PIRU

Personalisation in care homes for older people

Final report

Stefanie Ettelt, Jacqueline Damant, Margaret Perkins, Lorraine Williams and Raphael Wittenberg

POLICY INNOVATION AND EVALUATION RESEARCH UNIT

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Chapter 1
Introduction

About 350,000 older people in England live in care homes, generally for the final months or few years of their lives (Laing-Buisson, 2018, Age UK, 2019). It is estimated that about 70 percent of people in care homes have dementia or severe memory problems (Alzheimer's Society, 2019a). It is important for their wellbeing, and that of their families, that they should receive high-quality personalised care and not just 'warehousing'. However, providing personalised care in the collective care setting of a care home presents a number of challenges. This was highlighted by past studies, in particular our evaluation of the Direct Payments in Residential Care Trailblazers (Ettelt et al., 2017). It is therefore important to gain a better understanding of the barriers to achieving more personalised care in care homes for older people and the measures being taken in some care homes that could be taken more widely, to improve personalisation in the care home sector. This is the aim of the current study.

The evaluation of the Direct Payments in Residential Care Trailblazers is an important part of the background to our current study. The then Department of Health (DH) set up a programme involving 20 local authorities initially to test direct payments in residential care before they were made available nationally. Our evaluation of this trailblazer programme found that setting up and managing direct payments in care homes presented challenges for local authority commissioners and care home providers, and that direct payments were accepted by far fewer residents and their families than had been anticipated (Ettelt et al 2017). The findings raised questions about the suitability of direct payments as a mechanism to improve personalisation in care homes and we concluded that there are a number of issues that required further investigation to inform policy and practice. One of the factors that worked against the use of direct payments identified in the evaluation was the substantial level of need for care of many older people in residential care and the difficulties they experienced when exercising choice, often in the context of advanced dementia. While there was agreement that people with limited mental capacity should receive a personalised service as much as anybody else, the evaluation suggested there were practical limits to using direct payments as a tool for personalisation. This included the availability of family to help with decision-making and the management of a direct payment, and the limited ability of care homes to accommodate additional choice.

Against this background, the Policy Innovation and Evaluation Research Unit (PIRU) was commissioned to conduct a follow-on study of personalisation in care homes to address the following research questions:

1. How is 'personalisation' conceptualised in the research literature, recent policy documents and guidance documents relating to adult social care in England, and how does personalisation relate to 'person-centred care' and 'choice and control'?
2. What approaches are being adopted to promote personalisation in care homes for older people in England and to what extent is care provided to residents of these homes currently personalised?
3. What are the barriers and facilitators to achieving a higher degree of personalisation in care homes for older people?

To investigate these questions, we used the following methods:

1. A review of policy documents and guidance relevant to personalisation of care for older people in England;
2. A focused review of concepts relevant to personalisation in the scientific literature, using a systematic approach, building on previous work on personalisation;
3. A review of studies on approaches to promote personalisation in care homes for older people and the effects of personalisation on care home residents;
4. Interviews with care home managers to explore current approaches to personalisation in care homes for older people, and barriers and facilitators of personalisation in residential care for older people;
5. An analysis of comments on personalisation in a sample of Care Quality Commission (CQC) inspection reports of care homes for older people.

This report is organised as follows: The next section presents a brief overview of the concept of 'personalisation', and its close relatives, 'choice and control' and 'person-centred care', followed by the analytical framework developed for this report. Chapter 2 reviews the development of policy and practice guidance surrounding personalisation in England. Chapter 3 describes the methods used in the study. Chapter 4 presents the results from a review of studies of approaches, effects and contexts of personalisation in care homes. This is followed by two chapters reporting on the analyses of interviews with care home managers: Chapter 5 examines the approaches to personalising care described in the interviews with managers and Chapter 6 presents an analysis of the concepts underpinning approaches to personalisation also referred to by managers during the interviews. Chapter 7 presents the results of an analysis of examples of, and barriers to, personalisation reported in CQC inspection reports. This is followed by a final discussion in Chapter 8.

1.1 Conceptualising 'personalisation' in residential care for older people

In England, 'personalisation' is an established policy term that signifies the intention to put the user of public services at the centre of the organisation of these services, as opposed to expecting them to adapt to the services on offer. In 2007, the Cabinet Office referred to 'personalisation' as "the process by which services are tailored to the needs and preferences of citizens. The overall vision is that the state should empower citizens to shape their own lives and services they receive" (Cabinet Office, 2007: 33).

This broad ambition of an improved and more individualised service has been particularly resonant in health and social care. In health policy, 'choice and control' has been popularised in England since the 1990s for elective treatment by making providers more responsive to patient needs. The initial route to achieve this was through a split of the provider function of the NHS from its role as commissioner of services, and the drive to improve service quality by giving patients more scope to choose their provider. Yet, while greater patient choice has been supported, in principle, across the political spectrum, it has also attracted controversy. Critics especially expressed concern about the choice agenda promoting consumerism and the role of private sector providers in the NHS, the cost implications of increased choice (e.g. the need to maintain spare capacity) and the insufficient attention given to the potentially unequal distribution of desirable patient outcomes (Appleby and Dixon, 2004, Pollock, 2004). Personalisation – and its variants 'person-centred care' and 'personalised care' – have been more recent additions to the health policy vocabulary, resulting in a host of different manifestations such as personalised medicine, integrated personalised care and self-management. For example, the "Four principles for person-centred care" presented in a think piece from the Health Foundation emphasise the importance of care coordination for person-centred care, in addition to personalising services and treating patients with dignity, respect and compassion (Collins, 2014).

In social care, the drive for personalisation resonates with long-standing efforts of the disability movement to advocate for better services for people with disabilities. This movement has challenged the Government to improve the care for people with disabilities by demanding services to be provided in a way that supports the individual's autonomy and independence, and to shift the balance of decision-making power from public authorities and professionals to service users and their families (Lymbery, 2012). Direct payments, and later personal budgets, emerged as the preferred instruments to facilitate this type of personalisation of social care services, although direct payments have only been available routinely to people receiving domiciliary care, with a few exceptions. The idea is that if people were given the purse strings they would have more control over how funding allocated to their care could

be used and would choose services that were better aligned with their preferences. It is for this reason that 'personalisation' is often equated with 'choice and control' in domiciliary care (SCIE, 2011, Glasby and Littlechild, 2016).

In residential care, the idea of 'choice and control' has not been thought of in the same way as in health care or domiciliary social care. 'Choice' and 'choice and control' feature heavily in guidance on good practice relating to care homes, as well as in the inspection framework of the care home regulator, the Care Quality Commission (CQC, 2017a). However, in this context, choice is associated with residents' independence and involvement in decision-making, including in circumstances of high dependency and reduced mental capacity, and with the importance of staff observing residents' preferences when delivering care to meet their needs. Such uses of 'choice' do not dwell on the transactional relationship that underpins some of the thinking on choice of provider in health or domiciliary care.

Another prominent concept associated with personalisation in residential care is 'person-centred care'. Person-centred care also stipulates that residents' care needs are met with their preferences and wishes in mind, yet the term is mostly derived from an ambition to improve the quality of care for people with dementia. While the term is sometimes used synonymously with personalisation (e.g. in the Care Act 2014), person-centred care is more commonly used to indicate a shift in the philosophy and practice of care from treating diseases to a more holistic understanding of the physical, psychological and social needs of people in need of care. The concept specifically emphasises the role of care and caring, and the contribution of the 'care relationship' to the wellbeing of the person with dementia.

Most studies of person-centred care refer to the ground-breaking work of Tom Kitwood (1997) who derived the term from Carl Rogers' approach to client-centred psychotherapy. Kitwood put the concept of 'personhood' at the centre of his work, which he defined as relational and anchored in the human condition as dependent on the care of others, rather than a property or characteristic generated by a person:

> *"A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust."* (Kitwood, 1998: 8)

The need to maintain one's personhood therefore is dependent on relationships with others and is shared universally by all human beings, irrespective of their capabilities or mental capacity. Kitwood also underlined the importance of agency to maintain one's personhood, which necessitates that carers know about the person's personality, past history, likes and dislikes:

> *"A person in the fullest sense: he or she is still an agent, one who can make things happen in the world, a sentient, relational and historical being."* (Kitwood, 1993: 66)

The aim of person-centred care is therefore to support the person in maintaining his/her personhood and in living life as fully as possible, irrespective of any physical or cognitive limitations that may determine the person's need for care.

Building on Kitwood's original work, Brooker (2003) developed a framework for person-centred care based on four principles (the 'VIPS'). The framework includes:

- Valuing people with dementia and those who care for them (V);
- Treating people as individuals (I);
- Looking at the world from the perspective of the person with dementia (P); and
- A positive social environment in which the person living with dementia can experience relative wellbeing (S).

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While the framework puts the resident with dementia at the centre of the organisation of care, it emphasises the role of the carer, the relationship between resident and carer, and the relevance of the social environment for the wellbeing of the resident and the success of personalisation. It also draws attention to the changes in attitudes and behaviours needed to address the 'social malignancies' that Kitwood identified in dementia care.

Over time, other frameworks of person-centred care have been developed, although all of them pay a debt to Kitwood. A wider societal perspective was taken by O'Connor and colleagues (2007) who situate dementia care in its socio-cultural context. Their framework includes the subjective experience of the person living with a diagnosis of dementia; the interactional environment that includes both the interaction with others, especially the relationship between the person with dementia and any formal or informal carers, and the interaction with the environment, referring to the person's physical space and engagement with activities; and the socio-cultural context of people with dementia, especially as they relate to "race and ethnicity, social location, organisational practices and policies, and societal discourse" (p. 133). The authors argue that these cultural dimensions shape how people perceive concepts such as 'usefulness', 'autonomy' or 'independence' as relevant constructions of personhood which should be taken into account in any approach aimed at promoting person-centred care.

Another perspective on person-centred care relevant to care homes is the person-centred nursing framework developed by McCormack and McCance (2006). It merges earlier thinking on person-centred care with dimensions derived from the empirical literature on nursing. Dimensions of their framework include *person-centred processes*, which capture the delivery of care aimed at meeting service users' needs and preferences; the *care environment* that forms the organisational context of care provision; and *expected outcomes* that result from effective person-centred nursing. The framework also introduces an additional dimension, namely, the attitude of nurses, as a necessary *prerequisite* for person-centred nursing. It lays strong emphasis on the role of the care environment, characterised, for example, by supportive organisational systems, the facilitation of shared decision-making and an appropriate skill mix, in hindering or supporting the provision of person-centred processes.

Wilberforce et al. (2017) bring together concepts of person-centred care rooted in different academic and professional disciplines including general medicine, nursing, dementia care, social care and rehabilitation, to build a framework for person-centred care relevant to older people receiving domiciliary care. The authors identify twelve attributes that they group into three broad themes, specifically *understanding the person, engagement in decision-making* and *promoting the care relationship*. While their framework is aimed at person-centred care for people receiving services in their own homes, it highlights again the relevance of the care relationship and the role of carers in delivering person-centred care, which is equally relevant to personalisation in care homes.

In this study, we use 'personalisation' as the umbrella term denoting the principles and practices of providing care services tailored to the needs and preferences of service users. Service users in our study are people living in care homes, with care homes including residential care homes and nursing homes. We use 'residential care home' to denote an institutional setting that provides accommodation with 24-hour care for residents who may need help with their personal care; a 'nursing home' provides the same service with additional nursing services for those who require a degree of medical and nursing care provided by a registered nurse {Care to be different, 2020 #450}. Personalisation can be exercised as 'person-centred care' or 'choice and control', although both concepts, while not mutually exclusive, tend to emphasise different approaches to personalisation, and draw on different understandings of personhood, identity and individual agency.

1.2 Framework for analysis

Based on the review of the various conceptualisations of personalisation, person-centred care and choice and control presented in more detail in Chapter 4, we have developed a framework for this study which distinguishes four levels of analysis:

1. The level of the individual
2. The level of the care relationship and the role of the carer
3. The level of the care environment
4. The level of the wider community

The first level of analysis – the individual – focuses on the purpose of 'personalisation', which is to provide a person with improved, more appropriate and better tailored care. It also reflects the idea of supporting the person to maintain his or her identity, and sense of self or personhood, prominent in the literature on person-centred care. If the focus is on enhancing choice and control (e.g. through a direct payment), such approaches aim to benefit the individual by strengthening the person's autonomy, independence or individuality.

The second level of analysis – the care relationship – lies at the heart of the concept of person-centred care and most of the approaches to improving personalisation in care homes are aimed at this level. In the literature, the care relationship is particularly important for people with dementia who are reliant on formal or family carers for support. However, this does not mean that the care relationship is less important for other residents of care homes, irrespective of their cognitive capacity. Ultimately, it is the strength of the relational aspect of care (i.e. arguably the 'caring' in care) that distinguishes high quality, personalised care from care that is seen as institutional or 'one size fits all'.

The third level of analysis – the care environment – encompasses the organisational context of the care home, both as a form of communal living and as an organisational unit whose business and responsibility it is to provide care for people in need of care. The care environment therefore includes a number of sub-categories, including the physical layout of the care home, the way care homes are managed and organised, and the care home as a setting for communal living of residents.

The fourth level of analysis – the relationship to the wider community – reflects the role of the wider community and society in the delivery of personalised care in care homes. This relates to the relationships between the care home and the local community in which it is situated. A broader perspective relates to the relationship between residential care and the wider society, as expressed, for example, in a society's willingness to fund residential care collectively and the appreciation of life in a care home including the presence or absence of social stigma associated with care homes.

2.1 Personalisation policy developments

This chapter reviews the development of policy on personalisation in adult social care as set out in policy documents and practice guidance. It addresses that part of the study's first research question which asks how 'personalisation' is conceptualised in recent policy and guidance documents relating to adult social care in England. It also provides background to the remainder of this report.

The development of ideas on personalisation and person-centred care have been set out over many years in a number of governmental policy statements in Green and White Papers and then enshrined in subsequent legislation. Person-centred care, the promotion of independence, and choice and control in social care support for service users have been central policy objectives for at least the past twenty years. The term 'personalisation' has come to assume a preeminent position in more recent discourse on the aims and objectives for adult social care.

Since the 1980s, there has been growing interest among policy makers and service users alike in England in developing ways that enable adults who need support and help with day-to-day activities to exercise choice and control over that help (Glendinning et al., 2008). In the 1990s, pressure for greater choice and control over how people met their social care needs came from younger disabled people leading to pressure for direct payments enabling people to choose how to meet their needs as opposed to having to rely on the services organised for them by local authorities.

A direct payment in social care is a cash payment made in place of regular social service provision to an individual who has been assessed as needing support and eligible for social service support. Following a financial assessment, those eligible can choose to take a direct payment and arrange for their own support (SCIE, 2012). The 1996 Community Care (Direct Payments) Act (implemented from April 1997) gave local authorities power to make cash payments, in lieu of services in kind, to adults aged 18 to 65 who were deemed 'willing and able' to make the necessary decisions. However, direct payments could not be used to purchase health care or local authority services or to employ a close co-resident relative (SCIE, 2012).

Over the next decade, direct payments were expanded to all service user groups, including to older people in October 2000, but only for domiciliary care. It became mandatory for local authorities to offer direct payments to eligible individuals (that is, those eligible for social care services who consent to and are able to manage payments and who live in the community and not in a care home) (Glendinning et al., 2008).

Early ideas on increasing choice and control were set out in 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (DH, 2001b), focussing on people with learning disabilities, where the promotion of independence and choice was central to the government's modernisation agenda. This approach, supported by the social enterprise organisation *In Control*, promoted a greater role for service users in assessing the level of support they needed, allocation of resources to individuals according to relative levels of need, transparency over the level of resources allocated to each person, and support in planning how those resources are used to meet individual priorities and preferences. (Glendinning et al., 2008). This was seen to offer a new approach for this group of social care service users to exercise choice and control over their support arrangements.

Around the same time, the National Service Framework for Older People was developed. National Service Frameworks were established to improve services through setting national standards to drive up quality and tackle existing variations in care (DH, 2001a). Standard Two in this National Service Framework refers to the objective of moving towards person-centred care for older people to ensure that

older people are treated as individuals receiving appropriate and timely packages of care which meet their needs as individuals, regardless of health and social services boundaries. In reference to carers, it stated, "older people and their carers should receive person-centred care and services which respect them as individuals and which are arranged around their needs" (DH, 2001a: 2.1).

In 2005, three policy documents relevant to personalisation were published: The Prime Minister's Strategy Unit's report 'Improving the Life Chances of Disabled People' (PMSU, 2005); the 'UK Strategy for an Ageing Population' (HM Government, 2005) and the Department of Health Green Paper 'Independence, Well-being and Choice: Our vision for the future of social care for adults in England' (DH, 2005).

'Improving the Life Chances of Disabled People' sought to broaden the approach for those requiring care and support to focus on the promotion of independent living, not just to enable people to live in their own homes, but also to provide disabled people with choice, empowerment and freedom.

> *"Independent living is not just about having choice and empowerment in personal care."* (PMSU, 2005: 70)

The aim was to remove the barriers to social inclusion and equality experienced by disabled people of all ages (Glendinning et al., 2008). Other key points were the provision of better advice for service users and addressing existing problems with suitable housing and transport. Thus, the wider community in which people lived was seen as increasingly important in achieving the outcomes sought.

A move to pilot individualised budgets, seen to be the mechanism to promote individual choice and control, building on direct payments, was also set out in this policy document. These budgets, called individual budgets, aimed to combine the various sources of funding that disabled people could use into a single sum to be spent according to the person's preferences with choice as to whether to take these budgets as cash or as services. These sources included local authority adult social care, disabled facilities grants, equipment budgets, Supporting People for housing-related support and the Independent Living Fund among others but not health services. In practice, it proved very difficult to bring these together in a single budget and budgets have since been limited to those related to adult social care (and health) only. Individual budgets, therefore, differed from direct payments in two respects: They were not limited to adult social care and they did not require the service user or their family to manage the budget.

A fundamental principle underpinning individual budgets was a greater role for self-assessment than under usual arrangements and greater opportunities for self-definition of needs and desired outcomes with increased opportunities for users to determine for themselves how they want those outcomes to be achieved within the fixed budget (Glendinning et al., 2008).

Users were to be offered support planning to help them decide how to use the budget to best meet their needs. Several options were available to manage the individual budget: to receive local authority-commissioned services; to have an individual budget managed by a third party, for example a domiciliary care agency, a trusted person or a family member; or to receive it as a direct payment.

The 2005 Green Paper confirmed the plan to set up and evaluate a pilot programme of individual budgets, which were seen, along with direct payments, as budgets "to stimulate the development of modern services delivered in the way people want" (DH, 2005:14). The proposed individual budgets set out to offer many of the benefits of choice to the person using services to those who did not wish to have the worry

of actually managing the money for themselves through a direct payment. A pilot programme of individual budgets was set up in 13 sites and an evaluation of it was commissioned. The evaluation found that, when pooling data across the sample as a whole, the users of individual budgets were significantly more likely to report feeling in control of their daily lives and of the support they accessed and how it was delivered than those receiving services as usual, although older people were less likely than others to report higher aspirations as a result of an individual budget (Glendinning et al., 2008). They reported lower psychological well-being than those in the comparison group.

The 2005 Green Paper (DH, 2005), described as a 'vision' for the future of social care, set out a long-term programme over the following 10 to 15 years, confirming the move to person-centred, proactive and seamless services to advance the choice and control agenda with direct payments seen as the key mechanism through which this would be achieved. It stated:

> *"It is clear that direct payments give people that choice and control, and we think that this is a mechanism that should be extended and encouraged where possible."* (DH, 2005: 11)

The Green Paper also emphasised a strong strategic and leadership role for local government, working in partnership with other agencies, particularly the NHS, to ensure a wide range of effective and well-targeted provision to meet the needs of diverse communities. The requirement for good information about service provision was emphasised as key to delivering the vision, as was the focus on the assessment process, putting people at its centre, to give them greater choice on how their needs were met; indeed, guidance on the assessment process assumed increasing importance in future policy statements. At this point, policy considered only people living in the community with a reiteration of previous anticipated outcomes for adult social care, set in the context of a transformed method of delivery of social care for all adults in England.

The following year, saw the publication of the White Paper 'Our health, our care, our say: a new direction for community services' (HM Government, 2006), which confirmed the direction of travel. Services were to be flexible and responsive to individual needs, enabling and supporting health, independence and well-being. Well-being was broadly described as improved physical and emotional health; improved quality of life; making a positive contribution to society; choice and control; economic well-being; and personal dignity, reflecting a move to a wider and more encompassing vision of the outcomes for adult social care than previous policy statements. A greater emphasis on prevention was also confirmed with rapid and convenient access to high-quality cost-effective care, alongside a drive for greater integration and moves to address inequalities in access to care (HM Government, 2006).

In 2007, the document 'Putting people first: a Shared Vision and Commitment to the Transformation of Adult Social Care' (HM Government, 2007) set out proposals for the transformation of social care. Over 30 health and social care organisations including the Association of Directors of Adult Social Care (ADASS), the Local Government Association (LGA) and the Social Care Institute for Excellence (SCIE) and other key players in the field of social care, committed to this agenda, leading in 2011 to a concordat which was a sector-wide agreement entitled, 'Think Local, Act Personal' (TLAP) for adult social care, committed to transforming health and care through personalisation and community-based support (HM Government, 2007). The mechanism for achieving this in practice was through personal budgets, particularly if taken as a direct payment, which were set to become the mainstream way of supporting people eligible for publicly funded adult social care support in need of domiciliary care.

"Personal Budgets will ensure people receiving public funding use available resources to choose their own support services – a right previously available only to self-funders." (HM Government, 2007: 2)

Personal budgets were introduced rather than individual budgets, which were not rolled out nationally following the evaluation of the pilot programme. The Department of Health decided to bring together funds associated with social care only and to create the term 'personal budgets' to indicate the difference from 'individual budgets'. Personal budget were means tested and local authorities employed various methodologies to determine the sum of money available to service users as a personal budget.

While including previously desired outcomes for people such as their ability to live independently, to stay healthy and to exercise maximum control over their own lives, the concordat also set out a wider objective for people to participate as active and equal citizens, both economically and socially, a further broadening of the outcomes sought for adult social care. However, it did not include service users in residential care and, at this point, residential care users were excluded from using a personal budget.

Personal budgets could be taken as a direct payment, as an account held and managed by the local authority in line with the person's wishes, or as an account placed with a third party and 'spent' by the user in direct negotiation with the provider, or as a mixture of the above. Self-directed assessment, up-front allocation of funds and support planning to promote maximum choice and control were key to this process (SCIE, 2012). Personal budgets became available in 2008 to users of domiciliary care and were enshrined in legislation under the Care Act 2014, which included them for service users in care homes.

TLAP (2008) confirmed the objective of personalisation, alongside a strategic shift towards early intervention and prevention, the latter described as the 'cornerstone' of public services. Local partners were to 'own' and agree local strategic needs assessments and subsequent service commissioning. The involvement of service users and carers and agencies in the wider community was regarded as critical to creating a fair, accessible system that could be responsive to the individual needs of those who use services and their carers. These arrangements were seen as pivotal to the creation of a truly personalised care system.

The subsequent 2009 Green Paper, 'Shaping the Future of Care Together', not only focused on reforming care and support services for those eligible for them, but extended eligibility for help with finding and paying for care and support to everyone in the population of England, including those in need of residential care (HM Government, 2009).

These developments broadly continued after the Coalition Government took office in May 2010, for example, through the Green Paper, 'A vision for adult social care: Capable communities and active citizens' (DH, 2010). As set out in previous policy documents, personalised services and outcomes remained at the centre of social care policy, with personal budgets to be provided to all eligible people, preferably, in the case of community-based care, in the form of direct payments (DH, 2010: 15). The provision of good information about care and support was to be made available for all eligible people regardless of whether they received publicly funded care or funded their own care. This was an important provision that constituted a new duty on practitioners in local authorities. Again, there was an emphasis on local partnership working between individuals, communities, the voluntary and private sectors, the NHS and councils, including services such as housing. Developing a workforce with the skills to deliver the vision, including professionals as well as service users and family carers, was central.

The following White Paper, 'Caring for Our Future: reforming care and support' (HM Government, 2012), confirmed the objectives of the reforms as:

- Promoting health, wellbeing, independence and rights of individuals to be at the heart of care and support;
- Legislating to ensure that everyone can take control of their care and support by giving them an entitlement to a personal budget, preferably taken as a direct payment.

Personalisation is identified as one of the key principles of the vision for care and support, to be achieved when "a person has real choice and control over the care and support they need to achieve their goals, to live a fulfilling life, and to be connected with society" (HM Government, 2012: 18). This vision encompasses a broader range of outcomes, far wider than the ideas of ten years earlier, which had a more instrumental approach through the use of direct payments as the way to provide choice of, and control over, services primarily for people in their own homes. The White Paper also included care and support for residents of care homes, building on ideas developed in 'My home life', such as to help care homes and their residents to connect better to their local communities (HM Government, 2012).

The wider context of these proposals was the move to localism, devolving power from central government to communities and individuals, In addition, following a Law Commission recommendation in 2011, it was proposed that there should be a pilot of direct payments for people living in residential care in a small number of areas, in order to test their costs and benefits for this group of service users (Law Commission, 2011). The evaluation of this pilot programme was the forerunner of the current research project.

This series of policy statements culminated in the Care Act 2014. Well-being and outcomes were at its centre together with a focus on individuals and their needs, their choices and what they want to achieve. The 2014 Act replaced most previous legislation on adult social care and in the process rationalised the legal framework for social care. It was the most substantial piece of legislation on social care for 20 years.

There is substantial guidance on personalisation, especially as its relates to personal budgets and direct payments, in the statutory guidance to the Care Act 2014 (DHSC, 2018), which draws together the different aims and objectives for social care set out in the many previous policy documents discussed above. The guidance includes the following statements related to personalisation and personal budgets:

1. The care and support plan is key to putting people in control of their care, with the support that they need to enhance their wellbeing and improve their connections to family, friends and community (Guidance 10.1);

2. The personal budget in the care and support plan will provide everyone with clear information regarding the cost of their care and support and the amount that the local authority will make available, in order to help people to make better informed decisions as to how their needs will be met (Guidance 10.3);

3. The guiding principle in the development of the plan is that this process should be person-centred and person-led, with the process and the outcomes built holistically around people's wishes and feelings, their needs, values and aspirations, irrespective of the extent to which they choose or are able to actively direct the process (Guidance 10.5);

4. The local authority is responsible to ensure that information is available in a way that is meaningful to the person, and that they have support and time to consider their options (Guidance 10.33);

5.   Consideration of the needs to be met should take a holistic approach that covers aspects such as the person's wishes and aspirations in their daily and community life, rather than a narrow view purely designed to meet personal care needs (Guidance 10.38);

6.   The person can choose how the budget is managed, including as a direct payment, irrespective of whether the local authority or a service provider or a third party is managing the budget on the individual's behalf (an individual service fund), or a combination of these approaches. The person can have greater choice and control than under previous arrangements over the way the personal budget is used to purchase care and support, and from whom care is purchased (Guidance 11.3);

7.   The person must have clear information regarding the money that has been allocated to meet the needs identified in the assessment and recorded in the plan. The detail of how the personal budget will be used is set out in the care and support plan, or the support plan (Guidance 11.7).

Direct payments, along with personal budgets and personalised care planning, mandated for the first time in the Care Act, provide the platform with which to deliver a modern care and support system (Guidance 12.3). Thus, in the Care Act, the aspiration for personalisation goes beyond the group of recipients of direct payments and comprises all groups of service users, including those residing in care homes. No conceptual difference is made between personalisation, person-centred care and personalised care planning, which are all seen as approaches to individualising and increasing the quality of care. The focus of facilitating personalisation is through care and support planning and through personal budgets, i.e. planning at the level of care needs assessment and allocation of funding. While care planning and personal budgets apply to service users in care homes as well as to those in the community, the Act and associated statutory guidance give little attention to how personalised care is to be promoted within care homes.

2.2 Personal health budgets, integration and improved health services in care homes

These principles of personalising care also extend to the development of personal health budgets. They were introduced in the NHS in 2008 as a pilot programme initially, building on the findings of the evaluation of individual budgets described above. Personal health budgets are now an important current policy direction for health care in England. Personal health budgets are funds for individuals to purchase services, support and equipment to achieve their health goals, which are set out in a care plan agreed by the individual and health professionals that states the budget amount, what will be purchased and how the budget will be managed. As in social care, a personal health budget does not provide additional funding, but enables money that would normally be spent on a person's care to be used differently. It first became a legal right in October 2014 for people eligible for NHS Continuing Healthcare funding. Clinical commissioning groups can now also offer personal health budgets to other groups, as explained below (Jones et al., 2018).

The initiative is a key aspect of personalisation across health care services in England. Its aim is to improve patient outcomes by placing patients at the centre of decisions about their care, thereby encouraging greater responsiveness of the health care system (Forder et al., 2012). These principles are allied with those underpinning personal budgets in social care.

The scheme has been extended over time. The roll-out of personal health budgets was seen to provide a significant opportunity to combine them with personal budgets

in social care to create integrated personal budgets. To this end, NHS England developed an Integrated Personal Commissioning demonstrator programme that, from April 2015, aimed to test how individuals' care could be coordinated across sectors, such as social care and the NHS, including the option of an integrated budget (NHS Confederation, 2015). While personal budgets are wholly funded by a local authority, and personal health budgets are wholly funded by the NHS, integrated personal budgets are funded by both the local authority and the NHS (NHS England and Local Government Association, 2017).

Only adults receiving NHS Continuing Healthcare and children and young people in receipt of continuing care had the right to have an integrated personal health budget. In April 2018, the Department of Health and Social Care conducted a joint national consultation with NHS England to canvas views on extending the right to personal health budgets and integrated health budgets to other groups that might benefit (DHSC, 2019). The new groups proposed were:

- People with ongoing social care needs;
- Those eligible for mental health 'aftercare' services after hospital discharge who make ongoing use of community mental health services;
- Those leaving the armed forces;
- People with a learning disability, autism or both; and
- People who access wheelchair services whose posture and mobility needs affect their wider health and social care needs.

Putting the needs of the resident or person with care needs at the centre of any changes, services should be 'wrapped around' the individual and their family, who are connected to and supported by their local community, echoing ideas developed in 'My home life' and the 2012 White Paper. This should include improved access to primary care services, multi-disciplinary teams, reablement and rehabilitation, and high quality end of life care. Emerging evidence indicates that co-ordinated action on all the elements of the model produces the best results for users, carers and key stakeholder bodies. Many of these duties are enshrined within the Care Act 2014, underlining the increased similarities of goals, and conceptual overlap, of service integration and personalisation.

2.3 Practice guidance developments

This review also considers how the personalisation agenda has influenced the development of practice guidance, developed by governmental, arm's length and non-governmental organisations, as they relate to personalising the care for older people in residential care.

The National Service Framework for Older People, published in 2001, states that person-centred care, "requires managers and professionals to […] recognise individual differences and specific needs including cultural and religious differences and enable older people to make informed choices, involving them in all decisions about their needs and care" (DH, 2001a:23), taking a view inclusive of domiciliary and residential care.

More recent guidance documents echo similar themes (SCIE, 2012, LGA, 2014), often using the terms 'personalisation' and 'person-centred care' synonymously or as overlapping concepts. For example, TLAP describes personalisation as "a way of thinking about care and support services that puts [the person] at the centre of the process of working out what [their] needs are, choosing what support [the person] needs and having control over [their] life". Person-centred care is described as "an approach that puts the person receiving care and support at the centre of the way care is planned and delivered" (TLAP, 2019).

In practice guidance, co-production is identified as a facilitating mechanism for personalisation (LGA, 2014, TLAP, 2012). TLAP (2018) supports co-production in which commissioners and providers of services work in partnership with service users, carers and citizens to improve services. In advice to local authorities, the LGA (2014) states that personalisation must address the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy, to enable them to make good decisions about the support they need. While the document does not explicitly exclude individuals in care homes, it does not address any of the specific issues of personalisation that may arise in a care home context, but takes a general high level, service commissioning perspective (LGA, 2014).

The statutory guidance on the Care Act reinforced a focus on the promotion of well-being when a person is being assessed by a local authority. The assessment process is key to achieving a personalised outcome (DHSC, 2018).

> *"The process and the outcome should be built holistically around the person's wishes, feelings, needs and aspirations, irrespective of the extent to which they choose or are able to actively direct the process."* (DHSC 2018: 10.5)

National Voices, the coalition of charities that advocates for people being put in control of their health and care, has set out an ambition for the health and care systems in England to achieve genuinely person-centred care by 2020 (National Voices, 2017). Wider than just social care targets, the ambition includes health targets such as to reduce harm from smoking, drinking, poor lifestyle and wider causes of poor health, focused on those with the greatest burdens and risks of ill health.

While most policy documents, implicitly or explicitly, have tended to focus on personalisation in domiciliary care (including those on self-directed care and direct payments), practice guidance often takes a more inclusive perspective, with some aiming to improve personalisation, and person-centred care, in residential care specifically.

A number of organisations have developed practice guidance for personalisation in residential care that draw on ideas about person-centred care, dementia care, and choice and control. Based on this work, authors associated with the Joseph Rowntree Foundation developed a conceptual framework for best practice to improve the quality of care in care homes ('My home life') (Owen and Meyer, 2012). The framework is based on an extensive literature review and emphasises the role of 'personalisation', 'navigation' and 'transformation' for improving the provision of care, the management of the home, and ultimately the quality of life of residents in care homes. As part of the framework, the theme of personalisation specified the importance of 'maintaining identity', 'creating community' and 'sharing decision-making'. While these three dimensions of personalisation have informed the approach promoted by the Social Care Institute for Excellence (SCIE, 2011), the 'My home life' framework also specifically highlights the role of management and leadership for promoting a positive care home culture and for ensuring that staff have the required skills and level of training. From a practice perspective, personalisation, and its twin concept person-centred care, are thus almost synonymous with the idea of 'providing good care' in residential settings.

In an updated version of the framework, SCIE presented an action plan for care homes that wish to improve personalisation of their services (SCIE, 2019). The plan includes seven dimensions: transition into the care home; choice and control; identity and purpose; community capacity; co-production; person-centred approaches; positive culture; end of life; merging concepts of good care (transition and end of life) with aspects of choice and control and person-centred planning (which is called 'person-centred approaches') and joint decision-making (which is called 'co-production').

The National Institute for Health and Care Excellence (NICE) also developed quality standards for care homes for older people to provide guidance for local authorities (NICE, 2015). The guidance amalgamates concerns about personalising care to enhance people's wellbeing with concerns about safety and safeguarding, for example, by avoiding medication error, preventing falls or monitoring malnutrition. Reducing costs and tackling inequalities are also part of the guidance for local authorities in their role as commissioners and payers of residential care. However, the guidance explicitly underlines the role of local authorities in ensuring that care provided in care homes is person-centred, orientated towards the person's needs, respectful of personal identity and preferences, and promotes choice and control. From this perspective, at least some of the responsibility for ensuring that care homes observe the principles of personalisation/person-centred care rests with the local authorities and their commissioning arrangements.

All care homes in England need to be registered with the Care Quality Commission (CQC), which inspects them and publishes reports of their inspections. The CQC rates care homes on their overall performance as well as their performance on five key domains: safety; effectiveness; responsiveness; caring; and leadership (whether they are well-led). The ratings are on a four-point scale: outstanding; good; requires improvement; and inadequate. The frequency of inspections depends on the rating from the last inspection. One of the inspections' key lines of enquiry in the responsiveness domain is 'How do people receive personalised care that is responsive to their needs?' (CQC, 2019).

2.4 Conclusion

This review of policy and guidance documents has traced the development of policy and practice guidance on personalisation. It addresses that part of the study's first research question which asks how 'personalisation' is conceptualised in recent policy and guidance documents relating to adult social care in England. It also provides the backdrop to this study of personalisation in care homes for older people. As stated above, most of the policy documents focused on personalisation, choice and control for people receiving care in their own homes, with direct payments (and later, personal budgets) being the main instruments developed to promote personalisation. In most policy documents, no clear distinction is made between the concepts of 'personalisation', 'choice and control' and 'person-centred care'. While more recent policy documents have extended the ambition for personalisation to residents in care homes, most notably in the 2014 Care Act, the specific implications of personalisation in these settings and how it is to be promoted are rarely addressed, with the focus being on person-centred planning, commissioning and integration of health and social care.

This is in contrast with guidance for practitioners that specifically centres on person-centred care as an approach to improving care for older people in care homes. Most of this guidance draws explicitly or implicitly on previous work emerging from dementia care and conceptualisations of person-centred care as an approach to care aimed at improving the quality of life of individuals with cognitive and physical limitations in residential care settings.

Chapter 3
Methods

The following chapter describes the methods used for each of the analyses.

3.1 Literature review

3.1.1 Approach

Given the broad scope of this study, we conducted an extensive review of the international, peer-reviewed literature. We have used an integrative approach, inclusive of both qualitative and quantitative findings. Unlike systematic reviews, which examine the causal relationship between interventions and outcomes, we have applied a realist perspective to examine how the aims of personalisation in care homes are understood in the literature; the approaches developed to promote personalisation; the effects achieved by these approaches; and the contextual factors that help or hinder personalisation to achieve positive outcomes for service users. For this purpose, we have included two groups of studies in our review. The first group consists of studies that examine the effects of an approach (intervention) to promoting personalisation in residential care. The second group consists of studies that explicitly consider contextual factors that can explain the success and failure such approaches. Studies in the second group can include studies of approaches and effects, exploring which context and circumstances are explored to make sense of the study findings (e.g. difficulties implementing an approach explaining a smaller than expected effect size).

3.1.2 Scoping the literature

We conducted an initial search to explore the concept of personalisation in the UK and elsewhere. The search focused on personalisation in residential settings, as well as other health and social care settings, including domiciliary care where the term is primarily used. This search included the research literature, as well as reports from advocacy and provider organisations and government documents. This scoping exercise led us to develop our search strategy to include 'person-centred care' in addition to 'personalisation'. We also tested using the search term 'choice' and 'control', individually and in combination. We later abandoned these two search terms, as this search resulted in an excessive number of irrelevant results.

3.1.3 Search strategy

We conducted a number of searches using a variety of literature databases. These covered all disciplines relevant to this study: medicine and allied health care research (CINAHL Plus with Full Text, MEDLINE); economics (EconLit); political science (International Political Science Abstracts, PAIS Index, Policy File Index, Political Science Database, Worldwide Political Science Abstracts); social sciences and humanities (SocINDEX with Full Text, International Bibliography of the Social Sciences, Social Sciences Citation Index, Web of Science); commerce and trade (ABI/INFORM Collection, Business Market Research Collection, J.P. Morgan Research) and psychology (PsycINFO, PsychARTICLES).

Search terms included 'personalisation', 'person-centred care' and 'institutional care settings', using the search strings set out in Table 3.1 below. Searches were limited to peer reviewed articles published between January 1, 2000 and October 24, 2017, the date when the searches were conducted. The searches were also limited to articles written in English, French and German languages. Literature databases listed above are aggregated in the database search platforms EBSCO and Proquest, with the exception of PsycINFO which uses OVID and the Web of Science (Clarivate Analytics, 2018, Ovid Technologies Inc., 2018, Proquest, 2018). The search strings outlined in Table 3.1 were applied to each database platform, resulting in 546 and 84 hits in Ebsco and Proquest respectively.

Table 3.1 Search terms

	Search terms	Boolean term
1.	SU(personalisation OR personalization) OR SU("person centred" OR "person centered") OR SU("choice and control")	AND
2.	SU(care)	NOT
3.	SU(child) OR SU(inpatient) OR SU(hospitalisation OR hospitalization) OR SU(pharma*) OR SU(drug therapy OR drugs OR medications) OR SU(medical treatment)	

SU: Major subject heading

Using a more limited search string of 'personalisation' AND 'care', we also searched the online Social Science Research Networks resource, which yielded 2 results, which appeared in the previous search (SSRN, 2018). We also used the terms 'personalisation' and 'care' to search the Cochrane Library, yielding 26 results, where the results were either duplicates of references identified in other searches, or did not meet the inclusion criteria. The final reference list was exported into Endnote 8.

3.1.4 Selection of studies

Articles were included for studies that: took place in residential, nursing and hospice care settings; focused on caring for older people; included an approach (intervention) aimed at improving or promoting personalisation; and reported outcomes from the intervention relating to service users, staff and the care relationship (e.g. where person-centred care is the outcome), or the care home as an organisation. Studies in settings described as 'nursing homes' were included as the term 'nursing home' is often used interchangeably with 'residential home' outside the UK. Furthermore, nursing homes provide residential care in addition to nursing services.

Articles were excluded if they exclusively focused on clinical medicine, general practice, specialist psychiatry or clinical psychology contexts, and other health care settings such as rehabilitation, reablement therapy or primary care and pharmaceutical interventions. Articles with study populations of children or adolescents were also excluded.

In the first instance, articles were excluded by title, independently by two researchers (SE and JD). The two researchers subsequently discussed their results until consensus was reached on the list of 552 unique titles. The combination and exclusion process was conducted in Endnote 8.

In a next step, SE and JD independently reviewed the abstracts of the 552 included titles for their eligibility for inclusion in the review. Authors reconvened to compare results and discuss differences until they reached consensus. Primary reasons for excluding abstracts from the review included that they related to children and adolescents, or to health-related settings. The total number of eligible abstracts identified by category is outlined in Figure 3.1. Nineteen articles could not be retrieved as full text, resulting in a total number of full text articles of 281.

Full-text papers were then grouped into two categories: 1. Studies that reported on the effects of an approach to promoting personalisation in care homes for older people, and 2. Studies that reported or discussed contextual factors influencing approaches to promoting personalisation in care homes for older people. These categories are not exclusive as articles can report study results and discuss their context. Studies reporting approaches and effects, as well as contextual factors, were included in the 'approaches and effects' category. This step in the selection process resulted in 34 articles that examined approaches and their effects (with or without discussing contextual factors) and 43 articles examining contextual factors only.

To report approaches and effects, we included studies with all methods of data collection and analysis such as randomised controlled trials, non-randomised controlled studies, uncontrolled before and after studies, and various qualitative designs including interview studies, descriptive case studies and action research studies. We also include previous systematic reviews and meta-analyses.

Figure 3.1 Study selection flow diagram

Ebsco
546 titles

Proquest
84 titles

PsycInfo
515 titles

Web of Science
38 titles

Excluded titles:
- Duplicates
- Publications pre 2000
- Referring to children/ adolescents
- Non-English, French or German
- No obvious relevance
- No care element

Excluded titles:
- Duplicates
- Publications pre 2000
- Referring to children/ adolescents
- Non-English, French or German
- No obvious relevance
- No care element

418 titles

402 titles

552
Unique titles

Excluded titles:
- Duplicates
- Referring to children and adolescents
- Specific therapies, counselling, diagnoses
- No obvious relevance

Full text review of approaches and effects. Excluded papers:
- Reviews
- Community, clinical care settings
- No description of approach and effect
- No empirical evidence
- Discussions, comments

300
Eligible abstracts

281
Eligible full texts

Full text review of concepts of personalisation. Excluded papers:
- Community, clinical care settings
- No description, discussion of personalisation definition, conceptual framework

34
Eligible papers on approaches and effects

43
Eligible papers on contextual factors only

3.1.5 Data extraction and synthesis

Data were extracted into a table systematically. SE reviewed the full texts of articles whose lead author was based in the UK and JD reviewed articles whose lead author was based outside of the UK. Studies were then grouped into approaches that were focused on the service users; staff and the care relationship; and the care home as an organisation. We took inspiration from the analytical distinction proposed by Pawson et al. (2005) that analyses complex interventions by distinguishing several layers of context: interpersonal, institution, and infrastructure. Given the near perfect fit between these layers of context and our approach to grouping approaches we extended our analytical framework to include four dimensions relevant to enabling personalisation in care homes for older people including:

1. The individual
2. The care relationship
3. The organisation (care home)
4. The care home context (e.g. political economy and society)

A more detailed description of the framework can be found in the introduction to Chapter 4.

Information on all studies that met the inclusion criteria were extracted into a table. The table includes basic information relating to the publication (e.g. authorship, year, journal); descriptions of the settings, populations, and interventions; and information about the conceptual or philosophical approach to personalisation presented in the article. For the purpose of this report, we present a shortened version of the table, organised by framework category, in the Appendix.

This literature review does not give differential weight to different types of study designs according to a 'hierarchy of evidence', although we report the design of each study in our findings. We also did not appraise the quality or robustness of studies as such an approach would not be realistic for a broad review in a fairly short study. Our approach to scoping the literature yields studies of substantial heterogeneity, including heterogeneity of interventions both in each category of our framework and under each heading. For example, training in person-centred care differs substantially in the mode of delivery and the content being delivered. There is also substantial diversity in study setting and the organisational care, i.e. the features of context relevant to understanding the functioning and effects of each intervention. In line with the decision not to appraise study quality, we decided against reporting any effect sizes.

3.2 Interviews

3.2.1 Identification, selection and recruitment of care homes and managers for interview

The National Institute for Health Research (NIHR) network of 'research ready' care homes ENRICH (ENabling Research In Care Homes) was used to identify care homes to be approached for this study. The sample was selected purposefully to include care homes that were 'for profit' and 'not for profit'; homes with a small, medium and large number of residents; stand-alone homes and homes that formed part of a group or chain; and a few homes that served specific population groups such as faith communities. The sample also included care homes from a variety of geographical regions in England, operating in either urban or rural settings and receiving different quality ratings from the Care Quality Commission (CQC).

Support for recruitment of care home managers was provided through the NIHR's Clinical Research Network (CRN), following adoption of the study on the NIHR CRN portfolio in May 2018. All CRN regional leads were contacted directly by a member of the research team with an invitation letter (Appendix 1), information about the purpose and approach of the study, and our criteria for recruitment. Further information about the study was provided directly by a member of the research team (LW) where requested. To enable recruitment the CRN leads used one or more of the following methods: electronically disseminating written information about the study through their research networks; directly contacting managers from their ENRICH networks with information about the study; and disseminating information about the study to managers during one of their 'research network visits' to care homes. CRN leads, as well as any member of the Network's research team involved in helping recruit participants, maintained direct contact with a member of the research team (LW) who monitored recruitment.

All managers expressing an interest in participating in an interview were invited to contact a member of the research team by email or telephone. After they established contact, their name and contact details were entered onto a database and they were advised that a member of the team would contact them if they met the criteria required for selection. Additional information about the study was provided at this stage (Appendix 2).

All care home managers from care homes meeting the selection criteria were then contacted by a member of the research team and arrangements made to interview. Those that did not meet the selection criteria were sent an email to advise that they might be contacted at a later time if needed.

A sample of 25 care homes providing care for older people was selected, following agreement by their managers, to participate in an interview. Semi-structured interviews were carried out with care home managers in the 24 care homes included in this study. One manager agreed to participate, but did not find the time to arrange for an interview. Interviews were conducted between June and September 2018. Managers were interviewed at their place of work in person or over the telephone. Interviewees were asked to confirm whether they received sufficient information about the study and to provide their formal consent to being interviewed (Appendix 3). Interviews lasted between 35 to 90 minutes, were audio recorded with consent and transcribed verbatim. Interviewees were given a gift voucher of £30 in compensation for their time (Appendix 7).

Findings from previous research conducted by the research team on direct payments in residential care (Ettelt et al., 2017) and preliminary analysis of the literature on personalisation, conducted in a separate strand of this study, were used to develop the interview topic guide. Interview topics included: characteristics of the care home (e.g. number of beds, ownership status, type of care need served); views on the meaning and practical implications of personalisation in care homes; how personalisation related to different levels of care needs; measures taken to promote personalisation, including the types of choices available to residents, and how staff promoted joint decision-making, helped service users to maintain their sense of identity, and encouraged involvement of the local community in the care home; staff training, satisfaction and management; barriers to promoting personalisation; and the role of the CQC in assessing efforts to personalise care in care homes (Appendix 6).

3.2.2 Characteristics of care homes and managers interviewed

The 24 care homes of which managers were recruited to the study (Appendix 4) were located in 17 towns in six regions in England (no care home managers were recruited in London, the North East or East Midlands). There were a mix of small, medium and large care homes; the smallest catering for nine residents and the largest for 127 residents in total. Fourteen of the 24 managers recruited led care homes that were part of a group of care homes and, of these, three belonged to large groups of over 60 homes within the UK, and four belonged to smaller groups of between two and four homes. Ten care homes operated as free-standing homes and these accounted for four of the six care homes recruited to the study that had 50 residents or more. All care homes provided care for adults aged 65 years and over, although some managers said that a few of their residents were younger.

Table 3.2 provides a summary of the characteristics of the care homes and managers interviewed. Two-thirds of the care homes were private for-profit businesses, one third were not-for-profit organisations. Seventeen care homes were registered for nursing and residential care, seven were registered for residential care only. Managers of ten homes stated that all or most of their residents were self-funding their care, nine reported receive funding from the NHS or a local authority, and five had both self-funded and publicly-funded residents.

All care homes whose managers were interviewed for this study provided care for people with varying degrees of dementia, alongside other conditions, and most were registered for dementia care with the CQC. Managers of the two care homes without such a registration explained that they may have residents with dementia as a secondary diagnosis, in addition to other primary care needs. Two-thirds of the managers interviewed had a background in clinical nursing and most of these were currently registered to practice as nurses (Table 3.2). Among the 24 care homes selected, 3 were rated as 'outstanding', 15 as 'good' and 6 as 'requiring improvement' at their last available CQC rating. This means managers of care homes that had received a positive rating were overrepresented in our sample, compared to the distribution of ratings across all care homes in England. As a consequence, it is possible that, taken together, the managers in our sample provided an over-optimistic picture of the degree of personalisation provided in care homes. We addressed this potential for 'positivity bias' in two ways. First, we carefully considered any examples of personalisation or failed attempts to personalise provided by managers. It was illuminating that many examples of difficulties in providing personalised services were provided by managers of highly rated homes, perhaps showing a level of awareness that is less developed in managers of other homes. Second, we decided to analyse care homes with lower ratings specifically by examining reports of the latest CQC inspection. The findings of this analysis are reported in Chapter 7.

Table 3.2 Characteristics of care homes and interviewees

	Private for profit	Private not for profit	Charity not for profit	Total
Type of care home				
Residential only	2	1	4	7
Residential & nursing	14	1	2	17
Total	**16**	**2**	**6**	**24**
Funding sources (as stated by managers)				
Self-funded (all or most)	6	1	3	10
Both self and LA/NHS funded	4	0	1	5
LA/NHS funded (all or most)	7	1	1	9
Total	**17**	**2**	**5**	**24**
Care home part of larger chain or group?				
Yes	10	0	4	14
No	7	1	2	10
Total	**17**	**1**	**6**	**24**
Manager interviewed with clinical nursing background?				
Yes	13	1	2	16
No	4	1	3	8
Total	**17**	**2**	**5**	**24**

3.2.3 Characteristics of residents

Managers described their residents as mostly older adults, mostly in their eighties or nineties, with varying, often complex physical and mental health needs, requiring significant levels of care and support. Most residents were said to have a degree of dementia, some lacking cognitive capacity with Deprivation of Liberty Safeguards (DoLS) in place. Some managers noted that their residents could exhibit challenging and sometimes aggressive behaviours, requiring specialised care and support, including additional staff with the appropriate skills. The variability of dementia-related conditions meant that managers were frequently required to reassess risk, making any necessary care adjustments to protect both the individual and other residents and staff (e.g. in cases of particularly aggressive behaviour). In some instances, residents had to be moved within the care home, to enable the home to provide more support, or moved to a different care home, more suited to their needs.

3.2.4 Data analysis and analytical frameworks

Interviews were analysed using the Framework method (Richie and Spencer 2004). The Framework method is a method for analysing qualitative data employing a number of distinct stages allowing researchers to move from descriptive to more interpretative analyses.

Following a process of familiarisation with the data, and with our research objectives in mind, the research team identified two thematic frameworks to structure and organise the data in a meaningful and manageable way; allowing for more detailed analysis at later stages of the process. Categories were identified from a priori issues

and emergent themes resulting from engagement with the literature and close reading, by three researchers, of a subsample of interview transcripts.

The first framework aimed to describe care home managers' approaches to personalisation in residential care, as described in interviews. It drew on 'best practice themes' relating to personalisation in care homes informed by findings from a large review of approaches to improving the quality of care in care homes (Owen and Meyer 2012). This framework comprised three domains of personalisation in a residential care setting, at which approaches to personalisation can be aimed:

1. Maintaining identity
2. Sharing decision making
3. Creating community

Each of these domains resonates with the categories of our overall framework, in which we classify approaches to personalisation at the individual level (aimed at maintaining identity); at the relationship level (aimed at sharing decision-making); and at the community level, with a distinction made to analyse approaches aimed at the community within the care home and the local community in the areas in which the care home is situated (Appendix 5).

A more detailed description of the framework can be found at the beginning of Chapter 5. Interview transcripts were individually coded against the agreed coding framework, data extracted and charted within the framework matrix, using NVivo 9 software. Extracts were then summarised within each matrix so that summaries could be read across cases and themes. This allowed the research team to explore patterns in the data and interpret and identify further themes in relation to approaches to personalisation.

The second framework was developed to analyse the differences in the conceptualisation of personalisation by care home managers and the differences in practices resulting from these concepts. This analysis provided an additional approach to understanding how managers conceptualised personalisation and which 'models' of personalisation they aspired to when providing care and managing their home. This framework was developed from engagement with the data, rather than using an existing framework; however, it later transpired that other authors had made similar distinctions, although these frameworks used slightly different wording and were used for other, though related, types of analysis (Trigg, 2018, Davies, 2003).

The framework can be illustrated by a matrix that maps the type of personalisation provided by care homes against two axes: the closeness of the relationship between residents and care personnel, and the level of choice experienced by the resident. While this framework emerged from the data, its categories were then used to reconsider and recode the data upon a second reading. A detailed description of the framework for analysis can be found at the beginning of Chapter 6.

3.3 Analysis of inspection reports by the Care Quality Commission (CQC)

3.3.1 Selection of care home reports

Fifty CQC reports, published in 2018, were selected to reflect the diversity of services across England. In the first instance, reports were selected from each of the 15 regions of the Clinical Research Network (CRN) and to cover all 4 quality ratings received by the CQC following the inspection (Outstanding, Good, Requires Improvement, and Inadequate). In some CRN regions, no care homes received ratings on either extreme,

i.e. outstanding or inadequate, and therefore only 3 reports were selected from these regions. Table 3.3 outlines the number of reports selected from each CRN region and 3.4 shows the number of reports selected by inspection rating.

Table 3.3 Number of CQC reports selected by CRN region

CRN region	Number
East Midlands	3
Eastern	4
Greater Manchester	3
Kent, Surrey and Sussex	4
North East and North Cumbria	4
North Thames	4
North West Coast	3
North West London	4
South London	3
South West Peninsula	3
Thames Valley and South Midlands	4
Wessex	3
West of England	4
Yorkshire and Humber	4
Total	**50**

Table 3.4 Number of CQC reports selected by CQC rating

CQC rating	Number
Outstanding	10
Good	18
Requires Improvement	16
Inadequate	6
Total	**50**

Also taken into consideration during the selection were the potential differences between homes located in urban or suburban areas, towns, villages and rural settings. Table 3.5 shows the distribution of the care homes across various location types.

Table 3.5 Number of CQC reports selected by location

Location	Number
Urban or Suburban (e.g. of Manchester, London, Liverpool)	18
Town	17
Village and rural setting	15
Total	**50**

The number of beds per care home was also taken into account, in order to be able to examine the relationship between the number of residents cared and the level of personalisation of services provided. We used a grouping of small, medium and large homes (CQC, 2017), where small care homes care for less than 11 residents, medium care homes house between 11 and 49 residents and large care homes have more than 50 residents. Table 3.6 illustrates the number of care homes selected from each category.

Table 3.6 Number of CQC reports selected by location

Care home size	Number
Small (<11 beds)	1
Medium (11-49 beds)	30
Large (>50 beds)	18
Uncertain	1
Total	**50**

Our final criterion for selection was the type of ownership of the home, to identify potential variances in the level of personalisation according to ownership, i.e. whether it is privately owned or run by a charity or religious organisation. A small number of care homes were selected to represent settings providing care for specific faith and cultural groups. Our sample includes 32 privately owned homes, including one faith-based home, and 13 homes which are run by not-for-profit or charitable organisations, four of which are faith-based and one caters to a specific cultural group.

3.3.2 Data extraction and analysis

To guide our extraction of data from the inspection reports and our analysis of the data we compared the CQC inspection' 'key lines of enquiry' (CQC, 2017a) for each of their domains with the themes of person-centredness (Wilberforce et al., 2017) which we adopted for this study. Our mapping of the CQC guidance and Wilberforce et al (2017) dimensions is set out in Appendix 9. The 'key lines' which most correspond to the themes and attributes identified by Wilberforce belong to the 'effectiveness', 'caring' and 'responsiveness' domains. Fewer 'key lines' pertaining to the 'safety' and 'well-led' domains relate to the Wilberforce framework. Most of the relevant 'key lines' of the 'safety' domain fall under the 'Understanding the person' theme. A small number of 'key lines' of the 'well-led' domain appear in the 'Engagement in decision-making' and 'Promoting the care relationship' themes. The entirety of the CQC reports were read line by line and relevant data were extracted into a table. Data extraction aimed to be descriptive, using verbatim quotes for illustration. Findings were summarised in this report, referring back to the original data where necessary.

3.4 Research ethics approval

An internal self-certification of the study's research ethics was undertaken and approved at the London School of Economics and Political Science in January 2018 (Appendix 8). The study also received a favourable opinion from the Research Ethics Committee of the London School of Hygiene and Tropical Medicine (LSHTM Ethics Ref: 14727). As this study did not involve interviews with care home residents, approval from the NHS Research Ethics Committee was not required.

Chapter 4: Literature review of concepts, contexts and consequences of approaches to promoting personalisation in residential care

4.1 Specific aims and analytical framework

We conducted a review of the scientific literature on personalisation in residential care to find out which approaches to promoting personalisation in care homes are reported as being effective and which factors supported or hindered such effects. We have taken an international perspective on the topic and did not exclude studies from any country. However, the studies we identified were situated exclusively in high-income countries and have originated predominantly from Europe and North America, reflecting (we assume) patterns in the availability of residential long-term care in different regions and of research of this type being conducted. We have included systematic and (non-systematic) literature reviews, as well as individual studies, excluding those studies that were included in previous reviews.

The specific objectives of this review are as follows:

1. To clarify the purpose of personalisation in care homes for older people, as described in the international scientific literature;
2. To identify approaches used to promote personalisation in care homes for older people;
3. To assess the effects of these approaches on service users, care delivery and the care home; and
4. To consider the factors identified in the literature that help or hinder personalisation in care homes for older people.

For this review, we have expanded our analytical framework, described in the introduction, to be able to distinguish between approaches, effects and context at each of level of analysis. To recap, the four levels of analysis include 1. the individual resident; 2. the care relationship and the role of the carer; 3. the care home as the organisational setting in which care takes place; and 4. the wider societal context of residential care.

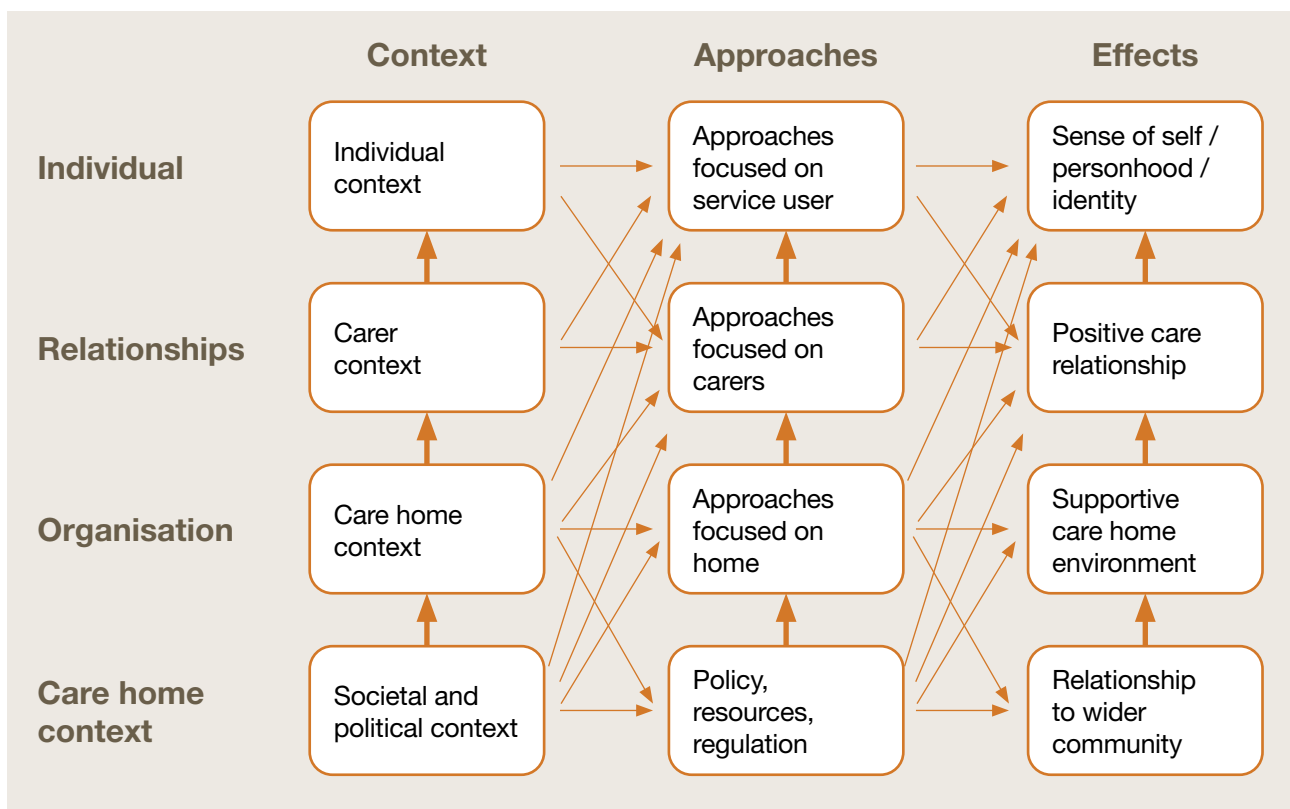**Figure 4.1 Analytical framework for the literature review**

Figure 4.1 illustrates the twelve categories resulting from applying the distinction between context, approaches and effects to our four levels of analysis. The arrows show hypothetical relationships between the different categories of the framework and the possible links between **approaches**, effects and context. For example, we have classified training provided to care home staff in person-centred care (PCC) into the 'relationship' category of approaches as the aims of the intervention are typically to influence the attitudes, knowledge and behaviour of care home staff for the purpose of improving the care relationship. The **effects** of these types of interventions are typically measured in relation to the service users (e.g. agitation; quality of life) or in relation to carers and the care relationship (e.g. improved knowledge, attitudes changed, increase in confidence). The **context** is formed by the characteristics of the individual (e.g. the level of care need; support from families), the organisation of the care home (e.g. the support for the approach to promote personalisation and for personalisation as an overall aim by the leadership of the home), and its wider societal context (e.g. the regulatory environment; availability of funding; the social status of residential care), which moderate or amplify the effects of training on carers and residents. Different from other types of reviews, we analyse the characteristics of residents as (individual level) contextual factors, to emphasise the perspective of care home staff and managers who deliver personalised care, rather than describing them as characteristics of study participants.

We present the review in the following sections: a summary of the conceptualisation of the purpose of personalisation in residential care settings; the approaches to promoting personalisation and their effects; and the factors that mediate these effects as far as they are discussed in the literature. It is important to note that most studies selected for this review explicitly reported the effects of approaches to promoting personalisation; however, the same does not apply to the reporting of contextual factors. Context was often discussed in the 'discussion' section only, when authors interpreted their findings. We have therefore included studies that specifically explored a particular aspect of context, even if they did not necessarily report on the effects of an approach to promoting personalisation. We have thus cast our 'net' more widely for the exploration of context than for the reporting of the approaches and their effects.

4.2 How do studies conceptualise the purpose of personalisation?

The studies included in this review vary in how they conceptualised the aims of personalisation in residential care. Broadly speaking, studies fell into two groups: The first group conceptualised the aims of personalisation as the maintenance of an individual's personhood, identity and sense of self. These studies usually cite the work by Kitwood and Sabat as their conceptual starting point (Kitwood, 1997, Sabat and Harre, 1992). Most of these studies associated personalisation with improving care for people with dementia and they typically used the term 'person-centred care' in lieu of personalisation, emphasising the role of care and caring for the wellbeing of people with dementia (Petriwskyj et al., 2016a, Petriwskyj et al., 2016b, Fossey et al., 2014a, Eritz et al., 2016, Cooney et al., 2014, Ducak et al., 2018, Stacpoole et al., 2017, Baker, 2015, Kim and Park, 2017, Roos et al., 2016, Yasuda and Sakakibara, 2017).

The second, smaller group of studies conceptualised the aims of personalisation as strengthening the autonomy and independence of care home residents. These studies tended to be less explicit about their conceptual foundations, although there were some exceptions (e.g. Brownie and Nancarrow, 2013). These largely emerged from the cultural change movement in residential care in the United States (US), and examined innovative models of residential care, of which the Green House model and the Eden Alternative are the most prominent in our sample (Cohen et al., 2016, Yoon et al., 2016, Yoon et al., 2015, Brownie and Nancarrow, 2013). The culture change movement aims to improve

long-term care for older people in nursing homes in the US by emphasising individualised care, homelike environments, close relationships between carers and residents, staff empowerment and continuous quality improvement (Koren, 2010). Studies of these models did not explicitly exclude people with dementia, but most tended to focus on domains of physical health and mental well-being as relevant outcomes and did not explicitly mention residents with dementia. Studies in this group highlighted changes to the physical environment of the care home and to the organisation of care to enable residents to live in 'home like', small-group environments rather than large wards (Yoon et al., 2015, Yoon et al., 2016, Hung et al., 2016, Roberts et al., 2015).

Both groups of studies conceptualised the aims of personalisation as contributing to the health and wellbeing of the person and emphasised the continuity of residents' habits and preferences before and after moving into a care home. However, it is relevant for this review to understand that studies did so in different ways, as approaches to promoting personalisation were used for different purposes. This difference in conceptualising personalisation is likely to inform differences in the approaches and their effects on older people in care homes.

4.3 Approaches to promoting personalisation in care homes and their effects

Our review identified three types of approaches to promoting personalisation in care homes for older people. These are approaches focused on the service user, approaches focused on the carer, and approaches focused on the care home as an organisation. No approaches have been identified in the literature that focus on the wider context of care homes, such as policy, regulation or the wider community.

Studies that conceptualised the aim of personalisation as maintaining personhood and identity typically examined approaches focused on the role of carers in providing person-centred care (PCC). Studies that conceptualised the aim of personalisation as enabling autonomy and independence tended to report on approaches focused at the care home as an organisation and its physical space, mostly associated with implementing culture change models of personalised residential care.

4.3.1 Approaches focused on the service user

Approaches focused on service users typically included therapies and activities aimed at improving the well-being and care experience of residents. Seven studies fell into this category, including one systematic review, one cluster randomised controlled trial (RCT), two interview studies, two action research studies, and one descriptive study. Both the systematic review and the RCT combined user focused approaches with approaches aimed at staff and the care relationship (Kim and Park, 2017, Ballard et al., 2018), while smaller, qualitative studies tended to examine user focused approaches in isolation (Cooney et al., 2014, Ducak et al., 2018, Stacpoole et al., 2017, Davis and Shenk, 2015). Baker (2015) reported on the experience of implementing the PEARL programme in care homes for people with dementia in the UK. PEARL is an accreditation programme involving guidance, training and support to care homes to promote PCC.

A systematic review and meta-analysis of effects of activities for service users, in combination with staff PCC training, concluded that this combination of approaches was effective in reducing agitation, neuropsychiatric symptoms and depression, and in improving the quality of life of people with dementia. Activities for service users had a greater effect on reducing agitation in the short-term than approaches aimed at staff, but staff-focused approaches were more effective in improving residents' quality of life in the longer term (Kim and Park, 2017).

A cluster RCT of person-centred and social activities for residents, in combination with training in PCC for care staff and a system for triggering review of antipsychotic medications (WHELD) in 69 nursing homes in the UK, found a significant increase in positive care interactions, improvement of quality of life, and reductions in agitation and neuropsychiatric symptoms in residents with dementia. The authors noted that people with moderately severe dementia experienced greater benefits from this combination of approaches than those with mild or severe dementia (Ballard et al., 2018). No difference between the intervention and control groups was found for all other outcomes (e.g. global deterioration, mood, unmet needs, pain and mortality).

A number of smaller studies, using qualitative data collection methods, case study analysis and action research, studied therapeutic approaches either in isolation or in combination with staff training. Approaches included the Montessori Method for Dementia (Ducak et al., 2018), the Namaste Programme (Stacpoole et al., 2017), reminiscence (Cooney et al., 2014, Davis and Shenk, 2015) and the use of 'rummage boxes' and 'empathy dolls' (Baker, 2015). All of these reported a degree of effectiveness on outcomes such as residents' quality of life, reduction in boredom, depression and pain (Ducak et al., 2018, Baker, 2015, Stacpoole et al., 2017). Two studies reported on user facing activities in combination with regular reviews of antipsychotic medication (Baker, 2015, Ballard et al., 2018). However, in isolation approaches focused on service users only appeared to be less successful in improving the care relationship and in sustaining their positive effects beyond the duration of the intervention.

4.3.2 Approaches focused on care relationships

The review identified 20 studies that reported on the effects of approaches focused on care home staff such as staff training in PCC, as well as supervision and feedback. Studies included two systematic reviews with meta-analyses, four RCTs, three of which were cluster RCTs, three quasi-experimental studies (before and after design with a control group), three before and after studies without a control group, four qualitative studies using interviews, focus groups or video observations, one multiple case study analysis, one action research study, one longitudinal survey and one (non-systematic) literature review.

Two systematic reviews concluded that approaches focused on staff including various types of PCC training were effective in reducing agitation and neuropsychiatric symptoms in residents (Fossey et al., 2014a, Kim and Park, 2017). However, only Kim and Park (2017) found PCC training effective in reducing depression and in increasing the quality of life of residents, while Fossey et al (2014) found no evidence of these effects. Both reviews combined studies on PCC training with those that included activities for service users.

The finding of positive effects on agitation and neuropsychiatric symptoms is also supported by a more recent RCT that combined PCC training with activities for users and a system for triggering review of antipsychotic medication (Ballard et al., 2018). A cluster RCT by Jacobsen and colleagues (2017) found PCC training effective in increasing staff's awareness of the use of restraint in dementia care and in increasing staff knowledge about alternatives to restraint. An RCT testing the use of a life history approach to increase staff's knowledge about residents in their homes reported that residents with dementia experienced improved quality of life, but found no effect on behaviour and aggression compared to an approach that focused on resident's medical history only (Eritz et al., 2016). Earlier qualitative studies suggested that life history approaches increased staff knowledge and improved staff attitudes towards residents with dementia (McKeown et al., 2010, Ashburner et al., 2004, Gammonley et al., 2015).

Recent studies not included in the systematic reviews suggested the training had improved residents' quality of life (Eritz et al., 2016, Roos et al., 2016, Yasuda and Sakakibara, 2017, Ballard et al., 2018), . A review of the literature on the effects of staff training to support person-centred meal times described positive effects on residents such as weight gain, reduced agitation and increased sociability, as well as improved attitudes and behaviours of staff vis-à-vis residents with dementia (Reimer and Keller, 2009).

With regard to outcomes relating to the care relationship, several studies demonstrated a positive relationship between PCC training and staff's attitudes and behaviour towards residents (Ballard et al., 2018, Barbosa et al., 2016, Rokstad et al., 2017, Passalacqua and Harwood, 2012, Ashburner et al., 2004, Hayajneh and Shehadeh, 2014, Kontos et al., 2010, Gammonley et al., 2015, Coogle et al., 2004). A controlled before and after study by Li et al (2017) reported beneficial effects of PCC training on residents' sleep patterns during the night, and increased wakefulness and social activity during the day. However, some studies, including one controlled before and after study, did not find such training effective with regard to changing behaviours (Beck et al., 2014, Coleman and Medvene, 2013). Villar et al. (2018) report that including residents with dementia in care planning meetings increased staff's understanding of, and communication with, the person with dementia, and reduced negative staff behaviours towards residents.

4.3.3 Approaches focused on the organisation

The review identified eleven studies that examine approaches focused on the organisation of the care home to improve personalisation of care for older people. This included one systematic review (Petriwskyj et al., 2016a), one before and after study (Hutchinson et al., 2017), two papers that draw on the same observational study comparing resident outcomes in Green House nursing homes with traditional nursing homes (Yoon et al., 2016, Yoon et al., 2015), a (non-systematic) literature review (Reimer and Keller, 2009), five interview or action research studies (Burack et al., 2012, Cohen et al., 2016, Hung et al., 2016, Leutz et al., 2010, Roberts, 2016), and one descriptive study (Baker, 2015). Most of these studies originated in North America, with five published in the US and three in Canada, in addition to one study published in the UK (Baker, 2015) and one in Australia (Hutchinson et al., 2017).

Petriwskyj and colleagues (2016a) systematically reviewed studies evaluating the effects of culture change models, such as the Eden Alternative, Green House, EverCare and others. The authors conclude that while there is some evidence of improved outcomes for residents (e.g. agitation, depression, neuropsychiatric symptoms, quality of life), many studies were inconclusive and findings were contradictory.

An interview study of a culture change programme in care homes in the US (which included PCC training, the employment of community coordinators, and a flattening of the organisational hierarchies) found that residents experienced increased choice in daily activities (e.g. how to bathe, when to eat, when to participate in leisure activities) (Burack et al., 2012). Three studies examined the transition of traditional care homes to Green House care homes organised in the US. The Green House model combines smaller unit sizes ('households' of 10-12 residents) with a philosophy of caring built around a general carer who does household tasks (e.g. cooking, laundry) in addition to personal and nursing care (Yoon et al., 2015, Cohen et al., 2016). These studies suggested that the model could provide residents with increased choice compared to traditional care homes and resulted in an increase in social engagement; but they also observed an increase in depressive symptoms and no difference was found in the deterioration in conducting daily activities compared with care as usual (Yoon et al., 2015). Cohen et al. (2016) noted that while residents experienced a substantial

increase in choice, staff found it difficult to adjust to the new regime and reported inefficiencies in organising care and difficulties in ensuring residents' safety, for example, when monitoring residents' using the garden of the home.

In contrast, Roberts et al. (2016) examining the effects of a re-configuration of a large home to small scale units in Canada found both an increase in choice for residents and an increase in feelings of empowerment and understanding in staff. A study by Hung et al (2016) assessed the redesign of kitchens and communal areas in two care units and concludes that residents experienced an increase in autonomy and independence in daily activities; however, the authors also noted that residents with cognitive impairment required more assistance to be able to exercise these choices. Cohen et al (2016) reported that the communal kitchens built as part of the transition to the Green House model home were only used infrequently by residents.

There are only two studies in this category that explicitly focus on residents with dementia. Baker et al (2015) in the UK describes the effects of changes to the dining room (in addition to PCC training) on the meals of residents with dementia. This study reports on the effects of the PEARL programme which is an accreditation scheme based on the implementation of the VIPS training programme. Effects included reduced depression and use of antipsychotics in residents in these homes, although these effects are only reported descriptively. In their review of studies of the effects of changes to the layout of the dining room and to practices during meal times on people with dementia, Reimer and Keller (2009) report positive outcomes for residents (e.g. weight gain, increased sociability) and improved relationships between residents and carers.

4.4 Context

Understanding aspects of context in order to explain the facilitators and barriers to promoting personalisation in care homes, was a key focus of our review. To this end, we examined the studies that specifically examined contextual factors, in addition to those that reported on approaches and their effects. We have structured aspects of context according to the four levels of our analytical framework, distinguishing factors relating to residents; factors relating to carers and the care relationship; factors relating to the care home as a whole; and factors relating to the wider societal context.

4.4.1 Factors relating to residents

A key problem that many efforts to promote personalisation in care homes aim to redress is the imbalance of power between residents and carers in day-to-day decision-making that arises from residents being in need of care and thus dependent on the support provided by carers. The greater the care need, the higher the risk of dependency and powerlessness. In dementia care, such imbalances are exacerbated by what Kitwood termed 'malignant social psychologies' that arise when people disregard the individuality of the person with dementia (Kitwood, 1997). Hence, there is a focus on improving the care relationship and strengthening PCC.

Some studies observed that residents with a high level of care need were less likely to benefit from interventions that promoted personalisation than those with less severe needs. Cooney et al. (2014) observed that residents with more advanced dementia and other co-morbidities such as deafness were less likely to benefit from reminiscence activities than residents with less advanced dementia. A systematic review of PCC interventions aimed at residents and staff indicates that PCC was more effective in people with less severe dementia than those with advanced dementia in reducing agitation, neuropsychiatric symptoms and depression, and improving quality

of life (Kim and Park, 2017). Findings from a cluster RCT of the WHELD intervention suggests that benefits to quality of life were greater in people with moderately severe dementia than those with mild to moderate or severe dementia (Ballard et al., 2018).

However, studies varied in their assessment of the underlying factors that can explain this observation. One argument was that people with a higher degree of impairment were less able to participate in activities or execute their preferences, for example because of limited mobility (Abbott et al., 2018), impaired hearing or blindness (Kajonius and Kazemi, 2016, Cooney et al., 2014). Bangerter and colleagues found that people with substantial physical impairment could find it more difficult to participate in cultural activities of their choice than those with less severe impairment and thus were constrained in exercising those choices (Bangerter et al., 2016, Bangerter et al., 2017).

Yet other studies suggested that the difference in outcomes for residents was dependent on the support provided to them, and thus corresponded with the attitudes and behaviours of staff towards people with high care needs, especially those with advanced dementia who were less able to communicate verbally.

Eritz et al. (2016) found that people with higher levels of cognitive impairment benefited less from a life history intervention than those with lower levels of impairment, largely because the staff involved in their care made unfavourable assumptions about the state of their personhood and were less supportive as a consequence. Other studies suggested that carers were less likely to spend time with people with dementia and those who had limited ability to communicate, either due to time pressure (Hunter et al., 2016) or because carers had difficulty finding information about residents due to documentation systems not being fit for purpose (Kolanowski et al., 2015). The study by Abbott et al. (2018) suggested that residents in nursing homes were constrained in exercising their preferences due to their functional ability, such as mobility limitations, but also because of a lack of support that would help them compensate for these limitations.

While some studies commented on differences in outcomes for residents, other studies did not make such distinctions. This was notable in some studies of the Green House model. Green House residential homes provided care to small groups of residents in a homely collective setting by carers who also did housekeeping tasks in addition to providing personal care. While such studies tended not to explicitly exclude people with dementia, references to cognitive impairment of residents were rare, which may suggest that these studies of 'culture change' models mostly included older people with mental capacity (Cohen et al., 2016, Brownie and Nancarrow, 2013, Yoon et al., 2015, Yoon et al., 2016). Another study observed that some Green House facilities, which have emerged in the context of the culture change movement in the US, struggled to provide structured activities for groups of residents inside or outside the home as a result of their approach to staffing and philosophy of resident-led living (Cohen et al., 2016). This raised questions as to whether some approaches to personalisation are more suitable to meet the needs of some groups of older people than others, and whether there is a risk that some interventions exacerbate existing disadvantages for residents with very high needs.

4.4.2 Factors relating to care home staff

A main theme emerging from the review was the role of staff support for PCC and the difficulty of improving outcomes for residents in its absence (Cooney et al., 2014, Broderick and Coffey, 2013, Abbott et al., 2018, Bangerter et al., 2016, Hermer et al., 2018, Reimer and Keller, 2009, Rockwell, 2012). Awareness of the importance of a personalised approach to care, as well as attitudes and behaviours of staff were identified as essential if approaches to promoting personalisation were to be effective. These were identified as key both for approaches aimed at service users

directly (e.g. reminiscence exercises) and approaches aimed at improving the care relationship (e.g. PCC training); i.e. those that aimed to address the very same situation proactively by improving carers' knowledge and awareness, and ultimately their provision of care.

Some studies showed that carers had different personality structures characterised for example by their openness or a propensity for neuroticism that made them more or less receptive of efforts to enhance personalisation and more or less effective in delivering them (Medvene et al., 2006, Snoeren et al., 2016, Corlin et al., 2017). Others found that poor training and poor literacy levels, for example of paraprofessional staff, tended to compromise efforts to promote personalisation (Passalacqua and Harwood, 2012).

Other studies noted that while providing PCC may make carers more satisfied with their jobs, it could also lead to more emotional exhaustion (Willemse et al., 2015), while others suggested that an (unspecified) 'modest' pay rise might generate additional motivation for culture change in the Green House model (Cohen et al., 2016).

There is also some suggestion that different professional values can come into conflict with one another, with medically oriented nursing students being more risk averse and less willing to compromise on safety for the sake of enhanced personalisation than students of social work (Dingwall et al., 2017). In another study, nurse assistants were reported to be concerned that efforts to build relationships with residents might be undermined if they missed a deterioration in health status or failed to meet residents' basic needs, for example, by not realising that agitation was a result of pain, reaffirming the prioritisation of the medical perspective in delivering care (Hunter et al., 2016).

Another study suggests that the lack of support from carers for a PCC education programme was caused by carers not feeling that their skills and knowledge gained in the programme were appreciated by care home managers, affecting morale during the programme (Barbosa et al., 2016). This hints at the importance of leadership and management support for personalisation within the context of the care home. Studies provide a reminder that it is important for implementing such interventions to be aware of the extent to which previous efforts to establish personalisation have prepared the staff for interventions, to understand staff members' 'point of departure' and the extent to which they expect personalisation already to have been established (Roos et al., 2016, Bangerter et al., 2017, Bangerter et al., 2016, Dichter et al., 2015).

4.4.3 Factors relating to care homes

A third theme emphasised in the literature is the role of the organisation of the care home, and the role of managers in promoting personalisation and shaping the care home culture to this effect. Not all studies that reported on the effect of approaches to promoting personalisation explicitly discussed the role of the care home organisation; however, many studies did, in addition to some that specifically focused on aspects of leadership and management (e.g. Backman et al., 2016, Lynch et al., 2018, Rokstad et al., 2015). Three aspects stood out in particular: the role of staffing and staff time to be able to give sufficient attention to individual needs and preferences; the importance of leadership and management to establish a care home culture supportive of personalisation and to enable principles established, for example, in PCC training to bed down; and the role of the physical space of the care home in providing opportunities for personalisation.

Staffing and staff time
The first aspect of care homes not having a sufficient number of staff available and staff not having sufficient time was discussed in a number of studies as undermining efforts to promote personalisation and limiting opportunities to personalise care and

facilitate choice (Barbosa et al., 2016, Beck et al., 2014, Cooney et al., 2014, Baker, 2015, Broderick and Coffey, 2013, Corlin et al., 2017, Hunter et al., 2016, Hermer et al., 2018, Kolanowski et al., 2015, Reimer and Keller, 2009, Brownie and Nancarrow, 2013). Studies emphasised that time pressure on staff resulting from substantial workloads were common in the care home sector, as observed by study authors from a number of countries. These often related to the funding context of care homes. with many facing both budget constraints and difficulties in recruiting and retaining staff. Some studies noted that in a context in which staff retention was often problematic for care homes, having stable teams was beneficial for PCC to bed down (Quasdorf et al., 2017, Sullivan et al., 2013).

Management and leadership
The second aspect identified in the literature was the importance of management and leadership for establishing a consistent culture of personalisation that supported staff in their efforts to provide PCC (Sjogren et al., 2017, Dichter et al., 2015, Quasdorf and Bartholomeyczik, 2019, Backman et al., 2016, Beck et al., 2014, Leutz et al., 2010, Barbosa et al., 2015, Hayajneh and Shehadeh, 2014, Jacobsen et al., 2017, Kajonius and Kazemi, 2016, Rodgers et al., 2012).

Authors noted the importance of staff receiving consistent messages from care home leaders in which expectations of high standards of care, including those relating to personalisation, were clearly communicated (Kelly, 2010, Dichter et al., 2015, Chenoweth et al., 2015, Kolanowski et al., 2015). Approaches aimed at staff were more successful in conveying the principles of personalisation in care homes in which staff themselves felt valued and appreciated (Baker, 2015).

Authors also noted that the effects of interventions aimed at improving the care relationship, such as providing PCC training to staff, were more likely to be effective in the longer term if care home managers worked towards a culture of personalisation (Hunter et al., 2016). Studies emphasised the complexity of the role of the managers, with some observing that those acting as credible role models actively involved in delivering personalised care were particularly successful. Jacobsen et al. (2017) observed that PCC training in which leaders were present had higher participation of staff than those in which the leaders were absent.

Others discussed the leadership style conducive to instilling the values of personalisation in staff, with some emphasising the need for 'situational' or 'authentic' leadership. Active listening, affirmative practice and the ability to form mature, non-judgemental relationships with staff were identified as elements of successful leadership, built on collaboration, mutual appreciation and trust (Dichter et al., 2015, Quasdorf and Bartholomeyczik, 2019, Rokstad et al., 2015, Lynch et al., 2018, Chenoweth et al., 2015, Fossey et al., 2014a, Jacobs et al., 2018).

Some argued that leadership was particularly important during times of transition and potentially less relevant once culture change was already established (especially if it makes care provision less hierarchical) (Backman et al., 2016, Stein-Parbury et al., 2012), although others argued that leadership and management would always be needed. McGreevy (2016) argued that leadership to manage the transition from task-oriented to PCC should involve a combination of leadership styles, appropriate to different situations, and different needs and development stages of staff members (e.g. directive, visionary, affiliative and coaching). A meta-analysis of the effects of PCC training on residents emphasised that such training needed to be combined with supervision to be effective and that such efforts needed to be sustained over a period of time to have any lasting effects (Fossey et al., 2014a).

Care home models that included management and leadership as part of their approach to providing personalisation (e.g. Green House) addressed such challenges upfront and might have an advantage as a consequence, although the success of

such models depended on whether they were implemented as intended (Petriwskyj et al., 2016a, Quasdorf et al., 2017). However, many studies were insufficiently specific about the precise models of care operational in practice (Petriwskyj et al., 2016a).

Design and layout of physical space
A third aspect mentioned in the literature related to characteristics of the physical space of the care home, and how the physical environment helped or hindered strategies to personalise. These related to the physical layout of the communal spaces of the care home, such as dining areas or corridors (Ågotnes and Øye, 2017, Reimer and Keller, 2009); spaces that residents used individually such as bedrooms and bathrooms, which might be shared with other residents (Nordin et al., 2017, Rockwell, 2012); and spaces predominantly used by staff and potentially 'off limits' to residents (e.g. kitchens, offices for administrative work, nursing stations) (Roberts, 2016). Efforts to promote personalisation were shaped by the existence and layout of these spaces, of the use space by residents and staff, and whether 'public' and 'private' spaces were seen as separate (Klaassens and Meijering, 2015).

Sjogren et al. (2017) identified the importance of dementia-friendly physical environments for providing person-centred dementia care in nursing homes in Sweden. Quasdorf and Bartholomeyczik (2019) noted that dementia care mapping was more easily implemented in care homes in which residents lived in small-scale homelike units and in which it was possible for them to participate in daily household activities and social interaction. Others also emphasised the importance of creating a 'home-like' environment for residents, similar to residents' previous living arrangements before they moved into care. However, approaches varied, with some studies of culture change models emphasising the importance of open kitchens and dining rooms for promoting casual interaction between staff and residents, as well as between residents (Hung et al., 2016). However, implementing changes to the physical environment also required staff to be appropriately re-trained to be able to support residents. Cohen et al. (2016) noted that such changes were likely to require substantial financial investment into the home.

Several studies noted that having smaller groups of residents living together was beneficial for personalisation and for supporting residents' autonomy (Roberts, 2016). This observation was shared by studies of the Green House model in which nursing homes aimed to create a homelike 'household' feel for small groups of residents (Yoon et al., 2015, Yoon et al., 2016). These models were aimed specifically at encouraging residents to live as independently as possible, taking a holistic approach to care provision. However, a study also showed that while such approaches could benefit residents' mobility, they were less successful in slowing other forms of decline as they did not offer structured group activities (Yoon et al., 2016).

Very few studies mentioned the external environment of the care home. Cohen et al. (2016) noted in a study of a Green House nursing home that its location in a residential neighbourhood helped residents to feel connected to the local community as the location allowed them to 'watch the neighbours'.

4.4.4 Wider societal context

The wider societal context of care homes and its contribution to personalisation was rarely acknowledged in studies, as contextual information such as societal expectations towards care homes or the availability of public funding were often not discussed in studies.

Cultural and social dimensions of care provision
It is widely argued that care home culture is reflective of a lack of appreciation and understanding of old age, frailty and dementia in society at large, including the

difficulty of recruiting suitable staff into a sector that in most countries is poorly paid (Owen and Meyer, 2012). For example, Barbosa et al. (2017) argued that difficulties of attracting staff to PCC training in a study in Portugal reflected disregard for care and caring in the care home and in society.

Another aspect was the medicalisation of long-term care, especially the acceptability of the use of anti-psychotic drugs in people with dementia, that was reported as undermining carers' motivation to prioritise alternative, non-medical interventions for residents (Ducak et al., 2018).

Policies affecting personalisation (e.g. emphasis on safeguarding)
A few studies noted that the policy environment created an obvious context for the implementation of measures to promote personalisation. Two factors were seen as particularly pertinent: policies aimed at promoting personalisation; and policies seen as potentially conflicting with this aim. Studies in a number of countries noted that policies had been introduced to encourage more personalised services in care homes, such as Sweden (Nordin et al., 2017, Roos et al., 2016); Ireland (O'Dwyer, 2013), the US (Grabowski et al., 2014, Poey et al., 2017), and Germany (Dichter et al., 2015). However, there were also a number of studies commenting that efforts to personalise care were hampered by conflicting policies or regulatory requirements, often relating to safety and safeguarding. These were particularly noted in studies in the US assessing the effects of changes to the physical environment in homes that often involved trade-offs between residents' autonomy and safety (e.g. allowing residents to use the equipment to be found in homelike kitchens unsupervised) (Hung et al., 2016, Roberts, 2016). Other studies of culture change interventions also cited regulatory requirements to adhere to safety standards as a barrier (Brownie and Nancarrow, 2013, Hunter et al., 2016, Rockwell, 2012). On the other hand, there were reports of efforts to change the regulatory and legislative environment, including provision of financial incentives for culture change in the US (Coogle et al., 2004, Doll et al., 2017, Grabowski et al., 2014).

Costs of change and availability of (public) funding
Only a few studies mentioned the cost of change and discussed the financial implications of interventions to promote personalisation. Ducak et al. (2018) suggested that the funding context for long-term care in Canada was not beneficial to recreational (Montessori) activities, as programme materials, adequate staff-to-resident ratios, and staff training all required a level of funding that was rarely available.

Roberts et al (2016) acknowledged that changes to the physical layout could be expensive for care homes participating in culture change initiatives. Other studies of care homes participating in culture change in the US also reported costs to be a barrier (Brownie and Nancarrow, 2013, Hermer et al., 2018). Grabowski et al. (2014) found that homes in the US were more likely to make such investments in markets that were more competitive than in markets in which care homes did not compete for residents.

4.5 Discussion

We have reviewed the literature on approaches to promoting personalisation in care homes for older people, their effects on residents, and factors that help or hinder embedding such approaches.

Our review identified approaches to promoting personalisation in care homes corresponding to three levels of our framework; those focused on service users directly; those focused on carers and the care relationship; and those focused on the organisation and physical environment of care homes. We also found that approaches were underpinned by different conceptualisations of the purposes of personalisation in residential care, with interventions at the first and second levels aiming to improve care

for people with dementia through the role of the carer and the care relationship (i.e. by providing PCC), and interventions at the third level aiming to enable residents to live as autonomously and in as 'home-like' environments as possible, to compensate for the loss of individuality in a setting of collective care provision.

Our framework helps to understand the relationships between approaches, effects and their context. Some approaches aimed at residents directly contributed to people's wellbeing, and in particular reduced agitation and challenging behaviours of people with dementia. However, studies that examined such approaches in isolation usually used qualitative designs making it difficult to identify whether these approaches were more effective than 'usual care'. Evidence of effectiveness was strongest in quantitative studies in which such approaches were combined with staff training in PCC as a joint intervention (Ballard et al., 2018) or where the review combined user focused approaches with staff-focused approaches (Kim and Park, 2017).

Approaches aimed at improving the care relationship mostly operated through providing various forms of PCC training to care home staff including techniques to improve staff's knowledge of residents and awareness of their needs (e.g. life story approaches). These approaches were mostly associated with settings that provided dementia care for older people, although this was not always so. There is now substantial evidence that providing training in PCC to care home staff is effective in improving the care relationship and enhancing some outcomes for residents, such as reducing agitation and improving quality of life. However, there were also a number of studies (including those with experimental and quasi-experimental designs) that reported no or negative effects on some outcomes. There was substantial variation in the type of training provided, outcomes measured and research methods applied, suggesting that attention needs to be given to the specific design of any training. Fossey et al. (2014a) found in the UK that while there are many training manuals on PCC available, only a small minority are based on evidence of effectiveness. While it is likely that such staff focused approaches benefitted from efforts being made over a sustained period of time, rather than provided as a single intervention, it is not clear from this analysis how differences in baseline (e.g. previous awareness, knowledge and practice of staff) and in exposure duration affected the effects measured in studies.

Approaches to promoting PCC aimed at carers benefited from an organisational context that supported staff in changing their care practices and in devoting time to providing PCC. It is not clear from this analysis how staff could make such changes without attention given to workload, staff time and funding. Our analysis also suggests that efforts to change care practice could only be successful if the leadership of the homes is supportive of personalisation in principle as well as in practice.

Approaches aimed at the care home as a whole described in the literature largely aimed at holistic organisational change associated with culture change models. These studies mostly originated in North America. It is not clear from this review whether such holistic approaches were absent in other countries, whether they have not been studied yet or whether they did not feature in this review for other reasons (e.g. other terminology used not covered in the search). While there were few studies that measured the effects of such culture change models robustly, the studies available raise relevant questions about the aims of, and approaches to, personalisation. For example, it is notable that while there are recent studies from the UK that have tested a combination of approaches (e.g. WHELD), demonstrating awareness of the relative merits of different approaches, a holistic view on 'culture change' that includes interventions at the level of the organisation aimed at management, organisational structure or the physical environment appears to be largely absent.

There are also questions relating to the characteristics of residents in care homes, the severity of their need for care and the type of care needed. While the literature suggests that relationship-focused PCC approaches are most appropriate for people

with dementia, there is residual uncertainty about some aspects of their wellbeing that may not be addressed sufficiently by PCC in isolation (e.g. the effect of boredom on agitation). There may also be limits to the effects of PCC on older people in care homes that do not have dementia (e.g. the frail elderly), which – as far as we can discern – have not been addressed in the research literature.

Our search identified a number of studies that mentioned changes in long-term care policy aimed at personalisation (e.g. in Sweden, US, Germany) and a few US studies mentioned funding models that provided financial incentives to stimulate care homes to personalise their care. However, our review did not identify a study that provided information about any measured effects of changes in policy, financial incentives or availability of funding. Such approaches (which we classified as 'wider societal') were, if at all, only discussed as the context of approaches aimed at individuals, staff or the specific care home.

Chapter 5
Approaches to personalisation in care homes – Interviews with care home managers

5.1 Introduction

This chapter reports on the findings from the interviews with care home managers to explore current approaches to implementing personalised services in practice in care homes for older people, the barriers to and support for such approaches they encountered.

To analyse our data, we have used an analytical framework derived from 'My Home Life', which resulted from the work of a partnership of academic and stakeholder organisations, including the Joseph Rowntree Trust, Age UK and BUPA. As part of its work programme, a literature review was conducted on factors that influence the quality of life in care homes (NCHRDF, 2007). The review identified eight themes, of which three are directly relevant to personalisation. The first theme, maintaining identity, requires staff in care homes to help older people maintain their identity or sense of self, to find out who they are, what is important to them, and how the care home can best meet their care needs without disrupting their sense of continuity and autonomy. The second theme, sharing decision making, underlines that decision making about care should be shared by residents, families and staff, shifting decision making power from professionals to service users ideally, although this would often involve residents' family members. The third theme, creating community, highlights the importance of relationships within the home and how care home staff can create a positive environment for residents both within the home and by fostering relationships between the home and the local community it is located in.

This chapter uses the data from interviews with care home managers and thus focuses the analysis on the role of managers in facilitating efforts to ensure and enhance personalisation. Whilst there is now a growing body of literature about the quality of English care homes, the literature on the role of care home managers is sparse. The reasons might be partly due to managers of care homes not being recognised as members of a profession in their own right, unlike nurses, teachers or social workers. However, a recent scoping review established that the work of care home managers is varied and highly demanding, involving high levels of responsibility and often conflicting demands from staff, residents, families and regulators, therefore requiring substantial dedication and a broad range of skills and knowledge (Orellana, 2014). Dudman et al. (2018) has argued that care home managers are exposed to substantial external and internal pressures, such as constraints on funding and on the availability of skilled staff, often in the face of an increasingly complex set of care needs, which means that some managers struggle to fully meet residents' care needs within the homes they are responsible for.

Risk aversion of managers in organising the provision of care has been identified as a perennial obstacle to personalisation in care homes, perhaps especially in homes in which a high level of nursing care is provided. Brannelly (2011) noted that the tendency to label residents with a high level of need, especially those with limited cognitive capacity due to advanced dementia, as 'burdensome' still persisted, while those providing care were constructed as 'burdened'. Dingwall et al. (2017) suggested that differences in risk aversion may reflect differences in professional training of managers, with those with a nursing background often seen as being more risk averse than those with a background in, for example, social work.

The role of managers in facilitating appropriate social relations between staff, residents and their families, which is a hallmark of personalisation, is still under-researched. In an ethnographic study for a doctoral thesis, Campbell (2014) noted that nurturing positive relationships was difficult for managers in the study site and often not fully embedded in organisational practice. In a survey of 92 care homes in England, Cooper et al. (2018) found that, in many homes, staff displayed neglectful or abusive behaviour, such as ignoring residents whose behaviours were deemed challenging,

allowing insufficient time for individuals to eat by themselves, and showing insufficient care when moving residents who were unable to move by themselves. Campbell (2014) also observed that staff seemed to accept that residents were frequently bored due to a lack of occupation and engagement.

Studies have established that leadership is essential to the provision of quality care in residential settings (Sjogren et al., 2017, CQC, 2017b). Rokstad et al. (2015), investigating the role of leadership in facilitating the development of person-centred care, found that those operating in a highly professional leadership role motivated their staff more than those with a market orientated or traditionally influenced role, as they showed vision and focus on professional development. This study also noted that having a leader present in the home was important to maintain morale of staff, with managers who were able to lead by example being particularly effective.

5.2 Approaches to support residents to maintain their identity

Most managers noted that the most important route to supporting and maintaining identity, was building a relationship of trust between residents, family members and care home staff. By trusting others, they explained, residents would have the confidence to express themselves, and better communicate their individual needs, choices and preferences. This was seen as particularly significant for people entering residential care during a period of crisis, when previous care arrangements had broken down, resulting in individuals feeling frightened, confused and potentially disorientated. Trust was also said to be important between residents' families and care home staff, particularly if the resident had reduced mental capacity. In these cases, family members were often involved in providing information to care staff about the resident's history and life journey, including communicating any knowledge they might have about their relative's needs and wishes, and they also provided the person with important emotional reassurance and continuity.

Managers described their use of various methods to develop a trusting relationship. These included approaches aimed at: getting to know the individual as a person; having a person-centred philosophy in the care home where choices and preferences were supported; ensuring staff were skilled and committed to working with residents; and seeking and being responsive to feedback.

Getting to know the individual as a person

Getting to know the individual was regarded as the basis of high quality person-centred care, as expressed by one manager who asked *"how can you be person-centred if you don't know the person?"* (Manager 3). Managers stated that they aimed to build trust as early as possible, typically starting before admission, when the manager met the resident and family members during the pre-admission assessment. Building trust was also seen as central on admission to the care home, which could be supported, for example, by assigning a specific member of staff (often termed a 'key worker') to the individual. This key worker would develop a care plan together with the individual and their families and would be responsible for coordinating and tailoring the care of the person. This often involved the creation of life histories, in which carers documented important events of the resident's life and portrayed their hobbies, interests and social activities, so that care staff were able to:

> *"Understand and respond to [the resident] as an individual person, with dignity, respecting their wishes and desires about how they want to live in the care home, and planning their care and support accordingly."* (Manager 4)

Another manager noted:

> *"Finding the essence of somebody, whatever it was that they did in their life before they got to this point"* and *"it's about keeping that going and keeping it alive in whatever small way you can."* (Manager 24)

Various tools were mentioned that managers and staff used to learn more about residents' pasts and personalities, such as the collation of life story books, memory albums or boxes or completing a 'This Is Me' booklet (Alzheimer Society, 2019). Alongside documenting the preferences for everyday life and activities, and their likes and dislikes, to enable personalised care and support planning, these present a history of who the person was before entering the care home, including what they used to do. Managers spoke about these approaches being essential to help the care home provide opportunities for residents to engage in meaningful activities that reflected their life history and were appropriate to their skills and experiences, such as continuing with gardening, preparing food or helping with the care home's laundry if they so wished.

Life stories and memory boxes or albums were viewed as important tools for those caring for people who had reduced mental capacity. They could also serve as an aid to communication, provided residents with familiar points of reference and gave care staff objects as 'talking points' that the resident could recognise. They also helped staff understand, and respond better to, residents' behaviours, and recognise triggers of these, such as key dates from the resident's past, or references to previous occupations. For example, one manager recounted how the tool helped staff understand the reasons why a resident wanted to get up very early in the morning (he used to be a farmer) or, in another case, provide an explanation for a resident who wandered around in the middle of the night (he used to be a poacher) (Manager 24). Such tools were also used as a distraction technique, as familiar objects could be used as suitable props to help calm confused or agitated residents (Manager 1).

Other strategies, such as the use of personal objects to individualise residents' bedrooms, were considered helpful in reinforcing personal identity. However, care homes varied with regard to the type of personal items they allowed residents to bring with them. Some managers noted that in their care home residents could only bring relatively small personal items such as pictures or photographs. In some care homes, all residents were required to use the care home's choice of curtains, carpets, furniture and wall colours. In contrast, managers of other homes stated that they allowed residents to bring their own furniture (as long as they complied with health and safety regulations) and choose their wall colours. In some homes, residents were able to decorate not just their own bedrooms, but also the immediate corridor outside their room, so that this also became 'their space' (Manager 18).

Many managers noted the importance of having accurate information about the personality of the resident, particularly if, in the case of residents with severe dementia, they had to rely on information from family or friends. However, managers often had only sparse accounts available to them, particularly if there were no close relatives or friends available to provide more detailed information:

> *"But, some [people], they don't have anyone. There's no-one. We've got a gentleman whereby [he was] not even known by the NHS. [He'd] never registered … trying to track [his] history, it was very difficult. And it was just a sudden, early onset of dementia. And [the gentleman] completely got confused. So, it's catching up a few phrases. And, then you think, okay, 'I think they used to like this. I think they used to do this'."* (Manager 23)

Even in some cases where family members were available, managers struggled to collect the information they required, if relatives were reluctant to share information about their family members entering the home.

Retaining links with previous service providers, such as enabling visits to a familiar hairdresser or barber, or continuing care with a life-long GP, was viewed as helpful for maintaining identity and a few managers said that they were able to facilitate these in their care homes. However, there were limitations to the extent this was possible. GPs would often not continue their service if the resident moved out of their catchment area. Some managers also argued that having the same or a small number of local GPs for all residents in the home would enable them to provide a more consistent service and ensure availability if an urgent visit was required.

Person-centred philosophy

The importance of care homes embracing person-centred attitudes, whereby all care staff valued residents as individuals, understood their personalities, and respected their dignity and privacy, was articulated by all managers interviewed. Approaches employed included developing a shared vision of the care home as being 'just like the resident's own home', having a 'family friendly focus', not being 'an institution', for example, by care home staff not wearing uniforms. Many managers described their care homes as 'very homely', 'cosy', 'calm' and 'comfortable' (Manager 24, Manager 14, Manager 15, Manager 17, Manager 18, Manager 8, Manager 9, Manager 21, Manager 6, Manager 4). Care home staff were expected to perceive themselves as 'members of the family' or as 'guests within the residents' home', and would normally be on first name terms with residents, unless residents wished to be addressed more formally. Some managers noted that they encouraged residents to be involved in aspects of the organisation of the care home (as they would likely be if they were living in their own homes) such as choosing menus, interviewing new applicants to staff positions and suggesting activities and outings. All care staff were expected to maintain residents' privacy, particularly when the residents were in their own bedroom:

> *"We embed it into the staff that their bedroom door is like your front door, so it has to be treated as such. That it isn't just a case of knock and walk in. That actually you should knock and wait and knock again even if you know the resident won't hear you."* (Manager 18)

Skilled and committed care staff

Supporting residents to maintain their identity, or 'be themselves', through relationship-centred care, required staff who were knowledgeable and skilled in caring for people with complex, changeable and sometimes challenging needs, and who could recognise and respond appropriately to behavioural triggers in a person-centred way. Having a core of stable, reliable and empathic staff was seen as an important factor in building relationships with both residents and family members. Most managers interviewed stated that having the 'right' staff, e.g. those with a positive attitude to caring for older people, was central to providing person-centred care, and that it was important that staff were able to emotionally connect with residents in their care. As one manager explained:

> *"… not everybody can do it … you can get some absolutely fantastic carers … they can do the tasks, but they can't give people what they need, you know, all the psychological aspects … they don't have it in them to be able to connect with people … it's like they're detached individuals."* (Manager 7)

Managers spoke about strategies employed to recruiting appropriate staff, such as including residents at interviews to assess the interviewee's verbal and non-verbal communication skills:

> *"I have staff come for interviews that pulled a face when she [the resident] started talking. Or would totally blank her and talk to me. And those people I didn't offer a job because I thought, 'if they can do that to her in front of me, what are they going to be like when I'm not about as well'?"* (Manager 13)

Another manager explained her approach to testing candidates' person-centred care skills even before the interview:

> *"I leave people out in the lounge for about three-quarters of an hour before I actually do an interview, so I can see whether they're sat there on their own, on their phone, or whether they're interacting with the residents that are around them."* (Manager 9)

Many provided examples of having a core team of committed, reliable long-term staff who shared their care home's person-centred values. Low staff turnover was considered a positive factor, particularly in a workforce that was hard to recruit and retain, as managers would not have to rely too much on short-term or agency staff, who were unlikely be able to provide the consistency required for building relationships. Some said that they operated a policy of not using agency staff, one suggesting that their 'family friendly flexible staff rotas' helped with continuity of care and staff retention rates (Manager 9).

Investment in staff, preferably through face-to-face training, which many preferred to 'on-line' versions, was recognised as important for developing skills in person-centred care. In addition to the mandatory training required for working in a care home, such as safeguarding and infection control, many managers said that they carried out their own in-house dementia and person-centred training courses for their staff. Some noted that they encouraged and supported their staff to train for a vocational qualification in care. Others said that they instigated a more individualised, tailored approach to ensuring that their staff met the required standards of person-centeredness:

> *"Anything we see that our staff are lacking, we find the trainers to do a bespoke [training]. And, then, whenever we phone up to say, we need this kind of training, I actually tell [the trainers] 'I've noted in the nursing home this [behaviour]. They are failing. They don't understand what respect is'."* (Manager 23)

Managers professed awareness of the importance of showing staff that they were valued in the same way that they expected their members of staff to value residents. For example, one manager who worked to change the culture in the care home so as to reduce staff turnover, the use of agency personnel and staff sickness rates noted:

> *"I think it's because we've been working really hard on the culture and it is how the management treat the actual staff as well. So if you're treating your staff in a very person-centred way they're more likely to, you know, be more person-centred to the people that have to live here." (Manager 7)*

Seeking and being responsive to feedback

Maintaining personal identity through a relationship of trust involves a person feeling and experiencing that their voice is heard and responded to. A variety of approaches to listening and responding to residents' views were mentioned by interviewees, including seeking feedback directly from individual residents and collectively through resident surveys such as 'Feedback Friday' forms, resident committee meetings, and other fora such as open events or coffee mornings for residents and relatives. Some meetings were specific to an aspect of care home life, such as 'meeting the chef', while others were organised around planning group activities or outings, typically hosted by the care home's activities co-ordinator. Meetings were normally organised and led by one of the care home managers, although one provided an example of having a residents' meeting chaired by a resident. Some managers stated that they operated an 'open door policy', whereby residents and relatives could see the manager in her office informally and discuss matters at any time, rather than having to wait for a formal opportunity such as a residents' meeting.

5.3 Approaches to enable shared decision-making

Managers spoke about approaches they employed to ensure that residents and their families were involved in the decisions that affected their lives in the care home. These involved decisions about moving into residential care; decisions relating to living in a care home, including choices of individual and group activities; and how expectation and risks associated with some choices were managed as part of this process.

These decisions were documented in the individual's personalised care plan, a practical working document identifying the resident's assessed health and social care needs, personal preferences, and the degree of support required. Information provided by the resident, the family and health and social care professionals, before and during the admission and transition period, contributed to the care plan, which most said to be regularly reviewed and updated to reflect changing needs and wishes. Managers stated that they encouraged residents and family members to contribute to reviewing and updating the care plan, so that care staff could provide appropriate support, particularly if the resident was not able to communicate his or her wishes easily.

Decision to move into a care home

Decisions to move into residential care, including the choice of care home which best meets needs, are rarely made in isolation. The person requiring care, and their relatives, would normally make this decision following meetings with health and social care professionals, including care home staff. Families also often seek information about potential care homes provided on-line, and by trusted others, such as friends.

Managers spoke about these decisions being very difficult for families, especially in crisis situations when current care arrangements were no longer sufficient, and moving into long-term residential or nursing care was the only viable option. Such decisions tended to require high levels of support and guidance from care staff, including home or hospital visits by care home managers to discuss options with the individual and family. Some managers noted that, on occasion, residents were admitted to a care home temporarily to test whether they would be happy being in a home, before committing to move.

However, managers observed that older people and their families sometimes struggled to come to a decision, especially if there was disagreement between the older person not wanting to move, and the wishes of family members. In such cases, care home managers described various tactics to convince people to make the decision to move into care, ranging from addressing fears and persuasion, to more deceptive tactics:

> *"… obviously, with the challenging behaviour comes the 'I'm not going to go into a home'. So, sometimes what we've done is 'sell' it to them as, like, a holiday break [or for] decorating … 'we'll go and decorate your lounge, mum, so what about you come [to the care home] for a two-week break?' And normally within those two weeks we've managed to coerce them round."*
> (Manager 22)

In such instances, moving into a care home was seen as a 'last resort' when all other options to care for the older person were exploited. Only a few care home managers mentioned residents making decisions to come into care as a positive choice, for example, to combat loneliness and isolation, or to better support their partner who was already a resident in the home. A manager recalled a couple who had sold their house to live in the care home so that they could take advantage of what it had to offer, such as company, meals and security "knowing someone is around twenty-four seven". This enabled them to continue their lives as before, but with additional support:

"[The couple] still go and do their own shopping, still go to church independently, one still goes to play bowls, and watch bowls." (Manager 8)

A few managers interviewed suggested that opting to enter a care home before it became a necessity could be a positive choice. Residents would then be more likely to enjoy staying in the home as they would have better health and mobility, and would, therefore, be able to engage more actively in the social opportunities offered by a community of their peers. On the other hand, Government policies of promoting personalisation, whereby individuals were encouraged to live in their own homes as long as possible, and the cultural stigma associated with living in a care home, were said to restrict choices of moving into residential long-term care.

"Often families are saying to me now, 'Oh, gosh, I wish, you know, I wish mum would have agreed to this a year ago. She'd have loved it'. But it's such a big step and because we are, quite rightly, with the personalisation, allowing people to stay at home for longer, and we haven't got rid of that 'you're being put in care' scenario … because of the age of the people, they know about care homes, they know about the institutions back [then] … and the [stigma of the] poor house." (Manager 10)

Decisions on care home life and activities

Decisions on how people want to live their lives once they have moved into a care home – such as when to get up, what to wear, when and what to eat – were reported to be made primarily by the resident, regardless of mental capacity, yet typically with support from staff. Other decisions, such as choosing to undertake individual activities, were often discussed by residents, care staff and family members, and were dependent on the level of individual need and the risks to the person arising from the activity.

Continually asking residents to choose and make decisions, even if answers could be predicted with a high level of confidence, were common strategies employed to ensure that residents were involved in decisions made on daily basis. For example, managers spoke about staff being expected to ask residents about what they would like for lunch rather than say 'Do you want a sandwich again for lunch? ', even if the resident had always chosen sandwiches in the past.

It was generally agreed that individual activities should be meaningful for the individual. Managers described residents making 'meaningful' decisions to engage in activities aimed at leisure and entertainment: such as taking a walk to the local pub or newsagent; reading a book; completing a jigsaw or crossword puzzle; and other activities relating to their past life history and skills, such as gardening; and simple building maintenance or household chores, such as folding napkins or preparing vegetables.

Activities that people would like to participate in depended on residents having mental capacity and there being an 'acceptable' level of risk for the individual, staff and/or family member. These were reported to be assessed on a case by case basis, although some choices might be obviously unacceptable and considered too risky for their client group.

Many managers noted that they had to balance the individual's wishes against the needs of the other residents and care staff. In some cases, this led to a degree of risk aversion among staff that could reduce the degree of choice available to the individual. However, many managers were willing to accept some risk if they judged the activity to be beneficial to the resident. For example, one manager defended her/his decision to enable one of the older residents to engage in her passion for horse riding, despite her physical frailty:

"We've got a picture of her with the biggest smile you've ever seen. She was on the horse for about five minutes. … I was thinking 'this is fine as long as it goes right, this is fine as long as it goes right' but it was worth every moment.

And she's got a picture of [herself on a horse] when she was three and a picture of when she was 85 or whatever it is. It's at the bottom of her bed…The difference in that woman for about three to four weeks, elevated." (Manager 10)

Residents with a Deprivation of Liberty Safeguard (DoLS) in place were usually required to be accompanied by a staff or family member if they wished to leave the home. However, one manager said that they had an agreement with a local taxi company to collect, wait for and return a resident with a DoLS on his chosen trips to the shops (Manager 22). This way, it was argued, the resident was allowed a degree of independence, despite the DoLS, and with agreement from the family. Another manager noted that they would telephone a local coffee shop to let them know that a particular resident (who had dementia) was on his way and *"then they ring us when he's coming, when he's leaving"* (Manager 15). In this case, the resident was known at his local coffee shop for a number of years before entering care, and the care home manager judged his visits to the cafe to be important to his wellbeing, so aimed to facilitate such visits in a safe and managed way.

Resource constraints were also identified as a potential limitation to choice of activities, particularly with regard to individualised activities outside the home if residents were required to be accompanied by a staff member. Many managers conceded that their care homes often relied on families or friends to escort residents. In one case, it was acknowledged that staff shortages meant they had to prioritise personal care over other activities, as staff were "too pushed" to facilitate them, and residents missed out as consequence (Manager 10). Thus, although managers endeavoured to facilitate activities that were meaningful to residents and resulted from their own decisions, it was not always possible within the organisational constraints of the care home.

Managers also explained that residents were typically expected to fund activities by themselves that were seen as relating to their lifestyles such as hairdressing, smoking and clothing, but that such choices could be limited by the availability of personal funds. One manager spoke about subsidising some of her/his residents' personal wishes if individual funds were not sufficient:

"… I have people who owe me an awful lot of money because they still want their hair done, they still smoke, and a packet of cigarettes is £8, £9 or whatever it is. … I wouldn't let people miss out because of the money. However, obviously people who don't have relatives, one thing, and secondly who only have the government funding pocket money to manage within, they can't." (Manager 2)

Supporting family co-operation

As with supporting individuals to maintain their identities, trust was viewed as important for enabling co-operation in decision-making, particularly with those lacking capacity as some choices may not be viewed as being in the resident's best interest or perceived as too risky. Building good relationships were viewed as important to help keep residents and relatives 'on side' and, using skills of good communication, could prevent disagreements. In the experience of managers, families could give the care home a 'hard time' if they did not agree with the care home in supporting their family member's choice.

Managers noted that working with family members to develop a shared understanding of their relative's care needs and abilities was an important part of their work. Many stated that having regular conversations with residents and family members, to plan and make decisions jointly around their care and their choice of activities, was fundamental to maintain a good rapport. Some expressed taking a different approach to decision-making for people without capacity, such as suggesting alternatives or agreeing a delay, whilst ensuring the resident's involvement in any decisions made:

"… you've got to try and gain co-operation, I think. You know, sometimes it's just a little bit about wording things so they think it's with their agreement that they have decided not to do things. And again, it's trust, isn't it, it's about explaining properly, and gaining trust, you know, well, 'maybe we could consider it', 'doing something a different day', or a 'different way', and usually people will respect that." (Manager 9)

Some managers conceded that it could be difficult to build relationships with family members especially in situations in which staff and family disagreed about the care needs of residents and how these could best be met. For instance, a manager spoke of family members wanting to bring certain types of food, ignoring the fact that their family member was unable to swallow this type of food. Another manager recalled a family being concerned that their relative was always in bed when they visited, although this was said to be the resident's preference rather than the care home's oversight.

Whose choice and whose decisions?
Some managers described that ensuring that residents remained in control of decisions could be difficult, as many residents tended to passively acquiesce with care home staff, or with their relatives, which could mask disagreements. A manager recalled an instance in which she faced difficulty in discerning whether a resident actually wanted to share a room with another resident, or whether the resident's agreement was reflective of a desire to appease family members (who may have wanted to save some money by paying a lower rate for a shared room). In this case, coming to any shared decision was difficult:

"… because what [the residents] say isn't always really the truth and what the families say isn't always the truth." (Manager 13)

Others spoke about their residents always consenting to care staff's suggestions about their care. One care home manager described this as a cultural and generational phenomenon, explaining residents' compliant behaviour as 'normal' for their age and cultural background, and therefore expressed the need for carers to be aware of this tendency when making suggestions (Manager 20).

Strategies to address this tendency to acquiesce in decision-making included building relationships and supporting residents' confidence to choose or refuse suggestions, or to change their minds if necessary. For example, a manager recalled a resident who said that she wanted to be involved in housekeeping tasks such as ironing. However, after a brief attempt she changed her mind:

"Then [the resident said] like 'I think you ought to get someone to do [the ironing] for you. It's about time you paid somebody to do that'. Okay, point taken. That's lovely that people are going, 'no, I'm not doing that'." (Manager 10)

In this case, the manager expressed satisfaction that the resident was able to express her preference, enabled by the relationship developed between the resident and herself. Managers also stressed the importance of being flexible and responsive (e.g. a willingness to change activities if residents changed their minds) and to be able to offer several options so that individuals were encouraged to choose, rather than passively to accept what was suggested to them.

5.4 **Approaches taken to 'create community'**

Creating a sense of community within the care home, and enabling the care home to be part of its local community, was identified as an important facet of personalisation. SCIE has set out the vision for the role of the care home as:

A "community of individuals who can derive support from each other" and therefore, "as in any community, people will have varied interests and skills". Person-centred care would therefore "encourage people to maintain, or recover their personal preferences by offering a wide variety of services. A care home which is open to the local community is able to provide many benefits to the residents by means of interaction with the community outside its doors. It can also become a valuable resource for the community. Going out can support independence, resilience, self-esteem, group solidarity and individual mobility. Bringing the 'outside' in, can widen residents' horizons, multiply services, combat loneliness and depression, and break down stereotypes." (SCIE, 2017)

As described in the introduction, creating community involves two components: the community of residents and staff *within the care home*, whereby the needs, interests and choices of residents as both individuals and as a community are supported; and the care home *within the community*, i.e. the extent to which the care home engages and interacts with its local community. In our study, we explored approaches reported by managers to foster both types of communities, and the challenges they encountered in doing so.

Creating a 'community of residents' within the care home
Managers explained how they tried to facilitate social relationships between residents in order to create a sense of community within their home. Approaches involved encouraging residents to engage in small or large group activities; attending at least one meal a day with other residents in the dining room; and creating environments to encourage residents to communicate with each other such as small social seating areas in communal parts of the home.

However, not all managerial efforts to promote social exchange were popular with residents. A manager found out that residents were regularly covertly rearranging the small-group seating she introduced to encourage residents to chat with each other, back to their preferred 'back to the wall' arrangement that the manager had aimed to abolish.

In addition to encouraging residents to engage with each other, managers also described how they involved residents in community living within the care home. Most managers mentioned organising residents' meetings or coffee mornings as opportunities to discuss suggestions about group activities or social events. Residents were also said to be involved in the organisation of the care home by sitting in on interviews with prospective new staff, and with day-to-day functions such as helping to choose menus. Some residents were said to have a desire to help with the preparation of food, laundry, light maintenance, gardening and cleaning, which the care home aimed to facilitate as part of their care and support plans.

In some care homes, residents' involvement in the running of the care home took the form of a residents' committee, whereby residents were encouraged to be involved in the day-to-day decisions of the care home, as they would be if they were living in their own homes:

"Well we have a committee of residents and there's probably only eight to ten people on that committee at any one time, but it does change. And the residents that want to get involved in the home, so they become the decision-makers.

So we go through our budget and know where we are, we go through our KPIs with them, we talk about new staff and how they feel they're getting on with them. We talk about any issues with staff and just generally how they're feeling about different services and what we need to put right to make it right and generally what's happening from their perspective." (Manager 18)

However, while committees and other fora were a common form of encouraging residents to become involved in the community of the care home, managers also noted that committees depended on residents' willingness and ability to engage in committee work and often relied on family members involvement. There was also a tendency observed for committees to be better at channelling feedback on services than proactively generating suggestions for enhancing community life within the care home.

Creating a community between residents and staff

Managers spoke about the importance of having skilled, caring staff who were motivated to work in a challenging, often physically taxing and emotionally charged environment. They also described approaches taken to developing, and maintaining, a sense of belonging and community that was inclusive of staff, as well as residents and their families. Approaches were largely interpersonal such as facilitating a culture of mutual respect and appreciation between residents, family members and staff, and one where managers led by example. Managers stressed the importance of care staff receiving the level of training and support required to be confident and motivated. One manager said that s/he provided a friendly and accessible working environment by openly expressing appreciation of staff on a daily basis:

"We give [care staff] a big hug every morning. When they walk in, they have the management hug and they go on to work. I think it's about that we're like approachable and they can come and talk to us about something anytime." (Manager 3)

However, recruiting, and keeping, good staff could be difficult, especially for those who ran care homes in areas, in which competition for qualified staff was high, and who provided care for people with challenging behaviours:

"And it's hard work, you know, 12-hour shifts…when you're going to get hit, spat at, verbally abused, it's hard. And the youngsters of today don't want to work [in this environment]. They can't manage 24 hours a week, because they get too tired." (Manager 22)

Such factors impeded the ability of care home managers to maintain consistent and sufficient staffing, which was seen as essential to maintain a sense of community among staff, as well as residents and families.

The care home as part of the local community

Descriptions of approaches to how care home managers built relationships with their local communities typically revolved around the same local groups such as school children, members of religious communities, and people bringing pets and other animals into the home *"because people do respond to children, don't they? Children and animals … they love it"* (Manager 8).

Approaches for residents to engage with their local community

Many managers provided examples in which they helped facilitate residents to engage in community activities related to their personal interests, such as maintaining a membership of a local sports club, or trips to the local library or community centre for classes or activities such as china painting or chess. Residents could venture out on their own, if they were physically and cognitively capable of doing so, or procedures were in place to ensure their safety, as previously described. However, some required

staff, relatives or friends to accompany them, which made it more difficult to organise such excursions into the local community, making them much rarer.

One manager mentioned that s/he planned to expand the community of the care home by creating a Dementia Friendly Community in the local area. Dementia Friendly Communities are promoted by the Alzheimer's Society and defined as:

"A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives." (Alzheimer's Society, 2018 p.12)

However, this was found to be hard to do without support from the local community, and the manager felt unsupported by the local authority (Manager 24). In this case, the manager decided to raise local awareness of dementia by providing support for specific dementia-friendly community activities, such as providing telephone support to informal carers of people with dementia, and writing articles about dementia in local newspapers.

Approaches for the community to engage with the care home
Approaches to inviting members of the local community *into* the care home were discussed by all interviewees, although there was variation between care homes about the amount, method and reasons for engagement. Some managers, especially those who cared for residents with a high level of care need, said that they opted to 'bring the community in' to the care home rather than seek community engagement outside the home, as their *"residents won't go out too much into the community"* (Manager 2). They judged that their residents were too *"vulnerable and unpredictable"* because of their frailty or lack of mental capacity to do so. For others, the logistics of travel and support, such as wheelchair capacity of transport and the availability of staff to accompany residents, meant that 'inviting in' was viewed as a more feasible option than organising excursions outside the home (Manager 5).

Managers referred to a variety of community activities, services and entertainments provided in-house by volunteers who visited the care home individually or as part of a programme. Volunteers from churches and schools were most commonly mentioned, offering to read to residents who were confined to bed, bringing dogs or other animals for therapy and providing musical entertainment.

A few interviewees stated that their care home aimed to act as a 'hub' for the community. This could involve the care home hosting coffee mornings, memory cafes or events such as 'knit and natter' for their local community. Others accommodated local support groups such as those for carers or related charities such as the Alzheimer's Society, or the local Rotary Club. One care home offered an in-house dementia class for those caring for people with dementia in the community, and a weekly lunch club for residents and local people with dementia. However, several managers noted that while they would like to offer such opportunities, they felt that their care home was not well suited to invite people in, for example, due to a lack of suitable communal space.

A few managers stated hosting charitable events such as community quizzes, murder mysteries, summer fetes, events for children, jazz afternoons and music evenings. One manager described her intention to create the care home as *"a place where it's not what people expect"* (Manager 18) in order to break down barriers and reduce the social stigma associated with residential care. Most managers involved in such activities ran 'not-for-profit' care homes where fundraising formed part of the business model and it was therefore viewed as important to be locally connected and 'visible', as well as being a source of interaction with the community with positive benefits to the residents:

"We had a teddy bear's picnic for the children…the fact that our residents were out there all day just watching them – if they haven't got family coming – it's just so good for them." (Manager 18)

Others suggested that inviting the community into the care home itself carried extra risks, both for residents and visitors, which, in some cases, they were unwilling to take. For instance, several managers said that they would not invite younger children from local schools to visit their care home, as some of their residents may display challenging behaviours or use graphic language in front of the children. Another manager decided against having open days or events because of the potential risks some community members may pose to their residents:

"I've [held open days] in the past, but, to be honest with you, when you hold open days or fairs you don't know what you're getting through the door sometimes. You've got to be very, very careful….No disrespect to anybody, but you don't know what you're getting through your door, do you?" (Manager 19)

Some of those seeking to widen their links with the local community faced barriers such as a lack of resources and a lack of interest within their local community or an unwillingness to engage. For example, one manager spoke about trying to involve the local community college for trainee beauticians to provide in-house 'pamper sessions' for their residents, but did not get a response despite repeated attempts (Manager 13). In another example, a scheme involving visits by new mothers and their babies was stopped due to lack of interest from the mothers concerned, whilst being popular with residents.

5.5 Summary

Care home managers described a host of approaches to promoting personalisation in care homes by supporting residents' individual identities; enabling shared decision-making; creating a community among residents and staff within their care homes and building relationships with the local community.

Strategies to support individuals to maintain their sense of self, especially those with declining cognitive capacity, rested especially on the ability of care home staff to build trusting relationships with residents and their families. Managers emphasised the importance of their staff knowing the people they provide care for, of creating a sense of continuity and consistency, and of generating a homely environment that allow residents to express themselves; responding to their need for emotional support, familiarity and respect. Ensuring consistent and well-motivated staff that are skilled and able to respond to individuals' needs and preferences was seen as vital to support these goals.

Managers also provided a large number of examples illustrating, and problematising, the aim of shared decision-making, including approaches to help people when moving into residential care and supporting decisions of daily living while living in the home. Importantly, while the rhetoric of personalisation tends to emphasise individual decision-making and choice, the picture painted by managers was one of deliberation, risk awareness and contingency, balancing the benefits to residents from choice with the possibility of harm to themselves and to others, and identifying the efforts involved in facilitating choice and managing any resultant risks. Involving family members in such considerations was deemed essential by managers, although many conceded that there could be tensions between the wishes of the family, the professional opinion of staff and the choices that residents wished to make.

Managers gave many examples of how they aimed to create a community within their care home that was inclusive of residents, families and staff. Managers especially highlighted the importance of trying to reduce boundaries between management and

staff, on the one hand, and between management and staff, and residents and their families, on the other. Some of these approaches appeared to be largely symbolic in nature (e.g. staff not wearing uniforms), while others were practical (e.g. inviting the articulation of dissent), but all of them aspiring to create a community of (near) equals. This also involved managers leading their staff by example, through being directly involved in giving care rather than 'just' leading by instruction or supervision.

Creating supportive links with the surrounding local community appeared to be challenging, with most managers recounting similar examples of school children, members of faith organisations and people with pets being the most likely members from the local community to engage with residents, provide support, or entertain. In the experience of managers, engagement with the local community was contingent on several factors, including the willingness of community members to engage, the existence of structures that facilitated engagement within the community (e.g. the existence of a local dementia café), and the capacity of the care home to encourage such engagement (e.g. the availability of suitable space, having a garden, sufficient staffing). Managers also noted that there was persistent stigma attached to residential care, and its association with old age, death and institutionalisation, and that they experienced as constraining the opportunities for care homes to engage with members of the local community beyond the usual groups. Relating to local communities seemed to be easiest for charitable organisations which tended to have established approaches to engagement of local people in their fundraising efforts, although many managers provided other examples of individual members of the community supporting residents and contributing to personalising their care outside the home in creative ways (e.g. by providing a bespoke taxi service).

Chapter 6
What is a 'personalised' care home? An investigation of care home managers' ambitions for personalised care

6.1 Introduction

In residential care, personalisation is largely used synonymously with person-centred care, or personalised care. This suggests that personalisation is generally regarded as an aspect of care and caring. In this conceptualisation of personalisation, the role of the carer takes centre stage, both individually through the act of providing care, and as a member of a skilled workforce. In addition, there is a competing narrative about personalisation as individual choice and control. In adult social care, this latter conceptualisation is mostly derived from domiciliary care, where it is expressed as choice of carer and service.

Less attention is given to the organisational context of the care home, in which the provision of care is situated and in which the person needing care has his or her permanent residence. This combination of collective care provision and communal living arrangements differentiates personalisation in care homes from personalisation as it is experienced in domiciliary care provided to people who live in their own homes. Collective care provision, especially if it is associated with the provision of a public (or publicly funded) service, is sometimes portrayed pejoratively as 'institutional care', emphasising the organisational routines and requirements of the care homes and their constraining impact on the lives of residents. Institutional care is then seen as the opposite of personalised care and anathema to individual self-expression, identity and choice.

In the following analysis, we have interrogated our data from interviews with care home managers to understand better how managers understand personalisation in the context of their care home and what version, or which aspects, of personalisation they aspire to within their home. We attempt to answer two questions: how do care home managers conceptualise the personalisation approach of their care home; and which models of personalisation do they follow or aspire to in the homes they manage?

For the purpose of this analysis, we have developed a framework taking inspiration from the interviews with care home managers and from the relevant research and practice literature. In the interviews, some managers referred to their homes aiming to be like a 'hotel' or 'family' – and not to be like an 'institution' – as metaphors to describe their ambition for personalised care in the care homes they managed. In our analysis, we have aimed to delve deeper into the meaning of these metaphors, especially as they reflect aspects of the two competing narratives about the relevance of choice and control, and the importance of relationship building. We have organised the resulting framework along these two themes: the nature of the care relationship and the degree of choice in the setting of residential care. These resulted in four models of the personalised care home: the care home as an 'institution', a 'family home', a 'hotel', and a 'cooperative', which we have used to organise our analysis

6.2 Background

There is growing research interest in investigating the concept of 'home' in relation to long-term care. Studies of residential care often highlight the importance of care homes making residents feel 'at home' and developing a 'homelike' or 'homely' environment. 'At homeness' has been linked with improved quality of life of residents and is associated with feelings of belonging, familiarity, privacy and safety (Cooney, 2010). However, there is no agreement as to what constitutes 'homeliness' in residential care (Molony, 2010).

The idea of being at home is often associated with the image of the domestic home, the environment, it is assumed, older residents are most familiar with, although it has been argued that such imagery – the family home as a safe haven organised around a nuclear family, with its gendered ordering of tasks – is overly simplistic (Dyck

et al., 2005). For many older people, the experience of being in their own homes is likely to be much more mixed: the domestic environment can be a lonely place and burdensome to maintain in the face of age-related decline, while at the same time being experienced as a place of autonomy and self-actualisation. It is therefore convincing that feeling 'at home' is a much more "complex blend of emotional, cognitive, behavioural and social bonds to a particular place" than the idealist imagery suggests (Cooney, 2010: 2). Yet the domestic home remains the prototypical place of care that combines both individual choice and the closeness of the care relationship associated with family bonds.

6.2.1 Individual choice and decision-making

Individual choice features highly among the characteristics of 'at homeness', but is by no means the only criterion. Unlike in their own homes, residents of care homes usually do not have the option to decide who they live with, but are faced with living with a collection of strangers, whose habits, moods and manners have to be tolerated. Living in a care home, therefore, takes 'getting used to' and involves an effort of substantial adjustment on the part of a new resident. Cooney (2010) notes that residents who move into a care home of their own volition are often happier and more likely to feel at home than those who were placed in a care home by their family or social services.

In the care home context, choice and control also translates into how boundaries between public and private spaces are maintained and navigated. Invasions of privacy are preeminent characteristics of institutional living, in which members of staff enter residents' personal spaces such as bedrooms or bathrooms without asking for consent. Other choices within the care home include activities of daily living, such as getting out of or into bed, dressing, eating a meal, or having a drink. It also includes how people spend their time, and who they spend it with. Are they allowed, in principle and in practice, to leave the home if they so wish? Such decisions have implications for the safety of people with diminished capacity, be this physically because of their frailty and concerns about prevention of falls, or cognitively such as in cases of advanced dementia.

Frameworks for person-centred care tend to emphasise 'joint decision-making' as an important feature of personalisation (SCIE, 2019). However, it is not always clear how decisions can be made jointly. In theory, decisions should still be made by the resident, with carers and managers playing a supportive role. Yet in practice, it may not always be possible or practical to shift power entirely from carers to residents, both for reasons of residents' capacity to make decisions and for reasons such as time constraints, safety regulation and professional judgement. In addition, decisions taken in a communal context are likely to impact on other residents, as well as on carers.

6.2.2 Care relationship

A second body of literature relevant to this analysis discusses the role of the care relationship for the wellbeing of residents in care homes, especially, but not exclusively, people with dementia (Hutchinson et al., 2017, Wilberforce et al., 2017, McCormack and McCance, 2006). Person-centred care, as discussed in previous chapters, emphasises the importance of staff knowing the residents of their care home, to value their past and their experiences, and to appreciate their preferences and personalities. It is logical therefore that the attitudes and behaviours of care providers are central to the concept of person-centred care, and to the physical and psychological wellbeing of the resident with dementia (Fazio et al., 2018). A classic portrait of institutional care describes the absence of any of these attitudes or acts of human empathy. Kitwood (1997) listed the 'malignant social pathologies' observed that characterised carers' treatment of people with dementia, such as infantilising, labelling or disempowering behaviour. Such attitudes and behaviours do not happen

without context, but reflect the notion that people with dementia are not valued, and often not taken seriously, by society (Brooker, 2003). An empathetic, compassionate attitude is therefore seen as essential to foster the positive relationship that values residents as full people undiminished by disability or cognitive decline, in the same way in which staff should be valued by managers and families (Brooker, 2003). People with advanced dementia, who are not able to express themselves well through speech, often respond to other forms of communication including physical contact (Ward et al., 2008, Kontos and Naglie, 2007).

However, there can be tension between the professional responsibilities of staff, and their role as carers 'who care' (Lynch et al., 2018, Rockwell, 2012). For example, staff have to balance compliance with regulation and with other aspects of caring within the care relationship. Staff are professional carers and their relationship to residents is different from family carers. They are accountable for their actions within a managerial hierarchy, guided by a complex regulatory environment, as well as multiple forms of collaborations with other professionals, and expected to be responsive to pressures and expectations from families and others.

Nakrem et al. (2013) note that relationships between residents and staff are often ambiguous. Residents experience staff as kind and competent, as well as busy, preoccupied and not immediately responsive because of high workloads and competing priorities. Residents can feel reassured and relieved to get help while being in a home, but at the same time feel helpless, dependent and regretful of requiring support in the first place. Thus the care relationship, despite all the ambitions expressed in various frameworks and writings, remains a complex and difficult aim to achieve.

6.3 Framework

We have developed a framework to map the differences in the understanding and practices of personalisation in residential care, as they were reflected in the interviews of care home managers (Figure 6.1). The development of the framework was an iterative process taking inspiration from the interviews with care home managers, with managers using different metaphors (e.g. 'a hotel service', 'like a family') to describe their ambition for the type of personalised care they aimed to provide in the care home they managed. We used these metaphors as a starting point to interrogate the research and practitioner literature on personalisation, person-centred care and 'at homeness' in residential care, finding commonalities and investigating contrasts between the two main narratives of personalisation: the importance of choice and the importance of the care relationship.

This framework presents four quadrants that contain analogies for the type of personalisation that care home managers aimed to provide, mapped on two axes: the closeness of the relationship between residents and care personnel; and the nature of decision-making affecting the resident. These quadrants describe the care home as: 1. an institution, 2. a hotel, 3. a family home; and 4. a co-operative. The first three quadrants are based on metaphors care home managers used in interviews. We included the 'co-operative' as a fourth option, to describe a logical alternative resulting from the analysis, this term was not used by managers.

The purpose of the framework is to understand better the differences in the conceptualisation of personalisation by care home managers and the differences in practices resulting from these concepts.

The framework is not intended to classify care homes, and it is unlikely that any care home, as portrayed by its manager, would fall entirely into any one category. Arguably, all care homes have elements of an 'institution' simply because they are a form of collective provision of care in a regulated welfare sector, a trait that seems perhaps more

pronounced in some homes than in others. Instead, the framework aims to develop a better understanding of the tensions between different meanings of personalisation, the choices care home managers make in delivering personalisation, and the challenge of providing individualised care in the context of (communal) residential care provision.

Figure 6.1 Care home quadrant

Distant resident-carer relationships[1]

Care home as hotel
(Decisions taken by customer; customer service orientation)

Care home as institution
(Decisions taken by professionals; task orientation)

Emphasis on individual choice[4]

Emphasis on communal living[2]

Care home as co-operative
(Joint decision-making; individual provision)

Care home as family home
(Joint decision-making; communal provision)

Close resident-carer relationship[3]

1
- Asymmetric or hierarchical relationships (e.g. indicated by insignia of status, lack of emotional involvement of carers)
- Emphasis on professional boundaries, discipline and risk avoidance

2
- Permeable boundary between individual and communal space
- Encourages companionship
- Joint meal times
- Joint activities
- Inability to leave
- No assumption of agency/ cognitive capacity

3
- Symmetric/non-hierarchical relationships between residents and carers e.g. not wearing uniforms; using first names and endearments, no titles (e.g. matron); bringing pets; banter; making friends; involvement in household tasks; physical contact
- Emphasis on empathy and compassion (attitude); trust; risk taking

4
- Strict boundary between individual and communal space (e.g. privacy)
- Encourages individuality
- Individualised meals
- Individual activities
- Ability to leave
- Assumption of resident agency/ cognitive capacity

Care home as an institution

The image of the care home as an 'institution' is perhaps the most durable one in the literature and the public imagination. It is captured by the theory of the 'total institution' established by Erving Goffman in his essay collection 'Asylums' (1961), described as places of "residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life" (Goffman, 1991: 11). Residents living in the institution Goffman describes are separated from the outside world, while staff have a life outside the institution and are able to traverse its boundaries. The concept has been applied to many forms of communal living (psychiatric hospitals, military barracks, monasteries), including care homes. Townsend's work on care homes as 'the last refuge' (1962) was another seminal piece cementing the negative image of care homes

in which the frail elderly are subjected to routines they cannot escape from while having little opportunity to express themselves or to access the outside world.

The care home as an institution combines the two characteristics of the framework: the distant hierarchical relationship between carers and residents; and the routine-driven arrangements of communal life. Both are associated with 'batch living' (Goffman) and routinisation of tasks that strip away individual identities, afford residents no privacy or personal decision-making space, and prioritise the efficiency of the organisation over the wellbeing of the individuals it is supposed to look after. In today's discourse, the institution has almost mythical qualities referencing the care home of the past that nobody operating a care home today wants to be associated with. And yet, the image of the 'institution' appears to have survived and not only in reports of poor care. It appears in the use of set routines in providing personal care especially in nursing homes (Johnson et al., 2010); the often blurred boundaries between communal and private space; and the tendency of regulatory compliance to prevent residents taking risks and executing tasks they would normally do in their own homes (e.g. to access the kitchen, boil water for a cup of tea; handle a kitchen knife).

Care home as a family home
The care home as a family home emphasises communal living, but in a personalised, relationship-focused way that is compatible with the emphasis put on the positive care relationship in person-centred care. It underlines the need for compassion, emotional investment and empathy, while also stressing the importance of homeliness, permanence and familiarity within the home. It is most easily equated with care provided at a domestic scale, even if in practices this will include dozens of residents and staff, with homely interiors and home-like practices. It is often seen as most suitable for people with dementia both with regard to the emphasis on the care relationship but also because it is expected that a home-like environment will be more familiar to people, and will therefore help them to orientate themselves more easily when they enter residential care (Smith, 2013).

In her study of care home laundry, Buse et al. (2018) distinguished the visibility of laundry compatible with the domestic home from hotel-like handling of dirty washing 'behind the scenes'. Domestic tasks like ironing laundry or laying the table can connect residents with their own domestic past and thus help to personalise their experience of the home. However, while these tasks can promote identity and social engagement (and are often referred to as 'meaningful' activities), Buse also notes a tension between the aspiration of domestic living and communal, institutional aspects of home life, such as a lack of privacy around 'bulk' washing of residents' personal items.

Care home as a hotel
The image of the care home as a hotel is often associated with the upmarket, privately paid versions of residential care and the glossy brochures in which they present themselves.

The emphasis here is on choice, privacy and comfort, which can be imagined as provided by a hotel rather than a facility specialising in personal care and support. This image of the care home is compatible with the consumer model of health and social care, characterised by private provision and private funding, in which residents are cast as 'customers', 'clients' or 'guests' rather than 'patients' (Stevens et al., 2019). It is also expressed in the architectural design of some homes, which gives prominence to private bedrooms with en suite bathrooms, and facilities looking 'clean' and 'nice' rather than 'cosy' or 'domestic'. They are more likely to compare themselves to 'smart hotels' or 'stately homes' in which people are waited on rather than recipients of care (Buse et al., 2017). As a consequence, the model is less emphatic about the personal relationships within the home, be it through the care relationship or among the group of residents, and there is likely to be substantial tension between the model of the resident as the service consumer and the intrusion, intimacy and 'messiness' associated with personal care.

Care home as a co-operative

The image of the care home as a 'co-operative' has not been derived from the interviews directly, but has been developed here for contrast and for completeness of the framework. It explores the possibility of having a residential living arrangement that prioritises individual choice but still takes place in a setting of communal living, based on close relationships between carers and residents. In the UK, such arrangements are reminiscent of settings such as housing with extra care or assisted living, in which residents can decide themselves about the level of care they will require over time. Such arrangements would shift decision-making power to residents, underpinned by financial and organisational provisions supporting the model (e.g. the resident owning or renting space 'with care'), but this means that they are not easily compatible with care homes as we know them in which care is provided predominantly communally.

6.4 Results

6.4.1 Care home as an institution

In our interviews, institutional care was a firm point of reference for managers. Managers evoked the care home as an 'institution' when they wanted to describe the type of home that nobody wants and from which they would like to distance themselves. The image of the 'total institution' was frequently used for contrast, to provide a negative counterpoint to the efforts made by staff to personalise care and make people feel 'at home'.

> *"Well, the philosophy of care is basically that this is the person's home, so everybody here, nobody wants to go in to 24-hour care, it's never really something people want to go in. So, the idea is that this is going to be their home, and we make it as much [like] home. We don't like to think of it as the traditional type of care home in an institutionalised setting. We do try to make it as personal and as friendly as possible."* (Manager 21)

Evoking the 'institution' was all the more powerful as it conjured up the image of people losing both their freedom and their ability to determine how they spend their time upon entering a care home. Some managers therefore likened the institution to 'a prison' that people cannot escape from and a place that nobody wishes to enter if it can be avoided, a place in which people are not treated as human beings but as commodities that are stored, rather than cared for. As one manager noted with regret, the care home as an institution was still the dominant imagery among people entering care, and among members of the public (Manager 20).

In the managers' accounts, the image of the 'institution' was associated with routinised, regimented approaches to organising care, evoking the military as another example of a 'total institution'. Although this was commonly seen as 'a thing of the past', several managers pointed out that it was impossible to organise care in the communal setting of the home without a degree of routinisation and scheduling. Managers were aware that regimentation of care would affect the lives of residents deeply, resulting in a loss of control over decisions as basic as which clothes to wear and when to go to the toilet (Manager 30). Such an approach would negate residents' individuality and was incompatible with the warm, homely and relational provision of care that most managers aimed for.

Yet at the same time, aspects of the institution were seen to creep back into approaches to personalisation. Some managers conceded that providing individualised care was always more demanding and more time intensive than not individualising care, and thus could be difficult to deliver consistently in the resource constrained context of a care home. Some noted the influence of nurses and nursing training on task

orientation, which was reminiscent of care provided in hospitals. Nursing care was also associated with a tendency to avoid risks to residents (as patients), even if this might mean that residents would be less able to execute their own wishes:

> *"I think if it was… you know, because registered general nurses tend to be just the way it always has been. They really need that regimented structured way of doing things, don't they? They got a procedure and it's done this way, this way and this way, but we, as psychiatric nurses, you know, much more liberal, laid back approaches are taken, positive risks."* (Manager 5)

There were concerns about safety and about the ability of the manager to be able to demonstrate compliance with regulation and the home's 'duty of care' (Manager 3). Such concerns were also seen as a response to external regulation and the need to be able to provide an account of events that might put residents at risk, even if those risks resulted from residents' own choices. One manager conceded that their home had invested in a surveillance system in the communal areas of the home to be able to understand, and presumably demonstrate to families, whether incidences of harm to residents were the responsibility of the home:

> *"We also put the CCTV in communal areas. So, we've got all the lounges under CCTV and the corridors are under CCTV, because we have got residents that will put themselves on the floor and say they've had a fall. So, we can play back the CCTV to see that actually they haven't fallen, they've put themselves on the floor."* (Manager 32)

While it may be understandable that the managers feel under pressure to justify their own practices, such practices would be incompatible with care provided in people's own homes and were reminiscent of the disciplinary surveillance associated with prisons (Bentham's Panopticon described by Foucault comes to mind (Foucault, 1977)). The example also illustrates the shifting boundary between public (i.e. communal) and private space (presumably the person's bedroom) in which residents could experience privacy and would be trusted to be left on their own. However, attitudes towards surveillance and risk taking varied substantially between managers, in part reflecting the needs of different care home populations, with people with advanced dementia often seen as less able to protect themselves. These differences in views led to different approaches to surveillance and protection (e.g. whether residents were able to leave the home on their own or smoke outdoors during bad weather if they so wished).

Many managers described having to balance, and potentially trade off, personalisation, risk management and the need to organise care effectively and efficiently within the constraints of the home. The need to uphold some routines therefore meant that personalisation happened at the edges of these routines (Manager 21). This seemed particularly pronounced in care homes that offered nursing care to a larger number of residents who had particularly high care needs, requiring substantial personal care such as feeding, washing, dressing and continence care:

> *"It's quite difficult. With the best will in the world, with day-to-day functioning of a very busy care home with very, very dependent people who have predominantly physiological needs, so they're mostly incontinent, mostly need feeding. Out of the 60 people, I probably have 40 that need to be fed and are incontinent. So therefore, with my hand on my heart, a person's previous life and experiences can be merged into just the normal day-to-day running. After the immediate breakfast and getting people washed and dressed up and things like that, then possibly when they go into the day centre, which will cater for people who are able to express preferences, then you can explore [opportunities for personalisation]."* (Manager 3)

Although all managers interviewed for this study agreed with the aim of personalisation and described a plethora of approaches to individualising care, some conceded that it was not always easy, and sometimes impossible, to organise care without recourse to routines, task orientation and risk management associated with institutionalised care, with some being less optimistic about their ability to provide a truly personalised service than others (Manager 14).

6.4.2 Care home as a family home

The care home as a 'family home' was the version of a personalised care home most popular with managers. Treating residents 'as family' was seen by many managers as the model of personalised care that they aspired to within their home, build around close relationships and a sense of equality between residents and carers.

> *"In terms of, I'm talking about the staff really, how the staff create the culture, that it's about belief and it's about enjoyment and making sure that they're part of the family, that is… Again, you did ask me and I'm probably talking about this in a very long-winded way, but the heart of family life in residential care is that we're all in it together. We're all part of this process of family life."* (Manager 24)

By evoking the 'family' as the ideal version of the care home community, managers elevated the care relationship as the all-important ingredient to personalised care, appropriate for people in need of care and valued by both residents and staff. In particular, managers emphasised the necessity for residents, their families and staff to trust one another, to be able to build close relationships.

> *"Oh, philosophy of care – I think you've got to build up trust, you've got to build up trust with the people you're caring for, and with the relatives. I think when you've got that, and you get them onside, then you can build up relationships, and I think that's the secret of it, is being sort of relationship-centred, really. We use first name terms, you know, you go into some homes, and it's Matron, or things like that – it's not, it's [first name of manager] here, and they have my mobile number, so, you know, we can keep in contact if need be."* (Manager 17)

Managers described various techniques used by staff to create a positive, trusting relationship with residents, for example doing away with staff insignia such as uniforms or titles (Manager 4; Manager 35). Others noted that they felt that staff showing affection towards residents (giving a cuddle or a kiss) and sharing jokes, helped to build, and demonstrate these close relationships. Another care home manager explained that their approach to making relationships less formal was by using terms of endearment. The manager was conscious that this may not be to everyone's liking, thus clarified that staff needed to be judicious in their use of informal behaviour and aware of individual residents' preferences (Manager 27).

Importantly, from a personalisation perspective, being part of the family was fully compatible with exercising individual choices, which were encouraged and facilitated by staff respecting residents' wishes and decisions, rather than influencing them to suit their own professional ideas of residents' appropriate behaviour. Indeed, the ability to make decisions enabled residents to be themselves and to feel 'at home' in the care home. However, managers who highlighted the appeal of the care home 'as a family' tended to emphasise the communal aspects of living in a care home, the type of community they aspired to creating, and the activities they would do together within the home.

> *"I think it's about recognising who people are and what their choices are and making sure that we can offer them what they want and so it becomes their home. It feels like their home and we become part of a bigger family for them."* (Manager 28)

Perhaps unsurprisingly, the image of the care home as a 'family' was often evoked by managers who operated small to medium size care homes, with some saying that caring for a smaller number of residents gave them the advantage to respond flexibly to residents wishes, even at short notice (Manager 25). However, the emphasis on the small size of the home is relative compared to family sizes prevalent in many Western societies, thus stretching the notion of family, with communal living in a care home typically involving many more people than the typical family. However, size mattered in the accounts of managers, with managers of large homes also often referring to having smaller 'units' or 'wards' to ensure 'familiarity' to residents.

In some respect, the 'family' therefore was an aspiration and an ideal, often aimed at invoking a particular form of care and caring in staff, a metaphor that could be used to translate how staff were expected to treat and relate to residents, rather than residents being expected to relate to staff or to the care home (Manager 23).

Another feature of the family model of personalisation mentioned in interviews was enabling residents to participate in domestic activities. These were seen as a method of encouraging community and a sense of belonging, but also of creating continuity between residents' lives before and after entering the care home. Such activities could include dusting, washing up, tidying up, ironing and gardening, some of which could blend in with programmes of activities (such as a 'seed to fork' scheme a manager mentioned, Manager 28), while others reflected individual residents' desires for useful occupation that the care home aimed to accommodate (Manager 35; Manager 29). However, managers also noted that such efforts sometimes remained symbolic, with residents wanting to 'help' staff while no longer being able to execute such tasks or remembering that they used to dislike domestic chores more than they appreciated the familiarity of the task.

> *"We've have the resident that said to me that she missed ironing so much. Now how can anyone miss ironing? But, you know? So, I asked the laundry girl to take the ironing board down to the quiet lounge where this lady was sat and said, could she support her in ironing some of the bedding? And I think she only ironed a couple of things and she said she'd forgotten how she hated ironing."* (Manager 23)

Evoking the idea of the 'family' was seen as an antidote to potential social isolation of residents, by emphasising the role of community and encouraging friendships between residents, as well as positive relationships with staff. This also extended to the use of physical space with some managers explaining how they used the care home to enable family occasions such as celebrating residents' birthdays or having 'a little party' for other reasons (Manager 30; Manager 31). This was also seen as an opportunity to bring residents' families into the home, with the care home taking a facilitating role by providing space and support. Celebrating people's lives, be it as birthday celebrations or by hosting wakes and organising events for remembrance were also seen as an important contribution to the lives of the residents in the home and their families (Manager 31: Manager 35; Manager 28).

A number of care home managers noted that they offered shared rooms to residents. Having to share a room with a fellow resident was often a necessity in some smaller homes with older premises, such as those operating care homes in Victorian buildings. Places in shared bedrooms can also be cheaper than in single rooms, which means that they may be occupied by residents who are unable to afford a bedroom of their own (in one case, local authority funding only stretched to fund a place in a double room). However, managers also noted that sharing a bedroom could be a choice for some including couples or siblings, but also individuals who preferred sharing their personal space with someone rather than being on their own.

"Because we have single rooms and shared rooms here. The shared rooms we've had husband and wives, sisters, brothers and then obviously of the same sex, which, it works for some people, it doesn't always work for others. But it stops a lot of the loneliness because single rooms can encourage loneliness and isolation whereas shared rooms, they build those relationships and it can have a positive impact. So, it can also have a negative. And on those occasions, we've moved people to different rooms if it hasn't worked with their roommate." (Manager 23)

However, managers were clear that such proximate relationships would not suit everyone, requiring managers to address situations in which such physical proximity was not wanted. This could include situations in which a resident's care need had increased, exacerbating behaviours which the care home manager felt would impact negatively on other residents (Manager 25).

6.4.3 Care home as a hotel

The care home as a 'hotel' was an image evoked as an alternative model of the personalised care home, although, on the whole, its use in interviews was rarer than reference to 'institution' and 'family', and produced a less coherent image of care. Reference to this model emphasised individual choice and a customer relationship between the resident and the care home.

Managers referred to the care home as a 'hotel' to indicate the quality of their services and the aspiration of the home as a place of choice rather than a place of necessity. This aspiration applied to the interior design of the care home, as well as to the provision of services. For example, one manager talked about the dining room as being presented as a restaurant, in which residents find menus on each table from which they could choose and order a meal they liked, rather than having to choose the day before or having no choice at all (Manager 28). This manager also likened staying in the care home to being on an expensive holiday, a metaphor they used in staff training to remind colleagues of the level of service and courtesy expected from them vis-à-vis residents, cast as paying customers.

"At the end of the day, we only want what's best for our residents and that can change on a daily basis so we have to change with it. Part of our training is if we went on holiday and paid £850 a week what would we expect?" (Manager 28)

Even managers who felt that their home did not provide a hotel-like service felt that this was how competitors in the sector would portray themselves, especially those who attracted self-funding wealthy residents, and that this was a business model that was appreciated, even expected, by those people who were able to afford it (Manager 29).

There were frequent examples of managers using customer relations techniques to elicit feedback on service quality and resident satisfaction. Asked whether and how managers encouraged shared decision-making between residents and professionals, some managers noted that they would regularly ask residents and their families for feedback on their services. Many homes organised meetings with residents or formed committees in which residents could make suggestions to and raise issues with the management of the home. Many used customer satisfaction surveys to be completed by residents or family members if residents did not have sufficient capacity to complete them. Such techniques were reminiscent of those used in service industries (such as hospitality, airlines and hotels); however, most managers conceded that they should only be used in combination with other feedback mechanisms and that personal rapport with residents and families was essential to maintain a positive relationship and positive service experience.

Reference to the care home as a 'hotel' tended to portray the care relationship as the provision of a service. This perspective firmly prioritised the customer experience, while casting staff as service providers whose needs were seen as secondary to the needs and wishes of the customer. When asked how to deal with a situation in which a resident and a staff member did not get along, a service-oriented response would argue that the customer's views counted more than those of the provider, emphasising the transactional relationship between a paying customer and the provider who received a wage for delivering a service.

> *"The bottom line is, if somebody needs something, you meet those needs. How you feel is secondary. Client needs come first. They pay our wages. Let's be mindful that they're not here for us. We're here for them. […] We're the hired help. […] They're paying our wages, and they pay a lot of money to live in a home. And they have a right to be treated with dignity and with respect."* (Manager 30)

However, while such a response emphasised the consumer rights of residents, there was also a risk of downplaying their level of care need, for example one manager referring to the care home as *"a hotel for older people … for people who might need some help with the laces on their shoes"* (Manager 20). This assessment would not have been shared by many managers of nursing homes whose clients had substantial personal care needs well beyond the tying of shoelaces.

Others noted that while they used the image of the 'hotel' as an ambition to measure the standard of their service provision against, in their experience there was a limit to the extent to which this would entail a shift in power from professionals to residents and that such a shift was aspirational rather than realistic.

> *"I can't say I've noted it with the residents. I'd be telling fibs if I said, oh yes – I can't say I've noted an equality with the residents. But we do try our very best to… you know, we are here to serve you, you are paying for a service, this is a service industry, you know, if you were staying in a five-star hotel, this is what you should be expecting in our home."* (Manager 17)

Thus, while care homes aspired to levelling the field between staff and residents, it was not seen as realistic to reverse the relationship entirely as many older residents were highly dependent on the services provided to them, irrespective of whether they paid for the service.

However, some managers were adamant that they should aspire to providing a hotel-like service, in which residents were treated as customers rather than dependent recipients of care.

> *"So, I said, you're paying a lot of money to be here, if you were in a hotel you would complain if something wasn't right. Well treat us as a hotel because we're providing a service. What I always tell the staff is, we work in their home, they don't live in our workplace. And that's on an interview and I said, for me, if you feel that you're doing the residents a favour by being here then you're in the wrong job because actually they are doing us a favour to be here, not the other way around."* (Manager 23)

6.4.4 Care home as a co-operative

A fourth model emphasised mutuality between residents and a high degree of choice of living and care arrangements. None of the managers referred to a 'co-operative' directly, which we had developed as a metaphor to indicate a form of care provision in a setting that both emphasised individual choice and close relationships between residents and staff.

Even so, the combination of these characteristics of the home was exemplified in efforts to level the distribution of power between professionals and residents, for example, by including residents in managerial decision-making. Some managers involved residents in job interviews with prospective carers, although it was unclear whether this amounted to the residents being part of the decision-making process (which they would be if this were a true 'co-operative') or simply being consulted.

> *"Please come in and have a cup of tea and a chat with us. Because I do involve the residents on my interviews where possible, because at the end of the day it's their home. I work in their home. Who am I to be the person to decide who looks after them?"* (Manager 23)

Other examples included efforts to involve residents in developing menu choices and activity schedules and their budget implications, although these efforts were not always seen as particularly successful and often required substantial inputs from staff (Manager 28; Manager 4). However, many managers commented that they would find it quite difficult to keep residents and family members engaged in meetings, with some noting that they had tried and failed to convince families to attend (Manager 32).

The 'co-operative' image also resonated with some managers' account of having to square individual residents' various, and sometimes conflicting, likes and dislikes, and having to manage behaviours of individual residents that impacted on other residents.

> *"And I do think sometimes, not always, it's difficult when you do have such a mix that we have, because somebody's behaviour can inflict one person's behaviour, can inflict on the whole home. Do you know what I mean?"* (Manager 16)

In a 'co-operative', existing residents would decide together whether applicants would be allowed to join the community. However, in the care home, this was not seen as realistic and none of the managers suggested that this was a practice they pursued (although the residents might have a voice in deciding who to share a bedroom with). Instead, it was usually the manager who decided whether an aspiring resident was 'a good fit' usually based on whether the care home was able to meet his or her care needs.

> *"Yes, I think it's interesting, and I mean, this is not totally related to what we're talking about, but the idea that the care home is sort of a place, a community that they can join, in a sense. Because, you know, it can be kind of lonely, as much as they're encouraged to be independent, and to rely on themselves, but that can become a very lonely experience."* (Manager 16)

Entering the care home was seen as a positive choice that individuals could make for themselves, appealing to an image of the care home as a place of choice rather than a place of 'last resort'. One manager recalled the example of a couple that had decided to enter the home together because they wished to be looked after, but they still enjoyed participating in a social life outside the home, being visited by friends and doing some of their own shopping (Manager 16). This was seen as the model that would enable people to feel at home in a care home, based on their own choice. However, in our interviews, such examples were rare and most managers noted that many or most of their residents were admitted to the home because they were unable to look after themselves and had insufficient support in their own homes. Yet, echoing the spirit of the voluntary 'co-operative', some managers interpreted the role of the home as helping new residents to 'ease into' home life and as encouraging residents to form personal friendships with other residents, even though joining the home was not necessarily an expression of choice (Manager 28).

In a similar vein, some managers noted that their care home aimed to have a culture in which residents and staff were treated as equals, sharing power, rather than having a customer relationship or professionally dominated relationship first and foremost, although again such efforts were seen as mostly aspirational (Manager 17).

6.5 Discussion

In the analysis above, we examined how managers of care homes interviewed for this study conceptualised the personalisation approach they aspired to in the care homes they managed. We developed a framework that mapped four metaphors used by care home managers to describe their approach (with the exception of the co-operative) on two variables identified in the research and practitioner literature: the importance of the care relationship and the level of choice experienced in the care home.

The four resulting models are not mutually exclusive as analytical categories. They are also not intended to classify care homes, as care home managers, in principle and practice, can combine different approaches, or use different approaches at different times or in different circumstances. However, the four models highlight some of the tensions between different interpretations of the meaning of personalisation, as they relate to the prominence given to individual choice and the importance of the relationships between carers and residents in the context of a care home.

While none of the managers would like their care home to be seen as an 'institution', some managers noted that there were elements of routinisation, task orientation and risk aversion in the provision of care in their homes reminiscent of the image of institutional care, especially perhaps in the organisation of nursing care for those with substantial care needs. This raises the question as to whether these managers allow practices that are incompatible with the idea of personalisation, which stipulates that such tasks would be provided more flexibly and in accordance with the preferences of service users. Yet this finding also hints at the difficulty of fully personalising certain types of services, especially under conditions that are in the way of flexibility such as staff shortages and financial constraints. High dependency nursing care is not very different from similar care provided in hospitals, which also faces similar, if not more extreme, challenges to reduce routinisation and 'one-size-fits-all' approaches to care.

The family home model was the most popular among managers. This model emphasised close, trusting relationships between staff and residents and an aspiration of treating everyone as equals. Many care home managers spoke about offering activities that are typically associated with the domestic home such as participation in household tasks or the celebration of family occasions. For managers, offering a 'home-like' environment was not incompatible with enabling choices for residents, yet these choices tended to be embedded in the communal context of the home.

In contrast, those who likened their home with a hotel emphasised individual choice and the customer service orientation that they tried to instil in their staff. This was expressed, for example, by emulating 'hotel-style' practices, such as presenting the dining room as a restaurant in which residents choose their meals from a menu. However, it was not always clear to what extent such renaming was tokenistic; the range of choices are unlikely to be much different from 'family' type of homes. In some instances, we noted a tendency to downplay care need, although this may have been rhetorical rather than representing actual levels of need present in the home. This finding resonates with earlier concerns about consumerist versions of personalisation being built on a "flawed conception of the people who use social [work] services" (Ferguson, 2007: 400) by underplaying the vulnerability and dependency of the people in need of care (Fine and Glendinning, 2005, Lloyd, 2010, Lymbery, 2010). This model is also associated with the premium sector of the market,

raising question as to whether access to such 'hotel-like' services constitutes a choice that is available to all social service users irrespective of their ability to pay for such a service individually.

We have included the 'co-operative' as an alternative model that brings together the idea of individual choice and close, perhaps more symmetric relationships. While, understandably, no manager spoke about his or her home as a 'co-operative', arrangements similar to this model can be found in the market for 'extra care' which predominantly provides appropriate housing with elements of care that can be scaled up as needed and organised according to people's preferences. However, whether this model is able to address the power imbalances inherent in the care relationship is debatable.

While it can well be argued that it is acceptable, perhaps even desirable, to have different models of personalised care provision existing in the care home market, giving people a choice of approaches they can select according to their preferences, such options are likely to be moderated by other concerns such as availability and affordability.

Chapter 7
Review of the Care Quality Commission care home reports: an assessment of care homes' efforts to personalise care

This chapter describes findings of a review of a sample of care home inspections reports conducted by the Care Quality Commission (CQC). The review of inspection reports was undertaken to ensure that the study included a wider range and diversity of care homes than could be included in the interviews with care home managers. Of the 24 care home managers we interviewed, 18 comprised managers of homes rated by the CQC as 'outstanding' or 'good'. The review of inspection reports therefore deliberately focused on care homes rated as 'requiring improvement' or 'inadequate'. This was to enable examination of the experiences and challenges of homes that received less favourable CQC ratings in relation to providing 'personalised' care.

All care homes need to be registered with the CQC, which conducts inspections of care homes and publishes reports of its inspections. The CQC rates the service on its overall performance as well as its performance on five key domains: safety, effectiveness, responsiveness, caring, and leadership (well-led). The service receives six ratings (overall rating plus rating on each of the five domains) on a four-point scale: outstanding (O), good (G), requires improvement (RI) and inadequate (INE).

Information in the inspection reports reflects the domains and criteria set out by the CQC. Since none of the domains is specifically concerned with personalisation, we extracted – and analysed – the material according to relevant aspects of personalisation around identity, decision-making and relationship.

The review addresses the following questions:

- How is personalised care characterised in CQC inspection reports for care homes rated as 'requires improvement' or 'inadequate'?
- What barriers to implementing personalised care are mentioned in the inspection reports?

7.1 Level of personalisation in care homes according to overall rating

We have focused our analysis on the inspection reports of the 23 homes care homes that have an overall CQC rating of 'requires improvement' or 'inadequate'. We undertook the analysis of CQC inspection reports to ensure that our study covered poorer quality as well as high-quality care homes. We reckoned that managers volunteering to be interviewed were likely to be associated with homes that had received, on average, a higher quality rating compared with the average of ratings represented in the care home market in England, with only six managing homes that had received a rating of 'requires improvement' at their most recent CQC inspection. We therefore decided to undertake additional analysis of CQC reports of homes with lower ratings to compensate for this lack of representativeness.

We found little variation in inspectors' reports relevant to personalisation in reports on care homes rated 'outstanding' or 'good' and fewer challenges to delivering care to a quality expected of CQC standards. For a care home to be rated as 'good' overall no more than one domain can be rated as 'requires improvement' and none can be rated 'inadequate'. To be rated as 'outstanding' overall at least two of the five domains need to be rated 'outstanding' and the remaining domains rated 'good'.

For our analysis, we have combined the CQC ratings of 'outstanding' and 'good' into a category of 'high' and the CQC ratings of 'requires improvement' and 'inadequate' into a category of 'low'. We describe the level of personalisation in a care home as 'high' when the CQC rating for each of the three most relevant domains (effectiveness, caring and responsiveness) is 'good' or 'outstanding', and 'low' when the CQC rating for any of the three domains is 'requires improvement'

or 'inadequate'. Table 7.1 below outlines the number of reviewed reports (by overall rating) that achieved 'high' and 'low' levels of personalisation according to this categorisation.

Table 7.1 Level of personalisation and effect on safe and well-led domains, by overall rating

Overall	Level of personalisation[1]			Safe	Well-led
	Effective	Caring	Responsive		
Outstanding	Number of reports reviewed =9				
High[2]	N=9	N=9	N=9	N=9	N=9
Low[3]	0	0	0	0	0
Good	Number of reports reviewed =18				
High	18	18	18	17	17
Low	0	0	0	1	1
Requires improvement	Number of reports reviewed =17				
High	5	14	4	2	3
Low	12	3	13	15	14
Inadequate	Number of reports reviewed =6				
High	0	0	0	0	0
Low	6	6	6	6	6

Notes:

1. Level of personalisation consists of the ratings for three domains of the CQC report: effective, caring and responsive

2. 'High' level of personalisation corresponds to a rating of 'good' or 'outstanding' in the 5 inspection domains.

   For example: We reviewed nine CQC reports of care homes that received an overall rating of 'outstanding'. All nine reports received either a 'good' or 'outstanding' rating for the effective, caring and responsive domains and were therefore categorised as having a 'high' level of personalisation for each of these domains.

3. 'Low' level of personalisation corresponds to a rating of 'requires improvement' or 'inadequate' in the 5 inspection domains.

   For example: We reviewed 17 CQC reports of care homes that received an overall rating of 'requires improvement'. Of the 17 reports, 12 were rated as either 'requires improvement' or 'inadequate' for the effective domain, and therefore are categorised as having a 'low' level of personalisation for that domain.

Table 7.1 shows the variability of the level of personalisation described in inspection reports. For instance, 14 of the 17 reports rated as 'requiring improvement' were described as having 'high' levels of personalisation in the domain 'caring'. At the same time, 13 of the reports were rated as 'low' in the domain 'responsive'. The table also shows that all six reports relating to care homes rated as 'inadequate' are categorised as having a 'low' level of personalisation.

Because of this variance in level of personalisation, we chose to focus on the 23 reports rated as 'requires improvement' and 'inadequate', with the aim of understanding the extent to which personalised care was delivered in poorly performing care homes and the challenges these homes encountered when organising and delivering care to older people.

7.2 Providing personalised care in care homes: examples from CQC reports

7.2.1 Maintaining identity: Understanding the person

The first dimension of the My Home Life (MHL) framework, *maintaining identity* revolves around the question: "how can the care home better understand who the resident is as a person?" (Owen and Meyer, 2012). This dimension comprises the central standard of person-centred care set out in the National Service Framework for older people (DH, 2001a), which directs care in residential settings to be supportive of residents' identity by: a) valuing residents, b) treating residents as individuals, c) understanding the perspective of residents, and d) establishing a positive social environment which promotes residents' wellbeing (NCHRDF, 2007).

Wilberforce et al.'s (2017) corresponding *understanding the person* theme identifies similar steps for delivering person-centred care: to maintain the uniqueness of every individual by appreciating their personal experiences, needs and ambitions and to personalise care accordingly. The authors identify four attributes of the *understanding the person* theme, which look at the different aspects of the residents' individuality: their experience of illness and disease; acknowledging the different aspects of life requiring support; understanding the person's values and preferences (in care); and, understanding their identity and well-being. Our analysis suggests that CQC reports identified all of these attributes to varying degrees.

Understanding persons' experience of illness and disease
According to Wilberforce et al. (2017), understanding the personal experience of illness and disability is essential to be able to provide personalised care. More specifically, the authors distinguish between understanding the pathology of disease and having empathy with the discomfort of feeling unwell that residents may have as a consequence.

Most reports commented on staff's knowledge and understanding of how to care for illnesses and disabilities. For instance, often cited was the type of advice and consultation staff sought from external health care providers to manage residents' symptoms and to reduce their risks of injury. While this may demonstrate an understanding of the disease trajectory and the specific care residents' need in relation to it, it is less indicative of an understanding of residents' feelings and experience of their limitations.

The reports provided only limited indication of staff understanding residents' experiences of illness. For example, a small number of observations demonstrated how staff took action to reduce residents' discomfort, before residents requested help, suggesting staff had an underlying understanding of residents' experience:

> *"Staff also encouraged and supported [residents] to rest when they did not recognise the need to do this …"* (Report 6RI)

In another report, the inspector observed that staff demonstrated an understanding of a resident's unease, prompting staff to rearrange the furniture in their bedroom:

> *"One professional told us that they had requested for a person's television to be moved to a different place as the person was having neck issues with where it had originally been located. […] staff were responsive in quickly moving the television to a better place to avoid health problems."* (Report 8RI)

An interpretation of staff understanding of residents' experiences of illness could be the adaptations they made to the home's physical environment and the interactive activities for residents experiencing cognitive and sensory limitations. For instance,

a number of care homes instituted 'dementia-friendly' (Alzheimer's Society, 2019) services, which enabled residents living with dementia to move around the home freely, participate in social activities and reduce their anxiety. Examples such as specific decoration, signage, communication methods and activities indicated that care home staff understood the daily experience of residents with dementia and responded by creating an environment that residents could be comfortable in:

> *"[Name of care home is a] purpose-built facility so residents could move around freely, signage to help residents if they got lost and to reduce anxiety when feeling lost; built dementia-friendly environment. […] Staff explained they received specialist dementia training."* (Report 1RI)

> *"People had memory boxes on the wall by their bedroom doors which described their life, work and people they knew. […] This information also helped people find their bedrooms if they struggled in locating certain rooms."* (Report 8RI)

Understanding the different dimensions of life requiring support

Wilberforce et al describe *understanding the different dimensions of life requiring support* as staff members' understanding of people's needs beyond their immediate health and biomedical status and their adoption of a holistic care approach in which all aspects of residents' lives are nurtured. For this attribute, we examined the reports for descriptions of staff organising or accommodating events or activities that did not involve care or treatment of disease.

One aspect of life many of the reports referred to related to diversion and leisure. A number of activities were offered at most of the care homes that stimulated, enriched and entertained residents, and promoted residents' *"wellbeing and a sense of fun and belonging … To get that momentary spark of joy or recognition"* (Report 6RI). Activities included book clubs, arts and crafts, games, music sessions and visits from outside contributors such as exercise trainers, pet therapists and local school children. Many activities were also designed to enhance the social environment of care homes through group events and parties:

> *"Weekly activities included knitting, bingo, arts and crafts, movie screenings, a choir and hairdressing and beauty therapy. The provider also had special activities such as a gardening group with local schoolchildren, a classical music session and seasonal activities to celebrate events such as New Year, Valentine's Day, Pancake Day and Easter. The provider held parties and barbecues for people using the service and their relatives during the year."* (Report 11RI)

Reports also discussed organised trips outside the home such as to garden centres, parks, and museums, offering residents opportunities to leave the immediate home environment and to participate in local community activities:

> *"[The provider] had sourced outside organisations to support them to introduce person centred activities to improve people's engagement and social lives […] The service had their own transport to take people to the local zoo, cafes and for days out. Staff told us how people enjoyed fish and chips out and went to [nearby towns] during the summer."* (Report 14RI)

A second aspect of daily life that reports commented on was residents' social wellbeing. Despite living in a communal setting, a large proportion of people living in residential care report being lonely (Victor, 2012), which in turn can have a grave impact on their physical and mental health (Holt-Lunstad et al., 2015). Therefore, preventing and reducing loneliness is a care priority amongst many social care service providers.

Several reports described interventions designed to encourage residents' social interactions with each other, staff and visitors. Ågotnes and Øye (2017) discussed the value of communal meal times in care home, in terms of encouraging interaction and building a sense of cohesiveness and community between residents. The inspection reports also discussed the benefits of meal times and communal areas to supporting residents' social wellbeing:

> *"Staff provided a supportive and relaxed mealtime experience. Dining tables were laid attractively, and music, chatter and laughter were all part of the dining experience. We observed two staff eating their lunch with people which provided encouragement and company."* (Report 6RI)

> *"People spent all day, apart from mealtime, in the conservatory area, which was light and airy; but we noticed that there was no television in that area […] the registered manager told us people were able to watch television in their own bedrooms and the other communal areas if they wished to. […] They added that having no television in this area encouraged conversation and facilitated activities."* (Report 13RI)

By welcoming and organising visits from family members, friends and local community contacts, some care homes encouraged residents to maintain their social bonds:

> *"People were supported to maintain relationships with others. People's relatives and those acting on their behalf visited at any time. Relatives confirmed this and told us they were able to visit their relative whenever they wanted and at a time of their choosing…"* (Report 2RI)

> *"[…] the service had been trying to improve social engagement and facilities with people and encourage them to partake in activities. […] they had converted an area into a resident and relative café. […] One relative we spoke with told us how when they took their mum to the café, they felt like they had been on a trip out and it had improved their day."* (Report 17RI)

The final aspect of residents' lives that was supported by care homes, was their spiritual and religious needs. For instance, a number of care homes arranged for residents to practise their faith and organised special events to mark different religious celebrations:

> *"Staff gave us examples of how they upheld and respected people's diversity which included making culturally appropriate meals and by celebrating various religious and cultural events."* (Report 16RI)

> *"[…] people were supported to practise their faith and the service had links with local places of worship that people attended. People were supported to meet people from different backgrounds and faiths by attending community lunches in a local Islamic centre."* (Report 10RI)

> *"People's religious needs were met. For example, a local person was an active member of their congregation before they came to live at the home. They maintained contact as members of their local church visited regularly and the vicar visited the home each month to bring them holy communion."* (Report 2INE)

Understanding the person's values and preferences in care

Wilberforce et al.'s description of *understanding persons' values and preferences in care* refers to the extent to which care providers can identify a person's values and preferences and take decisions about the resident's care accordingly. Demonstrations of this attribute were at times difficult to discern as it is closely aligned to the *flexible care services tailored to individual preferences*. We interpreted the subtle difference as staff's understanding of the residents' overall preferences, values and abilities,

which we distinguished analytically from residents' ability to take decisions based on their preferences at a particular moment in time.

For instance, a small number of reports described staff providing personal care according to residents' preferences for male or female carers, often stemming from staff's understanding of residents' cultural or religious background:

> *"[…] the registered manager asked people if they had particular expectations deriving from cultural and ethnic identities about how their close personal care should be provided and who should deliver it. […] A further example was people being asked if they needed additional assistance to dress in line with special personal requirements."* (Report 4INE)

> *"One person's care plan identified the person preferred female care staff when receiving support with personal care. Staff we spoke with [understood] this and ensured that only female staff supported them with their personal care."* (Report 15RI)

Other reports explained how some care plans interpreted residents' values and preferences through residents' sense of independence and perceptions of their frailty. For example, care plans outlined the residents' self-assessment of their ability to carry out their activities of daily living:

> *"Bed rails were not used for people who may perceive them as a barrier. Instead specialised equipment such as beds which lowered to the floor and padded mats on the floor were used to keep people safe."* (Report 6RI)

> *"[...] where a support need was identified, [the care plan] included information on how the person wished to be supported. Plans emphasised what people would like to do for themselves and those areas where they needed support from staff."* (Report 10RI)

Understanding person's identity and wellbeing

Knowing who residents are as individuals, their histories, their hobbies, their interests, and their values and beliefs is the core of the humanistic social model of care proposed by Kitwood and others (Kitwood, 1997, Brooker, 2003). Similarly, Wilberforce et al.'s (2017) attribute refers to the 'mapping' of key aspects of a person's narrative, especially for people with cognitive limitations, which includes recording their history, important relationships, usual routines, and likes and dislikes. As in Brooker et al (2004) *Dementia Care Mapping*, Wilberforce emphasises using key people in their lives (family, friends, carers) to help build the full picture of the resident's identity.

Several CQC reports indicated that care homes collected such information about residents in their care plans. Different terms were used to describe the recorded narrative of people's lives including 'life history', 'life story', 'My Life Book', 'All about me', and 'Getting to know me':

> *"As well as detail on people's physical and social support needs, care plans also contained information on their background, life history, likes and dislikes and personality. This helped to paint a picture of people as a whole and not just one that focussed on their current support needs."* (Report 10RI)

> *"The 'Getting to know me section' of each person's records included details about the person before they came to live in the home."* (Report 2INE)

Some reports referred to the use of dementia-specific charting tool for mapping the life of residents living with dementia, such as the 'This is Me' instrument developed by the Alzheimer's Society (Alzheimer's Society, 2019b):

"The head of care had devised a folder which noted people's choices and a 'this is me folder' which gave sufficient, portrait-styled information to new staff." (Report 7RI)

"Each person had a personalised care record which gave information around people's likes, dislikes and preferences and also the person's life history. [...] For example, one person's care file contained a photograph and detailed information completed on an Alzheimer's Society form entitled 'This is Me." (Report 9RI)

Several reports demonstrated how care homes utilised the knowledge of residents' 'personhood' to personalise their care and to enhance their wellbeing:

"Care plans were person-centred and included information relating to people's life histories, significant relationships, people's past hobbies and current interests. Care plans included an 'All about me' document that was used to develop care plans that recognised people as individuals. For example, one person's care plan stated, "I like reading, looking out of the window at the garden, listening to music and singing". We saw the person's room was arranged so that they could look out of the window and the person had music playing in their room." (Report 15RI)

"[…] we observed one of the housekeeping staff respond to a person's distress. They and another member of staff helped this person's wellbeing improve. In this case, doll therapy helped reduce this person's anxiety and distress. The member of the housekeeping team understood the importance of the doll to this person and related to the doll as if it were the person's baby. They did this in a caring and respectful way. The person began to settle and became less distressed." (Report 6RI)

Reports also referred to how care homes made use of information about residents' identity, interests and skills, to design leisure and entertainment activities:

"The activities organiser was passionate about the role they had taken on full time. They had plans for activities relevant to people's life histories and what they wanted to do." (Report 4RI)

Some care homes referred to residents' expressed preferences to ensure their personal environment reflected their life history, identity. For instance, reports described the personalisation of residents' rooms, including with belongings and furniture from where the residents lived prior to entering the home:

"People's bedrooms were decorated according to their wishes and were very individual. We toured the building and met several people in their bedrooms. We saw that some people had brought their own furniture with them. For example, one person was previously an antiques shop owner and wanted all of their own furniture in the room [...]" (Report 7RI)

"People were supported to personalise their rooms with their own furniture and possessions. One person told us, "I like my bedroom. I bought things from home." (Report 10RI)

In most cases, reports demonstrated staff's level of understanding of personal preferences, identity and experience by describing whether they adhered to residents' care plans. This is perhaps attributable to the diverging goals of the Wilberforce framework and the CQC inspection. The former tries to gain impressions of staff members' inner motivations and thoughts, whereas the latter records observable actions and does not prioritise understanding as such.

7.3 Engagement in decision-making

Wilberforce et al.'s (2017) *engagement in decision-making* theme describes this process as the central tenet of personalised care and is explicit about a person's involvement in taking decisions about their own care.

However, it is clear that, in residential care settings, many residents have reduced cognitive capacity to take decisions. We are therefore interested in how staff involve both residents and their families in decision-making.

Involving the person in the decision-making process

Wilberforce et al (2017) identified three types of shared decision-making: user-led, shared and practitioner-led. 'User-led' decision-making occurs when the resident leads the decision-making and the care practitioner acts as an advisor or broker. We identified a small number of examples of 'user-led' scenarios in the reports:

> *"The registered manager told us: "Our greatest concern in [name of care home] is [that it is] not an institution." […] For example, a person with an eating condition was encouraged to have meals but staff respected their right to refuse food. Another example of people having a say in their care was a person who wanted a medical device for their care discontinued. The service's staff liaised with medical professionals and the device was disconnected. The registered manager told us once this occurred, the person's care needs improved. People were actively involved in making decisions about their care, support and treatment, as far as possible."* (Report 7RI)

Reports also noted that staff acknowledged the limits to some residents' ability to take decisions, but nevertheless attempted to engage them in the process as far as possible:

> *"Another staff member told us they always ask consent each time they provide care and demonstrated their knowledge around decision making for some people who live with dementia by adding, 'I always ask each time as people can make a decision one day and then not the next'."* (Report 9RI)

Our analysis also identified examples of 'shared' decision-making, in which staff, residents and their family members participated equally in the decision-making process. Such examples included care plans being devised by the active involvement of carers, residents and their family members:

> *"People and their relatives were involved in writing their care plans. One relative said, 'We had a plan sent to us and they asked [my relative] what she liked and all sorts of things. They know how she likes things done'."* (Report 17RI)

> *"Some people could tell us that they had been involved in planning their care or that their relatives had. We saw some evidence of consultation with people in their care plans. There was information about their preferences and when they had made specific decisions. […] People were [also] supported to take part in reviews of their care plans.[…][Formal review meetings were] being introduced so that there was a clear process for checking that the person's needs were being met and that any decisions made about the person's life involved them and the people who could legally be a part of the decision-making process."* (Report 8RI)

In some cases, staff ensured that residents' preferences were represented in the decision-making process through the involvement of legal professionals, support workers and advocates:

"People and relatives said staff involved them in decision making about their care and treatment. Care records included details of close family members, and family or legal representatives who also needed to be consulted about people's care." (Report 2INE)

"People had access to an advocate to support their rights to have choice, control of their care and be as independent as possible. The manager understood when people might need additional support from an advocate." (Report 5RI)

'Practitioner-led' decision-making occurs when residents (or family members on their behalf) provide carers with information, which carers then use to take a decision in the best interest of the residents; carers would not have necessarily conferred with the person directly. Practitioner-led decisions are often taken for people with advanced cognitive impairment, where staff's understanding of residents' identity (e.g. history and personal information) is employed to take a decision.

Reports commented on care home staff taking decisions in residents' best interests, when residents lacked capacity. There were numerous examples of practitioner-led decision-making, based on information provided by relatives and practitioners' knowledge of residents' needs and wishes:

"[…] The registered manager and care staff were supporting people to make decisions for themselves whenever possible. They had consulted with people who lived in the service, explained information to them and sought their informed consent. Also, when people lacked mental capacity the registered manager had ensured that decisions were made in people's best interests. An example of this was the registered manager liaising with relatives and healthcare professionals when a decision needed to be made about people having rails fitted to the side of their bed. These are sometimes necessary so that a person can rest safely in bed without accidentally slipping and falling onto the floor." (Report 4INE)

The person's wishes shape decisions and care plans

Wilberforce et al. (2017) describe this attribute of personalisation as how residents' goals, preferences and wishes influence the organisation and delivery of care as a whole, as opposed to the service for the individual resident. In our analysis, we found examples of how care homes invited feedback from residents and relatives on their care in the form of review meetings, surveys and residents (and family) forums:

"Feedback was sought from people, relatives and staff using surveys and at regular meetings. Records of meetings showed they were used to discuss a wide range of issues and that feedback was encouraged. […] For example, in a food survey carried out all respondents agreed or strongly agreed that mealtimes were enjoyable. One person told us, "I go to the residents' meetings, they are alright. I do like living here." We asked a relative about the meetings, who responded, "They are useful." (Report 10RI)

"There were meetings for residents and relatives to attend. […] The service had a 'you said, we did' board, which showed action that had been taken as a result of relative and resident feedback, one example was the new café for residents and relatives." (Report 17RI)

Another report provided an example of a complaints procedure in a care home being used to address concerns of residents:

"People knew how to raise a concern or make a complaint and the provider had implemented effective systems to manage any complaints that they may receive. People were confident that they could raise a concern about their care

and there was information provided on how to make a complaint. […] We saw that when a complaint had been made the deputy manager had responded to it in a timely way and action taken to address the issue raised." (Report 5RI)

Flexible care services tailored to individual preferences

Wilberforce et al. (2017) note that whether a care home is able to respond flexibly to the wishes of residents depends on the micro-level decisions taken on a day-to-day basis. Their definition refers to the interpersonal exchange between care worker and resident, the level of choice and control a resident has over his or her daily care, and the flexibility with which the care is adapted to residents' daily needs and preferences.

In many reports, the flexibility of the care provided was discussed in terms of whether care staff obtained consent from residents when carrying out personal care tasks. This demonstrated staff members' openness to adapt care routines according to residents' changing preferences, which may differ from one day to the next:

"[…] we saw that people were asked their consent before providing care and support. One staff member we spoke with told us how they would always ask consent before providing care and support to people, they told us, "I ask if I am alright to help with something and if the person says no, then it can't be done." (Report 9RI)

Several reports also commented on the flexibility of care home staff when they respected residents' choice and control over their daily routines such as when to get up, what to wear and what to eat:

"We saw that people were supported at their own level and pace and were encouraged to make clear choices in how they wished to be cared for. We saw that people started their day when they wished to and were not hurried by staff." (Report 3RI)

"People were consulted throughout our visit about what they wanted to do and where they wanted to sit. For example, about the time they wished to get up or go to bed, what they wanted to wear and how to spend their day. Staff sought people's agreement before carrying out any care. They listened to people's opinions and acted upon them." (Report 2INE)

Being flexible in accommodating residents' choices also extended to residents who had no or very limited cognitive capacity:

"Some people who lived at the service did not have capacity to make certain decisions and there were some restrictive practices in place to keep people safe. Staff minimised restrictions where possible. For example, if people were able, they could move around shared areas of the building without restriction, spend time in their bedrooms and were encouraged to make a range of choices such as what to wear, what to eat and how to spend their time. The registered manager said where people had limited, or lacked capacity, staff supported them to maximise choice and independence." (Report 12RI)

Information and options are shared in clear format

Wilberforce et al. (2017) analyse the exchanges between carers and residents more closely, to determine whether carers provide residents with information about their choices in an understandable and accessible way. Depending on residents' capability and needs, this may include simplified choices, or the use of special formats and media to communicate with residents. Reports provided several examples of care staff's awareness of residents' communication needs and the different methods they

employed to ensure residents understood their options. Methods included visual aids, closer positioning of the carers and simplified sentences:

"… one person's care plan identified the person wore glasses which they needed to be able to see who was speaking with them. The care plan also stated, 'It can help to ask direct questions that require a yes or no answer. Explain things simply'. [...] Staff made sure they were at eye level and repeated questions, rewording them, if necessary, to ensure people understood." (Report 15RI)

"The manager told us they were in the process of having picture menus in place and people would be offered 'show plates' to help the people living with dementia make an informed choice. Our observations showed that some people were confused about the choice of foods and would benefit from additional visual aids." (Report 2RI)

"Information about how to communicate with people was recorded in people's care plans. Some people required information to be provided in different formats. For one person this sometimes [consisted of] printed information on different coloured paper." (Report 6RI)

One example describes a care home's adoption of digital technology as a means of communicating with the resident, following a discussion with family members:

"Staff aimed to build trusting relationships with people and work collaboratively with relatives so that they could support people's care needs and help them make simple choices about their daily activities. [...] We were told that one relative supported their relative's particular communication needs with an iPad. The relative and staff worked together to ensure they and the person communicated effectively with each other so that the person's needs could be better understood." (Report 6RI)

7.4 Promoting the care relationship

Wilberforce et al.'s third theme, *promoting the care relationship*, considers the quality of the "interpersonal relationships" residents have with carer practitioners and the care home community more widely.

Friendly, caring and respectful interactions

The first attribute of the *promoting the care relationship* theme involves examining the relationship between the carer and the resident. In a person-centred care environment, interactions between carers and residents are characterised by mutual respect and by valuing each other's contribution to the relationship, irrespective of the imbalance of power between the carer and the person in need of care. Many reports commented on the quality of the carer-resident interaction in terms of 'dignity', 'kindness' and 'respect'. Whether carers knocked on residents' room doors and waited for a response before entering, was often mentioned as an example of respect:

"People confirmed staff were respectful of their privacy. One person said, "The staff are always respectful and knock before they enter the room." (Report 8RI)

Other examples focused on the carers' discretion when providing personal care to the resident:

"One person said, "Dignity, oh yes. I certainly wouldn't have them do otherwise. […] they keep me covered as much as they can when they are helping me wash". Another person said, "I get respect and my dignity respected when I

am washing and dressing". […] we observed staff use a hoist to help mobilise a person in the communal area. Care was taken to cover the person at the back to prevent exposure of their underwear and a blanket was put in place at the front to protect modesty." (Report 4RI)

Continuity and coordination in care relationships

Wilberforce et al. (2017) suggest that successful personalised care is often the result of an affectionate rapport between carers and residents that develops over time. They cite examples of active listening, humour and banter, chat and social talk as indications of a deepening relationship between care staff and residents. For example, carers may reference residents' backgrounds or an event they participated in during their interactions throughout the day as a sign of involvement that is more than a professional encounter:

> *"Staff were able to engage well with people. They were cheerful and good natured and took time to speak with people, interacting and chatting with them throughout the day, not only when they were performing physical care tasks."* (Report 13RI)

> *"One person was waiting to have a medical intervention and appeared cross at having to wait. [...] The nurse managed to cheer the person up and encouraged them to sing, which they liked to do. This showed the nurse knew the person well and understood what would distract them and support them to feel happier." (Report 8RI)*

Reports also showed examples of how care staff formed more personal relationships with residents over time, through 'active listening' and 'human communication', and sometimes going beyond their contractual obligations:

> *"Even during busy times, the staff would interact with affection, warmth and compassion. Made eye contact by kneeling or sitting next to the residents, listening to what they were saying and responding accordingly."* (Report 2RI)

> *"Staff identified needing to have more one to one time with people. […] One staff member said some staff sometimes came in on their day off to take people out."* (Report 2INE)

> *"One relative said, "They are like a family. One carer brought her baby in to see my mum and it cheered her up no end!"* (Report 17RI)

Positive attitude to a person's capability and roles

Wilberforce et al. (2017) look at how care staff promote residents' strengths and value their relationship, rather than focus solely on their needs and limitations. For instance, many of the reports explained how care homes encouraged residents *"to help themselves as much as possible"* (Report 2INE), in particular, with respect to their activities of daily living:

> *"People's independence and right to choose was respected and promoted. A staff member told us the person was able to do most things for themselves when getting ready in the mornings. […] they allowed the person to do everything slowly and waited to be asked for help. This ensured the person's independence was not taken away unnecessarily. We observed that people in communal areas were also encouraged by staff to be as independent as possible. This included whilst walking, eating, drinking or completing other tasks associated with daily living."* (Report 7RI)

Reports noted that staff recognised residents' capabilities and the importance of supporting these to maintain their sense of wellbeing:

> "[The resident] is fiercely independent and they [staff] still encourage [the resident] to be." (Report 11RI)

> "Staff supported people to be as independent as possible. One member of staff said, "We must maintain people's skills for as long as possible. If we deskill them they will deteriorate quicker". (Report 15RI)

Reciprocity in the care relationship

Wilberforce et al. (2017) describe the *reciprocity in the care relationship* attribute in terms of the emotional investments made by staff and residents into building a deep bond; fostering an environment in which everyone is "in it together" and everyone reaps benefits from the family and community atmosphere that is created within the care home itself.

We did not identify any citations in the reports which articulated emotional investments or profound bonds between staff and residents that developed as a result. However, some reports commented on the family atmosphere that existed in the home.

Some comments explain the nature of bonds that developed in the home, creating a family atmosphere and a sense of belonging amongst the residents:

> "Another person remarked, 'Staff always say hello as they pass and so I feel part of the family'." (Report 4INE)

> "One relative said, 'It's very good here. Excellent care, [person using the service] is very lucky to be here with likeminded people, we know the majority of people, it is like a family'." (Report 8RI)

> "People were relaxed with staff and we saw that positive and supportive relationships had developed between everyone. Staff and people using the service had been together for many years and this had led to a strong feeling of community and friendship. One person told us, 'We are all growing on each other and developing a friendship.' Another person commented, 'I love living here'." (Report 16RI)

7.5 Barriers to providing a personalised service

As described above, we focused our analysis of CQC reports on those of care homes which were rated overall as 'requires improvement' (RI) and 'inadequate' (INE). Our strategy derives from our findings that reports of care homes with an overall rating of 'good' (G) or 'outstanding' (O) provided few examples of poor personalisation. The frequency analysis of the "level of personalisation" demonstrates that all reports in which care homes rated as outstanding or good overall had a high level of personalisation, according to the three key domains of effectiveness, responsiveness and caring. In contrast, the frequency analysis shows that several care homes with an overall rating of 'requires improvement' or 'inadequate' had variable ratings in the personalisation domains. The majority of care homes rated as 'requires improvement' were categorised as 'high' in the 'caring' domain. At the same time, for the 'effectiveness' and 'responsiveness' domains, the majority of care homes rated as 'requires improvement', and all care homes rated as 'inadequate', were categorised as 'low' in terms of personalisation. In contrast, none of the care homes rated 'good' or 'outstanding' were categorised as 'low' in any of the three personalisation domains.

This section considers how the CQC reports describe the difficulties care homes face when providing personalised services in care homes rated as 'requires improvement' or 'inadequate'. For this section of the analysis, we adopted a thematic approach. The themes were derived through a combination of those identified in the literature review and those identified in an early analysis of the interview data. After coding and grouping the excerpts from the CQC reports according to recurring themes, the emerging barriers to personalisation identified from the analysis include lack of leadership, staffing and physical space.

7.5.1 Lack of leadership

In our review of the scientific literature earlier in this report, we identified leadership as a key ingredient for promoting personalisation in care homes. Several authors commented on the influence that the care home leadership has over the quality and level of personalisation of the care home services. In their study of an education intervention for care assistants, Barbosa et al. (2015) showed the impact leadership had on care staff's awareness of personalisation and their knowledge about the limitations that residents experience. Beck et al. (2014) concluded that support from management is crucial for implementing a personalised approach to care. In their inspection framework, the CQC acknowledges the importance of leadership in the quality of care, by assessing how "well-led" a home is as one of the five domains. We found two aspects of leadership were particularly commented on in CQC reports that created barriers to implementing personalised care: a poor understanding of the legal framework applying to residential care in England, and a failure to create a person-centred culture within the care home.

Poor understanding of the legal framework for residential care
Several reports noted that the manager of the home demonstrated a lack of awareness or disregard for the care home's legal obligations and duties of care. In some reports, this lack of awareness was described as resulting in poorly personalised care. For example, one report described how low levels of understanding of residents' rights across all levels of staff led staff to treat all residents identically, regardless of their capabilities and needs:

> *"[…] there were a number of people who had not had mental capacity assessments completed when people were deemed to lack capacity and a decision needed to be made concerning a person's wellbeing. We found best interest decisions did not always include the appropriate professionals, advocates and relatives…. Staff knowledge of the Mental Capacity Act (2005) was limited, which placed people at risk of not being appropriately supported if they lacked capacity to make their own decisions. People were being restricted in their choices regardless of having capacity […] we identified one person whose rights had not have been protected because the registered manager had not assessed their capacity to consent to receiving care in bed and had not considered whether they had their liberty deprived unlawfully. This had resulted in the person's human rights also being impacted."* (Report 6INE)

Other examples described in reports showed that care home managers did not include residents or their family members in decisions about residents' care:

> *"We observed that people were not always included in decision making. We saw one person had a document in place to consent to care and treatment in the home but this was signed by the registered manager. Only people who had legal powers to do so, can give consent on another person's behalf."* (Report 3INE)

> *"We could not see that the registered manager had considered their compliance with the Mental Capacity Act 2005, Equality Act 2010 and Human Rights Act*

1998 to ensure people's rights were promoted or protected. Consequently, the registered manager had disregarded the needs of people for care and treatment." (Report 6 INE)

Failing to create a person-centred culture

The second aspect of leadership entailed the failure to promote a person-centred care culture. Backman et al. (2016) found the quality of the leadership correlated positively with the degree of person-centredness of the home, implying that the management is responsible for the overall ethos of the care home.

For example, one report described the failure of management to consistently and meaningfully instil a person-centred approach to care across all levels of staff. The report suggested a lack of adequate guidance led staff to focus on residents' immediate health needs and to pay less attention to the other aspects of their lives with which they may have required support:

> *"The culture of the home was largely task focussed, was not person centred and did not empower people to live fulfilled lives. The home had policies and procedures in place to offer the framework for how staff should conduct themselves but it was not followed through or embedded in their practice. The registered manager told us, 'There is a cultural issue and the staff are used to things the way they are'."* (Report 6INE)

Another report explained the effect that poor management of several aspects of running the home, such as adequate staffing levels and appropriate documentation, had on staff members' ability to provide personalised care:

> *"The provider had failed to recognise that the care within the home was not person-centred and that staff were task focussed. They had expectations that staff would provide activities for people but had not taken this into account when deciding on the staffing levels. […] People did not have access to activities which supported their individual interests and their preferences were not always considered. […] Care plans were basic and lacked the detail to support staff to provide person-centred care."* (Report 5RI)

In some instances, comments about care home policies were indicative of how well staff were led and supported to provide personalised care. For instance, one report described the lack of guidance staff received on how to involve residents in taking decisions about their own care:

> *"People were not always supported to have choice and control of their lives. Staff did not have the full guidance to support them in the least restrictive way possible; the policies and systems in the service were not always clear to support this practice."* (Report 14RI)

Communication

Effective communication between and across all levels of care home staff is key to successfully implementing a personalised approach (Brownie and Nancarrow, 2013). Kolanowski et al. (2015) also highlight the role of good leadership in fostering appropriate communication mechanisms such that staff can provide responsive and personalised care.

We identified several instances in which reports recorded a breakdown in communication between managers and care staff, and amongst care staff, that undermined efforts to provide a more personalised service.

One report described how communication between the manager and staff had broken down, making it difficult for the manager to coordinate the daily operations

of the home. This resulted in a resident's needs being underestimated, putting the resident at risk of severe injury:

> *"Accident reports showed a second person had four falls [over a two-month period]. Three of these falls required person to be admitted to hospital for treatment, one of which resulted in a serious injury. Although the acting manager was aware of the person's most recent fall, they were not aware the person had been admitted to hospital for treatment. This showed poor communication between the acting manager and the staff team about people's risks. […] Similarly, this person's risk assessment was [over a year ago] and their care plan was [out of date]. This meant their care records had not identified their increasing falls risk or further steps to mitigate risk."* (Report 2INE)

The documentation of residents' care needs in the care plans is an important form of communication between staff, and with affiliated care agencies (e.g. GP practice, local social care services). Findings from a study of residential care documentation by Broderick and Coffey (2013) suggested that the quality of the reporting of residents' care needs and life histories had a profound impact on the relationship between staff and residents, and subsequently the level of personalisation of the care. Broderick and Coffey also linked poor levels of person-centred documentation to poor understanding of personalisation throughout the organisation, which in turn related to the quality of direction provided by the management of the home.

The CQC reports commented on the quality of documentation, which affected the communication amongst staff and which posed a barrier to personalised care. For example, several reports described a lack of adequate documentation about residents' care needs, resulting in staff being unable to provide the appropriate care and treatment:

> *"During our inspection, we found there was conflicting information with regard to another person's capacity who was standing by the main door of the home, appearing anxious and unsettled. We attracted the attention of the nurse (agency staff) working on the ground floor. However, they were unable to provide any assistance and shrugged their shoulders and told us they did not know this person. We reviewed this person's care plan but could find no evidence of a best interest decision or DoLS application and no management guidelines in place on how to best support this person in times of distress or anxiety."* (Report 5INE)

Other reports demonstrate failures to document residents' personal interests, hobbies, past occupations and care preferences. Inspectors noted that the omission of 'personal information' undermined the rapport between staff and residents, and ultimately prevented staff from providing care that met residents' preferences:

> *"[The] information written in the care plans […] did not always reflect people's assessed needs and preferences. There was a lack of step by step guidance regarding people's preferred daily routines and information within this about their wishes and preferences."* (Report 14RI)

7.5.2 Staffing

Unsurprisingly, reports identified issues of staffing as a significant barrier to providing a better personalised service, including: high workloads, unhelpful attitudes and behaviours, and an insufficient level of skill and training.

Staff workload

Many reports commented on the challenges homes face of poor staffing levels, which resulted in staff having very limited time to provide timely, safe and dignified support to residents:

"We observed call bells were not responded to in a timely way and people told us they had to wait a long time before staff responded. They said, "They [staff] are very slow to answer. When you want the toilet they sometimes don't come soon enough and that's very upsetting [...]", "I fell over and managed to crawl along to my bell. I thought 'oh good now they'll be here in about half an hour'", "There aren't enough staff... I see others waiting a long time for help" [...] We observed one person's call bell had been ringing for 10 minutes. [...] The inspector had to go and find a member of staff, who were busy supporting other people." (Report 3INE)

Heavy staff workloads also meant that staff were unable to spend time with residents to get to know them and to develop a closer relationship. Some reports noted that staff had acknowledged the negative impact their workload had on their rapport with residents:

"[At the lunchtime meal] we observed staff approach each table [...] and simply poured out a glass of orange juice for each person without a choice being given or communicating with people. [...] Care and support were delivered to people in a task orientated way. [...] [A] staff member told us, 'We would like time to be able to just sit and chat with people but there never is time'." (Report 5INE)

Staff attitudes and behaviour
Bangerter et al. (2017) showed that the manner in which staff responded, interacted and formed a community with residents affected residents' perceptions of their choices, control and sense of independence. Authors also found that staff attitudes and behaviour had a significant impact on the provision of care and residents' satisfaction with the care they received.

Reports noted that staff attitudes and behaviours towards residents could impede the level of personalised care residents received. For example, some staff prioritised their own schedules before responding to residents' preferences for care:

"Another person commented, 'I get some choice about when to go to bed, but the girls like to take me up before the night staff come [...].' A staff member told us this was because the night staff would not support people to bed when they got on shift and then had to wait until midnight before night staff would support them. This meant day staff supported people to bed early, leaving some people in bed from around 6–6.30pm until 10.30am the next morning.

We were also told of a person who did not want their cup of tea at 6am in the morning, requesting a later time after 7am. A staff member raised this with a night staff member, who said 'Well, she [person] won't get one then'." (Report 3INE)

Another example shows some staff failing to treat residents as individuals, for example, when disclosing confidential information:

"We were also concerned to hear some care staff inadvertently disclosing confidential information when speaking with each other [...]. We heard two care staff organising their work. One of them pointed to a person who was sitting nearby and said, 'You take her now to the toilet and I'll check on (another person) in their bedroom to see if she's wet and needs changing'." (Report 4INE)

There were also examples of staff treating residents in a disrespectful and undignified manner; thereby disregarding residents' individuality and their values:

"We observed a staff member enter a person's room without knocking. They proceeded to sit opposite the person and did some paperwork without speaking. The person became agitated and kicked their covers off. The staff member did not speak or reassure the person but just threw the cover back

over the person and left the room. […] people were moved without staff speaking or explaining what was happening when providing care, staff walking into people's bedrooms without knocking and putting their bedroom lights on when they were still asleep. […] Another person we spoke with described an incident where a male carer walked into their bedroom and started looking through their drawers without asking or gaining permission to look through their personal items of clothing." (Report 5INE)

Other behaviour indicated that some staff were disengaged, distracted and showed a lack of empathy. Examples provided in reports demonstrate that, in some cases, these behaviours resulted in residents' needs being disregarded:

"One relative said, 'Some of the staff are a bit lax, I think they don't think about stuff, for example they come and turn [relative] just before meals then put on their side. How can they be fed if [relative] is laid on their side?'." (Report 1INE)

"One person told us 'One female carer doesn't always concentrate. On one occasion they didn't put the night bag on properly because they were talking too much. I had an accident and was covered in urine, and then had to wait one and a half hours to be cleaned up. I pushed the call bell when this happened and the staff kept cancelling it. I pushed it four times and on the 5th time they came after approximately forty minutes'." (Report 5INE)

There is an overlap between the examples of negative staff attitudes or behaviours and other challenges facing the care home such as workload, job-related stress and inadequate staff numbers. For instance, some behaviours which appear negligent or task-oriented can be a result of time pressures and the complexity of the care needs faced by staff. Equally, disrespectful behaviour could be interpreted as a lack of adequate training.

Staff skills and training
Studies suggest that the level of staff skill and training affects the delivery of personalised care in care homes. Edvardsson et al. (2014) demonstrated how approaches to improve staff members' knowledge of person-centred-care policies and practice improved their skills in providing personalised care. Hayajneh and Shehadeh (2014) reported that better skilled staff displayed more empathy and respect for residents than staff with less skill. Poey et al. (2017) found that staff training and skills were instrumental in meeting residents' needs and to successfully implementing a personalisation policy.

Some reports cited examples of staff being insufficiently trained. In some cases, the report commented that care staff lacked knowledge of how to treat specific conditions and consequently provided inappropriate care to residents:

"Some care plans had not addressed all the health conditions people were diagnosed with… and staff had not been offered training with regards to understanding these specific conditions […] For example, one person who had a life limiting condition […] [it required that staff have] an understanding of the involuntary movements the person made and how to interpret these […] The records seen demonstrated staff did not fully comprehend this condition. This person was described as being 'agitated and restless' and was regularly administered PRN medicines. However, this behaviour was very 'typical' of this person's condition and did not always require medicine but staff should offer support and comfort…" (Report 5INE)

"… it was clear that they had not all completed the full training they required, nor undertaken any specialist training to equip them to manage people's behaviour which may become challenging. We observed that when a person

had become agitated and distressed, a care staff member did not know what to do and walked away from the situation, another member of staff managed to distract the person and calmed the situation down." (Report 5RI)

Another example of staff lacking the adequate skills to sufficiently inform the resident about decisions related to their care, resulted in the resident becoming anxious and feeling less in control of their care:

"One person told us 'I am bit muddled about my medication. We used to have carers with medical experience but now the carers are late with my medication. I get worried because I don't get told what the medication is for and some of my tablets are missed. I have no control over what I am supposed to be taking'." (Report 3RI)

There were some accounts of staff lacking the skills to speak English fluently, preventing them from communicating with residents, fully understanding their preferences and developing a closer bond:

"We noted that some staff had a language barrier and did not always understand what we were asking them. This would have had an impact on communication with people who were less able, had limited communication skills or had a cognitive impairment." (Report 5INE)

"When we spoke with staff some of them did not have the communication skills to communicate very well with people with communication needs …" (Report 2RI)

7.6 Physical space of the care home

Another theme identified as a barrier to personalisation in CQC reports relates to the design of the care service in terms of the physical layout of the building and interior decoration of the home.

The effects of the physical layout of the care home on residents' quality of life is a key topic in the culture change literature. Hung et al. (2016) discussed the positive effects of a well-designed dining room on residents' social engagement, as well as their sense of autonomy and control. Yoon et al. (2015) found that residents living in small-scale home-like care homes were less likely to experience a decline in social engagement over time. At the same time, however, their findings showed that residents had an increase in depressive symptoms in these sorts of homes. Authors suggested that the rise in depressive symptoms could be a result of the close relationships that staff and residents developed in smaller settings, in which residents were at ease with sharing their emotions so that staff more readily recognised, and subsequently documented, their changes in mood. Roberts (2016) examined the impact of small self-contained 'cottage-like' care homes, with access to a living room, dining room and kitchen, on residents' wellbeing and relationships with staff. She found that a clear distinction between private and public areas allowed residents to build strong relationships with staff and with each other, and enabled them to express their individuality and exert control over their daily routines. However, Roberts also acknowledged the additional burdens staff incurred, which were brought about by the attention needed to manage the risks of supporting residents' (all of whom had care needs) autonomy in an open living space with few precautionary barriers.

Several reports commented on the effect of poor design of communal spaces on staff's ability to provide adequate care and to accommodate residents' needs and preferences:

"There was not sufficient space for everyone to sit at the table if they wished. A few people remained in the lounge area with lap tables. There was little space for staff to support those people who needed assistance. We saw one member of staff kneeling next to someone to assist them." (Report 5RI)

It could also be argued that the last example of how space potentially affects residents' social interactions shows how meal times, for instance, could become a subdued care process rather than an opportunity for residents to enjoy other people's company. Other examples described how the physical layout affected residents' privacy, social interactions and overall wellbeing:

"Families and friends were welcomed. However, there was no space for people to meet privately apart from their bedrooms. We saw that when people visited the staff did not have the time to offer to help people to their rooms, so people remained in the lounge areas with their visitors." (Report 5RI)

"Most people said their rooms were small and they hadn't been able to bring much from home to personalise them. They said, 'This room is very small, the best thing about this place is the view from the window, but there wasn't the space to bring much with me'. 'The room is very small, but a bigger one would cost more and as I can't get about, I don't see the point of paying extra' and 'Some of the rooms are diabolical; I've got one of the best here which opens on to the patio'." (Report 3INE)

In some cases, space constraints were compounded by the lack of staff to respond to personal requests. However, the common thread across all the examples discussing physical space is the issue of resources. Retrofitting or refurbishment of care homes to accommodate both a greater number of residents and individualised routines is often hindered by limited funding for infrastructure investment and may be impossible in some places.

7.7 Discussion

The use of the Wilberforce et al. framework to identify examples of personalised care in CQC reports following inspections of care homes was both useful and challenging. The framework was particularly helpful in identifying good practice in terms of documenting residents' individual needs and preferences. For instance, in relation to the first of the three themes, *understanding the person*, reports often described the contents of residents' care plans, which we used as an indicator of the staff's grasp of residents' identity, priorities and values. However, the framework posed limits to us obtaining a full picture of the staff's understanding, as we can only analyse the information that CQC inspectors observed and recorded using their own (CQC) framework. Arguably, determining staff members' genuine 'understanding' of residents is not feasible without directly asking the staff in question or observing their practices. As staff members' *understanding* of residents' personalities and preferences is not a specific CQC inspection priority, staff were not explicitly asked by inspectors about their knowledge of their residents. We therefore relied on indirect evidence from statements about care plans which described the care homes' *expected* level of staff understanding of residents, but this method does not fully capture the *actual* understanding of individual front line carers.

The framework was also helpful for identifying examples of the different presentations of shared decision-making occurring within care homes. There were several instances reported of appropriate use of resident-led, shared, and practitioner-led decision-making. Equally, reports commented on feedback and complaints procedures, the flexibility and responsiveness of the staff to residents' daily choices, and the adaptability

of staff to residents' communication needs. This finding is likely due to the fact that the framework's *engaging in decision-making* theme aligns closely with SCIE's definition of personalisation, which emphasises the 'co-production of services' where people are supported to take an active role in the design, delivery and assessment of their care (SCIE, 2012). Furthermore, several facets of the CQC guidance for appraising the 'effectiveness' domain of the inspection centre on the SCIE shared decision-making principles. As a consequence, the reports contained ample information which we could dissect into the more nuanced categories discussed in Wilberforce.

For the third theme, *promoting the caring relationship*, the framework helped distinguish good care from good relationships between staff and residents. We identified multiple accounts of respectful, dignified and friendly care, which were confirmed by inspectors, residents and their family members. We also pinpointed several examples of the personal connections between some staff and residents. Long-serving staff demonstrated a deep appreciation of individual residents and reports explained the positive effects these personalised interactions had on residents' wellbeing. However, we found few examples of genuinely reciprocal relationships, where staff and residents developed (and both benefitted from) close friendships or family-like bonds. This is perhaps due to the CQC's emphasis on person-centred care, where the resident is the focal point of the service, rather than the relationship between the residents and staff. In contrast, Wilberforce et al. developed their framework for community settings, where interactions between service-users and professionals are shorter and possible more focused compared to those in residential care. Our findings demonstrated that good care and meaningful relationships do not always co-exist. Indeed, we found examples of care homes, particularly in those rated as 'requiring improvement', where residents and staff expressed a deep fondness for each other, but where the level of care was problematic.

Overall, we identified several positive examples of personalised care in each of the inspection reports we reviewed, suggesting that CQC inspectors acknowledged that efforts to provide a personalised service in some form are made across all care homes, regardless of inspection rating.

The second part of the analysis highlights some of the obstacles care homes faced to providing personalised care, as they were described in CQC reports. We identified two distinct types of barriers to personalised care: endogenous barriers arising from the organisation of the care home; and exogenous barriers resulting from its external context. These are not necessary mutually exclusive, and barriers do not fall entirely into one category or the other.

The endogenous barriers are defined as problems emanating from the organisation, over which the care home – that is, the care home manager – has some form of control. For instance, the barriers related to leadership and staffing issues are often specific to the home and the care home manager can take measures to rectify them. Poor understanding of rules and regulations, and of the principles of personalisation, and ineffectual communication can be addressed through training and incentives, although this will come at a cost to the care home. Staffing problems, such as overwhelming workloads and poor skill sets can be addressed by altering hiring practices and instituting in-work education and training programmes. However, the effectiveness of these measures may be limited by factors outside the control of managers, for example relating to the availability of staff in the labour market and the care homes' ability to offer attractive wages, which will often be reflective of the funding available for residential social care.

Exogenous barriers are not specific to a particular care home. They result from economic and political circumstances of the region or country, over which care homes have little mitigating influence. For example, barriers created by poorly designed and

poorly maintained spaces could be a symptom of lack of resources, which in turn may be a result of the political de-prioritisation of social care funding.

Endogenous and exogenous barriers are often interlinked. For instance, staffing issues such as workload, attitudes and behaviours, as well as the deficits in leadership, can be a consequence of exogenous barriers. Funding, staff education, remuneration and job satisfaction are chronically low in the care home sector, which leaves many care homes facing severe challenges in terms of recruiting and retaining good quality staff. An acknowledgement of care homes' financial and political context therefore, could help with appraising care homes' ability to provide personalised care.

In conclusion, aspects of personalised care are evident in many care homes with poor inspection ratings. At the same time however, some of the care homes (especially those rated as inadequate) fail to provide the responsive and personal service that is expected. Further research into the barriers preventing care home managers from implementing personalised services may help distinguish the circumstances managers have some leverage over from those which they do not. Furthermore, a deeper understanding of the exogenous forces influencing personalisation in care homes could help inform social care policy and direct resources.

**Chapter 8
Discussion**

This study examined how personalisation is promoted and provided in care homes for older people. To this end, we analysed relevant policy documents and practice guidance in England, conducted a review of the international research literature, interviewed care home managers and explored a sample of reports of care home inspections by the Care Quality Commission (CQC). We investigated three questions specifically, which we will discuss in turn, bringing together findings from all parts of the analysis. These questions were as follows:

1. How is 'personalisation' conceptualised in residential care?
2. Which approaches are being adopted to promote personalisation in care homes for older people in England?
3. What are the barriers and facilitators to achieving a higher degree of personalisation in care homes for older people?

We also discuss the strengths and limitations of the study, and draw out implications for policy, practice and research.

How is 'personalisation' conceptualised in residential care?

This study was conceived as a follow-on from the evaluation of the Direct Payments in Residential Care trailblazers. Its first aim was to examine the different conceptualisations of personalisation in residential care as they have emerged in England and internationally. Direct payments were frequently portrayed as a means to enable residents to 'personalise' their care; however, our study identified a number of difficulties in implementing direct payments which meant that personalisation was rarely achieved as a result of a direct payment (Ettelt et al., 2017). This led us to investigate whether there are other ways of personalising residential care. However, we also realised that there are different concepts underpinning ideas of personalising care relevant to people in residential settings.

In policy documents in England, the concept of 'personalisation' was developed mainly with people in mind who lived and received care in their own homes, i.e. domiciliary care. More recently, this perspective has been widened to include person-centred planning and commissioning, merging personalisation with ideas associated with the integration of health and social care. Policy documents rarely discussed personalisation in residential care explicitly. In domiciliary care, personalisation was also closely aligned with ideas of choice and control, which in practice largely meant control over the budget allocated to service users and choice of service provider. More recent policy documents and legislation, such as the Care Act 2014, are more inclusive of residential care, for example, by extending personal budgets to residents in care homes. However, these documents tend not to specify the approach to personalisation beyond acknowledging that residents of care homes should be included in efforts to personalise care.

Practice guidance, in contrast, has long established the importance of providing personalised care in care homes, with documents particularly emphasising the role of care staff and the care relationship for providing personalised care. This finding reflects the idea of person-centred care in the practitioner literature, which was initially used to stimulate improvements in the care of people with dementia, although over time this constituency has widened (Kitwood, 1997, Brooker, 2003). Person-centred care does not exclude 'choice and control', but its emphasis is on alleviating need and distress, providing comfort and helping individuals to maintain continuity between their lives before and after developing a need for care. Practice guidance documents take into account more explicitly the practical implications of providing care for people with limited or fluctuating cognitive capacity and high levels of care need and dependency, especially towards the end of their lives.

These tensions between concepts were also found in interviews with care home managers, who provided contrasting narratives of their efforts and aspirations to personalising care in their homes. Managers drew on different paradigms to describe their aspirations for personalisation, for example, some emphasised the customer service orientation of their home (e.g. to be run like an expensive 'hotel') while others highlighted the close relationships between residents, their families and staff, and the home-like nature (e.g. like a 'family') of their care homes. Our analysis suggests that managers were, in part, able to resolve tensions between these aspirations in their daily practice, but they felt constrained by the realities and multiple demands of providing residential care, irrespective of which concept of personalised care they were trying to implement (see below).

Which approaches are being adopted to promote personalisation in care homes for older people in England?

In our review of the research literature we identified approaches to promoting personalisation at three levels: the level of the individual; the care relationship; and the care home as an organisation. The vast majority of studies examined approaches focused on improving the care relationship. Such studies predominantly examined the effects of various forms of person-centred care training and education on care home staff, with some studies also showing positive residents' outcomes. These effects depend on the content, delivery and duration of such training, but as Fossey et al. (2014b) observed, the vast majority of training available in the UK has not been evaluated and is not supported by relevant evidence.

Our research also found that some approaches aimed directly at service users show some promise in improving user outcomes, although we identified only a small number of studies in this field. Successful approaches addressed especially the need for stimulation and occupation for people with advanced dementia, which cannot always be served by improving relationships between staff and residents. This finding supports the development of multi-faceted approaches, such as the WHELD programme (Ballard et al., 2018).

Several studies examined approaches aimed at the organisation of the care home. These approaches were mostly associated with the culture change movement (e.g. the Green House model) whose proponents advocate a holistic approach to improving care for people in care homes (Koren, 2010). This includes promoting individual choice, changing the mode of care delivery and management of homes (e.g. by promoting flatter hierarchies and introducing the role of 'generalist' carers), and an emphasis on creating a physical, organisational and emotional space that is similar to people's domestic home. Such approaches were mostly investigated in studies originating in the US, although some of them relate to other countries, including the UK. We have not identified any studies that suggest that such approaches have had an effect on current policy and practice guidance in England. None of the studies we identified in this category examined the effects of management or leadership on user outcomes, although these factors were often discussed as facilitators or barriers when authors considered the implications of their findings (e.g. Quasdorf et al., 2017). This is particularly striking, as the role of the manager is a central concern in the inspections of care homes by the CQC, with an entire domain of the inspection framework being dedicated to the care home management (i.e. how the care home is run).

Care home managers interviewed for this study mentioned a large number of approaches to promoting and providing personalised care employed in their care homes. We grouped these approaches using the framework developed by Owen

and Meyer (2012), which distinguishes efforts to support people in maintaining their identity; sharing decision-making, including involving other family members; and creating a sense of community both within the care home and in relation to the local community in which the care home is situated.

Managers highlighted the importance of the care relationship for providing personalised care, and provided detailed accounts of their and their staff's efforts to support people lives when they are experiencing mental and physical decline. Many of those promoting a personalised approach emphasised trust as being essential to build good relationships between staff, residents and families; this also included trust between the manager and his or her staff. Managers provided many examples of sharing decisions about their care with residents, with varying degrees of involvement from residents, families and staff. While such examples illustrated the diversity of situations in which decision-making takes places, they also showed the difficulty managers faced when trying to 'share' decision-making, especially if this involved residents with different and sometimes variable levels of cognitive impairment. Arguably, this difficulty is not exclusive to care provided in residential care; facilitating shared decision-making is likely to be similarly challenging for family carers. However, in residential care the situation is more complex, partly due to the practicalities of care provision, including limits to staffing and financial resources, and the need for staff to comply with professional standards.

Managers provided a large number of examples of approaches aimed to promote a sense of community among the residents of their care home, and among the residents, families and staff. Examples included emphasising occasions for celebration and remembrance, and organising activities enjoyed by groups of residents rather than individuals only. Arguably, any effort to foster supportive care relationships also helps to establish a sense of 'togetherness' built on mutual understanding, trust and respect. Managers readily acknowledged that people had different social needs and preferences, with some people more inclined to share in communal activities than others. Participating in activities also depended on residents' health and cognitive status, including their ability to communicate with others. All managers demonstrated an acute awareness of the challenges associated with meeting the needs of residents with dementia. Their needs for community could be affected by difficulties in communicating which resulted in distress and 'difficult' behaviours. However, we also wondered about the social needs of residents without dementia (the remaining 30% of older people in residential care) and the difficulty of meeting their social needs in an environment in which many, if not the majority, of their fellow residents are living with a form of dementia.

Managers described how they managed risks to clients associated with more personalised care by weighing the potential benefits and risks arising from accommodating the preferences and chosen activities of care home residents, and balancing their duty of safeguarding with efforts to personalise care. Managers also explained the challenges and difficulties associated with developing and maintaining the type of attitudes and behaviours among their staff that they regarded as essential for providing good personalised care. This included concerns about staff recruitment, development and training, and retention. While managers were aware of their responsibility to address such concerns, they also felt that the wider conditions of care provision in care homes limited their options.

Some managers found that building relationships between their care home and the local community was difficult, beyond the usual involvement of schools, churches and animals. This in part reflects the persistently negative image of the care home as 'an institution' and 'a place of last resort'. Managers of some care homes seemed more successful than others in inviting members of the local community into the home, but these efforts were seen as dependent on a variety of factors including the physical space of the home (e.g. the availability of a garden and sufficiently large reception

rooms) and the willingness of community members to engage with the home. Some homes in not-for-profit ownership tended to build their community engagement around their charitable and fund-raising activities, which – if well maintained – may provide them with an advantage in building relationships with their local community. However, it is unclear whether and how this can be replicated for other types of care homes and whether this is the type of engagement older people benefit from socially (rather than benefitting the home financially). There is also the question as to whether the onus of improving these relationships should solely be on the care home or whether there is an opportunity for policy to support such efforts.

In our literature review, we did not identify any approaches to personalising care that were specifically aimed at improving the image and reputation of care homes in society or that aimed at enhancing the relationship between care homes and the wider communities they ultimately serve. This may be the product of our search strategy, but it may also hint at a potential gap in research and policy.

Our analysis of CQC inspection reports, focusing on care homes that had been rated as 'requiring improvement' or 'inadequate', found that CQC inspectors commented on many of the practices of personalisation, often drawing on accounts from residents, family members and staff. We found that the CQC particularly highlighted the role of the care home manager in promoting personalisation and ensuring that staff are capable, empowered and enabled to provide personalised care to residents (CQC, 2017a). The reports commented on shared decision-making in various forms (e.g. user-led, shared, practitioner-led) as an approach to implementing personalisation for residents with varying degrees of cognitive impairment. Shared decision-making worked effectively when residents' felt that their needs and wishes were being met and, perhaps most importantly, when they said that they felt "at home". Conversely, when they were not involved in decision-making, or their "personhood" was disregarded, residents and family members expressed deep dissatisfaction with services.

What are the barriers and facilitators to achieving a higher degree of personalisation in care homes for older people?

Our review of the research literature identified a number of contextual factors that impacted, positively or negatively, on efforts to promote and improve personalised care in care homes. Factors such as differences in levels of care need and cognitive capacity seem particularly difficult to disentangle. There were obvious patterns in studies of approaches relating to service users' care needs, with studies involving residents with dementia often focused on improving the care relationship (in line with the concept of person-centred care), while in other studies, especially those examining organisational approaches related to the Green House model, differences in cognitive capacity among study participants went uncommented. It is therefore not clear whether some approaches to promoting personalisation are more appropriate for some types of need rather than others, or whether this is an artefact reflecting researchers' choice of approach to be studied or choice of research design. However, it is likely that some approaches are better suited for some users, such as therapeutic approaches to provide stimulation and occupation for people with dementia.

Concerns about staffing feature prominently in discussions of contextual factors affecting outcomes in research studies, in interview accounts from managers and in CQC inspection reports. There is a question about the weight that should be given to recruiting the 'right' type of staff whose attitudes and behaviours support the type of care and caring required for personalised care versus the importance of training, supporting and supervising staff to encourage, regulate or demand such

behaviours in themselves and others. In practice, we suspect, care home managers will apply both approaches using their experience, which will likely reflect factors such as the local availability of staff who are skilled and motivated to provide the level of personalised care managers want to see in their homes as well as the availability of resources and opportunities for staff training and development.

Studies also identified a number of factors relating to the organisation of the care home as potential barriers and facilitators of approaches to promoting personalisation, including: staff and staff time; the role of managers and the leadership they execute; and the design and physical layout of the home. Some studies also acknowledged the wider societal context of residential care, including policies that promote (or hinder) personalisation, such as potential tensions between the requirement of homes to protect the health and safety of residents while accommodating the wishes of their residents, which may involve a degree of risk. Few studies also discussed the cost implications of personalisation, both with regard to the costs of changing to a more personalised approach to care (e.g. such as investments into training or changes to the physical layout of the home) and the continuous cost implications of providing individualised care, which requires care homes to move away from approaches aimed at achieving economies of scale.

These findings were broadly confirmed by the managers of care homes interviewed for this study and our analysis of CQC reports. They indicated that the increased complexity of the care needs of residents in recent years was making personalisation more difficult to achieve. Managers also reported that staff shortages could present a barrier to promoting personalisation.

Strengths and limitations of this study

This study was planned to be an investigation into the nature of personalisation in residential care for older people. The intention was to map the field rather than to give definite answers to the many questions that arise from the concepts of, and approaches to, providing personalised care to older people living in residential care settings. We did not examine the role of other organisations in supporting, or ensuring, personalisation of care in residential homes, such as the role of local authorities in creating incentives for care improvement. We also did not specifically explore differences in personalisation experienced by residents who are funded by local authorities and residents who pay for their care themselves.

We have reviewed a large number of studies of approaches to promoting personalisation in care homes, their outcomes and the contextual factors associated with these outcomes. Our inclusion of studies was guided by our choice of search terms, some of which were conceptual by nature (e.g. 'personalisation', 'person-centred care'), which means that – in contrast to, say, clinical interventions – they do not have agreed definitions and thus lack the hard boundaries that help to restrict search outputs. As a consequence, our search resulted in a substantial number of potentially relevant studies. By the same token, there are likely to be studies that we have not managed to identify, especially those that examine similar or identical approaches to personalisation that are identified using a different term. We also included studies of personalised care in hospitals, which, in some countries, may provide a similar service to care homes as we identify them. This overlap may be particularly relevant in relation to nursing care. Despite these limitations, we are confident that we have been able to examine, and map out, the key approaches relevant to our topic.

Our study was intended to scope the approaches managers use to promote personalised care in their homes and to map how they conceptualised their approach to personalisation. Given the modest number of interviews we conducted

(reflecting the initial ambition of this study) we cannot claim that we have accounted for all approaches to personalisation in care homes or described all barriers to personalisation. We have taken special care to sample care homes in a way that reflects the diversity of homes in the current care home market. The sample covers different geographical areas of England and includes care homes that support council-funded as well as self-funding residents in a similar proportion as reported by Laing-Buisson (2018). Yet we realise that our selection cannot be fully representative given the limited number and the substantial diversity of the care home market.

The care homes whose managers we interviewed were not randomly selected. We sent information about our study to Clinical Research Network (CRN) leads who disseminated it to their regional Network of Research ready Care Homes (ENRICH). Managers of care homes in the Network volunteered to participate in the study. We assume that managers were more likely to volunteer if they were confident of their home performing well with regard to providing personalised care. However, the sample included six managers of care homes that were rated as requiring improvement. It also included a higher proportion of nursing homes than are present in the current care home market. We expect that nursing homes face additional challenges in providing personalised care due to the high level of care need and limited mobility of their residents.

The selection of care homes for the review of CQC inspection reports was also not random. We purposively chose a set of care homes that contained homes from each CRN region and within regions that included each CQC rating. We focused our analysis on care homes with an overall CQC rating of 'requires improvement' or 'inadequate'. The purpose of our analysis of inspection reports was to ensure that our study included information relating to care homes of lower quality as well as higher quality care. We have relied on the contents of the report: we have not observed how inspectors arrived at their judgements. We recognise that the inspection reports were prepared to meet the CQC's objectives and responsibilities rather than as part of a research study. Nonetheless, they form a valuable independent source of published information about the performance of care homes in relation to the provision of personalised care.

A strength of our study is that we have sought and brought together evidence from four sources: policy and practice guidance documents; academic literature; interviews with care home managers; and CQC inspection reports. We are not aware of any other study that has drawn on information from these diverse sources to address important questions about personalisation in care homes for older people in England.

Some implications for policy, practice and research

We found that policy documents on personalisation still tended to focus on domiciliary care. Central government may want to make clear in future policy documents that personalisation is relevant and important for care homes, as well as for day and domiciliary care, but may also want to acknowledge that there are challenges to achieving personalisation through choice and control in the care home setting. Personalisation in care homes will always require awareness by staff of the physical, emotional and social needs of residents, with and without dementia, and thus depends on the quality of the care relationship. While policy cannot change attitudes and behaviours of carers, at least not on its own, as this requires wider cultural change, policy is crucial to develop the conditions in which care homes and their staff operate and provide care to residents. It is evident that, on the whole, a personalised service requires more resource than a 'one-size-fits-all' approach that is chiefly aimed at maximising economies of scale. While we have not undertaken a cost-benefit analysis, the observation that personalisation costs money is widely shared in the sector and is not surprising insofar as the provision of an attentive, individualised service requires adequate staffing, staff training and management support.

We also recommend that government and local authorities increase their level of awareness of the differences in care provision, which are reflective of different approaches to personalisation, within care home markets. In principle, it is entirely appropriate that there are different approaches to personalised care provision present in the care home market. However, there are two caveats. First, not all types of homes are accessible to those who are not able to pay for their care themselves and are unable to afford the higher rates required to enter certain types of care homes, perhaps with a more 'hotel'-style ethos and approach to personalisation. This limits the choices for those reliant on local authority funding. Second, both research and practitioner accounts strongly suggest that different types of personalised care may be more (or less) suitable for people with different types of care needs. An approach emphasising choice and control may be desirable for some residents (if this is their choice), but may be inappropriate for others. There is currently a lack of evidence of the effects of certain models of care provision (e.g. comparing 'hotel', 'family' and 'co-operative' (i.e. assisted living)) on service users with different types and degrees of care need.

The promotion of personalisation depends greatly on the commitment and quality of leadership of care home managers, and the skills and motivation of their care staff. The abilities and skills of the manager are a central domain of the CQC framework for care home inspections. However, there is less attention given to training and support for managers in other parts of the regulatory and policy landscape. Agencies responsible for providing or funding training for care home managers and care staff may want to review whether promotion of personalised care could be given greater coverage in their courses or other forms of training. Training and support may be particularly important for managers of care homes that are free-standing, or part of a small group, as these may be less able to access resources and develop their own management support infrastructure than homes that are part of a chain or larger group. However, such homes currently provide the majority of services and have a role to play in ensuring a diverse range of service providers are on offer in local care home markets.

Consideration should also be given to creating an infrastructure that enables and supports care home managers in providing more personalised care. This includes adequate care home funding, investments into the development of the care workforce and, where necessary, investments into improving the home environment and in activities aimed at building stronger relationships with the local community.

Future research could usefully include detailed (perhaps ethnographic) studies of residential care, including interviews with residents, their family members, managers and staff, to examine: their (potentially different) perspectives on what they would most value in terms of personalised care; how far they consider personalised care is being promoted and can be achieved; what barriers need to be overcome; and what measures government or other agencies could take to assist the further development of personalisation in care homes. It will also be important, as stated above, to investigate the different approaches to providing a personalised care service currently present in the care home markets and their implications for residents with different care needs, their families, staff and local care home markets.

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Appendix 1
Invitation letter

PIRU POLICY INNOVATION AND EVALUATION RESEARCH UNIT

Dear Colleague

We are a group of researchers from the Policy Innovation Research Unit carrying out a study about what personalisation means for those caring for older people in residential settings and how people are making it happen in practice. Our study is funded by the Department of Health and Social Care and has received ethics approval from the London School of Hygiene and Tropical Medicine.

We would like to explore with you how the term 'personalisation' is understood in a residential, as opposed to a community care, context, and how it relates to care home residents with differing levels of care needs. With your assistance we hope to discover if, and how, residential care can be better personalised for older people. We are discussing the study with Care England who are interested in it and supportive of its aims.

If you are happy to help us (and we very much hope you will be) we would like to interview you at a time to suit you at your place of work or over the telephone. The interview will likely take around 45 minutes and would be conducted confidentially: we would not name you or your organisation in any report or publication resulting from this research. To compensate you for your time we will provide you with a gift voucher for £30.

I attach an information sheet which provides more information about the study and the interview and what will be involved if you decide to participate. If you are happy to go ahead, please respond to us by email and we will be in contact with you with further details.

Thank you for taking the time to read this and we hope to hear back from you soon.

Best wishes

Lorraine Williams and Stefanie Ettelt
Policy Innovation Research Unit
London School of Hygiene and Tropical Medicine

Contact: lorrainecarehomestudy@lshtm.ac.uk

PIRU POLICY INNOVATION AND
EVALUATION RESEARCH UNIT

Personalisation in Care Homes
Participant Information Sheet

Principal Investigator:
Raphael Wittenberg, London School of Economics and Political Science

Names of Researchers:
Stefanie Ettelt; Lorraine Williams; Jacqueline Damant; Margaret Perkins

We are carrying out a study about how care is personalised for older people in care homes in England and would like to interview you for our study.

We are a group of researchers based at the London School of Hygiene and Tropical Medicine (LSHTM) and the Personal Social Services Research Unit (PSSRU) at the London School of Economics (LSE). We work together in the Policy Innovation Research Unit (PIRU) which develops research evidence to support innovation in health and social care policy.

This work is funded by the Department of Health from October 2017 to December 2018. Ethical approval for the study was given by the London School of Hygiene and Tropical Medicine on the 13th March, ref. 14727.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the research about?

The aim of this project is to investigate the range of approaches adopted to promote personalisation in care homes for older people in England and to what extent care provided to residents of these homes is currently personalised.

Why have I been invited to take part?

You have been invited to take part in this research because you are either a care home owner or manager providing residential care services for older people or working in some capacity for an organisation that provides information or services for older people in residential care.

Do I have to take part?

No, it is entirely optional whether you take part, but before you decide whether you want to take part we would like you to understand why the research is being done and what it would involve for you.

Why are we doing the research?

Recent research undertaken by us on the use of direct payments to better personalise care for older people in care homes indicated a number of challenges requiring further investigation to inform future policy and practice. We identified a need to gain a better understanding of a) what the current barriers are to achieving greater personalisation in care homes for older people and b) what measures are already being taken in some care homes, and could be taken more widely, to improve personalisation in the sector.

What are the researchers going to do?

We will be interviewing a number of owners and managers of care homes in England about their approaches to personalising/promoting person-centred care for older people.

What will happen to me if I take part?

If you agree to take part in the study one of the researchers will contact you and arrange an interview at a time convenient to you. With your permission the interview will be recorded. Only the research team will have access to the recordings and they will be destroyed at the end of the study. Transcripts of interviews will be anonymised and kept as data on servers at the LSHTM for a period of seven years following the end of the study, and then destroyed. The interview should not take longer than one hour and will seek your views and experience of how care can be personalised for older people in residential care, and whether you see any barriers against and measures to better facilitate personalisation of care for residents in care homes.

What are the possible benefits of taking part?

You will know that you are helping us to improve care and services to older people and to provide information of benefit to the care home sector.

What are the possible disadvantages and risks of taking part?

There are no disadvantages except the time element required from you. You can withdraw from the study at any time. If you do decide to withdraw from the study we will keep the information you have provided for the project unless we hear from you otherwise.

Will my taking part in this research be kept confidential?

Yes. All information collected about you and your organisation will be kept confidential. If you agree to take part the researchers will allocate a unique identifier separate from your name and organisation. We will not use your name or the name of your organisation in anything written about the study. All the information we collect will be kept securely: hard copies of research notes will be kept in locked cabinets in locked offices and all electronic copies will be kept on a secure LSHTM server, to which access is password protected. Only the researchers involved in the project will be given access to the data collected. Data will be stored for seven years after the end of the study so that it is available for verification, and then deleted.

Everything you say/report is confidential unless you tell us something that indicated that you or someone else is at risk of harm. We would discuss this with you before telling anyone else.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the research and the way you have been approached or treated, please contact the research team or Patricia Henley, Quality & Governance Manager, London School of Hygiene & Tropical Medicine Keppel Street, London WC1E 7HT, United Kingdom.
Email: patricia.henley@lshtm.ac.uk Tel: +44 (0)20 7927 2626.

What will happen to the results of the study and how will I know of them?

We will produce reports about the research for the Department of Health. We expect to present the findings of the research at conferences, seminars and other events. We will also publish our findings in reports and journal papers. Please let us know if you would like a summary of the findings. We will be happy to send you a report once the study is completed.

For information, questions and concerns please contact one of the research team:

Lorraine Williams
lorrainecarehomestudy@lshtm.ac.uk

We very much hope you will decide to take part in this research.

Appendix 3
Consent form

PIRU POLICY INNOVATION AND EVALUATION RESEARCH UNIT

Title of research: Personalisation in Care Homes

Principle Investigator: Raphael Wittenberg

Names of researchers: Stefanie Ettelt, Jacqueline Damant,
                                Margaret Perkins, Lorraine Williams

**Please
initial box**

1. I confirm that I have read and understand the participant information
   sheet dated ………................... for the above study. I have had the
   opportunity to consider the information, ask questions and have had
   these answered satisfactorily.

2. I understand that the interview that I participate in (whether face-to-face
   or over the telephone) will be audio-recorded and transcribed and the
   data will be securely stored on an LSHTM server.

3. I understand that my participation is voluntary and that I am free
   to withdraw at any time, without giving any reason and that my
   employment will not be affected.

4. I give my permission for the researchers to use suitably anonymised
   verbatim quotations, from the interview in which I am taking part, in
   any reports or publications.

5. I agree to take part in the above study.

_____   _____   _____
Name of participant   Signature   Date
(printed)

_____   _____   _____
Name of researcher   Signature   Date
(printed)

When completed: 1 signed copy for participant; 1 signed copy for researcher

Appendix 4 Characteristics of care homes and managers interviewed

Managers/ care home ID	Type / funding	Region in England	Part of group? Y/N	Size S/M/L	Care Categories of residents	LA/NHS supported residents?	Manager with clinical background/role?	Notes
Manager 1	Residential & nursing NFP(CIC)	SE	N	M	OA/Dem	CHC funded residents (all)	Yes	Single care home
Manager 2	Residential & nursing Private/for profit	SE	N	M	OA/Dem/MH	Mix of self, LA and CHC funded residents	Yes	Single care home
Manager 3	Residential & nursing Private/for profit	SW	Y	M	OA/PD/Dem/ SI	Mixture of self, LA and CHC funded residents	Yes	Small group (2-4)
Manager 4	Residential Charity/NFP	SE	Y	M	OA/Dem/PD	Mostly self-funded residents	Yes	Part of medium size group (>20)
Manager 5	Residential Charity/NFP	WM	Y	M	OA/Dem	LA funded residents (all)	No	Manager new in post (3 months)[1] Part of large group (>1,500)
Manager 6	Residential & nursing Private/for profit	WM	N	L	OA/Dem/PD	Mostly self-funded residents	Yes	Single care home
Manager 7	Residential & nursing Private/for profit	WM	N	L	OA/Dem/ MH/PD	Mostly LA funded residents	Yes	Provides care primarily for people of Jewish faith Single care home
Manager 8	Residential & nursing Private/for profit	SW	Y	M	OA/Dem	Mix of self and LA funded residents	No	Part of a medium size group (>10)
Manager 9	Residential Private/for profit	NW	N	M	OA/Dem/ MH/PD	Mostly LA funded residents	No	Single care home
Manager 10	Residential Private/for profit	SW	Y	M	OA/Dem/PD	Mostly self-funded residents	No	Part of medium size group (>10)
Manager 11	Residential & nursing Charity/NFP	YH	N	M	OA/PD/SI	Mostly self-funded residents	Yes	Some with diagnosis of dementia though not registered for dementia Single care home
Manager 12	Residential & nursing Private/NFP	YH	N	M	OA/Dem	Mostly self-funded	Yes	Owned by religious order to care for their elderly. Some 'private' residents Single care home
Manager 13	Residential & nursing Private/for profit	YH	N	M	OA/PD/SI	Mostly self-funded residents	Yes	Some with diagnosis of dementia though not registered for dementia Single care home

1 At time of interview

Managers/ care home ID	Type / funding	Region in England	Part of group? Y/N	Size S/M/L	Care Categories of residents	LA/NHS supported residents?	Manager with clinical background/role?	Notes
Manager 14	Residential & nursing Private/for profit	NW	Y	M	OA/Dem	Mostly LA funded residents	Yes	Small group (2-4)
Manager 15	Residential Charity/ NFP	SW	Y	S	OA/Dem/SI	All self-funded residents	No	Small group (2-4)
Manager 16	Residential & nursing Private/for profit	YH	Y	L	OA/Dem/PD/	Mix of self, LA and CHC funded residents	No	Part of large group (>200)
Manager 17	Residential & nursing Private/for profit	YH	Y	M	OA/Dem/PD	Mostly LA funded residents	Yes	Part of medium size group (>15)
Manager 18	Residential Charity/NFP	EE	Y	L	OA/Dem/PD	Mix of self and LA funded residents	No	Offers high dependency care Part of medium size group (>15)
Manager 19	Residential Private/NFP	SW	Y	M	OA/Dem	Mostly LA funded residents	No	Part of medium size group (>10)
Manager 20	Residential & nursing Private/for profit	SE	Y	M	OA/Dem	Mostly FNC (LA), some CHC funded	Yes	Single care home
Manager 21	Residential & nursing Private/for profit	SE	Y	M	OA Dem/PD	Mostly self-funded residents	Yes	Dementia specialist care home Some CHC funded Small group (2-4)
Manager 22	Residential & nursing Private/for profit	SE	N	L	OA/Dem/PD/ MH/SI	Mostly self or MH	Yes	Some funded by MH (section 117) Single care home
Manager 23	Residential & nursing Charity/NFP	SE	Y	M	OP/Dem/LD/ PD/MH	LA, NHS CHC or MH (section 117) funded residents	Yes	OP includes 60+ Small group (2-4)
Manager 24	Residential & nursing Private/NFP	NW	N	L	OA/Dem/ MH/PD	High number LA funded	Yes	Single care home

KEY

CHT	Community Health Trust
NFP	Not-for-Profit
CIC	Community Interest Company
OA	Older Age (mainly over 65)

PD	Physical Disabilities
FNC	Funded Nursing Care
SI	Sensory Impairment
MH	Mental Health
SE	South East Region
SW	South West Region

EE	East of England Region
WM	West Midlands Region
YH	Yorkshire and Humber Region
NW	North West Region
Dem	Dementia
CHC	Continuing Healthcare

Descriptive codes

Codes	Descriptors
Care home – characteristics	Types of residents and care, numbers of staff, staff ratio, staff turnover, ability to recruit, fee for places, collective provision of care (e.g. meals, GP) Dementia services -dementia friendly environment
Care home – regulations	Regulatory requirements (e.g. documentation, CQC, health and safety, MCA, DoLS) Space, buildings and limitations Finances, financial implications of PCC Risk taking
Care home – external environment	Relationship to community Location (e.g. accessibility of amenities)
Residents characteristics	Health and social care needs (complex, dementia, capacity) Attitudes feelings and behaviours (aggression/ loneliness) Expectations towards and satisfaction with care/care home Relationship with other residents
Families characteristics	Attitudes and behaviours (expectations, feelings of guilt) Relationship with staff, resident, tensions between professionals and families, families as source of knowledge about people
Staff characteristics (caring and care relationship)	Attitudes and behaviours of carers, professionalism (being a 'good carer' managerial strategies of leadership – mind-set of staff.

Personalisation framework

Theme	Descriptors
Maintaining identity	How rooms are personalised, memory boxes, identity tools ('this is me'), staff training in maintaining identity, philosophy of care home, issues in maintaining identity (capacity) Risks
Sharing decision making	How decisions are 'shared' (staff/residents, families/ individual/community decisions) involvement of resident and family - philosophy of care home – restrictions to sharing decisions (capacity, health and safety etc.) Risk and attitude
Creating community	Creation of community within the care home and how individuals/care homes interact with local community (own GPs, hairdresser, pubs) One way or two way – community hub? Risks

**Appendix 6
Interview topic
guide**

Personalisation in Care Homes
Topic Guide

We are interested in exploring how care in residential settings is provided and in particular the extent to which it is personalised. We'd also like to investigate what personalisation means in residential care and how it is conceptualised and promoted by professionals like yourself.

1. Introduction and Consent

Provide introduction to study and information sheet. Answer any questions about study and interview. Ensure consent form is signed.

2. Current role

Q 2a   How long in current position – if less than 5 years previous role/position

3. Care home (general details) [complete before interview if possible]

Q 3a   Number and type of clients cared for – how many residents publicly funded (approx %)

Q 3b   Is care home private/not for profit? – Is home faith based? Part of a chain?

Q 3c   Does the home provide nursing care?

Q 3d   Does the home offer day care to non-residents?

4. Care home (mission/philosophy/personalisation)

Q 4a   Tell me about your care home: What is your philosophy of care?

[prompt: Approach to choice – relationship with users – range of choices offered?]

5. Sharing decision making *'involve me'*

Q 5a   Tell me a little about how decisions are shared between yourselves and residents/relatives/carers – how do you ***involve*** residents and their families in sharing decisions about the home that they live in?

[probe with specific examples if required: can residents bring their own furniture and arrange own room if wanted?; choosing time to get up and go to bed?, choice of food?, participating in activities?, suggesting activities?] [Further prompts/examples – involvement in decisions relating to the individual and services received; involvement in decisions relating broadly to the care home (e.g. residents panel – co-produced aims) – provide narrative if needed]

Q 5b   Would you say that this works well? If not how could it be improved? Are there any barriers to this?

6. Managing identity *'see who I am'*

Q 6a   What does individual ***identity*** mean in relation to living in a care home?

Q 6b   Tell me, some of the ways in which you enable this?

[probe on how staff get to know residents as individuals and their preferences]

Q 6c   How do you know you are getting it right?

Q 6d   Are there times when this becomes difficult to manage? How do you deal with this?

[probe on choice and control if not mentioned; behaviour and aggression management e.g. in cases of dementia]

Q 6e   *[if not addressed before]* Can you tell me how your organisation helps staff caring for residents respect their individual identity?

[probe: Are there any resources available to support them e.g. training; if so, which type; how often provided and by whom]

Q 6f   What role does regulation (CQC) have in how you deliver personalised care? How supportive is this process in your opinion?

Q 6g   How helpful are Care Plans developed by the council for residents?

7. Creating community *'connect with me'*

Q 7a   Tell me about some of the ways that your care home connects to the local community

[if needed provide some examples of how care homes can connect – e.g. links/visits from local primary school – faith group visits]

Q 7b   Can residents admitted from your local area still register with same GP/dentist/hairdresser etc.?

Q 7c   Can residents suggest outings and decide whether or not to participate in them or have an individualised outing?

*[If necessary probe on how the care home supports residents to pursue interests **outside** home e.g. continue to attend local Adult Ed class; do they have access to the internet and IT support if necessary]*

Q 7d   What are your thoughts on involving your care home more actively in the community (e.g. as a community hub)?

[probe: how to achieve; feasibility; desirability]

Q 7e   Do you consult your residents (individually or as a group) about how they want to connect with the local community?

8. General thoughts on personalisation

Q 8a   Could you tell me, in one or two sentences, what personalisation means to you?

Q 8b   What would you say the key challenges are in relation to achieving personalised care for **older people** in care homes?

[probe: staff time/training/resources/self-funding/culture change/managing risk/negotiating inherent power balance between staff and residents/high level of needs]

9. Any further thoughts?

Thank you for your time.

**Appendix 7
Thank you
letter to
participants**

PIRU POLICY INNOVATION AND
EVALUATION RESEARCH UNIT

Personalisation in Care Homes Study

Thank you for speaking to us about personalisation in care homes. This has been most helpful to us. As a token of our appreciation for your help we have enclosed a gift voucher for £30.

We would be grateful if you could sign and date the attached receipt for the voucher and return it to us by one of the following means:

- as an email attachment* to [insert email address]
- or by post to [insert name and postal address]

If you would prefer to email us, but are unable to attach the receipt, it will be fine just to send us an email confirming you have received the voucher.

Once again thank you very much for your help with our research.

Kind regards

[Insert name and contact details]

On behalf of the Policy Innovation Research Unit team

Appendix 8
Ethics approval

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Observational / Interventions Research Ethics Committee

Dr Stefanie Ettelt
Associate professor
Department of Health Services Research and Policy (HSRP)
Public Health and Policy (PHP)
LSHTM

13 March 2018

Dear Stefanie

Study Title: Personalisation in Care Homes (PICH) **LSHTM Ethics Ref:** 14727

Thank you for responding to the Observational Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

1. Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

2. Conditions of the favourable opinion

Approval is dependent on local ethical approval having been received, where relevant.
Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type	File Name	Date	Version
Local Approval	Ethics confirmation – Personalisation in care homes	02/01/2018	1
Protocol / Proposal	PICH protocol	10/01/2018	1
Protocol / Proposal	Topic GuideV3	12/01/2018	3
Information Sheet	Participant Information sheet_ PICH_V2	12/01/2018	2
Investigator CV	CV Raphael Wittenberg	15/01/2018	1
Investigator CV	CV Stefanie Ettelt	15/01/2018	1
Investigator CV	CV Lorraine Williams	15/01/2018	1
Investigator CV	CV Margaret Perkins	15/01/2018	1
Information Sheet	Consent form_staff interview_V3	27/02/2018	3
Covering Letter	Letter to ethics	27/02/2018	1

3. After ethical review

The Chief Investigator (CI) or delegate is responsible for informing the ethics committee of any subsequent changes to the application. These must be submitted to the Committee for review using an Amendment form. Amendments must not be initiated before receipt of written favourable opinion from the committee.

The CI or delegate is also required to notify the ethics committee of any protocol violations and/or Suspected Unexpected Serious Adverse Reactions (SUSARs) which occur during the project by submitting a Serious Adverse Event form.

An annual report should be submitted to the committee using an Annual Report form on the anniversary of the approval of the study during the lifetime of the study.

At the end of the study, the CI or delegate must notify the committee using an End of Study form.

All aforementioned forms are available on the ethics online applications website and can only be submitted to the committee via the website at: http://leo.lshtm.ac.uk Additional information is available at: www.lshtm.ac.uk/ethics

Yours sincerely,

4. Professor John DH Porter Chair

ethics@lshtm.ac.uk http://www.lshtm.ac.uk/ethics/

Appendix 9 Data extraction codes for the analysis of CQC reports

Mapping CQC inspection guidance onto Wilberforce et al (2017) framework

Wilberforce et al. (2017) Thematic headings	Wilberforce et al. (2017) Attributes	CQC inspection guidance Key Line of Enquiry code[1]
Understanding the person	Understanding residents' experience of illness/disability	S3.1; S4.2; S4.5; S4.7; E5.4; E7.6; E7.7
	• Receiving appropriate healthcare support when needed • dentifying specific care needs • Dementia-friendly environment	E3.4; C3.2 E6.4; C1.3; R1.5, R3
	Understands the different dimensions of life requiring support	E1.1 E6.3
	• Entertainment and leisure • Social interaction • Religious and spiritual needs	E3.3; E6.3; C3.6; R1.4 E6.2
	Understands person's values and preferences in care	C3.1; C3.4 E3.1; E6.2
	• Religious practices • Sense of independence	
	Understanding residents' identity and wellbeing	S2.7; R1.2; R1.3; R3.1;
	• Life histories • Documentation of needs, preferences	E2.1; E4.1; E5.1; C1.4; C2.1
Engagement in decision-making	Involving residents (and families) in decision-making	S2.1; E5.3; E7.2; C2.3; R1.1, R.3.2
	• Involving residents in care plans • Involving relatives, advocates, external healthcare professionals • Decisions based on "best-interest" and DoLs	C2.1; R1.1; R3.2; S1.4 S2.2; S4.4; S4.6; E7.3
	Residents wishes shape decisions	W3.5
	• Feedback mechanisms (resident meetings) • Complaints procedures	S2.5; E6.1 S1.4; C3.4; R2.1; R2.2; R2.3; R2.4
	Flexible care services tailored to individual preferences	S2.4 E2.1
	• Consent at the point of care • Choice and control over daily routine	
	Information and options are shared in a clear format	C2.2; W3.4 S4.6; E5.2; C1.2; R1.5
	• Information about options • Adaptable communication • Accessibility	S2.4; E3.3; C1.3

Wilberforce et al. (2017) Thematic headings	Wilberforce et al. (2017) Attributes	CQC inspection guidance Key Line of Enquiry code[1]
Promoting the care relationship	Friendly, caring and respectful interactions • Treating residents with dignity, kindness and respect • Protection against discrimination	W1.6 S1.2; C1.1; C1.4; C1.5 S1.3; E1.2; R2.4
	Continuity and coordination in care relationships • Develop rapport with residents (chat, humour, banter) • Active listening, "human communication"	C1.2; C2.3; C3.2
	Positive attitude to a residents' capabilities and roles • Promoting independence	E1.3; E6.4; C3.5; W1.6
	Reciprocity in the care relationship • Deeper relationships between residents and staff • Benefits of relationships for residents and staff	None indentified

Note:

1 Care Quality Commission (2017) Key lines of enquiry, prompts and ratings characteristics for adult social care services, available at: www.cqc.org.uk/sites/default/files/20171020-adult-social-care-kloes-prompts-and-characteristics-final.pdf, accessed on June 6, 2019

POLICY INNOVATION AND EVALUATION RESEARCH UNIT

The Policy Innovation and Evaluation Research Unit (PIRU) brings together leading health and social care expertise to improve evidence-based policy-making and its implementation across the National Health Service, social care and public health.

We strengthen early policy development by exploiting the best routine data and by subjecting initiatives to speedy, thorough evaluation. We also help to optimise policy implementation across the Department of Health and Social Care's responsibilities.

Our partners

PIRU is a collaboration between the London School of Hygiene & Tropical Medicine (LSHTM), the Care Policy & Evaluation Centre (CPEC, formerly PSSRU) at the London School of Economics and Political Science (LSE), and Imperial College London Business School.

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