes

- 4.18. Typically, representatives visited 3-4 homes, depending on the number of homes in the desired location, that could cater for the resident's needs, and that had availability. These constraints on choice are explored later in this chapter. Representatives also said that it was preferable to look at only a few homes, as it was a distressing experience.

*"We didn't tour lots of care homes it was a very upsetting thing to have to do, and some of them were just nowhere where I'd want a parent to go." Representative (Wales, Residential home, Mixed funding)*

### Case study 4.2: families not having enough time

Social worker

Janine's work involved supporting clients in hospitals, helping people look for care homes, and visiting clients once they are in care homes.

A lot of her clients went to a care home directly from hospital following a crisis of some sort. In her experience, communication between the hospital and social services has tended to be poor. She felt that social workers are usually involved too late, at the point of discharge for example, when it would be more useful for her to be involved earlier on.

She could provide families with a list of care homes, meaning potentially visiting 16-17 homes, which Janine said was not a pleasant experience for them. She said the list also is usually not tailored to individual needs, and each family wants something different. She has often seen cases where the family is forced to make a decision on a care home in a very short space of time with limited support.

*"I heard of an incident recently of someone being given less than a week over the Christmas period (while social services was shut) to find a care home for a relative. The family member is still in shock now as they have had no time to process the grief and loss of the situation."*

## Considering a large number of homes

- 4.19. Representatives who felt they had time to make their decision could take a more considered approach to finding a home. Where there was availability in a range of homes, they were also able to spend more time visiting several homes – for example eight to ten homes – before making a choice. Participants living in Wales tended to visit more care homes, as care home availability tended to be a less limiting factor than in the other nations. For example, one family visited a range of homes, and then arranged for their relative to spend time in two or three of the homes before making a decision to ensure he was happy with where the resident was moving to. However, these considered approaches, such as the example in the case study below, were unusual.

*"[My mother] had decided she wanted to go in to a home. We had plenty of time and we looked at several places and we took her everywhere that we went, so she was very involved in the decision." Representative (Wales, Residential home, Publicly-funded)*

- 4.20. Additionally, even those who had spent time looking at homes were sometimes forced into a decision by circumstances – i.e. the resident's health quickly deteriorated. Those who had more time did not necessarily visit

more homes, although they might have done more research on homes (on the internet, for example). One representative in Scotland described how having more time to think and plan could help. They had identified the need for a care home for their mother early which, in turn, enabled them to sign up to – and stay on – a waiting list for their preferred home until a room became available. However, even in this case, the representative only visited three homes in total after much research on the internet.

### Case study 4.3: taking a methodical approach, with experience

Representative (Wales, Nursing home, Publicly-funded)

James had been in care homes for most of his life due to health issues. Harry – his cousin and representative – also had previous experience of finding care homes for another relative. They needed to find a new care home when they were notified that James' care home was due to close down and they needed to find somewhere new.

In order to ensure he made the best decision, Harry set up a matrix to evaluate the strengths and weaknesses of four or five options they were looking at, weighting the options in favour of the needs and desires of the resident, and what he thought would work best.

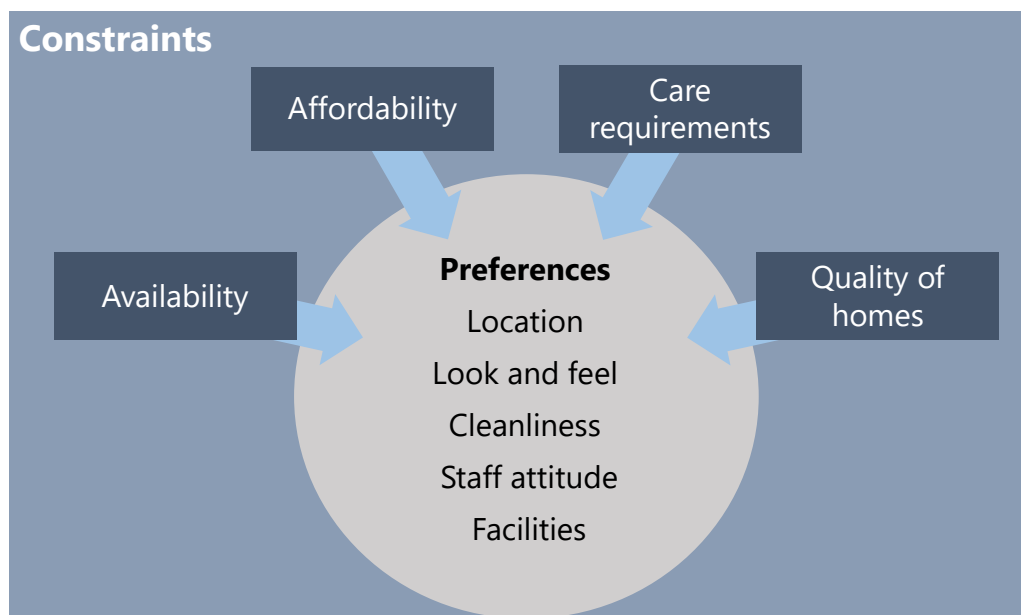
Other areas that were particularly important for the chosen care home were cleanliness, warmth and homeliness, the ability for the resident to socialise with the general community, and pursue their own interests, such as playing the piano. Also, the representative felt confident that the home could care for the resident's specific needs, as there were other residents with similar health conditions, age, and interests. The representative felt his cousin wouldn't stand out or be isolated.

*"The one that ticked most of the boxes for [the resident] was the one I went for but the weighting I applied the most was his own particular request."*

## Deciding on a home

4.21. Representatives weighed up a large number of factors when deciding on a home. Their preference was to have a home that was nearby, and one they felt was homely, clean, had good facilities and friendly staff. These preferences are presented in figure 4.1 below. However, there were a **number of factors that constrained a representative's perception of choice**. The care home had to have availability, be within budget, and be capable of taking care of the resident – all these factors were non-negotiable. Furthermore, as representatives visited homes they saw many that were of an unacceptable quality which reduced their choice further. These were all perceived as constraints on participants' choices and are presented in the dark blue squares outside the circle.

## 4.1 Deciding on a home



### Preferences for a care home

4.22. Representatives had the following preferences for the care home they wanted:

- located close to the family/friends;
- good look and feel of the home;
- cleanliness and tidiness;
- good attitude of staff; and
- appropriate facilities.

4.23. Location was one of the most important criteria in representatives' search for a care home. Having a care home **easily accessible for family and friends to visit was a priority for representatives**, even before they began visiting homes. It also had the advantage of being in a resident's familiar surroundings, and on occasion having the resident's friends nearby or in the home itself. Location was therefore one of the things representatives considered very early on in their search, as they were compiling a shortlist.

*"I just identified one in a reasonable area, probably about a four or five-mile radius of home, because obviously if you're going to visit I didn't want to be traipsing too far."* Representative (England, Nursing home, Self-funded)

4.24. In some cases, a care home being close by was more important than any other factor in their search because of the convenience it offered for visits, and the advantages of keeping a resident in a familiar environment, close to the places and people they knew.

*"I suppose I eventually settled on this one which was located very close to our home which was a big plus for me. It was really convenient to have one close to my house. That was a deciding factor in it I suppose."* Representative (Northern Ireland, Self-funded)

- 4.25. However, representatives also said that the feel of the home was a significant deciding factor, which is why visiting homes was so vital during their search. They were first and foremost looking for somewhere that would be comfortable for the resident, and suited their preferences; for example, by having a **homely and welcoming feel**.

*"I didn't necessarily have a list of requirements, I was just basing my decision on what I knew of my dad and what he would like and not like, and then some of them I think I looked at a few and I thought, oh God, that just looks grim."* Representative (Wales, Residential home, Self-funded)

- 4.26. Other factors like **attitude of staff, and facilities such as en-suite bathrooms** featured strongly in people's decisions. For example, if they visited a home and found the staff attentive, friendly and knowledgeable, representatives were reassured that the home should be a good one. They also liked to see staff who had been there for a long time, as they felt that a high staff turnover was an indication that staff were unhappy or not committed to the role.

*"We rang up, made the appointment, there was somebody to meet us, somebody to answer all our questions, somebody who had been there for years. Some of the women there have been there for years which was another plus because I know these places have high levels of turnover of staff."* Representative (Wales, Residential home, Mixed funding)

- 4.27. It was also important for representatives that a home was **organised, clean, and tidy** – especially if they knew this was something their family member valued. One representative, for example, inspected the nurse's station at each home she visited to assess how organised and tidy the staff were.

*"My mum has always been someone who quite likes things tidy and clean, and so we felt if she went anywhere that wasn't clean, she wouldn't like that from the start. So, I wanted somewhere that was clean and smelled clean."* Representative (England, Nursing home, Self-funded)

- 4.28. As the representative in the below case study suggests, these more visible or tangible qualities were the only things representatives were able to judge for themselves, not having the expertise necessary to judge things like quality of care, or the qualifications and experience of the staff. These were therefore not raised as important considerations when choosing a home, although representatives felt they were implicit in the cleanliness, homeliness, or friendliness of the home and staff. For example, they felt that if the staff were friendly and welcoming then they had nothing to hide and they were reassured that the staff were caring and honest. If the home had a bad smell, they were concerned that the residents were uncared for and neglected. Representatives had to trust in their own experiences of these things as **more measurable performance factors were harder to find, harder to interpret, and less trusted** – in part because they sometimes failed to match what they saw when visiting. As such, these were not relied upon when choosing a home.

- 4.29. Representatives described not knowing what they should be asking or looking for, especially the first time they found a home, so having to rely on the visible qualities because they weren't sure what they should know. Representatives also described not knowing what warning signs of poor care to look for – as will be discussed in Chapter 8. Where there was urgency to find a home, representatives also struggled to plan for a resident's health deteriorating or – if self-funding – what would happen when the money ran out. Where representatives had experience, they were less

concerned with some of these tangible qualities – like the cleanliness, which might vary depending on if a resident had just knocked something over for example – and more about how informed the staff were.

#### Case study 4.4: weighing up the different options

Representative (Northern Ireland, Self-funded)

Francine and her daughter looked at four different homes, when they were looking for somewhere for her husband. All homes were as near as possible to where she lived.

One of the homes had a limited number of en-suite rooms, and as her husband is severely arthritic and has reduced mobility she felt he needed a bathroom, so ruled the home out. Another had a reputation for good care but Francine felt the environment was “industrial” and she wanted more space, more fresh air, and a garden, so she discounted that one too. Nor did they get a friendly welcome from the matron at this home.

The third home was a large, remote home in the countryside, and Francine felt that it was very well managed. However, when they were sitting downstairs she heard people running backwards and forwards upstairs, and was worried that the noise would be too disturbing for her husband.

The final home they looked at felt modern, with a newer building, and the residents looked as if they were content. It was also the home closest of all to where she lived and so they decided to go with that home.

Overall, Francine pointed out that she was only able to make her decision based on these surface qualities – how the home looked and felt – rather than what the care was like.

*“When you look at residential or nursing homes, you're looking at bricks and mortar. You're not really getting a taste of what the care is like or what the staff is doing. You're just an observer from the outside.”*

### Constraints on choice

4.30. Alongside these preferences, there are a number of **non-negotiable factors that a care home must meet** in order for it to be a viable choice. These factors limited the number of homes any individual could choose from.

Representatives felt there were the following constraints on choice:

- availability in the care home;
- affordability;
- care requirements; and
- the perceived quality of the home itself (and, consequently, the inferences made about the care it would provide).

4.31. **Availability:** Whether a home had capacity was a significant factor limiting representatives’ decisions, and added to the pressure they felt when choosing a home. This was either because of a limited number of homes in the area (i.e. rural areas), or many homes not having capacity. Homes and social services also gave people relatively short time frames – sometimes as little as a day – to decide before the room would be offered to someone else.

Representatives therefore had to make quick decisions as they felt that spaces were limited and only open for short



periods of time. This also meant that they were sometimes unable to send the resident to their first choice of home, particularly if staying on a waiting list was not an option.

*"We only knew there was about three nursing homes in the area. Well when I say in the area, within a 50-mile radius so we knew that the chance of even getting anywhere was really tight." Representative (England, Nursing home, Mixed funding)*

- 4.32. Because of limited capacity in local homes, participants said they felt lucky or fortunate once they had found a home because availability was so scarce. This feeling of being lucky to find a home was felt strongly across the interviews.
- 4.33. **Affordability:** Representatives also had to consider their budgets when looking for a home, and exclude from their choice any home that was too expensive. For self-funders this meant that where they were able to, they tended to only visit homes that were in their price range – finding out the price on their website or by calling the home where possible, or going by general perceptions of which homes would be out of their budget. However, prices were often not clarified in advance of a visit, and those given could vary from the final price agreed. Those who were funded by the local authority depended on them to provide accurate information about their budget, which was not always the case as illustrated in the case study below. The decisions made about funding and paying for care are explored later in this report.

*"We wanted her to be in one nursing home, but it was £850 a week. Well it was £100 cheaper where she is now...the one we did pick for her and went and visit, was £1,200 a week, that was a big shortfall. So, we knew we couldn't get her in that one." Representative (England, Nursing home, Mixed funding)*

#### **Case study 4.5: considering top-up fees**

Representative (England, Residential home, Publicly-funded)

Rebecca and her family were originally told by the council that their budget was higher than it actually was, and as a result settled on a home that was too expensive for the council to pay for.

The family discussed the possibility of making up the shortfall with a top-up fee. However, between the four sisters they were not able to afford the top-up, particularly if something meant one of the sisters were not able to keep up with the payments, so they settled on a more affordable home.

*"We found a really nice home. The budgets were going up into £900 a week which was well over, and these were the occasions where we all did sit down and ask can we possibly afford it for today...and how long have we got to afford it for."*

- 4.34. **Care requirements:** Representatives needed to find a home that was capable of catering for their relative's needs – for example, a nursing home rather than residential home, or a home for residents with dementia. This was something representatives found challenging, as the differences could be unclear to them, or they were unsure of the resident's specific care needs. Furthermore, they pointed out that only a handful of homes in their area might be able to accept the resident based on their care needs. Even once they felt they had found a suitable home, the care assessment might indicate that a resident's care needs were too severe or specialised for the home to accept them.

The care home might therefore have to refuse a resident; this was another pressure on families who were trying to ensure a home accepted their relative. In their minds, this was another constraint on the choices they had.

*"All homes are not equal. If you said, well there's a nice home there, they may or may not accept an individual based on their needs. It's all right saying, well there's 10 homes in your area, but there might only be three who could accept an individual." Representative (England, Residential home, self-funded)*

- 4.35. **Quality of homes:** Representatives also felt their choices were limited due to potential care homes failing to meet what they considered acceptable standards. They described poor living conditions, unfriendly staff, bad smells, unresponsive residents, describing some as care homes they "would not have put a dog in". Representatives were, therefore, unwilling to lower their standards and consider these homes as viable options. Participants occasionally referred to stories in the media of abuse and neglect in homes – for example television documentaries – that, though assumed to be rare, raised their suspicions of the care home sector more widely. These negative experiences of homes also drove them towards their final choice as, by comparison, they described the home they chose as the 'good enough' option.

*"Probably all together we looked at eight or so and some of them I would say were pretty dire. So, in terms of the one we'd chosen, my sister and I both felt it was probably the nicest one." Representative (England, Nursing home, Self-funded)*

## Perceptions of choice

- 4.36. Participants did **not feel they had much of a choice of care homes**, due to the constraints outlined above and as demonstrated in the case study below. Again, the urgency with which they felt they had to make their decision also contributed to this sense that choice was limited.

### Case study 4.6: a false choice

Representative (England, Nursing home, Publicly-funded)

The location of the care home was very important to David and his mother; in the rural area they lived in there were only two available homes. One of these care homes was rated poorly, so the family dismissed it straight away. The other had very good reviews both online and from family and friends who had experience of the home, and so David's mother went there.

Consequently, the family didn't feel that they had much of a choice because they felt there was only one home they could realistically consider.

*"It kind of forces your hand in your decision making. But luckily it turned out that they were a good place anyway."*

- 4.37. Because of this, participants were constantly having to make compromises in order to find a home. For example:

- Compromising on activities: *"At the time what was important to us were activities within the home, but when it came down to it, it was where had a bed was the big thing."* Representative (Northern Ireland, Mixed funding)

- Compromising on location: *"We said X area or Y area and if nothing came back, we would obviously have to extend the area because ultimately she has to go into a nursing home."* Representative (England, Residential home, Mixed funding)
- Compromising on first choice of home: *"The one he really wanted to go in was third on the list, because of the waiting list. That's when we were advised you're better taking one, getting in, and then when a space becomes available, the one you want, he would get moved there."* Representative (Scotland, Nursing home, Self-funded)

4.38. Even if they had a few homes to choose from representatives still said that choice was limited because they were unable to go for their first choice, or find 'the perfect home' that met all their requirements. Representatives felt that they were under pressure and had to make the best choice that they could at the time.

*"Trying to get the home that you wanted, that was a big problem, obviously. We had to settle for second best, and wait until that one came available but he ended up staying."* Representative (Scotland, Nursing home, Self-funded)

4.39. Participants whose care was funded by the local authority reported similar experiences. Limited capacity, and the urgency with which they had to decide, had an impact on perceptions of choice. There were also examples where participants were not aware they had a choice if the care was being funded by the local authority. Although these cases were rare it suggests more can be done to ensure local authority funded residents are aware that they can decide between different options.

*"I didn't know whether we could choose, because the state was paying for everything for her."* Representative (England, Residential home, Mixed funding)

4.40. Representatives funded by the local authority sometimes felt that the choice offered by social services was limited. They said that once social services had offered a home to visit, because of limited capacity they felt forced into choosing it, even if it wasn't the right one for them. This perception reflected the lack of agency people felt by being guided by someone whose expertise and authority they felt obliged to defer to – a risk associated with the absence of the expert advice often requested by participants, discussed in the previous chapter.

**Case study 4.7: no choice offered by social services**

Representative (Scotland, residential home, Mixed funding)

Audrey decided she needed to go to a care home after a series of falls that lead to a hospital admission, and on the recommendation of a hospital consultant. She wanted to go to a home where her friends were living, and had visited these homes but there were no vacancies. Audrey's daughters were told by the hospital that if they wanted to wait then she would need to do this at home and they would need to look after her. This wasn't possible as the representative, her daughter Yvette, lives over 100 miles away, and her mother's home has stairs which means she could not move around it unaided.

Yvette and her sisters had a sense from social services and the hospital that they had to accept the first home that became available, so they did. They felt the only other option they had was to send their mother home alone. Audrey wasn't even offered a visit at the home as the priority was to get their mother out of hospital. Consequently, the family felt they were not able to choose where their mother went.

*"I would say we didn't have a choice of care home. This was the one which was presented to us and it was that or nothing, so we had to take it."*

4.41. There were also representatives who were happy with the choice available to them. This was because they were able to get their first choice, for example they had a home they considered good nearby and a room was available. Alternatively, they had looked across a wide area to find the right home, or they felt that social services gave them the opportunity to refuse certain homes until they found the right one. Those who had more time to look for the right home rather than responding to a trigger event also felt that they had a choice – although as discussed above, these people were in the minority. There were examples of participants in England, Wales, Scotland and Northern Ireland feeling they had a choice, but largely across the research participants agreed that choice was limited.

*"We took her to other nursing homes that we knew about in the area and we knew what the reports were about them. We took her to those. Also, they had built a new nursing home local to us, we took her to see it as well. So, we gave her a choice of where she wanted to go...there were a number of nursing homes she could have had in the area."* Representative (Northern Ireland, publicly-funded)

## 5. Funding care

## 5 Funding Care

- 5.1. This chapter explores peoples' understanding of the different funding options available to them and their experiences of finding out about these options. It will look at the range of experiences and perceptions of the process of securing funding for care homes and how these vary according to people's circumstances.

### Chapter summary

Participants in the research were split into those who were self-funded, publicly-funded, and those who had mixed funding. In this report, those paying top-up fees are included with those described as publicly funded or mixed-funded, where appropriate. Those receiving continuing healthcare funding are included with those described as publicly-funded. In the interviews, participants who were publicly funded often described themselves as mixed-funded – it was clear that people did not understand the various sources of funding and associated assessments.

Representatives were not strongly engaged with the details of the funding system and few sought information on the funding system or on the options available to them. Instead, it was something families felt powerless to change and they preferred to prioritise the needs and comfort of their relative. For example, top-ups were not widely considered – possibly because participants were not aware of them, nor always an option because families could not afford them.

The funding system was considered complex and difficult to understand, particularly for those who were not self-funding. Those applying for local authority funding described a stressful experience due to paperwork and lack of information about the funding options. Consequently, representatives could give a broad description of how the resident's care was funded but could not go into detail.

### Key challenges

A **lack of face-to-face support** made it challenging to navigate the system, or understand the implications of a relative's funding options.

The **funding system was seen as rigid** and something that representatives were not able to influence.

**Complex paperwork** involved in applying for funding was a significant challenge, especially for those who could not access the face-to-face support they needed.

Finalising funding arrangements could happen **once a resident had moved into a home**, largely due to a lack of clarity initially about how much they would have to pay.

Awareness of top-up fees was low, where participants were paying top-up fees, they were often unaware of what they were for and how they were being used.

Other challenges participants faced in managing the funding process was the perception that information was opaque, and local authorities were not open about the help available or the procedures for getting that help.

### Key supports

When it was available, having **face-to-face support**, for example from a social worker, meant that navigating funding was felt to be more straightforward.

**Care homes themselves were helpful in providing information and support** about funding, and signposting to sources of guidance.

## Different types of funding

- 5.2. Participants discussed a range of different funding options during the interviews. Care was funded in a variety of ways:

### Self-funded care

- 5.3. Residents had to fund their own care when their total assets were above a threshold to receive public funding. People who funded their care in this way were either already aware that they would need to pay for their own care through their own research or prior knowledge of the funding system, or they had a financial assessment in which the assessor explained that they met the criteria for self-funding.

### Care funded by a mix of local authority and self-funding

- 5.4. If residents' total assets were below the threshold for fully self-funded care, but were above the maximum threshold for fully funded care, residents were required to contribute to the cost of their care. Residents in this group had their pensions absorbed by the local authority to be put towards the cost. Relatives or a third party might also be paying top-up fees.

### Publicly-funded care

- 5.5. Residents whose assets fell below the threshold for full local authority funding were required to contribute their pension towards the cost of care, but not any of their savings. Residents who were home owners but had a dependent living in their house also fell into this group. The local authority paid for their care, using the resident's pension as a contribution to this. Those paying a top-up fee were also included here.
- 5.6. Additionally, residents from all the funding groups were entitled to receive a nursing allowance from the NHS if they were in receipt of nursing care, while those with complex medical needs could also apply for continuing healthcare (CHC) funding, through which the NHS would pay for the full cost of the care.

## Navigating the funding system

### Finding out how care would be funded

- 5.7. Representatives found out about how their relative or friend's care would be funded in a variety of ways, and described a range of experiences when it came to navigating the funding process. While there were occasional cases where participants found the system straightforward, or had had very little involvement, the process of establishing the funding for their relative's care was **widely considered complex and stressful**. There were several factors relating to this. A noticeable trend was that those with public funding described a more stressful experience, as did participants who had to engage with large amounts of paperwork and application forms, or did not have face-to-face support from social workers, hospital or care home staff, or local authority finance teams.

#### Case study 5.1: a straightforward journey of establishing funding

Representative (Northern Ireland, Publicly-funded)

Robert went into a care home following some respite care after a fall. While they were looking for a care home his daughter, Clare, spoke to a social worker who provided her with the forms to fill in for the financial assessment.

Clare provided bank statements and proof of house deeds to prove that he did not own the property. She then spoke to the local authority again to discuss the contributions Robert would make with his pension. She found the forms complicated, but also that the process was straightforward once the details had been established.

There was no top-up fee to pay, and it was clear how much of an allowance he would have after his pension had been taken into account. Overall, Clare felt well informed and did not find the process overly complex.

*"The form was complicated but the process itself was reasonably straightforward once I put in the detail. They sent me through what he had to pay, what was taken out of his pensions obviously in terms of payments for it. There was no top-up fee or anything, so I think his pensions came to about £210 or something in a week and then he was allowed to keep £24. So it was reasonably clear cut what he could and couldn't do and how the process worked."*

- 5.8. While self-funders tended to have a clear understanding of the financial details of the resident's care, **the knowledge of those in receipt of full or partial local authority funding was limited and people described the way their care was funded in different ways**. For example, when those who were mixed or fully publicly-funded stopped receiving their pension, or where the representative was paying a top-up fee, may have described themselves as self-funders.
- 5.9. **Participants considered the funding at a number of points in the process**. While more well informed participants considered how they would pay for the care ahead of choosing the home, for others, in particular those who had to make an urgent decision, funding came secondary to the task of finding a suitable care home. Representatives of residents who were self-funding expressed concerns about appearing to be 'penny pinching'.

*"Well it's something we didn't actually ever think about. I don't think any of the family would have thought about what we were worth because mum was good to us for a long number of years and we had to treat her right whenever she went into a home, so we never thought about what it was going to cost us."* Representative (England, Residential home, Self-funded)



- 5.10. Others whose care was paid for by the local authority had to spend more time discussing funding with social services. Due to the impact of funding type on the breadth of choices available to these participants, funding discussions had to precede the choice of care home, and shape the decisions that families made later on. See paragraphs 5.28 and 5.30 for evidence of people having to make choice on a care home before entitlement to local authority or NHS funding has been determined.
- 5.11. Time pressures coupled with difficulties understanding the information available meant that the **process felt opaque and overly complex**, particularly for those applying for benefits, continuing healthcare funding, or local authority funding. These participants had higher levels of engagement with social services, and there was a greater degree of bureaucracy involved in the process, as they had to complete more paperwork and provide financial evidence, compared with self-funders. Those applying to funding nursing care on the other hand found that this was arranged by the care home although there were cases where this was delayed and representatives had to pay for the nursing care and be reimbursed at a later stage.

*"I had to jump through so many hoops and we had to have so many assessments and forms to fill in and it was an absolute nightmare. It's almost like everything's hidden under stones, you can't find it." Representative (England, Residential home, Self-funded)*

- 5.12. Residents were generally **unaware of details of how their care was funded, apart from in broad terms**. Residents who were confident that everything was being dealt with by someone they trusted weren't concerned by this, but others were distressed that they didn't know what was happening. This could particularly be the case if they worried that the money was not being paid and they might be thrown out or if they were concerned that a family member was having to fund their care. Where a social worker had taken the time to explain how their care was funded to a resident in these circumstances, this had been reassuring.

*"I think I pay for most of it.... The only thing I worry about is have I got enough money to be here? That it's not putting [daughter] in any trouble at all." Resident (Nursing home)*

### Levels of engagement with the funding system

- 5.13. Regardless of how their care was paid for, participants did not take a great deal of time to understand the broader funding system, often **lacking the time to spend on getting to know the intricacies of the funding options available**. These individuals felt that there was little benefit to researching the financial options given that they would not be able to influence the outcome of a financial assessment, so being well informed would not necessarily change their situation.

*"But it does seem to be quite complicated, there certainly seem to be quite a lot of things to consider. So, really not a great deal of research on that front. We can't change the financial side of things, it is what it is." Representative (Scotland, Nursing home, Self-funded)*

- 5.14. People took different approaches to finding out about the funding options, choosing to research the system online before making decisions about who to contact. Alternatively, they would get in touch with a member of the local authority, or wait for somebody to contact them. Participants who took a hands-on approach to arranging the funding with the local authority described taking proactive steps towards establishing funding for their relative's care. Those who did so needed to push for conversations with the local authority and care homes. They took the lead to avoid delays, but this also meant they found it harder to access the information they needed.

*"I got in touch with the social department about what's going to happen, because immediately I got in touch with homes and I got all the usual hanging about ... and talks and shuffling of papers. You realised that, oh I must find out what's available, move on and make it happen."* Representative (Scotland, Nursing home, Self-funded)

- 5.15. There was no universal experience of how actively participants engaged with the process. While there were participants who kept the process moving and chased up paperwork, there were others for whom the funding was organised by a social worker or the care home, and so they did not have much involvement in it. These latter participants found it easier to navigate the system, because they played a passive role and allowed the funding to fall into place.

#### **Case study 5.2: family not being involved with establishing funding**

Representative (Northern Ireland, Publicly-funded)

Mavis moved into a care home and her daughter, Rebecca, did not have significant involvement in the process of arranging the funding.

The social worker organised the funding, carried out an assessment and told Rebecca that the care would be fully funded after they had examined her savings and income. They weren't sure about how the funding would work at the time, but the social worker explained it.

*"A social worker sorted [the funding] all out for us, they just found out how much she had in savings and what her income was, and from that they worked out that she would be funded by the government. So we really weren't really involved much in that, they just told us she would be funded."*

- 5.16. Despite self-funders having to take control of the funding earlier in the process, they faced other barriers to looking into the different ways their relative's care could be funded. They tended to make assumptions about their relative or friend having to pay for their care based on home ownership, or knew about the funding thresholds. They did not see themselves as having alternative options to paying for the care themselves and so often took a passive approach to researching the funding.

*"The assumption is that that's what it is, that we haven't got any rights to any funding, we sold the house and that money is obviously there for mum. I think we just assume that that's what it is, and there are no other ways of funding it."* Representative (England, Residential home, Self-funded)

- 5.17. Self-funders disengaged with social services after it was established that the local authority would not be funding the care, although they suggested that more support from social services would have been welcomed. However self-funders tended to move on at this stage to finding out about the prices of the care homes and discussing these with the homes themselves. Finding out the prices of the care home took place at times after the resident had moved in. They described a lack of support, as although these individuals no longer relied on the local authority to organise the funding for the care, there were still difficulties with managing the resident's affairs, or selling the resident's house. These individuals also missed out on the signposting and provision of information resources that social services may otherwise have provided, and limited their awareness of sources of funding such as CHC which they may otherwise have been eligible for. This had a knock-on effect on their experience of choosing a home as there was no mechanism for supporting representatives through these specific challenges, and so these individuals felt less supported.

*"I think as soon as it's decided, a nursing home, and I know when you're self-funding, the social worker kind of pulls out from it. I think it would be quite nice to have someone kind of support you through it."* Representative (Wales, Nursing home, Publicly-funded)

## Experiences of applying for funding

### Overall experiences

- 5.18. While representatives of care home residents were not focused on the wider system of social care funding, concentrating instead on their own resident's personal circumstances, it seemed that the difficulties people experienced were a key factor leading them to disengage from the process. Participants faced challenges in organising the paperwork and accessing the advice they needed and so did not always explore the full extent of the options available to them before making a decision.

*"You have to keep finding the right people to talk to, that's what you have to do. I took the easy option when I found an option that worked, I went along with it. I should have looked at other options but I didn't."* Representative (England, Residential home, Self-funded)

- 5.19. Other challenges participants faced in managing the funding process was the perception that **information was opaque, and local authorities were not open about the help available or the procedures for getting that help**. They described feeling that the local authority was reluctant to pay for care, and that this not only led to errors due to insufficient communication, but also placed a burden on them when it came to applying for funding and filling in paperwork.

*"I think the tone and the amount of paperwork that you have to encounter, it's not particularly friendly in terms of communication, it's just one of those things. The state give you money but they don't really want to."* Representative (Wales, Residential home, Self-funded)

**Case study 5.3: problems with establishing how the care would be paid for**

Representative (Wales, Residential home, Mixed funding)

David went into a care home and his son Gary was looking after his affairs. Social services did an assessment and concluded that because he was in residential care only, he would only receive part-funding for the care and David would be left with £48 per month.

The local authority initially took into account the house David lived in and assessed him as not qualifying for funding, but they made an error as David didn't own his home. Gary had to get a solicitor to confirm this was the case and eventually the local authority agreed to part-fund the care with a contribution from David's pension.

The local authority recently tried to increase David's contributions and Gary pushed for them to reassess David's finances. Once the reassessment took place the council did not increase the fees after all. Gary felt that the local authority wasn't forthcoming with the information about the finances, and thought that he would have been overcharged if he had not pressed for a reassessment.

*"They must be paying something. What the exact figure is we won't know, because these figures are hidden in the background. Things are hidden away from you, they don't want to tell you. It makes you feel as though, well if you don't want to tell me, maybe I'll go and challenge you and if I challenge you, are you taking the right amount off me or are you taking more than you should be?"*

- 5.20. Lack of clarity about how much the resident would have to pay also arose from **insufficient communication from the council** about the information they needed, and participants described experiencing problems establishing how much the resident would have to contribute. Mixed-funded residents had more problems with finding out the exact amount they would have to pay and so the fees often changed several times before a conclusion was reached. While this was at times as a result of errors made by the council, residents' financial situations also tended to change with their changing needs and from events such as the sale of a property.

*"Anyway, they're insisting that she's been getting £100 and something from a pension that was her husband's. As a result of that they're hounding my sister. She keeps getting invoices from the nursing home telling her that she's got to pay this, because my mum's only being given this and she's only getting £90 something state pension. The authorities can't work it out, my sister's provided the bank statements, my mother's bank statements, the lot, and they're still insisting."* Representative (England, Nursing home, Mixed funding)

## Experiences of applying for continuing healthcare

- 5.21. Participants who had applied for or received continuing healthcare funding did so through social services or healthcare professionals, either playing an active role in gathering the evidence, or relying on the hospital or care home to do this. Those who had experienced delays also got solicitors involved who could help to push the application onwards. While it was social services or healthcare professionals involved in the resident's care who instigated the process, and at times put in the application itself, others had to go through extensive assessments and paperwork to establish their relative's eligibility for the funding.

*"There wasn't an assessment about continuing care because I asked about that years later. Nobody ever mentioned continuing care where the NHS pick up the tab for everything, and I wasn't aware it existed until my brother went to some open surgery about care for the elderly. I think it's something that very few people either know about or can actually get."* Representative (Wales, Residential home, Mixed funding)

5.22. The process of applying, for those who were involved in completing the assessment, was considered complex and lengthy, with **considerable lapses of time between submitting the application and receiving a decision**. There was a perception that this daunting process was prohibitive to those who may otherwise have qualified for CHC.

5.23. There was a **lack of clarity about the criteria used to assess residents**, and representatives were rarely certain that the resident qualified for it, or had been told it was unlikely that the resident would qualify. Representatives felt that different people had different views on the resident's needs. They felt they would have benefited from guidance on the application process. A lack of sufficient medical evidence due to unavailable or incomplete medical records disrupted applications.

*"We did look into it and I think you could do with someone to help you through that process as well. I would have some of the staff nurses saying, "I think your dad would be appropriate for CHC if you did the decision support tool", but then another nurse didn't agree."* Representative (Wales, Nursing home, Publicly-funded)

5.24. This view was echoed by social workers, who viewed continuing healthcare as **prohibitively difficult to apply for**, often meaning that those who they felt were eligible did not receive support they were entitled to. This was seen as a deliberate policy decision to make the threshold higher in the guidance than the case law from appeals would suggest was appropriate.

*"I think they make it really difficult to get that funding. And unless people are very versed in the law very often people miss out on that. I would argue that there are vast numbers of people not getting that funding who are eligible for it. The guidance is setting the bar extremely high and not really in compliance with the law."* Social Worker

#### **Case study 5.4: applying for CHC funding taking a long time**

Representative (England, Nursing home, Self-funded)

Rowan needed nursing care and required supplies such as incontinence pads. The nursing home told his daughter, Katie, about continuing healthcare funding and suggested they apply, saying that the Matron at the care home would be able to coordinate the application.

Although they first applied for the CHC funding last year, Katie followed up several times but has not yet been able to receive the funding. The family are now using a specialist solicitor to progress the application for CHC funding who is gathering evidence about the resident's needs, but they no longer think that they will ever receive the funding.

*"They said to me, well you can apply to funding. She said if you have a word with sister there, or the matron, she will sort it out. I had a word and sister said, "OK, I'll do it but you probably won't get it". I said, "OK, well can you go ahead with it anyway?" And that was in September. Nothing happened for weeks, so I'm doing it direct with a solicitor now".*

## Financial assessments

5.25. Participants reported mixed experiences of the financial assessment. While it appeared to be a standard step in the process of establishing the funding, there was **no uniform way in which it was carried out**. Some cases had a face-to-face assessment, and others simply filled in paperwork and sent it off. There were also mixed views on how helpful the assessment was, with some finding it did not provide them with any useful information or clarity about funding, and there were instances where the financial assessment did not take place at all.

5.26. For participants who were not already aware of the way the care would be funded, **the financial assessment was the point at which they found out how the residents' care would be paid for**. In spite of this, participants did not always remember having a formal financial assessment, or recall the details of what was discussed. The conversations were, however, felt to be matter of fact but not always helpful, particularly for those who were assessed to be self-funding.

*"They were very short conversations to be quite honest. All they're interested in is your ability to pay, if you have means that exceed the government threshold then you're expected to pay and that's pretty much the extent of the conversation. There's an annual assessment offered, to check whether your circumstances have changed, but that's the extent of those discussions."* Representative (England, Residential home, Self-funded)

5.27. Those who found the financial assessment useful said it helped them to understand the process, and the assessment for these people acted as a gateway to a greater clarity of the resident's circumstances and the resulting financial implications. This chimes with the sentiment expressed by participants that a key measure that would have helped them with the funding process would have been to have a face-to-face conversation. Those who carried out the financial assessments were seen to be in a better position to explain the funding than social workers or care home staff, but also provided the direct conversation that participants found essential. This was echoed by social workers, who said there was normally a specific team involved with funding who were more involved in the details, although they could help collect evidence.

*"We were completely in the dark until we talked to the Community Finance Officer and she explained it fairly thoroughly. Everything went by in a blur at the time, everything happened so quickly. We didn't really have any option and were terrified that we wouldn't be able to pay for this service."* Representative (England, Nursing home, Mixed funding)

5.28. Financial assessments did not always take place before the resident had moved into the care home, due to local authority policies or due to the urgency of the move. This meant that the representative took on a financial commitment in uncertain circumstances, and the impact on these participants varied; although it didn't always create a sticking point financially for families who found they had to pay for care they couldn't afford, it led to confusion for those whose financial assessment led to a financial burden they weren't prepared for.

*"Well [the financial assessment] happened concurrently with her actually moving. Because the hospital wanted her out so quick they happened jointly. We did get a financial assessment and it was flagged up again that she needed pension credit but the care home got there first. So, it did happen, but not necessarily the right way round."* Representative (Wales, Residential home, Mixed funding)

5.29. Participants reported instances where they had not realised they needed to pay for the care, and so expected to receive public funding, but were then told after they moved in that they would need to pay for the care. Because of

being poorly equipped with knowledge of the funding system, they came across unpleasant surprises later on in the process.

*"Well the social worker had said that they would send through a package and then I got a letter telling me how much I had to pay. But we didn't meet with anybody to discuss how it worked, it was just when I got the letter then I realised that I had to be paying something."* Representative (England, Residential home, Mixed funding)

- 5.30. Social workers interviewed about their involvement with the funding process described similar situations in which residents' finances were assessed after the placement had been made. They took steps to inform representatives and residents in advance that they would need to be aware of this when making their choice of care home.

*"They'll get an idea of how much the care home costs, but the [finance] team won't go and do an assessment until they're in a placement. They've signed a contract...so you're taking on a financial commitment without actually knowing what the commitments are."* Social worker

#### **Case study 5.5: financial assessment taking place after the resident moved into a care home**

Representative (Scotland, Nursing home, Mixed funding)

Rose went into a care home after having a fall and had to urgently move into a care home. At the time her family were not sure how the care would be paid for because Rose had few savings and had an outstanding mortgage on her house.

Care home administrators sent a Service User Agreement two weeks after she moved in which they had not agreed to, and they could not pay the fees as they had not yet sold Rose's house. They were highly concerned at the time that Rose would need to move out of the care home until she had the funds.

After this, the council got involved and sent letters telling Rose's family how much she would have to pay, and eventually a financial assessment took place, and Rose's daughter completed the forms. The local authority then agreed to part fund the care for 12 weeks, after which point Rose would need to pay for her own care.

The process was confusing and because no financial assessment took place, they did not know how much they would have to pay until much later.

*"I really don't know. Letters arrived from the council saying the schedule of care for my mother was that she's in the nurse care home and she's long term residential... it said what her free personal care entitlement would be. All things we had no knowledge of at all. Nobody sat my brother and I down and chatted through the whole process until way on in the process."*

### **Paying top-up fees**

- 5.31. The **awareness of top-up fees among participants was low**, particularly when it came to the detail of what the top-up fee was for and how they were used. Participants who had public funding tended to avoid top-up fees; while some had actively chosen a home without a top-up fee, others simply hadn't come across them as a means by which to access a care home that wouldn't otherwise be available to them.



- 5.32. There were those who paid a top-up fee but felt they did not have a choice in the matter, because there had been no availability in homes that didn't charge the top-up fee, or because it wasn't made clear to them that they would need to pay a top-up before the resident moved in, by which time it was too late. These participants did not dispute additional charges, or were happy enough with the care to pay 'that bit extra' for what they considered to be a higher standard of care or better facilities, such as a bigger room.
- 5.33. These participants thought about the top-up in a similar way to self-funders' views on paying for their care. Paying the fee was considered part of 'the way things are'. In addition, there was a lack of up-to-date information about top-ups – as discussed earlier, the information provided by the local authority was often inaccurate when it came to listing which care homes charged the top-up fee.

*"I was advised by some don't go for anywhere with a top-up because you'll have to pay extra money. I found out from a friend, and the list of care homes that the social services gave me said no top-up and then when I phoned them they said there was a top-up. Because it was out of date." Representative (Wales, Residential home, Mixed funding)*

- 5.34. Despite this, participants came to pay a top-up fee either out of necessity due to care home availability, or because this information wasn't made available to them until after they made their choice. In particular, there were examples of those who had moved care homes finding themselves having to pay a top-up fee at the new care home, where they hadn't previously paid one, although this was not always the case.

#### **Case study 5.6: finding out about a top-up fee after choosing the care home**

Representative (Wales, Residential home, Publicly-funded)

Barbara's mother, Mary, received publicly-funded care in a home that did not charge a top-up fee. However, Mary's care needs increased and the care home told Barbara that she would need to find a new care home for her.

Originally, Barbara found out from a friend about top-up fees, but had been advised against choosing a care home that charged the fee because it meant that she would need to pay extra. She found however that the list of care homes she was given by the local authority had out of date information about which care homes charged top-up fees, and found out that more care homes had them once she began to contact them.

Barbara chose a new care home for her mother, but hadn't asked them about the top-up fee upfront. This meant that when she moved Mary into the care home she then found out that she would have to pay the top-up fee. She wasn't sure what extra services Mary was receiving as a result of the top-up fee, but having seen the high quality of the care Mary is now receiving, is happy to pay the fee.

*"I'm willing to [pay the top-up fee], to be honest. For some reason, I didn't ask them on the phone, I normally ask them on the phone, but I didn't. I went there believing there wasn't a top-up, but having seen it and how streaks ahead it is of all of the others that I saw, I'm willing to pay the top-up."*

- 5.35. While the top-up fee was intended to give publicly-funded residents a greater choice of care homes, being publicly-funded in the first place meant that top-up fees were also out of reach if the relevant third party was unable to pay the fee. The high prevalence of care homes charging top-up fees had a limiting influence on the choices available. For participants who had to choose a care home that the local authority could pay for in full, they found that many homes then charged a top-up fee which they often couldn't afford. This narrowed down an already limited choice



further, and social workers also noted that in their local areas increasing numbers of care homes are choosing to charge a top-up fee, with only “one or two” care homes locally available to those who could not pay that top-up. Social workers found that when their clients were choosing a care home they were having to make a difficult choice between taking on a top-up fee, or having a more limited choice of home.

*“One of the issues for families is that a lot of the care homes charge a third-party top-up fee, but that burden is falling on families and it’s a very limited choice if the family can’t afford to or choose not to pay that third party fee.” Social worker*

## Information and support available

5.36. Participants did not widely mention using sources of written information available online or resources from the local authority for further information about funding. Those who did described their research as brief, but **were able to quickly establish whether the resident would have to pay for their care**. In cases where the resident owned their own home, it was straightforward to conclude that the resident would be self-funding, and these individuals felt that they did not need any more comprehensive information.

5.37. Others **described the information they received from the various sources as complex and found the process of sifting through that information confusing**. Although it was available to them, they felt it was not as helpful as it could have been. Those who had not had a helpful financial assessment or any other face-to-face discussion, and had had to turn to other sources of information felt this way more than others. Among those who had found information provided to them straightforward, this was more due to not needing it, rather than them finding the information clearer than others.

*“We were getting letters that were actually quite complex and quite confusing. If you were familiar with them it wouldn’t be too bad, but the letters are not that simple. ‘You can find out more on leaflet INF4/PC’, and all that sort of stuff and you’re like oh my God what’s this?” Representative (Northern Ireland, Mixed funding)*

5.38. Participants had a preference for and relied heavily on personalised support from social workers, care managers and care home administrative staff to provide tailored guidance. Often, **social workers provided valuable assistance for participants who needed support to understand their options**, even though written information was available. Those who had face-to-face support to understand the funding found the process more straightforward, and appreciated guidance to navigate an unfamiliar system.

*“It was pretty straight forward. You just got the forms, filled it in with your income. But the bottom line is, if you’ve got a certain amount of money, and I think it’s only £26,700 roughly, you pay the lot. [The social worker] helped an awful lot, I was just getting thrown in at the deep end and she really helped.” Representative (Scotland, Nursing home, Self-funded)*

5.39. Perceptions of the support provided by social services were mixed however. Alongside the view that social workers and care managers provided important guidance, there was a sense that social workers and other council or care home staff are stepping in to support representatives to explain the funding process in the **absence of more specialist support, such as financial advisors or dedicated financial teams**, who knew the system intimately and could answer their questions. Participants who had difficulties felt that other professionals involved, such as care home administrative staff and social workers, lacked expertise, which led to further confusion and a sense that there was

inadequate support available, which did not go far enough towards mitigating the pressures participants faced in this area.

*"The social worker, he's a very nice person but he didn't seem to know exactly what he should be telling us. And he seemed to be going round in circles quite a lot. In the end we had to get the family solicitor involved because some things he was coming out with didn't sound quite right, we had to make sure things were correct."*

Representative (Scotland, Nursing home, Self-funded)

- 5.40. Additionally, there was a broad sense among participants that there was a **lack of comprehensive information about the funding**, and that there hadn't been anybody available to explain how it worked. They felt that the person responsible for the financial assessment "just told them" how much they would have to pay, without explaining why. This made understanding the process difficult and participants felt disempowered as it contributed to the sense that the funding system is inflexible, and that they were not given access to the tools to negotiate and take control of the process.

*"I don't think anyone's ever sat down with us and said, this is how the funding works, so these are the options that are open to you. It's just like you fill out countless forms then they say, right you can have this care home. But to me it doesn't really make any sense. I tried to look it up, I don't understand what I read about it."*

Representative (England, Residential home, Mixed funding)

- 5.41. Those who had to arrange for deferred payments fell through the cracks between the group who had local authority funding and by extension maintained extensive contact with the local authority throughout the process, and the self-funded group who had far less contact with the local authority, but felt less supported. There was a lack of information about this part of the process in particular – this group needed additional local authority support.

## Planning for care in the future when financial circumstances have changed

- 5.42. In general, participants who were self-funding had **not made plans for when their savings had been used up**, even if they were broadly aware of what would happen when this situation arose. While they were aware of this as a theoretical eventuality, those for whom it wasn't an impending reality had not thought about it in detail. Participants made assumptions that local authority funding would begin but weren't sure how it worked.

*"We used to get assessed every year, but they don't do that anymore. They just send a letter saying when the money falls below a certain amount, re-submit the form again, and we'll take it from there. Which I'm assuming will be when they'll start paying something in, and he'll start paying less. But I'm assuming, I don't know."*

Representative (Scotland, Nursing home, Self-funded)

- 5.43. Social workers said in their interviews that representatives and residents had the option of remaining involved with social services even if they were self-funded. In these cases, social workers said that they encouraged people to think about the long-term affordability of homes when making their choice of care home, particularly those whose savings were closer to the threshold, and especially those who had mixed funding. They were aware of the possibility that the resident may have to move and so encouraged families and residents to look at homes which were less expensive and so were less likely to need the resident to move when the local authority began to pay for the care.

5.44. Participants had also taken the long-term affordability of the care homes into account when making their choice, considering homes that they would be able to afford for several years. This was particularly the case where the representatives themselves were contributing to the care, in contrast to cases where the resident could fund their own care so the representative did not feel the funds were their own money and price should therefore not be a priority. Representatives covering some of the cost themselves faced a greater financial burden that they had to take into account from early on.

*"These were the occasions where we all did sit down and ask not only can we afford it for today but you don't know how long have we got to afford it for. So, would we have been able to sustain that kind of overpayment for a long period of time?" Representative (England, Nursing home, Mixed funding)*

5.45. When discussing the possibility of funds running out, participants who hadn't considered what might happen at this point were **uncertain about how they would continue to pay for their care and had a degree of anxiety about this leading to negative consequences**. Participants who were disengaged with the funding process, assuming they would have to pay without looking into the funding system, had also made assumptions about the local authority stepping in to pay for the care, without making contingency plans or understanding the impact of this. However, participants were not always certain of local authority funding starting when the money ran out and worried about the burden falling to the resident's family to pay for the care home.

*"I'm pretty scared about that because when the funds run out we don't have anything and I'm afraid that she might get moved out of the home but we've probably got enough for a few years. I'll have to worry about that at the time because I'm absolutely powerless to do anything at the moment." Representative (England, Nursing home, Self-funded)*

5.46. Where participants thought about the future of the resident's finances, they had conversations with the care home or with the local authority about what would happen, and how the care would continue to be paid for. Those who did still lacked clarity about the exact process of continuing to fund the care, and felt that they couldn't rely on what they had been told.

*"We were very upfront with them and said, this is the financial position. We'll see what happens. But they basically said no, they wouldn't, just move him to a different room or kick him out when he moves to socially funded. We'll see, we're not at that stage yet so I don't know if the care will change." Representative (Scotland, Nursing home, Self-funded)*

## Measures to improve the support available

5.47. People named several measures they felt would have helped them more easily navigate the process of funding their relative's care.

5.48. **Face-to-face support:** Most notably, people valued face-to-face support, with detailed explanations of how the funding worked and what it meant for their relative, in their specific circumstances. While participants were often unclear about what form this support should take exactly, others had more specific ideas about the kind of face-to-face engagement they would have benefited from, including workshops to attend, or case workers to help them navigate the process.

*"If somebody said to me, look there's this workshop going on, you can go here and they'll explain exactly how it works, I'd find a way of getting myself there and understanding how it works. But it's never been easy for me to find that information."* Representative (England, Residential home, Mixed funding)

5.49. Participants who did not receive the face-to-face support they felt they needed. They mentioned a lack of information available about what support was available that they could have accessed. They suggested clearer signposting would have helped them access that support more easily.

5.50. **Transparency of information about public funding:** There was a perception that local authorities could be more transparent about the funding system, as participants found the system opaque, complex, and difficult to navigate. People who had to engage with the local authority found the information they provided lacking, and those who had public funding were unclear on how much the care cost overall and how much the council were paying. They felt that if this system was clearer, it would be easier to find the appropriate advice and support.

*"I think the fees is obviously the biggest one, that needs to be a bit more transparent right at the beginning."* Representative (England, Residential home, Mixed funding)

5.51. **Written information about funding:** Participants felt that the lack of clear information about funding made it challenging to understand, as the complexity of the system meant there was a lot of information to take in. They felt that if there was clear written information, they would have been able to read and digest all of the options available during an otherwise busy and stressful time, and as a result been more well informed.

*"Well it would be nice if you could have everything written down. That said, I was in a bad place anyway, so I probably didn't take on board a lot of stuff. It would be nice if it was just written down, so you could read it in your own time."* Representative (England, Nursing home, Publicly-funded)

5.52. **Simplification:** The system was widely described – by representatives, residents, and social workers – as highly complex and difficult to understand. Regardless of the support and information provided, participants felt a simplified approach would help people with limited time and make it easier for experts to explain to those people facing decisions about choosing a care home.

## **6. Moving into a care home**

## 6 Moving into a care home

- 6.1. This chapter looks at people's experiences of moving into a care home, once the choice of care home has been made; particularly how representatives engage with this process, and what level of control they feel they have in discussions with the care home. It begins by exploring the priorities that representatives and residents have during the move. It then looks at how, if at all, representatives engage with contracts and terms and conditions.

### Chapter summary

Representatives' priorities while the resident was moving into a care home focussed on the comfort of their relative, rather than the paperwork involved such as contracts – particularly if the move was urgent. The experience was dominated by feelings of relief that a home had been found and a resident was safe. This was therefore a distracted time that made it difficult for representatives to engage with contracts and terms and conditions.

As a result, representatives had limited recall of what was in the contract and whether the terms and conditions were standard or unique to that care home. There was an assumption that contracts would be regulated. For those who received public funding, they may not have seen a contract at all. In a few cases, this low engagement with contracts caused problems where notice periods had not been expected.

### Key challenges

Moving into a home is often a frantic and rushed time, and therefore there was **limited time to engage with contracts** and terms and conditions.

Representatives exhibited **limited awareness of how important contracts were** until it was too late – for example, they had to pay more for a notice period once a resident had moved or died.

Representatives felt they **lacked power to participate in discussions** about terms and conditions with the care home.

Representatives assumed that contracts and terms and conditions were **standard or otherwise regulated**, even when this was not the case.

### Key supports

Moving into a home was made easier when **care homes were flexible**, and provided support to representatives.

**Social workers also eased the process of moving in** by acting as a conduit between the family and care home.

**Standardised contracts** might offer an opportunity to provide more generic support about contracts, and help families understand what to expect.

## Priorities during the moving process

6.2. Representatives' priorities during this period, particularly with the speed at which this was happening, **were comforting and supporting the resident, their own emotional wellbeing**, and if the resident had any specific needs that made finding a care home difficult, **ensuring the care home would take the resident**. All of this had an impact on the representative's capacity to engage with the contract and terms and conditions.

6.3. As discussed in Chapter 2, the context of moving into a care home meant there was **often little time to decide on a home**. Once the decision was made, residents then often moved into the home quickly. Representatives commonly referred to a matter of days between the care home being decided on and the resident moving in, which gave them little time to engage with the process.

*"They organised for somebody to go to the hospital to assess her and talk to her and probably within a week or ten days she was in the home and the ambulance brought her in. Everything was all very fast."* Representative (England, Nursing home, Self-funded)

6.4. Similarly, the emotional state of the representatives and guilt about moving the resident into a care home could have a large impact. As they were focussed on the impact for them of the decision and making the process as smooth as possible for the resident to minimise the upheaval, the technicalities of the decision were less important to them.

*"I suppose we were trying to become emotionally adjusted to the whole idea and I just did what I had to do."* Representative (Northern Ireland, Self-funded)

6.5. Residents were often particularly vulnerable at this point, and were rarely involved. They had little awareness of the practicalities that had been involved when they were moved in – particularly where they had moved from hospital.

*"At the time, I wasn't really thinking very much, coming straight out of the hospital and into here. I needed the help anyway, so I don't think I really thought very much."* Resident (Residential home)

6.6. To try and ensure the transition was smooth for the resident, representatives tended to focus on the **practicalities of physically moving the resident in**. This included the practicalities of moving residents from the hospital, rehabilitation centre, or their home into the care home and ensuring they had their furniture and belongings around them, to help them feel comfortable.

6.7. When a representative had been the main carer for a resident, this often had a negative impact on their own physical and mental well-being. This was particularly the case where the resident had been moved into the home because the carer could no longer cope. As a result, representatives in this situation were often strained during this period and couldn't focus on minutiae or future planning. Instead, the main focus was getting the resident into the home.

*"I had to pay attention to my own health as well because it had deteriorated with me looking after her for so long." Representative (Scotland, Nursing home, Self-funded)*

- 6.8. Representatives also talked about the **relief of finding a care home, and knowing the resident would be safe there**. As the alternative was felt to be continuing with the current situation, which was not considered an option at that point, getting the resident into a care home where they would be safe was the priority.

*"To be quite honest we were so relieved that, this sounds dreadful, this sounds awful, we were so relieved that he wasn't coming home. I didn't sleep at night thinking, if he comes home we cannot manage him. So it was a relief for him to be going in somewhere." Representative (England, Residential home, Self-funded)*

- 6.9. **Care homes were generally flexible** during this time, and representatives spoke about appreciating care homes' willingness to meet their needs and the importance of feeling like things were organised around them. This included instances of flexible moving-in dates, allowing representatives to visit the home and move objects in before the resident moved in, and flexibility around initial payments.

*"[The care home] were very clear that even if we decided on moving in day that we didn't want to come, we [could change our mind], which I appreciated." Representative (England, Nursing home, Mixed funding)*

- 6.10. However, particularly for publicly-funded residents, there were examples where **representatives had not been involved in the moving process at all**, or where residents had been moved into care homes from hospital without the representative being notified. This could be very distressing for the representative, particularly where they were very close to the resident. On the other hand, where they were less involved, representatives could find it a relief that others were organising this process for them.

*"The hospital just found her a place at [the care home] and they just took her in. And she was fine." Representative (England, Residential home, Self-funded)*

- 6.11. Where the resident had specific health concerns, particularly behavioural issues as a result of dementia, representatives were **limited by care homes that would accept someone with the resident's needs**. In these cases, representatives were particularly focussed during this time on the role of the care assessment, in ensuring that the care home would agree to take the resident, rather on the terms and conditions they were agreeing to. There were also often medical benchmarks to be met, such as ensuring medication was controlling the behaviour of the resident, before the resident could move in. As such, the **power was with the care home to reject the resident**, rather than the representative to choose the care home, which meant that representatives were prepared to do what it took to ensure the care home would choose them.

*"They had a lot of problems with her and in fact at one point they were even suggesting that she would have to go to a different home, one that was more set up for people with severe dementia behavioural problems, but she's OK now." Representative (England, Nursing home, Self-funded)*

- 6.12. These aspects made it **difficult for representatives to engage effectively or negotiate with a care home** over terms and conditions.



## A lack of engagement with contracts and terms and conditions

6.13. Due to the **representative's own priorities and the lack of power they felt they had over the situation, they were not able to engage with the contract effectively**. Representatives were generally unconcerned about the lack of engagement they had with the contract, because they assumed that they had been told everything they needed to know and that terms and conditions were standard – or a price worth paying for a care home they were happy with. This meant they were broadly unaware of the variety of terms and conditions available and this occasionally caused issues when terms and conditions – such as notice periods – were not clear to them upfront.

6.14. The discussions about terms and conditions that representatives remembered tended to be **informal conversations with the manager about what to expect when the resident moved in**. This might happen during the finding stage, and often very little, if anything, was written down.

*"I don't remember there being anything in writing about any of that but...I think we felt we certainly knew what the score was."* Representative (Scotland, Nursing home, Self-funded)

6.15. This **informal discussion was more important to representatives**, who did not particularly remember the contract or what it included. They were more nervous about the official elements of the contract – filling in forms, providing personal information. Once this was done, however, it was generally perceived to be 'simply paperwork' to confirm prior the informal discussion, i.e. putting the things that had already been discussed into an agreement.

*"I was slightly apprehensive when the administrator lady said, I need to get this contract drawn up...I was expecting something worse than it was I think, and on reading it, there was really nothing too surprising in it at all."* Representative (Scotland, Nursing home, Self-funded)

6.16. Where the placements were organised by the local authority, **representatives may not have seen a contract at all**, as all the procedures were organised between the care home and the local authority. If the move was particularly urgent, whatever the funding type, the paperwork was also sometimes **organised after the resident had moved in**.

6.17. Whatever the terms and conditions, representatives seemed to assume these were **standard across all care homes**, or in some other way regulated, and did not particularly think about them.

*"What was in the contract? I think there was the basic fee, the fact that the fee would go up in line with the council...I think there would be if you have any complaint, how to make a complaint, a regulatory body, the standard sort of stuff."* Representative (Wales, Nursing home, Self-funded)

6.18. In some local authorities, the terms and conditions for placements organised through the local authority were agreed against a standard contract. In Scotland, care can be organised through the National Care Homes contract, which is a standard contract for all local authority placements, or self-funding placements where the resident or representative decides to use the standard contract. However, this is not the case across all local authorities and terms and conditions may vary between authorities that do have standard contracts, or between care home chains within the local authority area. Representatives also did not show specific awareness of the National Care Homes contract or standard contracts of the area, where these were in place.

*"We have a set of homes owned by [a care home chain], they have their own separate contract. But apart from them, the local authority has one contract which we ask all the homes to sign up to." Social worker*

- 6.19. Generally, the representatives interviewed were **not worried by the limited engagement** with the contract or terms and conditions. They felt if there was something to worry about, they would have noticed, and – as discussed above – they had other priorities at the time.

*"I don't remember [whether they saw a contract]. I'm sure I did because they gave me a pack of all sorts of paperwork, so I probably did." Representative (England, Nursing home, Self-funded)*

- 6.20. It was very **unusual for a representative to get a professional to look at the contract** or to discuss any of the terms and conditions. The only exception we found was where a family member was a lawyer or solicitor who could look the contract over informally.

*"I don't even remember [the contract]. My husband's saying he found it very easy to understand but then he's a retired a lawyer so he's used to contracts." Representative (Northern Ireland, Self-funded)*

- 6.21. However, this lack of engagement meant that there were cases where **issues had arisen due to lack of awareness of details**. For example, where there was not clarity at the beginning about whether a care home was permanent or temporary, this could be very upsetting to a representative who was scared about the resident being moved. Similarly, where there was lack of clarity about how long a notice period was required, or what constituted giving notice, representatives and residents could end up being charged for the care home for time when the resident was no longer living there.

#### **Case study 6.1: lack of awareness of notice periods**

Representative (England, Nursing home, Public funding)

Phillip had been moved into a care home for Continuing Health Care, funded by the NHS, after time in hospital following an operation.

When moving in, his daughter, Jenny, had not realised that there was a strict notice period in place.

Jenny had been discussing moving her father out of the care home informally with staff for some time, once the CHC funding ran out and they were moving him to somewhere permanent. However, when she told the care home she had a date to move Phillip, the care home told her that she hadn't given them enough notice, and would be charged for a month from then, even though Phillip would have moved out before that point.

*"I didn't realise you had to give a month's warning to them that you're going to leave. ... So now we've got to pay for the weeks when my dad isn't there."*

- 6.22. Representatives **rarely went back to the contract**, even when issues had arisen. They relied on the care home to provide them with the details they needed. However, in cases where representatives had been promised things before moving in that had not been put into practice, **it was suggested that including these in the contract**, could give representatives more power to hold the care home to account.

*"I would have contracted for more, I would have been fussier about what was on the contract because I believed the glossy brochure that there would be five activities a day. You could argue it in court, but who's got the time and energy to do that?" Representative (England, Nursing home, Self-funded)*

## 7. Paying for care

## 7 Paying for care

- 7.1. This chapter explores the way in which participants approached the process of paying for their care, including their experiences of setting up payments with the care home, bills and unexpected fees, and dealing with fee increases.

### Chapter summary

The process of setting up and making ongoing payments for care was relatively straightforward for participants. They largely paid by direct debit or by cheque and described the process of setting up these payments as easy to do. Bills themselves were inconsistent between care homes, with some providing a breakdown of fees and others not. However, representatives rarely scrutinised bills in detail. Those receiving public funding were unclear of the details of paying for care as they had little involvement in it.

Once a resident had moved in, families were happy to pay for extra charges (such as for hairdressing) but had not anticipated these costs from the outset. For cases where a resident had been in a home for a prolonged period, they had seen the fees increase year on year. This was seen as something inevitable as care home's costs rise with inflation. However, participants felt disempowered to challenge or negotiate these increases. They saw their only option as moving home, but acknowledged that fee increases would take place everywhere, and were reluctant to move their relative.

### Key challenges

Extra charges were not always explained in advance, and a **lack of clarity about bills** created uncertainty around what extra charges were for.

**Fee increases were seen as an unavoidable part of paying for a care home**, but participants faced anxiety about covering the increase, and were unclear on what they were for.

There was often **inconsistency in the billing from month to month**, particularly in the beginning of the residency while funding arrangements were still being organised.

### Key supports

Those who had difficulties at the point of establishing funding found the **care homes' patience and flexibility** a key support as they did not feel under pressure to pay for the care.

**Deferred loans were helpful in allowing leeway** when the resident's money was not immediately available.

Those who received a **breakdown of charges** found them helpful, although not all care homes provide this.

Clarity about the **exact fee the resident would have to pay** from the beginning of the residency was important to people.

Advanced **warning of charges**, and clarity on how they can be disputed, would help representatives feel more empowered about what they were paying for.

## Setting up payments for care

- 7.2. The **process of setting up the payments to the care home was largely considered straightforward**, particularly in comparison to participants' perceptions of the funding system as a whole. While participants found the process of establishing a source of funding for the care difficult, once it came to liaising with the care home itself, there were fewer challenges. Payment was set up in a variety of ways, with participants choosing to pay by direct debit or by cheque. Others who paid their pension to the council had this deducted automatically.

*"It couldn't be any simpler, to be honest. You just get the bill every month and that's it."* Representative (Scotland, Nursing home, Self-funded)

- 7.3. Ahead of moving into the care home there were several possible steps that took place before the payments themselves were set up. The first of these was a means test which took place for a handful of self-funders, where the care home individually assessed the resident's assets to confirm that they could afford the care home for a certain amount of time, usually around 18 months. This was more prevalent in Scotland, and in one case the resident had already moved into the care home, after which point they could not prove their assets were sufficient, as their home had not yet been sold.

*"A lot of them wanted to be able to demonstrate that you've got two or three years' worth of self-funding, my father wasn't in that position. There's no point in ensuring it's a wonderful room if you say, actually we're not going to take him because he's only got 18 months' worth of self-funding. we had to be open and upfront about that."* Representative (Scotland, Residential home, Self-funded)

- 7.4. There was **inconsistency among the different care homes regarding deposits**, with no distinct pattern to whether or not homes charged an upfront fee before the resident moved in. While participants largely could not recall having paid a deposit fee, there were isolated cases in which care homes charged a fee of up to £3,000 for administrative costs. Despite the lack of clarity about what the costs were for, participants did not question the need to pay the fee, nor did they mention having been assured they would get it back.

*"It was a deposit and for work being done, probably paperwork, administration. She did say we'd have to pay a deposit but not if it included administration. I thought there wasn't much I can do about it now."* Representative (England, Nursing home, Self-funded)

- 7.5. Participants felt that they would have **benefited in hindsight from a more focused discussion about the payments**. This was in spite of the fact that need to focus on the practicalities of finding care and moving into the care home meant that the process of setting up payment for the care was considered less complex in comparison.

*"I just felt that, look let's get her into the home and we'll have to ask those questions once she's in. But I guess those discussions probably should have been more extended than they were looking back on it."* Representative (England, Residential home, Mixed funding)

- 7.6. Self-funders universally had direct control over the care home payments. In contrast, those who were publicly-funded had less knowledge of how the care was being paid for and how it worked. There was an assumption that the council had an agreement with the care home and that payments were made without the need for their input. While the way in which the care was paid for was largely unimportant for representatives, this uncertainty about how much the council paid led to issues if there were disputes about how much the representative would have to pay. There appeared to be a lack of transparency between the council and the representatives.

*"Because my mum had this house which was sold, I am assuming that the council are paying something towards her care, because all she's now paying is about £390 per week. I don't have a piece of paper that says the council are paying this towards her care. All I get is bills from the council to pay every month."* Representative (Scotland, Nursing home, Mixed funding)

- 7.7. While the majority faced no problems in organising payments to the care home, there were obstacles that arose for participants including delays in setting up payments or errors in billing. These participants included those who had received incorrect information from the local authority. If there were disputes or complications surrounding the funding process, this had a knock-on impact on representatives' ability to easily set up the payments to the care home, as it led to delays in clarifying exactly how much the representative would have to pay. The burden then fell to the care home to defer billing, and representatives faced a larger backdated bill.

#### **Case study 7.1: experiencing problems with setting up payments**

Representative (England, Nursing home, Mixed funding)

Liz's mother moved into a care home after having a stroke. She received local authority funding and Liz had contact with the local authority about how much she would have to pay. There were inconsistencies between how much the local authority asked for and how much the care home wanted them to pay. While she was receiving around £100 in pensions per week, the care home told her that they owed £130 per week, which Liz's mother can't afford.

They only found this out from the care home manager recently, a long time after she had moved in, and the discrepancy was due to the local authority mistakenly assessing Liz's mother as having two pensions. Liz now needs to speak to the local authority about the issue.

*"She's not paying the full amount she's supposed to pay. And I got told by the manager in the care home yesterday she's supposed to pay £127 and some pennies, but she's only getting £95 pension. She's not getting no family credit pension because they reckon she's getting two private pensions. And so I don't know what's going to happen because they can't actually chuck her out, can they? So I don't know, but I've got to go this morning and check it, to sort this out with the council people."*

- 7.8. Participants generally set up payments to the care home just before or soon after moving in, however there were participants who felt the **care homes were slower to provide information about the payment methods and billing than they would have liked**. This meant that they did not start paying for the care for a period after their relative moved in, and were left waiting for a bill. The impact of this however was fairly minimal, as the funds tended to be available in a lump sum in the resident's bank account.

*"Actually, I don't really know what's happening because they're all behind with the payments. You'd think they'd want the money in, the state the councils are in but it hasn't come out yet. I got a letter saying they were going to*

*take it out either this month or next month. So, he'll get it all taken out at once instead of it coming out as it should do every month."* Representative (England, Residential home, Mixed funding)

- 7.9. Again, a factor contributing to this was the **time pressure representatives were under to move the resident into a care home**. A lack of time available meant that setting up payments came secondary to the other details as the process felt rushed and they had just a few days to organise the funding. Participants described the uncertainty caused by this, and felt that they would have preferred to set things up in advance.

*"But once he got there they were quite slow giving us information on how they accept payments for him in the home. We didn't have all the information on how to get the standing order set up. But maybe because it was all quite rushed towards the end maybe that's why the delay was. It would have been easier for us to have had everything in place."* Representative (Scotland, Nursing home, Self-funded)

- 7.10. Participants who felt ready to start paying for the care because their funds were available found the uncertainty of this unsettling. However, for participants whose funds took longer to gather – for example when their house was yet to be sold – there was a general perception that care homes were accommodating whenever challenges arose or there was a need to clarify details before beginning to pay for care. This, on top of care homes appearing not to be forthcoming with payment information, paints a picture of care homes themselves deprioritising the care home payments. For these participants, the lack of emphasis on the payments themselves by the care home provided them with a grace period in which to clarify the situation.

*"The home was very easy to deal with and they didn't put any pressure on us, and I think that we had at the finish, that we had to pay two months at one go whenever we get everything sorted out. The home was accommodating in us getting the funding sorted out, they were very accommodating."* Representative (Northern Ireland, publicly-funded)

- 7.11. Residents were rarely directly involved in paying for care. This was generally the responsibility of a funding body, local authority, solicitor or representative and many had handed over Power of Attorney for their finances. As discussed in the chapter on funding care, where residents had a trusted person taking responsibility for this, they were generally unconcerned. However, where they were worried about a loved one having to pay for their care or that they were not paying enough towards their care, this could be distressing. Residents were aware of the money held in a 'kitty' by the care home for their needs and extras.

*"I know I get pocket money off my solicitor, per month, so that I can buy what I want then."* Resident (Nursing home)

## Deferred loans on residents' property

- 7.12. When participants had been involved in selling their relative's home before or after they moved into the care home, deferred payments were a possibility when it took time to sell the residents' property, or a residents' living relative was still living in the house. The local authority would take on payment for the care, and once the house was sold the proceeds from the sale would be used to pay back the local authority for the sum owed.
- 7.13. This introduced additional complexities to the process of paying for the care. Often, particularly in the context of time pressures faced when looking for and moving into a home, the process of selling the house took longer than would



have allowed them to begin paying for the care at the beginning of the residency. When this was the case it was possible for participants to access funding from the council which was borrowed against the value of the house. In general, this process worked well, often taking place by default.

- 7.14. There was a lack of transparency at the end of the loan period, however. Participants who had not realised the care home would charge more once their relative became classified as self-funding were surprised to find that the fees increased once the house was sold.
- 7.15. While for many deferred funding was not a problem, there were cases where difficulties in accessing the deferred loan, or charges for the service, deterred participants from taking this step. Instead, they had to make alternative arrangements to pay while the house was being sold.

### **Case study 7.2: taking out a deferred loan**

Representative (Wales, Residential home, Mixed funding)

Mary's father, David, moved into a care home after becoming unwell. The council explained that because he had a low income, and very few savings, that the council would pay for the care while the house was being sold. The family filled in the necessary forms and the council agreed to pay for the care.

*"So the council didn't take a charge over the house, they knew it was there, they didn't ask us to sell it, they didn't ask anything about it, they just knew it was there. We kept having the funding until we as a family or my father actually said first, after two years, I think I want to sell the house"*

Eventually they sold David's house and the funds from the sale went into his bank account. The local authority then contacted Mary and told her that David owed the authority all of the money they had paid to the care home on David's behalf. After this, David was considered to be self-funding.

When Mary took over the payments, the cost of the home went from around £500 per week to over £700 per week, as the care home charges a higher rate for self-funded placements compared with publicly-funded placements. They had not realised this would be the case, and so there was a degree of confusion when it came to finding out how much David would owe.

## **Billing and extra charges**

- 7.16. Participants **tended not to question or scrutinise the bills** they received regardless of whether they were consistent and straightforward, or varied month to month. The nature of the bills themselves ranged from containing a simple topline figure for payment owed, to a detailed breakdown of extra charges as well as details of the components paid by the local authority where applicable.

*"So long as there's money in the bank it works fine. I get a monthly statement from the people who look after the account for the care home and I get notification of what has been deducted each month. I put those in a file and forget about them."* Representative (Northern Ireland, Self-funded)

- 7.17. Participants who found that aspects of the billing process were unclear had not questioned them. Those who had support from financial advisors or solicitors seemed more inclined to check the bills they received and question it if they felt the need to. Administrative errors made by the care home or the local authority led to confusion about the

sums the resident should be paying and it took time to iron these out, particularly when the resident's funding situation was complex – for example those with mixed funding.

*"They didn't cash my cheque, so there was a whole load of argy-bargy for the first couple of months about what I'd paid for and what I hadn't paid for. It was fine because I had enough liquidity to cope with suddenly having to pay £12,000 but the financial administration was not good and that was partly because people kept changing. They still are, if I'm honest."* Representative (England, Nursing home, Self-funded)

### **Case study 7.3: questioning discrepancies in the care home bills**

Representative (Scotland, Residential home, Self-funded)

Jenny's father, George, moved into a care home. Jenny was uncertain how much she would have to pay towards the cost of George's care. When Jenny was arranging the funding with the local authority, she found it challenging to find out exactly how much she would have to pay.

The invoices Jenny received from the local authority contained details of the billing period but they were still confusing. At the time the funding was managed by the Access to Funds team as they did not have Power of Attorney, and this meant that discrepancies in the bills were queried with the contact within that team. Jenny felt this complicated things, and that bills weren't dealt with logically; recently she was told the local authority owed them a refund of around £700, but she owed them over £1,000.

*"It was actually just last week that she had phoned him and said a similar thing and my husband said well, what I think we should do is wait until you are clear about what you're doing, what the situation is before we start paying extra money in. Because of my husband having the Access to Funds thing, it's very difficult because he can't just pay it willy-nilly without going through them."*

- 7.18. There was a lack of consistency regarding itemised bills, with participants describing **large variations between the level of detail in the bills they received**. While there were cases in which every individual component of the care and extra charges were detailed on the bill, most cases received a more top-level bill, with a weekly breakdown at most. Participants who did not have a breakdown of what their fees went towards said that they would have found it helpful to see, although a factor leading to participants not questioning this was the emotional impact of the situation, and relief at having finalised the funding arrangements. Those who did receive an itemised breakdown, for example with details of the nursing component deduction, and the extra charges listed separately, found this helpful and appreciated the transparency.

*"Even now I'm a little bit unsure of what exactly I'm paying for, but I was just so relieved that I was going to be able to pay it, so I was quite happy."* Representative (England, Nursing home, Mixed funding)

## **Extra charges**

- 7.19. Part of the billing process included the breakdown of extra charges. Participants were aware of extra charges such as hairdressing and chiropody, and were willing to pay for these. Those who had been made aware of the charges upfront didn't find these a surprise. However, occasional lack of clarity from the care home about what they charged extra for meant that people found out about these after the resident had moved in.

*"I didn't know that I had to pay for soap and shampoo. It was only when one of the carers said to me, oh, I've found this little bit of soap to wash your dad, sorry, that's all I've got left. I didn't know I had to provide soap and shampoo and personal toiletries. That was a surprise." Representative (England, Nursing home, Mixed funding)*

- 7.20. Participants whose relative had moved care homes noticed discrepancies in what care homes charged extra for. The interviews revealed inconsistencies in what care homes charged for – for example in isolated cases, care homes charged extra for a carer to accompany the resident to appointments, or did not provide incontinence pads.

#### **Case study 7.4: representative unhappy with extra charges**

Representative (England, Nursing home, Self-funded)

Tom was shocked by how much the care home cost, particularly the extra fees, and was upset that his uncle would have to pay while others had their care paid for.

Before Tom's uncle had moved into the care home, he and his wife had been cutting his uncle's hair and looking after his feet. However, they found on a visit that these had been done by the care home and charged unexpectedly. Tom would have preferred to continue carrying out these tasks.

Although they were given a booklet with fees when they moved into the home, they weren't clear on costs and weren't expecting the costs to increase as the Tom's uncle's care needs increased. The representative had not raised these concerns with the care home, as he is worried about reprisals for his uncle.

*"It would take less than five minutes for my wife to whip round his hair and then all of a sudden, they did it one day – we were presented with a bill of I don't know how much. It doesn't really matter that side of it, but it's the principle."*

## **Fee increases**

- 7.21. Fee increases were seen as inevitable to participants, who **did not feel they had control over whether or not the care home would increase the fees**, and rarely considered questioning it. This was part of the broader perception self-funders held that the financial aspect of moving into a care home was a foregone conclusion. For participants who had to pay, fee increases were seen as inevitable due to inflation and increased costs. Representatives, in cases where the resident had been in the care home for a year or more, had typically seen an annual increase.

*"In two years, the fees went up 7%. I wasn't given any options, I've just accepted that it's inflation. They do give me reasons and mostly it's inflation and just general costs. It's unavoidable, unfortunately." Representative (England, Residential home, Self-funded)*

- 7.22. Because of this, **representatives did not feel able to question fee increases, nor did they see the benefit of challenging the care home about the increase**. While care home fee increases were seen as reasonable given the nature of inflation and increasing costs, there was also an element of participants feeling powerless to avoid the increases. They felt that the same would be the case at every care home, and the alternative of moving to a different care home would be too challenging to justify avoiding the fee increase.

*"They basically have you, don't they? Because they just put the fees up with reference to inflation, but you do feel you have no control over it, because you haven't got the normal buyer's rights of saying, well no I don't agree. You have little power unless you're prepared to move the resident."* Representative (England, Residential home, Self-funded)

#### **Case study 7.5: fee increases being backdated**

Representative (England, Residential home, Self-funded)

Robert lives in a care home and his daughter and son-in-law have power of attorney and organise a standing order for these payments.

The fees go up yearly following a discussion with the council and the representatives are notified in June. These increased charges are then applied retrospectively to April, and they have to pay this amount separately and then increase the standing order. They expect this, as they understand there are delays in the council notifying the home of the changes.

When asked, the representatives said they understood the current market and the financial difficulties a lot of care homes are in, so would not be particularly concerned about an increase in fees.

*"It would have to be abnormally high and individual to that home for me to be concerned, and generally, I would be prepared to pay it unless it was absolutely out of this world."*

- 7.23. Despite a fatalist attitude towards fee increases, participants still expressed **uncertainty and anxiety about the impact of fee increases**, particularly if they were large. Part of this stemmed from a lack of certainty about the funding system and concerns about the long-term affordability of care. It was important to participants to receive notice of the fees, and information about why they were being raised; although participants knew the general reasons why fees increased – for example inflation, pay rises for staff and increased costs – they wanted care homes to justify larger increases.

*"I'm already concerned about what happens when the money from my mum's house runs out. So, if there was a big hike in prices I would have to ask for it to be justified. Would that mean just getting a better menu? Or if the carers were being paid more. But if it was a huge increase I would have to really bite the bullet and ask why."*

Representative (Scotland, Nursing home, Mixed funding)

## **8. Raising concerns and making complaints**

## 8 Raising concerns and making complaints

- 8.1. Following on from the previous chapter, which discussed how representatives raised concerns about financial issues with the care home, this chapter looks at how representatives, residents and social workers raised concerns in general with a care home. It then explores the distinct responses to different types of complaints. Finally, it discusses perceptions and experiences of escalating concerns or raising concerns externally.

### Chapter summary

Participants said they were generally willing to provide feedback and raise complaints when they were unhappy. They said this was important to do in order to provide residents with a voice. This was particularly the case with every day, practical concerns such as laundry, food and personal hygiene. Representatives were less inclined to feedback on consumer type complaints such as fee increases or contract terms, because they felt particularly powerless to make changes to these aspects of the home. Of greatest concern was the resident's care, and these concerns were most likely to be escalated outside the care home. Yet representatives were generally resistant to raising concerns outside the care home and unaware of the process for doing this.

Social workers were involved in safeguarding issues, but were not mentioned as a means to raise other types of concerns.

### Key challenges

A fear of **repercussions for making a complaint** sometimes made representatives hesitant to make a complaint, or complain too often.

Residents who were particularly vulnerable were **unable to provide feedback** themselves.

Representatives **felt powerless to challenge consumer type concerns** such as fee increases. They either felt moving was the only way to change things (and were unwilling or unable to move a resident), or assumed that these concerns would be similar across all care homes.

Representatives **lacked awareness of how to make complaints externally** or escalate issues when a problem had not been resolved.

### Key supports

Care homes that encouraged an **open culture of providing feedback**, for example an approachable care home manager, encouraged representatives to raise an issue.

Some care homes had mechanisms in place to **proactively seek feedback** from residents and their families and friends, for example resident meetings – although these were not always targeted at gathering complaints.

Residents said that better support to **recognise what 'warning signs' to look for** around poor care would help them identify instances of negligence or inadequate care.

Increased **transparency about how to raise an issue**, as well as clearly defining what **kind of things constitute a complaint**, might reassure families about feeding back.

## Concerns and providing feedback in general

- 8.2. Representatives described themselves as feeling **comfortable providing feedback**, which they generally raised **informally, face-to-face**, with care home staff. Where representatives or residents didn't feel comfortable with providing feedback, they expressed **concern about backlash** from the care home towards the resident.

### Positive experiences

- 8.3. Representatives talked about their **own willingness to provide feedback** or raise concerns in general, and that this was something they felt able to do in the care home.

*"I'm the type of bloke that, I don't mince my words. If I didn't like something, I would just go to the management and just say, look."* Representative (Northern Ireland, Mixed funding)

- 8.4. Where representatives were able to visit regularly, they **knew staff and were able to provide regular feedback face-to-face**. Where representatives were **less able to visit, they would call or email**. Residents who had a good relationship with the care home and staff also expressed confidence sharing their views in general.

*"I'm visiting mum twice a week because it gives me a chance to keep an eye on the property as well at the same time. So I have had quite a lot of direct contact with the staff, so I've got to know them. I don't find that a problem approaching them at all."* Representative (England, Residential home, Self-funded)

- 8.5. In cases of particularly vulnerable residents, representatives also expressed a need to speak for them and ensure their needs were met, as they were unable to do so themselves.

*"On that unit, none of them [residents] have got a voice, so if we see something that we don't agree with...we say it."* Representative (England, Residential home, Publicly-funded)

- 8.6. Perceptions of how receptive care homes were to feedback also had an impact on how willing representatives and residents were to provide feedback. Where representatives were completely satisfied with the home and had no experience providing complaints, they emphasised how much they **appreciated the care home raising issues with them**, rather than them needing to be proactive and notify the care home of issues.

*"They are much more likely to tell us of what they've noticed ... They will make a point of stopping you and saying, this is what happened last week. They take a great interest and so the worries, the concerns that some people seem to have with nursing homes, we've not had them, because we've had such good relationships with the care home and with the carers."* Representative (Wales, Nursing home, Self-funded)

- 8.7. Similarly, representatives who had positive relationships with staff felt comfortable providing feedback – particularly where staff and the care home management proactively encouraged such feedback. Although representatives in

these homes described specific activities to encourage feedback – such as anonymous books at the entrance, resident and representative meetings, surveys – **the attitudes of the staff were most important in encouraging, expecting, and reacting to feedback**. An open-door policy with access to the manager was also important for representatives to feel like they could easily provide feedback.

*“Any time we’ve had to chat, they’ve always been there and always willing to sit down and have a conversation, and discuss things. If there’s anything we ever need or anything we want, we can just knock on the door and come and have a conversation.”* Representative (Northern Ireland, Self-funded)

- 8.8. Residents were generally willing to provide feedback to staff directly, as they built up relationships with them. They were pleased when things were resolved, but did not consider escalating issues if they were not resolved. Residents also liked providing feedback as part of a group, such as in a resident’s meeting.

*“They very quickly pick it up and change things if there is anything I don’t like - they’re very good like that.”* Resident (Residential home)

## Negative experiences

- 8.9. However, where representatives described care homes as resistant to feedback, this was normally not described as a lack of procedure, but a culture of staff being resistant or defensive when approached with feedback, or nothing changing following a complaint being made. Having limited access to more senior members of staff also meant representatives felt less willing or able to raise issues. And where there was high staff turnover, there were concerns that feedback was not passed on, so issues were not – and could not be – be dealt with longer term.

*“I find that certain people don’t want you to give them feedback, you get that impression. The manager’s supposed to check and see what’s going on on every floor and it seems like she just stays in the office.”* Representative (England, Nursing home, Mixed funding)

- 8.10. Where representatives were less likely to provide feedback, they talked about **not wanting to offend the staff, or fear of negative ramifications**, such as mistreatment of their relative or being forced to leave the care home. Some participants described being unwilling to provide any feedback to the home due to concerns about “rocking the boat”.

*“Am I going to be offending anyone or is there going to be any sort of repercussions for complaining about such and such a thing?”* Representative (Scotland, Nursing home, Self-funded)

- 8.11. Although they might still provide feedback, representatives who mentioned this as a concern for themselves or the resident took into consideration both **what feedback they gave and how they gave feedback**. Representatives suggested they might feedback more informally or prefer not to put things in writing where possible, to try and avoid negative consequences.



*"I don't think I would trust the management. I have voiced my opinion down the phone to them, saying that I wasn't happy ... But I don't think I would be happy to put anything in writing, just because of, perhaps, repercussions." Representative (Scotland, Nursing home, Mixed funding)*

8.12. The willingness to complain, and how much impact the fear of negative ramifications had, varied depending on the type of complaint, as will be discussed below.

## Types of complaints raised

8.13. There were **three main types** of concern that were raised by representatives in relation to care homes. These were:

- **"Small" or "everyday" concerns**, in terms of how easy they were considered to raise (and, at least from a customer's point of view, for the care home to deal with), were short term practical concerns that needed to be dealt with immediately. Examples included: the resident not being got out of bed by the time the representative visited; cleanliness or state of repair of the rooms; or the resident being left without incontinence pads being changed. They also included low-level practical concerns that could be relatively easily resolved, such as issues with the food or laundry.
- **"Large" issues** were considered either repeated "everyday" or "small" concerns which the care home did not respond to, or more institutional issues or "consumer" complaints, like the type and amount of activities, staff turnover or attitude, or financial concerns like fee rises.
- **"Safeguarding" concerns** were cases where representatives felt the resident was at immediate risk of harm, such as medication mix-ups, neglect of the resident, or abuse from staff.

8.14. The type of concern had a large impact on how comfortable representatives were raising these with the care home, and how comfortable they were leaving them unresolved if the care home was resistant.

## "Small" concerns

8.15. Representatives were generally **very willing to provide feedback on concerns they considered "everyday"**. They normally provided these directly to staff working with the resident, face-to-face during visits.

### Case study 8.1: quickly resolving a small complaint

Representative (Northern Ireland, Self-funded)

When Tom came to visit his father, Kenneth, one day, he found dirty linen on the side in Kenneth's room. Tom thought his father himself had left it there, but he was concerned that no one had come and cleaned it up.

He immediately went and found a nurse, who apologised and organised for it to be cleaned up immediately. The nurse also said he would make sure it would never happen again, which it hasn't.

*"We've never had any major issues, just silly things. But that's it."*

- 8.16. Representatives normally had some experience of raising these kind of concerns, and felt very comfortable doing so. They also normally described the care home as having quickly resolved these issues.

*"What I tend to do is if there's something I'm not happy with, I speak to the girls. Nine times out of ten they do sort things out."* Representative (England, Nursing home, Mixed funding)

- 8.17. Where these issues were not resolved, they were normally repeated because of more embedded problems, such as a resistance from the care home to recognise or respond to the issue, or a lack of staff consistency to ensure resident or representative wishes were passed on.

*"There's no point me going hammer and stick about my mum's diet because she doesn't have a dedicated care person and there isn't an ongoing manager."* Representative (England, Nursing home, Self-funded)

- 8.18. In these cases, the problems became "large" problems, which representatives found more difficult to deal with.

### "Large" concerns

- 8.19. Where concerns were about "large" issues, in terms of how comfortable representatives felt raising them with the home, or consumer issues, representatives normally discussed these directly with management. However, care homes tended to be more resistant to these changes and representatives were more likely to feel powerless to change things.

- 8.20. Where these were being raised, representatives were **more likely to want something written down**, to ensure there was a record; although, as mentioned above, they still focussed on providing feedback informally.

*"If it's something that I don't want someone to forget and I want a record of me saying it, I'll email them. That's normally if there's a bit of maintenance to do in the room or if it's something really important about food, if she's not eating or if she's had stomach ache, I'll email about it so there's a trail. I try to keep it as informal as possible."* Representative (England, Residential home, Mixed funding)

- 8.21. Representatives were also **more likely to go directly to the manager**, rather than approaching the front-line staff, as they would for everyday issues. However, where these were unresolved, representatives normally **felt powerless to change things, unless they were prepared to move the resident**, which for many was not an option, unless it was a safeguarding issue.

*"It is difficult to negotiate anything other than what you're given. You have little power unless you're prepared to move the resident or you're prepared to be there all the time in their faces nagging about stuff you aren't happy with for your money."* Representative (England, Nursing home, Self-funded)

- 8.22. These were also the types of concerns representatives were most likely to assume were the case across all care homes, so there was felt to be little alternative but to accept it.

### Safeguarding concerns

- 8.23. Potential safeguarding concerns, where relatives were concerned about the immediate safety of the resident, were the **most important concerns for representatives**, whether they had received poor quality care or not. They would often highlight them with the immediate care team and these were the issues representatives were most likely to

escalate. These were particularly rare compared to the other types of concerns, but there were instances described by participants.

- 8.24. Concerns about the quality of care were often paramount for representatives, trumping any other concerns, including a resistance to moving.

*"If the standard of care and attentiveness wasn't there. Obviously, if you have a food issue, you could have a care issue. Or you could have issues maybe where a member of staff was taking advantage of a resident. I think those would be reasons for leaving."* Representative (Northern Ireland, Publicly-funded)

- 8.25. Where there were concerns, these were highlighted with the immediate care staff, to deal with immediately, and would be raised repeatedly if they continued. However, when these were not immediately resolved by the care home, **representatives who were not able or willing to move or raise complaints externally felt powerless to take things further to change them** – for example, due to the resident's reluctance to move or lack of an available alternative home.
- 8.26. Some representatives also **had low expectations, or lack of experience, and struggled to spot warning signs** that a home was not delivering the care required. Where this had been brought to a representative's attention, it was normally because it had got to a stage where the resident was hospitalised, or an external body got involved and highlighted the issues. Once these representatives were given experience of a better care home, they were **more discerning and felt guilty that they had not known what to look for earlier**.

### **Case study 8.2: Lack of awareness of warning signs**

Representative (England, Nursing home, Self-funded)

Meera was living in a care home that was then closed down by the CQC due to concerns over the quality of care.

After this happened, her son, Pranav, wished he had paid more attention to warning signs, such as high staff turnover and Meera complaining she wasn't given enough to eat.

Pranav had not had previous experience of care homes so didn't know what to expect and felt very guilty that he had not realised what was happening before the home closed down.

Meera is now in a new care home, which Pranav feels is much better and he is more demanding, to ensure any concerns are addressed.

- 8.27. Where residents had dementia, representatives were wary of trusting *only* a resident's word when raising a complaint – there were concerns the resident might have forgotten or misunderstood something. Particularly vulnerable residents were also not able to communicate any concerns they might have. This meant **representatives had to rely on their own experiences, but were aware they might not know what was happening when they weren't there**. This could make them less likely to raise a complaint where there was any uncertainty.

*"This is the difficulty, I think [the resident's] perception of things might not always be how they are. She thinks they are sometimes a little bit rough, which they might be, but she got a lot of arthritis...so just getting her dressed or moving her can hurt."* Representative (England, Nursing home, Self-funded)

8.28. However, where representatives felt that these issues were continuing, they were the **issues representatives were most likely to escalate**.

### Escalating complaints or raising complaints externally

8.29. Typically, representatives treated raising complaints externally as a **last resort and were unsure of what the process would be**. Examples of this were relatively rare. Where residents found the care home resistant to feedback, they typically continued to provide it to the care home, even if it remained unresolved, rather than considering escalating it. However, where they were aware of safeguarding concerns, they were most likely to escalate these, usually via a social worker or other external body they were already aware of.

*"I'm happy to raise it. I find it is the norm that what I observe is ignored, that my views don't count and that sort of thing, it's something I'm getting used to."* Representative (England, Nursing home, Self-funded)

8.30. Representatives had **limited knowledge of formal procedures** of raising a complaint within the care home, although assumed they would be able to find this information if they needed it – either within the care home, or by looking through the contract or paperwork when they moved in.

#### Case study 8.3: lack of awareness of how to make a complaint

Representative (England, Nursing home, Mixed funding)

Kelly had been raising concerns with the care home about the care her mother, Elizabeth, was receiving for several weeks. This included concerns that she was losing weight and not being encouraged to eat.

Kelly then received a call from the care home to say that her mother had been hospitalised, due to dehydration.

She wanted to make an official complaint, as she felt this was unacceptable, but she did not know how to raise a complaint.

This was particularly a concern as she had had a difficult relationship with Elizabeth's social worker. Kelly had not wanted her mother to move into this care home at all, and felt the social worker had moved her mother in against her wishes.

8.31. Where representatives were aware of external bodies who they could approach to escalate issues, they were generally either aware of them for other reasons – such as working in the medical profession already – or they knew of them but were unaware of the process to make a complaint. Where they knew a care home was part of a chain – large or small – representatives also mentioned potentially raising it to the 'Head Office' or board of directors of the care home chain.

*"I've spoken with the manager, I would speak to her again if it's not happened, and if she's not dealing with it I would probably have to go to her head office to say what's happening here. And if they didn't deal with it within*

*a timespan I suppose the next step is the Care Inspectorate. I don't know, I haven't got a policy page from them saying if you're unhappy about something what steps you follow."* Representative (Scotland, Nursing home, Self-funded)

- 8.32. Social workers or care managers were not usually mentioned within this plan for raising a complaint externally if they had one, particularly for self-funders. This seemed to be because the focus was providing feedback about things other than safeguarding concerns. Where safeguarding concerns had been escalated, social workers or care managers were normally involved. Social workers described providing feedback about a range of issues between residents or representatives and the care home as a key part of their job, not just complaints regarding care.

*"I would speak to the individual and their family members. I would feedback anything that they asked me to. Anything and everything we can feed back on."* Social worker

- 8.33. However, where there had been difficulties with a social worker or care manager initially, representatives could be reluctant to raise complaints through them, which could make them less likely to raise complaints externally.

*"What I've found in general is that the Care Manager and the home, they try to smooth things over. I don't know whether it's because all the time with a heavy workload, it could be that, and they don't really want any hassle."* Representative (Northern Ireland, Mixed funding)

- 8.34. Where representatives had experience of **escalating a complaint or raising a complaint externally**, this was normally related to **safeguarding issues**. These could involve a variety of external stakeholders or bodies, such as the local authority, social services, the police and/or local politicians.

## **9. Moving between care homes**

## 9 Moving between care homes

- 9.1. This chapter looks at people's experiences and perceptions of moving between care homes. It starts with how representatives' perceptions of moving homes change once the resident is moved in, followed by the perceived difficulties of moving between homes. It then explores the experiences of representatives and residents who had moved between care homes.

### Chapter summary

Moving care homes was often considered an option when initially moving a relative into a home. For example, if a resident needed to move into a care home urgently, representatives may forgo their first choice and consider moving them at a later date. Social workers also encouraged families to take a room that was available rather than waiting for a preferred home – particularly if the resident was being discharged from hospital.

However, moving care homes was rare as it was difficult to move a resident once they had settled into a home. Representatives also had low expectations of what else would be available so were reluctant to look for a new home.

Where a move was made, it was usually for practical reasons such as meeting a resident's increasing care needs, and was considered a last resort. Finding a new care home was sometimes easier than finding a care home for the first time as families had more experience of the sector, although they still faced the same restrictions discussed in Chapter 4 (such as limited availability, and perceived poor quality homes).

The process of settling into the new care home could sometimes be difficult for residents, and where a resident had moved, representatives remained reluctant to move them again.

### Key challenges

Once a resident was settled, representatives were **reluctant to move a resident because of the distress** they thought this would cause.

Concerns about the challenges of finding a better or more suitable care home prevented families from moving, as they had **low expectations about the quality and availability of homes elsewhere** and were **uncertain whether a new home would be better**.

Because they were unwilling to move a resident, families had **fewer opportunities to hold the care home to account**, exacerbating their feeling of being powerless to change their situation.

### Key supports

**Longer term planning**, and better **support for families as they find a home**, might help them identify the right home early on – negating the need to move at a later date (as discussed in Chapter 4).

More **support to understand what different homes are on offer** and the process for moving homes would also help those moving care homes (as it would for those finding a care home for the first time, as discussed in Chapter 4).

**Clarity around notice periods** (both for residents asking to leave and care homes asking residents to leave) and support arranging the practicalities of moving between care homes would make the process of moving more smooth for residents.

## Perceptions of moving between care homes change over time

- 9.2. As residents became settled into a new care home, the option of moving them became less realistic to representatives. This reluctance continued to be the case unless there was no other option.
- 9.3. Moving between care homes was **considered an option for representatives before the residents moved in**. This could form part of the original choice, where representatives weren't completely satisfied with their chosen care home or saw a home as an interim solution whilst they waited for their first choice home to become available. Representatives talked about moving the resident into a care home with the perception that they could move if they didn't like it. This was particularly the case where the move was urgent, where they felt this would allow them more time to find a better home while the resident was at an acceptable home.

*"We thought if he goes in there and we don't like it we will look for somewhere else."* Representative (England, Residential care, Self-funded)

- 9.4. Where a social worker was involved, representatives described them **encouraging the view that the most important thing was to get the resident settled in a home**, and then think about finding a better home. As discussed in Chapter 4, this combined with representatives reported feelings of being **rushed by social services to decide quickly**.

*"We were advised you're better taking one, getting in, and then when a space becomes available at the one you want, he would get moved there. The social worker at the time said, this will probably happen, your dad will go in to one, he'll get comfy, he'll get used to it, and he won't be bothered about moving to his original first choice. And that's what happened."* Representative (Scotland, Nursing home, Self-funded)

## Reasons for moving between care homes

- 9.5. Where residents had moved between care homes, this was normally a **last resort**, for practical reasons outside their control, unless the resident wanted to move and had capacity to make decisions on their own.
- 9.6. Where the resident did not have dementia and was capable of making their own decisions, representatives felt more comfortable organising a move to find a care home that better met their needs. For example, finding a care home that was more accessible or had more residents at a similar cognitive stage, to ensure residents without dementia could socialise with other people. This was normally led or supported by the resident. Residents generally lacked the capacity to have these conversations, so examples were particularly rare.



- 9.7. Where the resident did have dementia or their capacity was impaired, moves were normally the result of a practical concern out of the representative's control, particularly where the care home could no longer meet the resident's care needs or there were concerns about the care being delivered by the home.
- 9.8. Although this was occasionally highlighted by the representative themselves, this was normally a decision made externally, either in discussion with the care home or social services, following a reassessment or the care home giving the resident notice to leave.
- 9.9. Where the resident was given notice to leave, and this didn't feel like a discussion about care needs deteriorating or part of a reassessment, this was **particularly traumatic for representatives**. They were usually given very little notice to find a new care home, which could be more difficult due to the new needs of the resident. They also felt isolated and that the decision had been made without their input.

#### **Case study 9.1: experience of being asked to leave a care home**

Representative (Wales, Residential, Mixed funding)

After moving into her first care home, Trudy escaped by setting off the fire alarm. Following this, the care home asked her to leave immediately and she was sent to a secure hospital wing the following morning. Her daughter, Emma, was not involved in this move.

*"The care home then basically evicted her and said, we can't have her here if she's going to do that. Even though they were on the paperwork an elderly EMI unit so her security should have been part of their remit. But they didn't."*

Trudy stayed in hospital for several months, while assessments were undertaken and options discussed between Emma and social services, and she has now moved into a different care home.

- 9.10. The final reason representatives moved residents, was to **move them closer to make visiting easier**. This occurred where the representative themselves moved – and then moved the resident as well – or where the representative had not been involved in the original choice of care home, so had not been able to ensure visiting was easy during the first process.

#### **Difficulties with moving between care homes**

- 9.11. Representatives and residents perceived a variety of different challenges involved in moving between care homes. They were particularly concerned about:
- potentially **unsettling the resident**;
  - **struggling to find an alternative care home**;
  - **low expectations** about the quality of other care homes available; and
  - **fear of the risk of maltreatment** at a new care home for the resident.

- 9.12. The main concern representatives had was that they **did not want to unsettle the resident**. Representatives described difficulties for residents in settling into the new care home – particularly where they had dementia – and did not want to repeat this unless there was no other option.

*"The most valuable thing I can give my mum now is stability, and it doesn't come cheap." Representative (England, Nursing home, Self-funded)*

- 9.13. This was particularly the case where residents were perceived to be very vulnerable, and the impact of the move would therefore be intensified. Where representatives had examples of relatives or close friends who had passed away following a move, this also had an impact on their willingness to move the resident. For these representatives, the risk of the resident dying as a result of the move was a serious concern.

*"Moving your relative in and out of care homes, especially if they're very elderly, if they're infirm, if they're immobile, if they have memory loss...my experience is that it can be the end of them." Representative (Wales, Nursing home, Self-funded)*

- 9.14. Where representatives wanted to move a resident who had capacity, unless the move was led by a dissatisfied resident, they described a lot of resistance from the resident on the subject of moving.

*"As a family, yes, we talk about it quite often, but if we broach the subject with him, he just says 'Nope, I'm happy, I'm saying where I am'. He just doesn't see what he could have." Representative (Northern Ireland, Mixed funding)*

- 9.15. This was generally echoed by the residents interviewed unless they were particularly dissatisfied with the care home. Those who did not want to move were **usually distressed by the idea of moving**, and emphasised that they were settled where they were, particularly those who had been in their care home for several years.

*"I'm here to the end of my days." Resident (Nursing home)*

- 9.16. Where representatives had struggled to find a care home, they also raised concerns that they would have to start the search again if they decided to move, and might struggle further to find a new home. This could be because the resident had specific care needs that few homes met, or because they had struggled to find a home they considered acceptable when first looking.

*"The chances are there might not be anywhere else that could take him, and it depends if he has any special needs, if he is a dementia patient. You'd have to start from scratch again." Representative (Northern Ireland, Self-funded)*

- 9.17. In addition, representatives often had **low expectations about what was available**. Where there were specific problems – such as a lack of activities – this was expected to be the case in all care homes. As a result, representatives usually did not consider moving as an option to resolve these types of issues.

*"I think one care home is much the same as the next in that respect." Representative (Northern Ireland, Self-funded)*

- 9.18. Low expectations also pervaded participant's views of other care homes. Concerns about media reports of poor care meant that representatives were risk averse and reluctant to move their relative. They were therefore **more**

comfortable keeping their relative in a home they had experience of rather than risking sending their relative to a home that *might* provide poorer care.

*"I do worry that it looks great on the outside but you don't know the people inside. Is the care going to be better for him or worse?" Representative (England, Nursing home, Mixed funding)*

- 9.19. Representatives with concerns about their care home or about the funding often focussed on trying to resolve these within their current care home, rather than moving. As discussed in the previous chapter, they did not always consider taking their complaint beyond the care home. Where these concerns were not resolved, those who felt they couldn't move also expressed a feeling of powerlessness in these discussions, as they felt they had **no option but to accept the situation**.

*"He'll be staying there so we're over a barrel really." Representative (Wales, Residential home, Mixed funding)*

- 9.20. Representatives also expressed concern that the resident would be **forced to leave the care home by circumstances outside their control**. They were worried that the care home would force the resident to leave if their condition worsened, their needs became more difficult to meet, or the representative or resident became seen as 'too much trouble' – particularly if they thought this had happened to another resident, or they had experienced this directly themselves previously.

*"My fear is that if my mum changes from being like a beguiling four-year-old who wants everyone to look at her silver shoes and her freshly painted nails and starts being a pain...are they going to throw her out too?" Representative (England, Nursing home, Self-funded)*

- 9.21. To try and avoid this, representatives who were able to think long-term **prioritised care homes that offered different types of care**. This would mean the resident would not need to move home if their condition deteriorated. Where residents were self-funding but were close to the threshold, social workers mentioned **encouraging representatives to consider homes where the resident would not have to move if they switched to local authority funding**.

*"We would have liked particularly one which had nursing home facilities as well as residential home facilities because it's a traumatic change if you're getting ill in a residential home, to find a nursing home." Representative (Wales, Nursing home, Self-funded)*

- 9.22. Social workers also mentioned the potential difficulties in finding a new placement for a resident. However, they placed **more importance than representatives on understanding that moving might be necessary** and ensuring placements were regularly reviewed.

*"All placements are temporary, they need to be reviewed, they need to be constantly assessed." Social worker*

- 9.23. Where representatives had discovered later on that a move to a care home they thought was permanent was temporary and being reviewed by a social worker, this was a significant concern for them, as they worried about the impact of a move on the resident.

*"I think I would say that the social worker needs to sit down with us and explain everything to us, and to explain about homes and to explain about your choices and explain if it's a permanent or a temporary placing and things like that, that we never discussed."* Representative (England, Residential, Mixed funding)

## Experiences of moving between care homes

9.24. For the reasons discussed above, examples of moving between care homes was a **relatively rare occurrence**.

However, where respondents did have experience, moving was described as **a difficult process, even if the practicalities went smoothly**. Although normally the process of moving resulted in a more suitable home for the resident and representatives usually described the process of finding a new care home easier the second time around, representatives expressed a reluctance to move again.

9.25. Where residents had moved, representatives described having found some parts of the process of finding a care home easier, as they were **more aware of what the resident needed and what a care home would be able to provide**.

*"I think it was more location then, because when you look back now, we would never have picked it in a million years. Because it wasn't the best. You sort of walked into the lift and you could smell a urine smell coming down from upstairs. But obviously the first home that we looked at, we didn't know what we were looking for."* Representative (England, Residential home, Mixed funding)

9.26. However, all the **difficulties of finding a care home discussed in Chapter 3** such as limited availability and lack of up to date information, still emerged during these searches for a care home to switch to. Where the resident had increased care needs, this could also make the search more difficult, depending on the availability of homes that could provide for their new requirements.

*"I actually got a new list which was exactly the same as the old list, but over a year later, and went through the list again and by that time I phoned everybody that had vacancies. And there were only two that had vacancies."* Representative (Wales, Residential home, Mixed funding)

9.27. As with Chapter 6, once the care home was found, representatives generally found the **practicalities of moving into a new care home simple**, and **care homes tended to be flexible** to insure the process was smooth. Where there were difficulties, it was normally due to notice periods at the care home they were leaving, or being unsupported in the practicalities – i.e. transportation or moving belongings. However, as discussed above, care homes were usually involved in the decision to move the resident out, so this was rarely the case.

*"[They sent] somebody to come and assess dad over in [his previous care home] before they accepted him, and then it was arranging transport and things like that for dad. They were very supportive. They have a dedicated member of staff who helps with people moving in actually."* Representative (England, Nursing home, Mixed funding)

9.28. Where a representative had moved both parents with different care needs into a care home, they also normally had to move several times to find an appropriate place that would take both residents, which they described as the most difficult part of the search.

**Case study 9.2: moving parents between homes so they could stay together**

Representative (Northern Ireland, Self-funded)

Both Coleen's parents – Hilary and Frank – are currently in the same care home and have had to move several times, for a variety of reasons.

Originally, they were in separate care homes, as they had different care needs and Coleen struggled to find homes that she was happy with the standard of both types of care. When Hilary's health deteriorated, she had to be moved to a new home that could support her needs, and the new home 'took pity' on Frank when he visited and agreed to let him move in, although they did not generally take residents only requiring residential care. Coleen and her family then moved house, and moved both parents to a care home near her new home so that she could continue to visit regularly.

*"The main challenge was finding a good place for both, that would accommodate both, that was good for nursing, residential and EMI nursing. There's very, very few homes that even offer all three, never mind being good."*

Coleen found moving between care homes very difficult, both for herself, and for her parents. This was particularly the case for Hilary (who had dementia), but also for Frank, who had to get used to new people and new routines. She said she would be reluctant to move them again.

- 9.29. Once the resident was physically moved into the new home, **settling in was important**, and a major concern for representatives before moving the resident. This could be particularly difficult for new residents, especially where they had dementia, as they had to get used to new environments, routines and people.

*"If you're moving into a different environment, it's very unsettling and I think especially for a vulnerable older person it's very unsettling. It takes quite a long time to readjust."* Representative (Northern Ireland, Self-funded)

- 9.30. Following a move, because of the difficulties finding a new care home and concerns about the impact on the resident's wellbeing, representatives were still **generally resistant to the idea of moving again**, unless absolutely necessary. This was the case even if the move had gone smoothly.

*"With regards to doing it again, that's not going to happen at the moment because she's quite settled and it's convenient for all of us."* Representative (England, Residential home, Self-funded)

## **10. Participant's ideas for improvements**

## 10 Participants' ideas for improvement

- 10.1. This section looks at the areas participants identified that would have improved their experience of navigating the care home sector.
- 10.2. Throughout this report, a number of challenges associated with finding and moving into a care home have been identified. These include a lack of forward planning and early thinking about care homes; the speed with which families had to get to grips with the complexities of the care sector and make a decision on a care home; complicated and 'opaque' funding arrangements; and limited awareness of the terms and conditions relating to care homes.
- 10.3. A number of things that would have helped families have a better experience, and allow them to find appropriate care more effectively were identified in the interviews. These can be summarised as follows:
- promoting early planning to avoid having to make a rushed decision;
  - developing more support and guidance to give people more confidence;
  - improving access and provision of information on care homes; and
  - simplifying the administrative aspects of moving into a home.

### Early planning

- 10.4. A key challenge families faced was having to make a quick decision on a care home that they were unprepared for. They felt that **if they had more time, and were not under pressure to make a choice, they could have made a better decision**. This might have helped them feel more confident in their decision on a particular care home, and also ensure the right care home was chosen and make moving homes unnecessary.
- 10.5. Key in convincing someone to move to a care home was a professional's advice – for example, a doctor. Those who did not have a professional involved (for example, self-funders with no social worker) and had a relative or friend who was resistant to moving to a care home could find it difficult to convincing them that a care home was needed. **Trusted professionals to broach the topic of care homes**, and help families and friends spot the early warning signs before it becomes essential, could therefore help people plan ahead earlier than they do now.
- 10.6. This would be important for both the resident and representatives. Identifying families who are under strain from worrying about a relative's safety and talking to them about ways that formal care arrangements could help them may encourage them to think about the option of care homes sooner. For example, they could assess the options and place themselves on a waiting list, in preparation for a time when it may be needed.

### More support and guidance

- 10.7. Representatives said they felt alone when deciding about a care home, and as a result lacked confidence that the choice they had made for a relative was the right one. They said they would have benefitted from having **tailored support – ideally provided face-to-face – from someone who understood their needs and preferences**, and could

help them navigate through the care options available. Suggestions ranged from a 'back of an envelope' list of care requirements to help someone look for the right kind of home (for example, residential versus nursing), to an individual working with families to **champion their views and recommend a course of action**. This would tackle the sense of being 'left alone' that people described when choosing a care home.

- 10.8. There were also suggestions for helping representatives become more quickly informed about elements of the care sector. For example, **a list of questions to ask a care home when visiting so they know what to look out for**. This could be built around the elements representatives said they valued when looking for a home: friendly staff, low staff turnover, cleanliness and smell of the home, how contented the residents appeared to be etc.
- 10.9. There was a perception that **local authorities could be more transparent about the funding system**, as participants found the system opaque, complex, and difficult to navigate. People who had to engage with the local authority found the information they provided lacking, and those who had public funding were unclear on how much the care cost overall and how much the council were paying. They felt that if this system was clearer, it would be **easier to find the appropriate advice and support**.
- 10.10. They also suggested that **support to recognise the early 'warning signs' of poor care** would equip them to be better judges of the home once their relative moved in. Residents said that they were sometimes hesitant to provide feedback to the homes, because of fear of negative ramifications. Therefore, reassurance about how to complain as well as types of things that families might want to feedback on might help families feel more confident about providing feedback.

### Better information provision

- 10.11. Representatives felt there was **a lack of information that was easily accessible and easy to understand** about the sector and individual homes. They said that a **facility to compare and contrast care homes** – online for example – would have helped them understand what homes were available. They would be looking for information on location, type of care home (for example, the care needs they cater for), price, staffing levels and turnover, and inspection reports to help them understand their options in the area. This would help representatives feel more empowered and informed when making a decision.
- 10.12. Participants also said that reviews of care homes would be useful. **Anecdotal feedback from friends and neighbours was valuable in helping people to navigate the system** and choose a care home. For example, positive feedback from a friend about a care home was persuasive in making a decision on a home. This type of feedback was trusted by representatives as it came from people who had experienced the same difficult circumstances as themselves. Representatives said that **more could be done to share experiences of care homes**, such as access to reviews from friends and family of existing residents online, or being able to speak to other 'users' of the home.

### Simplifying administrative aspects

- 10.13. The **paperwork associated with finding and moving into a care home was considered complex**. This was partly because of a lack of engagement – families had bigger priorities such as the comfort of their relative at the time of looking for a home.



- 10.14. However, there was a particular challenge among those who were local authority funded around the stress participants experienced over paperwork and lack of information about the funding options. **Clear written information on funding options, making the differences explicit and simpler to understand** (written in layman's terms) could therefore help people quickly digest complex information. Having someone on board to help people understand funding would also be particularly valuable.
- 10.15. Furthermore, although representatives said that contracts were simple to understand, they were not engaging with the detail of them. Therefore, **clarity around details in the contract, such as notice periods**, might improve awareness of these things at the time – for example, a meeting with the care home manager to discuss these specifics. Standardised contracts that are used in some areas might help with this, and might mean that generic guidance on contracts could be made available to people.
- 10.16. **Advance notification of fee increases:** Fee increases, although not unexpected, often came without much notice, which meant that participants had to find the extra money quickly. Those who did receive advance notice of the fee increases felt that this was helpful, particularly if there was information about how they could query the increase or raise any concerns they may have. In general, information about fee increases and what they were for was expected by participants, who felt that given the care was already expensive, any increase would need to be justified.
- 10.17. **Clarity about what residents were paying for:** Representatives who felt unclear about what exactly they were paying for said that a breakdown of charges would help them to understand the bills. This was particularly the case for those who had concerns in general about the cost of the care, and these participants said that a breakdown of the costs would reassure them that there weren't hidden costs.
- 10.18. **Advance discussion about payments:** Clarity about the exact fee the resident would have to pay from the beginning of the residency was important to people. They also felt unable to negotiate prices with care homes. Participants felt that any delays contributed to uncertainty about the affordability of the home. These participants said that they would have liked greater efficiency and improved communication from the home and from the local authority to ensure that residents' financial responsibilities were clear from the beginning. Participants who did not discuss this with the home ahead of the residency start date felt that they would have preferred to discuss it beforehand for peace of mind.

## 11. Appendix

# 11 Appendix

## 1: Advanced letter to representatives

13<sup>th</sup> February 2017

NAME  
ADDRESS 1  
ADDRESS 2  
ADDRESS 3  
ADDRESS 4  
POSTCODE

CMA ref:  
xxxxx

Dear Name, «GreetingLine»

The Competition and Markets Authority (CMA) is a UK non-ministerial government department, which aims to promote competition for the benefit of consumers. We are currently conducting a market study into care homes for the elderly. More information about this study is available on our website at <https://www.gov.uk/government/news/cma-launches-review-of-uk-care-and-nursing-homes>.

We have asked Ipsos MORI, an independent research organisation, to conduct a research project about people's experiences of choosing and living in a care home.

We are writing to you because you have been identified as a contact point for someone living in one of the care homes selected for the research. We are giving you the opportunity to opt out of having your details passed onto Ipsos MORI for the purposes of the research. It is most likely that you are a family member or a friend of the resident; however, you could be involved in some other capacity, for example, as their social worker.

The CMA obtained your contact details from your family member/friend's care home for the purpose of conducting this research. In your case, this was NAME OF CARE HOME in LOCATION. The CMA has legal powers to compel organisations, including care homes, to provide information necessary for us to carry out our work, which can include personal data. More information is provided in the accompanying information leaflet.

We also obtained the name of the care home resident and the date that they started living in the care home. As around 6 in 10 care home residents have some form of dementia, with many more having considerable physical needs, the CMA has decided not to write to all residents directly to inform them that we hold this information and about the research that we have commissioned. If you think that your family member or friend in the care home will understand the purpose of our research, please would you inform them that we have been given these details, and that it is possible that they will be approached to ask if they would be willing to be interviewed in connection with our research? We would not approach your family member or friend for an interview without discussing whether this would be appropriate with you first.

To enable Ipsos MORI to conduct the research, the CMA will pass the contact information obtained from the care home onto them. Ipsos MORI will then select some people to interview. If you are chosen, a researcher from Ipsos MORI may be in touch with you to ask if you are willing to participate in a telephone or face-to-face interview.

Any information you provide during the interview will be held in the strictest confidence and will be handled securely throughout. The research findings will not identify you nor your family member/friend and no personal information will be shared with any third parties.

Participation in this research is voluntary and will not affect the care your family member or friend receives, now or in the future. Everyone who participates in an interview will receive £30 as a thank you for their time.


**If you do not want to take part in an interview, or if you don't want the CMA to pass your contact details to Ipsos MORI for the purpose of conducting this research**, please let the CMA know by **22nd February 2017**, by email to: **carehomesresearch@cma.gov.uk**, or by telephone on: **020 3738 6212**. If you do this, please make sure that you quote your individual CMA reference number, found at the top of this letter. You can also write to the CMA at the following address:

Project Officer,  
Care Homes Market Study,  
Competition and Markets Authority,  
7th floor, Victoria House,

37 Southampton Row,  
London, WC1B 4AD.

Alternatively, you can let the Ipsos MORI's interviewer know that you don't want to take part, if they call you at a later date.

If you are selected to be interviewed and agree to take part, your contribution will provide the CMA with valuable information that will help us to understand how people choose a care home and their experiences of those care homes. Following evidence gathering, we plan to produce a report on the care homes market setting out any concerns we identify and if appropriate we could make recommendations to regulators, industry or government.

Yours sincerely, 

Douglas Cooper  
Project Director

## 2: Information sheet for representatives

### Care Homes Market Study: Research to understand experiences of choosing and living in a care home

This leaflet answers some of the questions you may have about our access to and use of your contact details, or about taking part in this research.

#### Who are we?

The Competition and Markets Authority (CMA) is a UK non-ministerial government department, which aims to promote competition for the benefit of consumers. We are currently conducting a market study into care homes for the elderly, to review how well the market works and whether people are treated fairly. More information about this study is available on our website at <https://www.gov.uk/government/news/cma-launches-review-of-uk-care-and-nursing-homes>.

Ipsos MORI is an independent research company. It is not part of the CMA or the government, but it is contracted to the CMA for the purposes of carrying out this research. Ipsos MORI is bound by the Data Protection Act and the Market Research Society Code of Conduct, both of which guarantee confidentiality should you choose to take part.

#### Why are we contacting you?

The CMA has commissioned Ipsos MORI to conduct some research based around a small sample of care homes across the United Kingdom. We are writing to you because you are listed as a main contact for a resident in one of the care homes in the sample and Ipsos MORI may contact you in the future to ask if you would be willing to take part in the research.

In many cases the resident in question will be a family member or friend of yours, however in some cases you may be another representative, such as a social worker. For simplicity we will use the term 'family member or friend' throughout the letter and information sheet.

#### How did you get my contact details?

The CMA obtained your contact details from your family member/friend's care home for the purpose of conducting this research. The information requested was the minimum required to carry out our research in connection with the Care Homes Market Study.

The CMA has legal powers, under section 174 of the Enterprise Act 2002 (as amended), which may be used to compel organisations, including care homes, to provide information necessary for us to carry out our work; this information can include personal data.

In this case, we requested the following personal information:

- For you, the main contact: name (title, first name, surname); full postal address; primary and secondary telephone number; and e-mail address (not all these details will have been applicable and available for each individual.)
- For the resident: name (title, first name, surname); start date of residency

#### What about data protection?

Where disclosure is compelled by law by the CMA, certain requirements of the Data Protection Act 1998 ('DPA') will no longer apply.<sup>6</sup>

#### What will you do with my contact details?

Unless you opt out, as discussed in the letter, the CMA will share your contact details with Ipsos MORI. Ipsos MORI will use your contact details for the purpose of randomly selecting people and then inviting those selected to take part in the research. Ipsos MORI will handle your contact details securely and use them for this research only. No-one outside the research team will have access to your personal data. Your personal data will only be used to assist the CMA in carrying out its work in connection with the care homes market study, and will be kept no longer than necessary for this purpose after which it will be securely destroyed by the CMA, and by Ipsos MORI where your details have been passed to them.

---

<sup>6</sup> Section 35(1) and sections 27 (3) and (4) of the DPA define the scope of the exemption.

### Have you contacted my friend or family member in the care home?

We would also like to interview some care home residents as part of this research project. As around 6 in 10 care home residents have some form of dementia, with many more having considerable physical needs, the CMA has opted not to write to all residents directly to inform them that we hold their data and about the research we have commissioned. If you think that your family member or friend in the care home will understand the purpose of our research, our letter to you asks that you inform them that we have been given their details (their name and the start date of their residency only) and that it is possible that they will be approached to ask if they would be willing to be interviewed in connection with our research, which aims to find out about people's experiences of choosing and living in a care home.

If you are selected to take part in the research and agree to an interview, at the end of your interview we may ask you whether you think it would be appropriate for us to invite your family member or friend in the care home to take part in an interview as well.

If you tell us that this would be appropriate, we may invite them to take part. They would be able to say no and then we would not contact them again. If they say yes, we would ask them some questions before we interview them to check they are providing voluntary informed consent.

If you tell us that this would not be appropriate, we would not contact them at all. We would still like to speak to you whether or not your family member or friend can take part.

### What is the research study about and what will the interview be about?

The purpose of the research is to find out about people's experiences of choosing and living in a care home. It will help the CMA to find out whether the market for care homes is working well for residents and their families and friends.

If you are selected to take part in the research and you agree to take part, the interviewer will ask you to talk through your experience of choosing a care home with, or for, your family member or friend, and your views of the care home so far.

### How are you choosing people to take part in the research?

We want to interview people who have a friend or family member living in a care home, and who were involved in choosing that care home, and/or are involved in the care home placement in other ways (for example in connection with the financial aspects).

We will be inviting a range of people to take part in the research to make sure we hear from people with varying views and experiences. If you are selected, we hope you agree to take part as your views are important to us. However, participation in the research is voluntary and you do not have to take part if you do not wish to.

### Can someone else take part on my behalf?

Ipsos MORI would like to speak to a selection of people who have a family member or friend living in a care home. The interview will focus on the decision to move to a care home, the choice of a care home, and life in the care home. In the first instance, we have only contacted one family member or friend for each care home resident. If you are selected for the research and you think someone else would be able to contribute views additional to your own, or would be better placed than you to discuss these issues, then please tell the Ipsos MORI recruiter when they call you.

### Is this research confidential?

Yes, any information you give to Ipsos MORI will be treated as strictly confidential, unless you tell the interviewer something that indicates that you or someone else is at risk of harm. The interviewer would discuss this with you before telling anyone else.

Ipsos MORI comply with the Government Social Research Code and the Market Research Code of Conduct. Your name and details will not be passed on to anyone without your permission and nobody will be able to identify you or your family member/friend who lives in a care home from any published reports.

### What will happen to the information I provide during the interview? Will participating in this research affect my family member's or friend's care?

The information you provide to Ipsos MORI will **not** affect the care your family member or friend receives, either now or in the future.

### What happens next?

If you do not contact the CMA to say that you do not want your contact details to be passed to Ipsos MORI, Ipsos MORI will randomly select people to invite to take part in the research. If you are selected, an Ipsos MORI recruiter may contact you to ask

if you would like to take part in an interview. At this point, you can either arrange a convenient time for the interview, or you can say that you do not want to take part.

### **If I'm selected, what happens during the interview?**

When you are first contacted the interviewer will answer any questions you may have about this research, and then ask you to confirm that you want to take part.

A researcher from Ipsos MORI will then call you on the phone at a time that is convenient for you and has been arranged in advance. The interviewer will ask you questions. The interviewer isn't trying to test you; they just want to learn about your experiences, so there are no right or wrong answers.

If you would prefer an interviewer to come and see you in your home or at another location convenient to you, then we can arrange that. You can choose to have a friend, relative or other person with you during the interview if you don't want to be interviewed alone.

It is important that you tell the interviewer what the experience of choosing a care home was like for you, as well as your views of the care home so far. Understanding your experience will help the CMA to understand how well the care homes sector works so please be as open as possible during the interview.

The interview will last about 45 minutes, depending on how much you want to say. You will be able to explain your experiences in your own words.

If you want to stop the interview you can do this at any time. The interviewer can arrange to continue after a short break or, if you don't want to continue, the interviewer will just stop. You are free to withdraw at any time without giving a reason.

The interviewer will ask you if they can audio-record the interview, so they do not have to take notes while you speak. The audio recordings will be destroyed after they are no longer required in connection with the CMA's market study into care homes. If you do not want the interview to be recorded, just tell the interviewer when they ask you.

### **Do I have to answer all the questions?**

No. If there are questions you'd rather not answer just tell the interviewer and they will simply move on to the next question.

### **What if I become distressed during the interview?**

We appreciate some of the topics we will discuss might be upsetting or sensitive for some people. If you become distressed, the interviewer will ask you if you want to stop the interview, or have a break and continue later. If you want to have a break, the interviewer will give you time to compose yourself.

### **Will I be paid?**

Yes. You will be given £30 to thank you for your time and help. This has been agreed with the CMA and will not affect any benefit that you may be receiving.

### **Can I withdraw from the research once the interview is complete?**

If you withdraw from the study before it is finished, the information you provided during the interview will be deleted from Ipsos MORI records and not included in the final results of the study. You will not be contacted again for this research.

### **Research assurances**

The information you provide during the interview will be handled according to the requirements of the Data Protection Act (1998). It will be held in the strictest of confidence and handled securely throughout. The findings will not identify you and no personal information will be shared with any third parties.

### **What happens next? Will I be able to see the findings?**

Ipsos MORI will look at all the answers people have provided, and the findings will be summarised in a research report. The CMA will use this report to inform its market study, the findings of which will be published on its website:

<https://www.gov.uk/government/organisations/competition-and-markets-authority>.

### **Where can I get more information?**

If you have any comments or concerns that are not addressed by the information above and in the CMA's letter, or you would like more information about the project, please contact:

Eileen Irvin  
Ipsos MORI

**FREEPHONE:** 0808 1413 052

**Email:** [cmacarehomes@ipsos-mori.com](mailto:cmacarehomes@ipsos-mori.com)

**Post:** Eileen Irvin, Ipsos MORI, Public Affairs, 1<sup>st</sup> Floor, 3 Thomas More Square, London, E1W 1YW

Or, if you would want to contact the CMA directly:

**Phone:** 020 3738 6212

**Email:** [carehomesresearch@cma.gov.uk](mailto:carehomesresearch@cma.gov.uk)

**Post:** Project Officer, Care Homes Market Study, Competition and Markets Authority, 7th floor, Victoria House, 37 Southampton Row, London WC1B 4AD.



### 3: Information sheet for residents

#### Care Homes Market Study: Research to understand experiences of choosing and living in a care home

This leaflet answers some of the questions you may have about taking part in this research or how we got your name.

#### Who are we?

The Competition and Markets Authority (CMA) is a UK non-ministerial government department, which aims to promote competition for the benefit of consumers. We are currently conducting a market study into care homes for older adults, to review how well the market works and whether people are treated fairly. If you have access to the internet, more information about this study is available on our website at <https://www.gov.uk/government/news/cma-launches-review-of-uk-care-and-nursing-homes>.

Ipsos MORI is an independent research company. It is not part of the CMA or the government, but it is contracted to the CMA for the purposes of carrying out this research. Ipsos MORI is bound by the Data Protection Act and the Market Research Society Code of Conduct, both of which guarantee confidentiality should you choose to take part.

#### Why are we contacting you?

The CMA has commissioned Ipsos MORI to conduct some research based around a small number of care homes across the United Kingdom. We are writing to you because you are listed as a resident in one of these care homes and Ipsos MORI may contact you to ask if you would be willing to take part in the research.

#### How did you get my name?

For the purpose of conducting this research, the CMA obtained your name and the date you took up residency from the care home where you are living.

The CMA has legal powers, under section 174 of the Enterprise Act 2002 (as amended), which may be used to compel organisations, including care homes, to provide information necessary for us to carry out our work; this information can include personal data.

In this case, the personal information we requested relating to you was just your name (title, first name, surname) and the date that your residency started.

In some cases, we obtained your phone number from the family member, friend or social care representative who we also approached for this research.

#### What about data protection?

Where the CMA compels an organisation to provide information using its legal powers, certain requirements of the Data Protection Act 1998 ('DPA') will no longer apply.<sup>7</sup>

#### What will you do with my personal data?

The CMA has given your name to Ipsos MORI so that they can approach selected people to see if they would like to take part in the research. Ipsos MORI will handle your details securely and use them for this research only. No-one outside the research team will have access to your personal data. Your personal data will only be used to assist the CMA in carrying out its work in connection with the care homes market study, and will be kept no longer than necessary for this purpose, after which it will be securely destroyed by the CMA and by Ipsos MORI.

#### What is the research study about and what will the interview be about?

The purpose of the research is to find out about people's experiences of choosing and living in a care home. It will help the CMA to find out whether the market for care homes is working well for residents and their families and friends.

If you are selected to take part in the research and you agree to take part, the interviewer will ask you to talk through your experience of choosing a care home (which might have been in conjunction with a relative or friend, or another representative such as a social worker) and your views of the care home so far.

---

<sup>7</sup> Section 35(1) and sections 27 (3) and (4) of the DPA define the scope of the exemption.

**How are you choosing people to take part in the research?**

We want to interview some people who are living in a care home, and also some people who are involved with care home residents, such as friends and relatives.

We will be inviting a range of people to take part in the research to make sure we hear from people with varying views and experiences. If you are selected, we hope you agree to take part as your views are important to us. However, participation in the research is entirely voluntary and you do not have to take part if you do not wish to.

**Can someone else take part on my behalf?**

If you are selected for the research and you think someone else would be able to contribute views additional to your own, or would be better placed than you to discuss these issues, then please tell the Ipsos MORI recruiter or the care home manager.

Ipsos MORI are speaking to family members and friends of people living in a care home, but it is important that they also gather views of people actually living in care homes as well.

If you are willing to be interviewed, you can have someone you know with you during your interview if that would make you feel more comfortable or reassured.

**Is this research confidential?**

Yes, any information you give to Ipsos MORI will be treated as strictly confidential, unless you tell the interviewer something that indicates that you or someone else is at risk of harm. The interviewer would discuss this with you before telling anyone else.

Ipsos MORI comply with the Government Social Research Code and the Market Research Code of Conduct. Your name and details will not be passed on to anyone without your permission and nobody will be able to identify you or your family members/friends who are involved in your residency from any published reports.

**What will happen to the information I provide during the interview?**

If you are interviewed, all information you provide to the researcher will be held in the strictest confidence and the research findings will not identify you and no personal information will be shared with any third parties.

**What happens next?**

Ipsos MORI may invite you to take part in the research. They would contact the care home where you are a resident in the first instance to discuss whether this would be appropriate. They may also approach a friend/relative of yours first to ask them if they think that you would want to take part and also arrange for you both to take part in the research, if appropriate. If you are approached, you can either arrange a convenient time for the interview, or you can say that you do not want to take part.

**If I'm selected, what happens during the interview?**

Your interview would be most likely to be face-to-face and in the care home where you are living, unless you would prefer to hold it elsewhere or over the telephone and this would be appropriate. When you are first contacted, the interviewer will answer any questions you may have about this research, and then ask you to confirm that you want to take part.

A researcher from Ipsos MORI will arrange a time that is convenient for you and the interview will take place in a location where you feel comfortable and at ease. The interviewer will ask you questions about your experiences. The interviewer isn't trying to test you; they just want to learn about your experiences, so there are no right or wrong answers.

You can choose to have a friend, relative or other person with you during the interview if you don't want to be interviewed alone.

It is important that you tell the interviewer what the experience of choosing a care home was like for you, as well as your views of the care home so far. Understanding your experience will help the CMA to understand how well the care homes sector works so please be as open as possible during the interview.

The interview will last about 45 minutes, depending on how much you want to say. You will be able to explain your experiences in your own words.

If you want to stop the interview you can do this at any time. The interviewer can arrange to continue after a short break or, if you don't want to continue, the interviewer will just stop. You are free to withdraw at any time without giving a reason.

The interviewer will ask you if they can audio-record the interview, so they do not have to take notes while you speak. The audio recordings will be destroyed after they are no longer required in connection with the CMA's market study into care homes. If you do not want the interview to be recorded, just tell the interviewer when they ask you.

**Do I have to answer all the questions?**

No. If there are questions you'd rather not answer just tell the interviewer and they will simply move on to the next question.

**What if I become distressed during the interview?**

We appreciate some of the topics we will discuss might be upsetting or sensitive for some people. If you become distressed, the interviewer will ask you if you want to stop the interview, or have a break and continue later. If you want to have a break, the interviewer will give you time to compose yourself.

**Will I be paid?**

Yes. If you are selected and complete an interview, you will be given £40 to thank you for your time and help. This has been agreed with the CMA and will not affect any benefit that you may be receiving.

**Can I withdraw from the research once the interview is complete?**

If you withdraw from the research before it is finished, the information you provided during the interview will be deleted from Ipsos MORI records and not included in the final results of the study. You will not be contacted again for this research.

**Research assurances**

The information you provide during the interview will be handled according to the requirements of the Data Protection Act (1998). It will be held in the strictest of confidence and handled securely throughout. The findings will not identify you and no personal information will be shared with any third parties.

**What happens next? Will I be able to see the findings?**

Ipsos MORI will look at all the answers people have provided, and the findings will be summarised in a research report. The CMA will use this report to inform its market study, the findings of which will be published on its website:

<https://www.gov.uk/government/organisations/competition-and-markets-authority>.

You can also contact the CMA to ask for a paper copy of the report.

**Where can I get more information?**

If you have any comments or concerns that are not addressed by the information above and in the CMA's letter to you, please contact:

Eileen Irvin  
Ipsos MORI

**FREEPHONE:** 0808 1413 052

**Email:** [cmacarehomes@ipsos-mori.com](mailto:cmacarehomes@ipsos-mori.com)

**Post:** Eileen Irvin, Ipsos MORI, Public Affairs, 1<sup>st</sup> Floor, 3 Thomas More Square, London, E1W 1YW

Or, if you would want to contact the CMA directly:

**Phone:** 020 3738 6212

**Email:** [carehomesresearch@cma.gov.uk](mailto:carehomesresearch@cma.gov.uk)

**Post:** Project Officer, Care Homes Market Study, Competition and Markets Authority, 7th floor, Victoria House, 37 Southampton Row, London WC1B 4AD.

## 4: Discussion guide for representatives

### Introduction

- Thank participant for taking part and introduce self/ Ipsos MORI
- Explain purpose of interview. To explore people's experiences of choosing and living in a care home, and identify any improvements.
- Confidentiality – reassure participant that all responses are anonymous and that any information about individual cases passed on to CMA will not allow identification of the people involved, nor will it affect their friend's / relative's care – we are just here to gather their views
- Reiterate that the interview can be paused or stopped if participant is uncomfortable at any stage.
- Check capacity and consent:
  - Can I ask what made you decide to take part?
  - What do you think the benefits to taking part might be?
  - Do you have any concerns about the interview?
- Seek permission to record for the purposes of analysis
- Interview length – typically 45 minutes depending on what they have to say
- Check if they have any questions

### Relationship with relative/friend

**Can I confirm what your relationship is with [your relative/ friend]?**

**What involvement did you have in deciding which care home [your relative/ friend] went to?**

- PROBE:
- Reasons for their involvement
- Others who were involved in the decision, including involvement of [relative/ friend] throughout

### Context for entering a care home

**I now want to ask you about the events that led up to [your relative/ friend] moving into a care home. Talk me through the situation leading up to the decision...**

**When did the decision take place?**

- PROBE:
- Events leading up to the decision
- At home / already in a care home / in hospital
- Anything that changed which made the decision necessary – i.e. care needs of friend/relative
- First time [friend/relative] had moved into a care home or if had been through this before and any differences this time to previous

**How did you feel when the decision was being made?**

- PROBE:
- Emotional state
- Sense of control over the decision
- Extent of involvement in decision
- Urgency or not of decision; what made this urgent (or not)?

**What did you know about the different care options available at this point?**

- PROBE:
- Different types of care considered (at-home care/ self-care/ types of care home)

**Funding process**

**I now want to talk about funding [your relative/ friend]'s care...tell me about how you found this part of the process, starting with what point you first considered how [your relative/ friend]'s care would be funded...**

- PROBE:
- Information and advice available to them (cost of care home/ funding options/ speaking to Local Authorities/ charities/ independent financial advisors/ brokers)
- Sources of funding information
- Usefulness of information
- Challenges / what would have made this easier
- Was there a care assessment? Was there a means test / financial assessment? Which order did these two assessments happen in?
- What was discussed in the financial assessment? Did the resident have a home? Deferred payment (if had home) or did they sell it to pay for care?
- For those who are receiving funding from the NHS or funding from another body, what were your experiences in securing funding? What services/costs are your contributions covering?

**How did you feel when looking into funding?**

**FOR SELF-FUNDED/MIX: When did you find out the prices/fees of homes?**

- PROBE:
- At what stage were you told about the prices/weekly fees
- Differences between initial quotes and the final price
- Ease of finding this information for different homes

**Finding a care home**

*MODERATOR NOTE: some participants may not have considered different care homes, or not had a choice about where to send their relative/ friend, so some questions may not be relevant.*

**I now want to discuss the process you went through when finding a care home. What was the first thing you did to identify a care home for [your relative/ friend]?**

- PROBE:
- What information did they look for to help find a care home?

- Cost, type of funding, specialised care, location, managers, staffing levels, staff to resident ratios, vacancies/waiting lists, whether home has contract with LA, facilities, activities for residents, atmosphere of the care home

**What was most important to you? What made that important?**

- PROBE:
- Extent to which available options met this
- Factors that they wished they had paid more attention to

**How did you find out about the different care homes available to you?**

- PROBE:
- Number of homes contacted
- Number of care homes considered
- Number of care homes visited
- Factors influencing this

**What information on the care home/each care home did you consider?**

- PROBE:
- Promotional material/ CQC rating or another rating/ facilities/ reviews/ contract and fees/ complaints/care home annual report and accounts

**Where did you find this information?**

- PROBE:
- Where did they start?
- Information one stop shops (e.g. [www.firststopcareadvice.org.uk](http://www.firststopcareadvice.org.uk) in England, [www.careinfoscotland.scot](http://www.careinfoscotland.scot), Dewis Cymru in Wales), Care Home directory from LA, websites, contacting the care home, on-site visits, trials, telephone
- Who was spoken to (a professional e.g. GP or Local Authority/ talking to friends and family/ charities or support services)
- Information and advice from the Local Authority – information offered/ usefulness/ etc.
- Ease of finding information

**What information or advice was most useful [when making your decision]?**

- PROBE:
- Information on fees/ staff numbers/ activities/ facilities
- What made it useful?

**To what extent did you feel informed enough to make your decision?**

- How did this make you feel?
- What information was missing/ would have been useful to have in hindsight?

**Given all the things we've just discussed, what made you decide on this care home as your final choice?**

- PROBE:
- Trading-off the relative advantages/disadvantages of the options

- First choice/ preferred choice – why/ why not?
- Ease or difficulty in deciding on a care home – what would have made it easier?

**Overall, to what extent do you feel you had a choice about what home [your relative/ friend] could go to?**

- PROBE:
- Enough options/ limitations on choice (bespoke care needs/ a lack of homes in the area/ limited choice from the Local Authority/ funding)
- How this made them feel

**Moving into a care home**

**Let's discuss what happened after you'd made your choice. What contact did you have with the care home before [your relative/friend] moved in?**

- PROBE:
- What information did you receive from the care home? E.g. welcome packs
- How useful was this information?
- What other information would have been helpful?

**What discussions did you have on how the fees would be paid on an ongoing basis?**

- PROBE:
- How agreement was reached
- Understanding of how [relative/ friend]'s care would be paid for
- Need to guarantee payment of the fees/ commit to a minimum period
- Understanding of this
- [MIXonly] Discussions with local authority and/or care home about paying top-up fees?
- Understanding of how and why fees might increase over time

**Did you have to pay anything to the care home before [your relative/ friend] moved in?**

- PROBE:
- Deposit/ advance payment/ administration fees/ advance fees
- Understanding of what these fees were for

**Did you see a contract?**

- PROBE:
- When they saw a copy of the contract
- Key information provided (weekly fees/ what is included or excluded/ fee increases/ additional charges). Notice periods.
- Ease of understanding the contract
- Support or advice with the contract
- Usefulness of support / advice

**What would improve the process of moving into a care home?**

- PROBE:
- How would this improve things?

- For who?

#### **Paying for care FOR SELF-FUNDED CARE/MIX ONLY**

**Let's talk about paying for the care. How easy do you find the process of paying for [your relative/ friends]'s care?**

- PROBE:
- Ease of understanding
- Extent to which this has gone as expected
- Any discussion of additional fees – with who? What were they for?

**What elements of paying for care were unexpected or only became clear after moving in?**

**How often have the standard fees changed?**

- How were you informed about this change?
- What options were you given if you were not happy with the change?
- Extent to which fee changes influenced views of staying or moving care homes

**Looking ahead, how will [your relative/ friend]'s care needs be paid for?**

- What discussions have you had about this with the care home/ Local Authority?

#### **Experiences of providing feedback, making complaints, and moving homes**

**I now want to discuss how you would raise a concern with the care home if you weren't happy about something.**

**First of all, tell me how you can you provide general feedback to the care home?**

- PROBE:
- Information provided by the care home on raising a concern
- How they feel about raising a concern to the care home
- Things that might stop them providing feedback (i.e. not knowing how to/ don't understand the process/ lack of follow-up to previous feedback given/ fear of retaliation)

*MODERATOR NOTE.* THIS DISCUSSION SHOULD ENCOURAGE THE RESPONDENT TO THINK WIDELY ABOUT HOW THEY WOULD RESPOND (E.G. WHAT WOULD CONSTRAIN THEIR ACTIONS) RATHER THAN JUST THINKING ABOUT WHAT MECHANISMS THERE ARE AVAILABLE TO THEM TO COMPLAIN.

**Let's think about what you might do if you had a problem with the care home. If you had any of these issues with this care home, what would you do?**

EXPLORE FOLLOWING EXAMPLES:

- If the food was bad**
- If there were too few or not good enough activities for residents**
- If there was a large fee increase or unexpected charges**

*MODERATOR NOTE:* IF PARTICIPANT WANT TO TALK ABOUT THEIR OWN EXPERIENCE OF MAKING A COMPLAINT, THEN GO WITH THAT – THIS EXERCISE IS ONLY HERE TO HELP EASE A POTENTIALLY TRICKY DISCUSSION.



**FOR EACH:**

- Who would you raise this concern in the first instance?
- How would you do this? E.g. letter/ phone call/ face to face feedback
- What other ways could you raise this concern with the care home?
- What would stop you from raising this with the care home?
- To what extent would you consider making a formal complaint to the care home or escalating the issue to an external party? Why/why not? PROBE: don't know how to/ lack of follow-up to previous feedback given/ fear of retaliation

**Overall, how do you feel about the opportunities to feed back or make complaints to the care home?**

- How could this be improved?

**Let's talk about moving care homes. I'm going to talk through a scenario and get your thoughts on what this person should do...****READ OUT**

**Michael's father, Gregory, moved into a care home seven months ago. One of the reasons why Michael chose the care home for Gregory was because it organised regular activities for the residents. Due to a change in management, the care home no longer organises activities for the residents. Because of this, Michael is concerned that the care home is no longer suitable for his father, and is considering looking for a new care home.**

**What do you think Michael should do if he is unsure about the care home?**

- PROBE:
- Who should he speak to? What makes you say that?
- Who could he speak to in the care home? How do you think that discussion would go? What makes you say that?

**What challenges might Michael face if he tries to move to another care home?**

- What information would Michael need before moving care homes?
- How easy or difficult would he find it to get this information?
- What other barriers or obstacles might there be to moving homes? [PROBE: lack of availability elsewhere, need to pay large upfront fees in new home, long notice period to leave the current home, Gregory has made friends, the move might be detrimental to his health]
- What other reasons might Michael have for looking to move his father to a different care home?

**MODERATOR NOTE:** IF PARTICIPANT HAS MENTIONED SOMETHING EARLIER THAT THEY WERE DISSATISFIED ABOUT SOMETHING THAT WAS IMPORTANT TO THEM, DID THEY THINK ABOUT MOVING CARE HOME? IF THEY DIDN'T WHY DIDN'T THEY THINK ABOUT MOVING? (TO RELATE THIS BACK TO THEIR OWN CIRCUMSTANCES)

**MODERATOR NOTE:** IF PARTICIPANT WANT TO TALK ABOUT THEIR OWN EXPERIENCE OF MOVING HOME, THEN GO WITH THAT – THIS PROJECTIVE EXERCISE IS ONLY HERE TO HELP EASE A POTENTIALLY TRICKY DISCUSSION.

**Wrap up**

**To summarise all that we've discussed today, how easy or difficult has it been to find appropriate care for [your relative/ friend]?**

- PROBE:
- Main challenge
- Biggest help
- What would they do differently if had to do it again

INTERVIEW WITH RESIDENT:

**We're interested in conducting an interview with some residents to explore their experiences of choosing a care home. The interview would involve myself, or another researcher from our team, visiting [your relative/ friend] at their care home to talk through similar issues to those we've discussed today. Would [your relative/ friend] be interested/capable to take part in a face to face interview?**

IF YES, EXPLAIN THAT THE RESIDENT WOULD NOT NECESSARILY BE CONTACTED AND THAT CARE HOME WOULD BE INVOLVED TOO. GATHER CONTACT DETAILS INCLUDING: NAME, CARE HOME, EMAIL ADDRESS

IF OTHER DECISION MAKERS INVOLVED:

**We are also interested in talking to other people involved in choosing a care home for [your relative/ friend]. You mentioned [REFER BACK TO OTHER DECISION MAKERS MENTIONED AT THE START OF THE INTERVIEW] was also involved in the decision. Do you think that they would be interested in taking part in an interview about choosing a care home for [your relative/ friend]?**

GATHER CONTACT DETAILS INCLUDING: NAME, NUMBER, EMAIL ADDRESS

**Finally, I just need to confirm a couple of things so I can arrange for your "thank you" payment...would you prefer this payment to be by cheque or bank transfer?**

IF CHEQUE: *gather full name and address of participant*

IF BANK TRANSFER: *gather full name, account number and sort code*

THANK AND CLOSE

## 5: Discussion guide for residents

### Introduction

- Thank participant for taking part and introduce self/ Ipsos MORI
- Explain purpose of interview. To explore people's experiences of choosing and living in a care home, and identify any suggestions they have for improvements.
- Confidentiality – reassure participant that all responses are anonymous and that any information about individual cases passed on to the CMA will not allow identification of the people involved– we are just here to gather their views
- CMA letter and information leaflet – explain that more information about the research was sent in the post and they may have been through it with someone from the care home/their family member or friend. Offer to go through the letter again if they are not familiar with it.
- Reiterate that the interview can be paused or stopped if participant is uncomfortable at any stage.
- Check capacity and consent:
  - Can I ask what made you decide to take part?
  - What do you think the benefits to taking part might be?
  - Do you have any concerns about the interview?
- Seek permission to record for the purposes of analysis
- Interview length – typically 45 minutes depending on what they have to say
- Confirm that they will receive £40 as a thank you for taking part.
- Check if they have any questions

### First of all, tell me about your time here...

- How long have you lived in this care home?
- Tell me one thing you like about the home?
- Tell me one thing you don't you like?

### Context for entering a care home

**I now want to ask you about the events that led up to you moving into this care home. Talk me through the situation leading up to the decision...**

#### When did the decision take place?

- PROBE:
- Where were you living before moving into the care home – at home / did they spend time in hospital first?
- Was someone else already looking after them [at home] – e.g. spouse, daughter/son, carers?
- Did anything change that made you decide to move into a care home?

#### How did you feel when the decision was being made?

- PROBE:

- Emotional state
- Sense of control over the decision
- Urgency or not of decision; what made this urgent (or not)? How did that affect them?

#### **What did you want to happen at the time?**

- PROBE
- Where did you want to go? Stay at home/ go into a home/ have carers come in?
- Why?

#### **Who helped you with the decision?**

- PROBE:
- Family or friends/ social worker/ hospital staff/GP/professionals/charities
- How did they help you find a care home?

#### **What did you know about the different options you had at the time?**

- PROBE:
- Were there any other living situations you considered at the time - at home care / sheltered accommodation.
- Who did you talk about these with?

#### **Finding a care home**

*MODERATOR NOTE:* SOME PARTICIPANTS MAY NOT HAVE CONSIDERED DIFFERENT CARE HOMES, NOT BEEN PART OF THE DECISION MAKING PROCESS, OR NOT HAD A CHOICE ABOUT WHERE TO GO, SO SOME QUESTIONS MAY NOT BE RELEVANT.

#### **I now want to talk about how you chose a care home. How involved were you with choosing the care home you live in at the moment?**

- PROBE:
- What role they had in choosing the care home
- Others who were involved in the decision, relationship with them
- Extent of involvement: did they do everything together? Was the resident only involved in some things and not others? Why was this the case?
- Did they feel happy with their level of involvement in the process?
- Were there any practical barriers preventing them from engaging?

#### **How did you find out more about the different care homes you thought about going to?**

- PROBE:
- Establish their involvement in this process
- What information did you/your family member or friend look at? How did you/they get the information?
- How many care homes did you/they contact or visit?

#### **What sorts of things did you want to know about the care homes you considered?**

- PROBE:

- How easy was it to find out those things?
- What was the most important thing you wanted your care home to have?
- What else did you want the care home to be like?
- What did your family member/ friend/ social worker want to know about the care home?
- What should have been important but you didn't think about it at the time?

**What made you decide on this care home as your final choice?**

- PROBE:
- Who made the final decision? You/ your family member or friend/ LA?
- How did that make you feel?
- How did you feel about coming to this care home?
- Was this your favourite home that you looked at? Why? or Why not?

**How much choice do you feel you had about which care home to live in?**

- PROBE:
- Did anything limit the choice you had?
- How did that make you feel?
- What would you have liked to be different?

**How involved did you feel in the process of choosing your care home?**

- PROBE:
- Would you like to have been involved more/ less? Why?
- What would you have liked to be different? What impact would this have had on your choice of care home, do you think?

**Funding care**

*MODERATOR NOTE:* NOT ALL PARTICIPANTS WILL KNOW ABOUT HOW THEIR CARE IS FUNDED, OR BE INVOLVED IN PAYING FOR THEIR CARE, SO NOT ALL THESE QUESTIONS WILL BE RELEVANT.

**I now want to talk about how your care is funded. What do you know about the way your care is being funded at the moment?**

- PROBE:
- Establish whether they fund it themselves/ their care is publicly funded/ whether there is a mix
- How much do you/ the LA pay towards your care?
- Does your family/ friends pay anything in addition to the fees you pay? (Do they pay top-up fees?)

**How did you find out about funding for the care home?**

- PROBE:
- Who, if anyone, helped you find out how much the care home costs?
- Where did you find out about the different ways you could pay for the care home? Who did you speak to? (Did they have a financial assessment?)
- What else would you have liked to know?
- What would have made it easier to find out how you would pay for your care?

**When did you first consider how your care would be paid for?**

- PROBE:

- Establish whether funding was considered before or after finding a care home

**What impact did that have on which care homes you considered?**

- PROBE:
- Did it limit how many care homes you could visit? Why?

**How did you feel when looking into funding?**

- PROBE:
- What would have made it better for you?
- What did you find difficult?
- What would you have liked to happen?

**Moving into a care home**

*MODERATOR NOTE: THE PROCESS OF MOVING INTO A CARE HOME MAY BE ACCOMPANIED BY DIFFICULT CIRCUMSTANCES AND SO MAY BE SENSITIVE TO DISCUSS. REASSURE THE PARTICIPANT THAT WHAT THEY SAY WILL BE KEPT PRIVATE.*

**Let's talk about what happened after you'd made your choice.**

**How did you find moving into the care home?**

- PROBE:
- What happened on the day you moved in?
- How did you feel about the care home when you arrived?
- Who met you there? Who else came with you?
- What belongings did you bring?
- Was your room as expected?
- How easy was it to settle in?
- What could have been made better about the process?

**What information did you have in advance about what the care home was like and what would happen when you moved in?**

- PROBE:
- What else would you have liked to know?

**Did you see a contract?**

- PROBE:
- When they saw a copy of the contract
- Key information provided (weekly fees/ what is included or excluded/ fee increases/ additional charges). Notice periods.
- Ease of understanding the contract
- Support or advice with the contract
- Usefulness of support / advice

**Paying for care**

**Let's talk about paying for the care. How easy do you find the process of paying for your care on a regular basis?**

- **PROBE:**
- Who pays the bills?
- How much involvement do you have in paying for the bills?
- What information is included on the bills?

**What elements of paying for care were unexpected or only became clear after moving in?**

**How often have the standard fees changed?**

- Why did the fees increase? PROBE: inflation/ cost of living/ change in care needs
- How were you informed about this change? PROBE: letter/ bills? How clear was this?
- What options were you given if you were not happy with the change?
- Extent to which fee changes influenced views of staying or moving care homes

**Looking ahead, how will you continue to pay for your care?**

- Who have you talked to about this (family or friends/ care home/ Local Authority)?

**Experiences of providing feedback, making complaints, and moving homes**

*MODERATOR NOTE: THIS MAY BE A SENSITIVE TOPIC AND PARTICIPANTS MAY HAVE CONCERNS ABOUT RAISING FEEDBACK WITH THE CARE HOME OUT OF FEAR OF REPERCUSSIONS. FOR THIS REASON IT IS IMPORTANT TO CONTINUE TO REASSURE PARTICIPANTS THAT EVERYTHING THEY SAY IS ANONYMOUS, AND WE WON'T PASS ANYTHING ON UNLESS WE ARE WORRIED THAT THEY ARE AT RISK OF SERIOUS HARM AS A RESULT OF WHAT THEY HAVE SAID.*

**I now want to discuss what you would do if you weren't happy about something in the home. We just want to find out how easy people find it to give feedback about their care homes for the research, and your care home won't know about anything you have said to me today – we are just finding out people's views.**

**First of all, how happy are you with this home?**

- PROBE:
- What are the best things about the home?
- What improvements would you make to the home? What makes you say that?
- Have you told anyone about these improvements? Staff, family?

**If you wanted to let someone at the care home know about a change you wanted the care home to make or you were unhappy about something at the care home, how would you do that?**

- PROBE:
- Who would you speak to first? What makes you say that?
- And who else would you speak to?
- What has the care home told you about how you can give feedback if you want to?
- How would you feel about making a complaint to the care home?
- What would they do if issue not resolved/nothing changed as a result?
- Is there anything that might stop you from wanting to give feedback or making a complaint?

**I'm going to give you some examples of things that someone might have an issue with. I'd like us to think now about what you would do if...**

EXPLORE FOLLOWING EXAMPLES:

**D. If you didn't like the food you were being served**

**E. If there were too few or not good enough activities**

**F. You were unhappy with the treatment you receive from one of your carers**

**MODERATOR NOTE:** IF PARTICIPANT WANTS TO TALK ABOUT THEIR OWN EXPERIENCE OF MAKING A COMPLAINT, THEN GO WITH THAT – THIS EXERCISE IS ONLY HERE TO HELP EASE A POTENTIALLY TRICKY DISCUSSION.

FOR EACH:

- Who would you talk to about this first?
- What other ways could you let someone know about a problem you had with the care home? Who else could you speak to?
- How comfortable would you feel about raising a concern? What, if anything, would stop you from speaking to someone at the care home?

**Overall, how do you feel about the opportunities to feed back or make complaints to the care home?**

- How could this be improved?

**Let's talk about moving care homes. Have you ever thought about moving to a different care home?**

- PROBE:
- What sort of things might make you consider moving?
- Changing circumstances, friends moving elsewhere, family suggest moving
- How do you feel about the idea of moving?
- What might stop you considering this?
- Price, effort, comfortable where you are

**MODERATOR NOTE:** IF PARTICIPANT HAS MENTIONED SOMETHING EARLIER THAT THEY WERE DISSATISFIED ABOUT SOMETHING THAT WAS IMPORTANT TO THEM, DID THEY THINK ABOUT MOVING CARE HOME? IF THEY DIDN'T WHY DIDN'T THEY THINK ABOUT MOVING? (TO RELATE THIS BACK TO THEIR OWN CIRCUMSTANCES)

IF THE PARTICIPANT HAS MOVED IN THE PAST, WHAT WERE THEIR REASONS FOR DOING SO AND THEIR EXPERIENCES OF MOVING?

## Wrap up

**To summarise all that we've discussed today, how easy or difficult has it been moving into a care home?**

- PROBE:
- Easiest thing
- Hardest thing
- What they would have liked to go differently
- What would help them to have a better experience in the home

**Finally, I just need to confirm a couple of things so I can arrange for your "thank you" payment...would you prefer this payment to be by cash, cheque or bank transfer?**

IF CHEQUE: *gather full name and address of participant*

IF BANK TRANSFER: *gather full name, account number and sort code*

THANK AND CLOSE



## 6: Discussion guide for social workers

### Introduction

- Thank participant for taking part and introduce self/ Ipsos MORI
- Explain purpose of interview. To explore people's experiences of choosing and living in a care home, and identify any improvements.
- Confidentiality – reassure participant that all responses are anonymous and that any information about individual cases passed on to CMA will not allow identification of the people involved or be passed on to employers – we are just here to gather their views..
- Reiterate that the interview can be paused or stopped if participant is uncomfortable at any stage.
- Seek permission to record for the purposes of analysis
- Interview length – typically 30 minutes depending on what they have to say
- Check if they have any questions

### Role as social worker

#### Can you tell me a bit about your role and your involvement in choosing a care home for people?

- PROBE:
- Length of time in job
- Training they have had
- How many residents they have placed, balance by funding , dementia/nursing care.
- Type of area – e.g. rural/urban, demographics, levels of deprivation
- In what cases do they get involved
- How proactive are they in that involvement
- Main responsibilities
- Who else is typically involved (just them, other professionals, resident, friends/family)? Who else can be involved?
- How long they stay involved in the placement, circumstances where they would stay involved for more or less time.

### Context for entering a care home

#### I now want to ask you about the events that lead up to people moving into a care home. Talk me through the situations that can lead up to the decision...

#### When can the decision take place?

- PROBE:
- What does this depend on?
- Events leading up to the decision
- At home / already in a care home / in hospital
- Anything that can change which makes the decision necessary – i.e. care needs of the resident

- Typically involved the first time the client had moved into a care home or if they tend to get involved with people moving / looking for permanent care after experiences of respite care etc., or people with other experiences of social services
- How much involvement would the social worker typically have when making the decision?
- Care assessment - what is there involvement? When does this take place? Under what circumstances would the timing of this differ?

**What do your clients / their family and friends typically know about the different care options available at this point?**

- PROBE:
- Different types of care typically considered (at-home care/ self-care/ types of care home)
- What should they know?
- How easy or difficult is it to discuss the different types of care at this point?

**How do you think your clients/ their family or friends feel when the decision is being made?**

- PROBE:
- Emotional state
- Extent of involvement in decision
- Urgency or not of decision; what makes these urgent (or not)?

**To what extent do you think your client are informed enough to make the decision?**

- What information do you feel would be useful to have for clients / their friends and family which they do not typically receive?

**Funding process**

**I now want to talk about funding care...how is the care of your clients typically funded?**

- PROBE:
- Under what circumstances are they involved in funding? (e.g. LA / mixed funding, mental capacity of resident etc.)
- What involvement do they have when care is privately funded? How does it differ from when LA funding is involved?
- What steps do they go through with their client / their family or friends around finances? What is the clients/family members and friends awareness of the different funding options available? What information do they provide or signpost to clients / family and friends on funding?
- Is there typically a means test or financial assessment? What is discussed in the financial assessment? Involvement in assessment
- Did the care assessment or financial assessment happen first?
- If client has a home, what is the process? E.g. deferred funding, support with sale etc.
- What funding from other bodies are clients able to access? What are their experiences in securing funding from those bodies – who is responsible for this? How does it vary between bodies / funding streams? (e.g. NHS (funded nursing care, continuing health care), DWP (attendance allowance)?)
- *INTERVIEWER NOTE – attendance allowance doesn't directly contribute to care home funding and will be taken away if LA funded.*

- If funds are being covered/topped up their client or their friends/family what is the process? What services/costs do their contributions cover?
- 

### Finding a care home

**I now want to discuss the process you go through when finding a care home for your clients. How does that process typically work from your perspective?**

*MODERATOR NOTE: There may not be much to talk about here, depending on situation, but ask basics and prompt where appropriate.*

- PROBE:
- In what cases are they involved with this stage? How does this vary depending on context?
- What information do their clients/ their family or friends need to help them find a care home? What information do they consider?
- DO NOT PROMPT, but may cover: Cost, type of funding, specialised care, location, managers, staffing levels, staff to resident ratios, vacancies/waiting lists, whether home has contract with LA, facilities, activities for residents, atmosphere of the care home
- How do they find out about specific care homes (Number of homes contacted, Number of care homes considered, Number of care homes visited, Factors influencing this)
- Is there normally several options to offer the client? If just one, how is this raised with the client / friends and family and what challenges does this pose?

### And what is most important to you/ the LA? What makes that important?

- *BE AWARE, THIS MAY BE DIFFICULT AS TALKING ABOUT THEIR EMPLOYER – BE SENSITIVE*
- PROBE:
- Extent to which available options meet these
- How are your / the LA's priorities similar or different to the priorities of the resident / family / friends?

### What information do you consider on the care home/each care home ?

- PROBE:
- Promotional material/ CQC rating or another rating/ facilities/ reviews/ contract and fees/ complaints/care home annual report and accounts
- Which information do you provide / which does the care home provide to the client / friends and family?
- Did you provide this information proactively or do people ask for this information?
- Do you expect clients / friends and family to source this information themselves?
- Ease of finding information for clients
- Other sources of information signposted to? E.g. Information one stop shops (e.g. [www.firststopcareadvice.org.uk](http://www.firststopcareadvice.org.uk) in England, [www.careinfoscotland.scot](http://www.careinfoscotland.scot), Dewi Cymru in Wales), Care Home directory from LA, websites, contacting the care home, on-site visits, trials, telephone
- What more do you feel social workers / the LA / the NHS could be doing to provide information to people moving into care homes? What makes you say that?

### What information is most useful to you when finding a care home for a client?

- What makes it useful?

- How easy do you find it to access this information?

**Given all the things we've just discussed, what makes you suggest/decide on a specific care home, depending on the circumstances?**

- PROBE:
- In what cases do they suggest vs decide?
- What is the key area to consider? In what cases is this important to consider?
- Trading-off the relative advantages/disadvantages of the options
- First choice/ preferred choice – why/ why not?
- Ease or difficulty in deciding on a care home – what would make it easier?

**Overall, to what extent do you feel there is a choice about where what home your clients go to?**

- PROBE:
- Enough options/ limitations on choice (bespoke care needs/ a lack of homes in the area/ limited choice from the Local Authority/ funding)
- How this makes the client/ family and / or friends feel
- Should "choice" be important in this market

**Moving into a care home**

**Let's discuss what happens after the choice is made. What contact do you have with the care home before your clients move in? How does this vary, depending on the resident's circumstances?**

- PROBE:
- What information is provided to you / what information is provided directly to your client / friends / family?
- What information do you pass on to the family at this point?
- Is there any information that is often not covered which you think would help, or ways that the information given could be improved?

**How would you characterise your interactions with care homes?**

- Formal procedures / informal conversations
- What impacts them? (e.g. concerns about bed blocking in hospitals, previous contracts, established relationships, block booking of beds)
- What tends to work? What doesn't work?
- To what extent is it your responsibility to liaise with the care home?
- Do you think these interactions / processes can be improved? How?

**What information do you client/ their friends or family have on how the fees will be paid on an ongoing basis?**

- PROBE:
- How agreement is reached
- Understanding of how the client's care will be paid for
- Need to guarantee payment of the fees/ commit to a minimum period
- Discussions about paying top-up fees?
- Client/ friends / family understanding of how and why fees might increase over time

**How is the contract organised?**

- PROBE:
- When they/ their client/ family or friends see a copy of the contract
- What involvement do they have with this, depending on the resident's circumstances?
- Are contracts standard within / across care homes?
- Ease of understanding the contract for client / friends / family
- Do they provide any support or advice with the contract?
- What support are they able to give / do they feel it is appropriate to give at this stage?

**What would improve the process of moving into a care home?**

- PROBE:
- How would this improve things?
- For who?

**Paying for care****Let's talk about paying for the care. What kind of changes happen to how your client's care is paid for after they move in?**

- PROBE:
- What circumstances change?
- How involved (if at all) are you at this stage?
- How is this communicated to your client / friends and family?
- What happens if the resident moves between different funding types, e.g. from fully funded into being mixed or LA funded? What involvement do you have at this stage?

**How often do the standard fees change?**

- How are your client/ friends/ family informed about this change?
- Understanding of why fees change? e.g. changes in annual cost of living/changes in care needs. Do clients understand why fees change?
- What options are given if you / your client/ the friends and family are not happy with the change?

**Experiences of providing feedback, making complaints, and moving homes****I now want to discuss how concerns with the care home are raised if you, or your client / friend or family member weren't happy about something.****First of all, to what extent are you typically involved in providing general feedback to the care home? In what circumstances?**

- PROBE:
- How the client/ friend/ family typically feels about raising a concern to the care home
- To what extent do the client/ friend or family member come to them about providing feedback / raising a complaint? In what circumstances? (e.g. if no representatives, if a more serious complaint?)
- Things that might stop them or the client/ friend or family member providing feedback (i.e. relationship with the care home as a whole /not knowing how to/ don't understand the process/ lack of follow-up to previous feedback given/ fear of retaliation)

- In what circumstances (if any) would they raise a concern that had not been raised to them by the resident / friends / family?
- What type of things do they / the resident / friends/family complain about?
- Are there formal procedures for processing complaints through the care home?
- Are there informal procedures for providing feedback to the care home?

**Let's talk about moving care homes. In what circumstances would you get involved if a client/ their friend or family member wanted to organise for a resident to move care home?**

- What role have you/ would you play in moving care homes? Would they ever trigger a move or request a client be moved? In what circumstances?
- What information do your clients/ their families need before moving care homes?
- How easy or difficult is to find this information?
- What other barriers or obstacles might there be to moving homes?

**How easy or difficult is it to move care homes?**

**What happens if a client moves between local authorities, e.g. when moving care homes? What impact does this have on their role?**

**Wrap up**

**To summarise all that we've discussed today, how easy or difficult is it typically to find appropriate care for your clients?**

- PROBE:
- Main challenge
- Biggest help
- What would they change if they could

**Finally, I just need to confirm a couple of things so I can arrange for your "thank you" payment...We can donate this to a charity of your choice, or we can send this to you. Which would you feel would be most appropriate?**

**IF DONATION TO CHARITY: Which charity would you like us to donate the money to?**

**IF MONEY DIRECT TO THEM: Would you prefer this payment to be by cheque or bank transfer?**

IF CHEQUE: *gather full name and address of participant*

IF BANK TRANSFER: *gather full name, account number and sort code*

THANK AND CLOSE

## 7: Quota table for care home placements

Care home					Funding		Care		Joined			Gender	Ethnicity	
				Minimum number of placements (3 per Care Home)						Last year: 1/1/16 – 30/9/16				
Nation	Nursing/ Residential	Chain or Other	Area		Self funded	Public/ Mixed	Dementia	Nursing Care	Recen: since 1/6/16		Before 2016			
Northern Ireland	R	O	Rural	12	At least 4 placements	Remaining placements a mix of public/ mixed funding	At least 5 placements	At least 7 placements	At least 4 placements	At least 4 placements	At least 4 placements	Mix across all interviews	Mix across all interviews	
Northern Ireland	N	C	Rural											
Northern Ireland	R	C	Urban											
Northern Ireland	N	O	Urban											
Wales	R	C	Rural	12	At least 4 placements		At least 5 placements	At least 7 placements	At least 4 placements	At least 4 placements	At least 4 placements			At least 4 placements
Wales	N	O	Rural											
Wales	R	O	Urban											
Wales	N	C	Urban											
Scotland	R	O	Rural	12	At least 4 placements		At least 5 placements	At least 7 placements	At least 4 placements	At least 4 placements	At least 4 placements			At least 4 placements
Scotland	N	C	Rural											
Scotland	R	C	Urban											
Scotland	N	O	Urban											
England	R	C	Rural	30	At least 10 placements	At least 12 placements	At least 15 placements	At least 10 placements	At least 10 placements	At least 10 placements	At least 10 placements			
England	N	O	Rural											
England	R	O	Urban											
England	N	C	Urban											
England	R	C	Rural											
England	N	O	Rural											
England	R	C	Rural											
England	N	O	Rural											
England	R	O	Urban											
England	N	C	Urban											
England	R	O	Urban	9	At least 4 placements	At least 5 placements	At least 7 placements	At least 4 placements	At least 4 placements	At least 4 placements				
England	N	O	Urban											
England	R	C	Urban											

**Paul Carroll**

Associate Director  
Paul.Carroll@ipsos.com

**Rachel Burkitt**

Research Manager  
Rachel.Burkitt@ipsos.com

**Eileen Irvin**

Research Executive  
Eileen.Irvin@ipsos.com

**Leanora Volpe**

Research Executive  
Leanora.Volpe@ipsos.com

## For more information

3 Thomas More Square  
London  
E1W 1YW

t: +44 (0)20 3059 5000

**[www.ipsos-mori.com](http://www.ipsos-mori.com)**

**<http://twitter.com/IpsosMORI>**

### About Ipsos MORI's Social Research Institute

The Social Research Institute works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. This, combined with our methods and communications expertise, helps ensure that our research makes a difference for decision makers and communities.