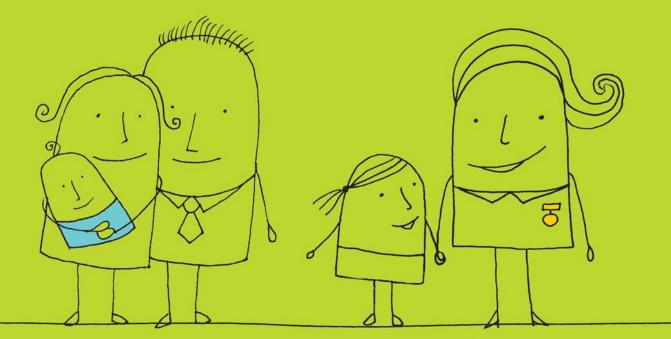
Patient and Client Council

The experience of living in a nursing home

Literature review and summary of key issues raised with the Patient and Client Council Complaints Service

June 2018



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1. Overview

Care delivered in nursing homes is a significant and essential part of care for the frail and elderly in our society. Many people report positive experiences of care, however, there are aspects of nursing home care that people are worried about and there is evidence of these concerns in our work at the Patient and Client Council (PCC). Issues identified through PCC work include concerns about staffing levels, personal care (particularly toileting and continence care), activities for residents, end of life care, residents' access to health care services, and undesirable stereotypes of and negative press on nursing and residential care.^{*} The PCC also have intelligence on issues relating to nursing home care from their Complaints Support Service. Understanding and sharing these issues can help support learning and the improvement to existing services.

This report describes key themes about care in nursing homes in Northern Ireland arising from complaints or issues/concerns raised with the PCC Complaints Support Service. It makes recommendations for sharing and learning to improve existing services.

^{*} See PCC. Consultation engagement on the review of minimum standards of nursing homes. Belfast: PCC; 2014; *People's Priorities 2014*. Belfast: PCC; 2014; *Older People's Health and Wellbeing Framework Reference Group. Final Report.* Belfast: PCC:2012; PCC. *Care at Home.* Belfast: PCC; 2012; PCC.

2. Introduction

2.1 Definition of 'nursing home'

There are a number of categories of care home in Northern Ireland; residential, nursing, and dual registered homes. Table 1 below provides a description of each type of care home.

	Residential care takes place in statutory, voluntary or			
	private residential care homes. They are staffed 24 hours			
	a day, providing board and general personal care to the			
Residential care home	residents. Such premises are provided for those who			
	require ongoing care and supervision in the			
	circumstances where nursing care would normally be			
	inappropriate.			
	Nursing homes are residential facilities staffed by nurses			
Nursing care home	24 hours per day, which provide services for clients/			
	patients requiring residential nursing care.			
	These are nursing homes that are also registered to			
Dual registered home	provide residential care and have a number of places/			
	beds available for residential care.			

Table 1: Types of care home in Northern Ireland

Source: Department of Health, Social Services, and Public Safety. Statistics on community care for adults in Northern Ireland 2015/16. Belfast: DHSSPS; 2016¹

Note that in other parts of the UK care homes are not categorised in the same way. Much of the literature on nursing home care from outside of Northern Ireland uses 'care home' as a general term to refer to all types of residential care including nursing home care.

Since June 2017, the majority of care homes in Northern Ireland are now registered as either a nursing home or a residential care home.

2.2 The current provision of nursing home beds in Northern Ireland

At 30 June 2017, there were 10,700 available nursing care beds in Northern Ireland. This comprised 5,938 beds in 139 nursing homes and 4,762 nursing care beds in 112 dual registered homes. This was similar to the number of nursing care beds available at 30 June 2016 (10,692) and represented a decrease of 2% since 30 June 2013 (10,872).

Of the 10,700 nursing care beds available, almost all (99.8%) were in the independent sector, 45% of which were in dual registered homes, and only a small proportion (0.2%) were in the statutory sector¹.

2.3 DHSSPS Care Standards for Nursing Homes (2015)

In early 2014, as part of the engagement process in developing new care standards for nursing homes, the DHSSPS commissioned Age NI to undertake discussions with residents and carers/relatives of residents in a sample of nursing homes. The aim was to gather their views on their care and the home. Overall findings and emerging themes from the engagement were used to make recommendations for the proposed revised standards. Age NI spoke to 124 individuals in 15 nursing homes across 5 Trusts; of the 124 individuals, 8 were carers/relatives.

Age NI found that many residents felt that the nursing home was understaffed and that they wanted staff to spend more time with them. There were mixed reports about the quality and variety of activities on offer by the homes. Some residents were active and satisfied with the activities on offer, whereas others stated they were bored and wanted more activities. Many of the residents felt that the food on offer was of average or below average quality and there was a lack of variety and choice. Relatives were made to feel welcome in the home but some indicated that there were restrictions on visiting times and that they had nowhere private to see visitors other than their bedroom².

There was an overarching sense that the task-driven nature of much of the care delivered left little time for meaningful engagement with residents³.

Based on the findings of their engagement with residents, Age NI made a number of recommendations for inclusion in the new care standards. These included: care and support should be person centred and relationship centred; care plans for each resident should capture the 'lived experience' of the individual and their wishes, needs and aspirations should be incorporated into their plan; models of care should include social interaction; residents should be supported to participate in community life as much as possible; and models of shared decision-making should be established that give residents a say in how they live their life in the home².

In addition, in 2014 the PCC also carried out engagement discussions with 20 nursing home residents and 15 relatives and carers of residents. The objective was to form a response to the public consultation on the new minimum standards for nursing home care drafted by the DHSSPS. A number of issues and concerns were highlighted: both residents and relatives felt that staffing levels were not always sufficient to allow residents to be assisted to the toilet in a timely fashion; daily activities for residents were not always possible due to staff constraints; and there were issues for residents using patient transport to attend medical appointments outside the home⁴.

In 2015, the DHSSPS published revised Care Standards for Nursing Homes, with the aim of improving quality and consistency of care for people living in nursing homes in Northern Ireland. The care standards are designed to be used by providers to set a benchmark of quality of care and also by the RQIA in registering and inspecting nursing home services.

The DHSSPS stated that the values and principles underpinning the standards are dignity and respect; independence; rights; equality and diversity; choice; fulfilment; safety; privacy and confidently. The views of nursing home residents were sought to help ensure that the care standards provide for personalised and meaningful nursing home care³.

These standards have been developed with the aim of keeping person-centred care to the fore, and the views of residents living in nursing homes were sought and are included in the document³.

2.4 Regulation and Quality Improvement Authority (RQIA) and Nursing Home Inspection Programme

The RQIA is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland and for encouraging improvements in the quality of those services. The RQIA inspects a range of health and social care services, including nursing homes. The RQIA will inspect every nursing home at least twice per year; in the majority of cases, these are unannounced inspections⁵.

RQIA inspectors examine and report on four areas when they inspect a nursing home:

- Is care safe?
- Is care effective?
- Is care compassionate?
- Is the service well-led?

During the course of an inspection, RQIA aim to seek the views of residents and/or their relatives, talk to management and staff on duty on the day of the inspection, and examine a range of records relating to the nursing home. They will provide a report on inspection findings, which will outline any areas for quality improvement where failings are identified⁵.

RQIA nursing home inspections are underpinned by the following policies:

- Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003;
- The Nursing Homes Regulations (Northern Ireland) 2005;
- Care Standards for Nursing Homes April 2015;

- DHSSPS Adult Safeguarding Prevention and Protection in Partnership July 2015;
- NICE guidelines;
- NMC and NISCC Best Practice Guidance;
- The Human Rights Act 1998.

3. What we did

The PCC's 2017/18 business plan includes the following objective in relation to nursing home care:

The PCC will seek to understand residents' experience of care in nursing homes.

- The PCC will scope evidence available on residents' care experience including previous PCC engagement work and complaints support and the work of other organisations.
- The PCC will work with RQIA to complete this project.
- The PCC will share the outcomes with key stakeholders in HSC and nursing home management.

The PCC's research team undertook a review of published literature related to the experience of nursing home care (Section 3.1).

The research team also reviewed cases raised with the Complaints Support Service relating to nursing home care. One objective was to explore the core issues being raised by people in Northern Ireland about nursing home care. Another objective was to identify any potential learning regarding how these issues or concerns could be addressed (Section 3.2). This approach was approved by the PCC Research Committee.

Discussions were also held with the RQIA to explore whether they held any data that could be included in the project. While the review of complaints received by nursing homes is a part of routine inspection, RQIA does not get involved in individual complaints. This is the responsibility of the nursing home and Health and Social Care Trusts. As such, RQIA do not hold information on the cause of complaints and were unable to partner the PCC in the project.

4. What we found

4.1 A review of published literature

A review of recent literature on residents' experience of nursing home care highlights a number of significant themes. The following is the overarching theme of all the literature reviewed:

• **Dignity and respect**: ensuring that people living in nursing homes are given the opportunities and support necessary to enable them to live a full and dignified life.

Other key themes from the literature focus on:

- Quality of life;
- Personal care;
- Health care;
- Food and nutrition;
- Safeguarding from abuse;
- Making decisions about care.

4.1.1 Dignity and respect

The DHSSPS Care Standards for Nursing Homes maintain that values such as dignity and respect, independence, rights, choice, and fulfilment underpin the standards they have set for nursing home care in Northern Ireland³. Ensuring that people living in nursing homes are given the opportunities and support necessary to enable them to live a full and dignified life is an overarching theme of all the literature on experience of nursing home care.

The United Nations Principles for Older Persons resolution⁶, adopted in 1991, stated that in the area of 'care' governments should ensure that all older persons:

- should be able to utilise appropriate levels of institutional care providing protection, rehabilitation, and social and mental stimulation in a humane and secure environment; and,
- should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

As the United Nations resolution suggested, good care for residents of nursing homes should extend beyond meeting basic medical and personal needs. It should encompass issues such as choice, involving people in decisions about their care, respect for privacy, respect for beliefs, meaningful social interaction and mental stimulation.

Care based around the individual needs and wishes of residents and supported by strong relationships with staff has been a central message in much of the literature on quality of nursing home care in recent years.

The Commission on Dignity in Care was established in July 2011 by Age UK, the NHS Confederation, and the Local Government Association. The aim was to try and understand why poor care for older people persists and to put forward best solutions. The Commission's 2012 report, *Delivering Dignity*⁷, makes 37 recommendations for hospitals and care homes aimed at promoting a major cultural shift in how the system thinks about dignity in care. The report recommended that when care homes and hospitals are recruiting staff to work with older people, the compassionate values and behaviours needed to deliver dignified care should carry equal weight with clinical skill. The report also recommends that care homes should ensure that every resident has a care plan that identifies their own wishes, preferences and priorities and addresses the support they need to retain and develop their sense of dignity and personal identity.⁷

Dignified care also means having a positive attitude to ageing and working together with older people, families, carers and advocates to shape care around individual needs⁷.

In 2012, the Care Quality Commission (CQC) carried out 500 unannounced inspections of care homes across England (including 217 homes registered to provide nursing care) with a particular focus on the issues of dignity and nutrition⁸. Almost two thirds of homes met all the standards checked, which meant that staff were respecting and involving the people who used the services. However, the inspectors found that people living in 1 in 6 of the care homes (80 homes) did not always have their privacy and dignity respected or were not involved in their own care. More homes that provided nursing care (20%) were found to be failing to respect and involve people than homes that did not (13%). Furthermore, homes caring for people with dementia were less likely to be meeting the standards relating to respect and safeguarding.

Examples of areas where inspectors found care homes were failing to deliver dignified care include: inappropriate behaviour of staff towards residents; lack of privacy when providing personal care; not establishing residents' individual preferences; and not providing a choice of activities for residents⁸. The report on the inspections concludes that:

Many of these issues arise from cultures of care that put tasks before people⁸.

In 2012, the Northern Ireland Human Rights Commission (NIHRC) published the report *In Defence of Dignity⁹*, which aimed to improve human rights protection and dignified care for older people across all nursing homes in Northern Ireland. The report found that 'there is a risk of multiple forms of human rights abuse' and that there were 'significant structural barriers to the implementation of the human rights of older people in nursing homes in Northern Ireland. The NIHRC called for a range of legislative and policy measures that explicitly linked human rights standards with nursing home care. To ensure that care delivery improves the lives of residents the report concluded with practical recommendations to nursing homes. These included;

ensuring that residents are enabled to access the outdoor environment of the home; that they receive appropriate and timely assistance with continence needs; and have adequate access to food and water at all times of the day and night⁹. The recommendations from this report were used to inform the DHSSPS revised care standards for nursing homes.

Age NI, in their 2015 document *Agenda for Later Life¹⁰*, emphasised that the new minimum standards for nursing homes must be closely monitored and enforced in the interests of the human rights of residents. All nursing home residents have a human right to a dignified and rewarding life:

Our engagement with older residents across nursing homes in Northern Ireland has revealed that while basic needs are usually met, social, emotional and cultural needs are often neglected.

All older people have the right to live fulfilling, dignified lives, that go beyond having their most basic needs met. This right applies equally in a care setting, and for people with dementia. Older people living in these locations express a desire to have a more engaging life¹⁰.

4.1.2 Quality of life

In 2006, more than 60 academics from across the UK worked together on a review of literature on quality of life in care homes¹¹. They concluded that quality of life is different for every individual and recommended that care home staff should seek to understand each individual's priorities for quality of life such as environment, meaningful activities, community and relationships.

Quality of life is complex and difficult to define. Integral to quality of life is what makes life meaningful, enjoyable and worth living¹¹.

Recent literature on care home experience identified a number of priorities for residents in relation to quality of life in nursing homes. Recreational activities and residential environment are two factors that are consistently found to influence

residents' satisfaction with quality of care and daily life in the home^{2, 4, 8, 9, 12}. The preferences of residents in terms of cultural and spiritual needs and their relationships with family, friends and carers outside the home are also identified as important aspects of quality of life. Much of the literature recommended that staff should take the time to record and understand these preferences^{2, 7, 13}. Relationships with the people providing care can have a significant impact on how residents view their quality of life; many residents would like staff to have more time to talk to them and get to know them as individuals^{2, 4}.

The evidence brought together by the National Care Homes Research and Development Forum¹¹ formed the vision for My Home Life. This was a UK-wide initiative that promotes quality of life and aims to deliver positive change in care homes for older people. A central message emerging from the work of the My Home Life programme is that good practice in care homes recognises the importance of relationship-centred care and transformational leadership. My Home Life has developed three personalisation themes to encourage a more relationship-centred approach in care homes. This is based on providing residents with 'voice, choice, and control':

- maintaining identity 'see who I am!';
- ° sharing decision making 'involve me!'; and
- ° creating community 'connect with me!'¹¹

Maintaining identity, sharing decision making, and creating communities are significant themes in the literature on quality of life in nursing homes in Northern Ireland^{2, 4, 9, 10}. Age NI suggested that 'personalisation' is the central emerging theme from their engagement with nursing home residents². Residents of nursing homes want to be treated as individuals who have their own wishes, beliefs, and aspirations.

A significant proportion of older people expressed a strong sense of becoming part of an institution when they came to the nursing home, with little sense that their individual needs, wishes and desires were taken into account². Through their engagement with people living in nursing homes, both the PCC and Age NI found that residents often feel very detached from the community they were once part of before moving into the home. They also felt that their nursing home life bears little resemblance to their previous life. Often this sense of detachment is down to restrictions on aspects of daily life such as, not being able to: attend church; eat or drink what and when they choose; make a cup of tea for visitors; go to the library; or, read a daily newspaper. Consequently, many residents felt that their quality of life deteriorated when they came to live in the nursing home. That staff are often too busy to socially interact with residents can add to these feelings of loneliness and isolation in nursing homes^{2, 4}. It is clear from the evidence that for residents and their relatives quality of life is as much about ensuring that residents see the nursing home as their 'home', as it is about the provision of personal and medical care.

It became apparent that being cared for meant a lot more than being the subject of a series of health related tasks².

Much of the recent literature on experiences of nursing home care in Northern Ireland suggests that residents and their relatives/carers believe that the number of staff on duty in nursing homes can negatively affect the quality of life of residents by placing limitations on their choice, voice, and control^{2, 4, 9}. The NIHRC report questioned if inadequate staffing resources had become an 'accepted indignity' in Northern Ireland's nursing homes. The report concluded that fundamental concerns emerging from their investigation were due to poor staffing levels and that staffing levels were rarely set at a level that allowed for more than minimum essential levels of care. As a result, nursing home staff rarely had time to interact meaningfully with residents⁹.

In November 2017, the Chief Executive of RQIA formally notified the Department of Health of a serious nursing shortage across healthcare settings in Northern Ireland. After a series of inspections in hospitals and nursing homes, the RQIA identified staffing levels as being a problem in almost every area. Inspectors in the RQIA stated that the cumulative effect of 'staffing issues across services was leading, in some cases, to less effective care being provided for patients'.

It is evident across the literature that access to a varied programme of meaningful activities and regular opportunities for social interaction with other residents, staff, and people outside the home, are central to residents' quality of life in nursing homes^{9, 11, 12}.

For older people living in nursing homes [quality of life] is likely to encompass all aspects of their medical and personal care as well as the daily experience of living there ... In particular, the availability of activities and opportunities for social and emotional stimulation all impact on residents' quality of life⁹.

However, it is clear from the literature on residents' experience of nursing home care that many residents feel that their nursing home does not offer a wide range of activities and that consequently they are not provided with adequate levels of mental stimulation and social engagement^{2, 4, 8, 9, 10}. The revised care standards for nursing homes reflect the importance of activity and social interaction to residents. The criteria state that activity and meaningful engagement should be seen by staff as an integral part of the care process and that the nursing home's programme of activities and events should provide positive and meaningful outcomes for residents³.

4.1.3 Personal care

Standard 6 of the Care Standards for Nursing Homes relates to 'privacy, dignity, and personal care'. The criteria for meeting this standard are aimed at ensuring residents are treated with respect and that their right to privacy is upheld. Included in the criteria are: residents are enabled to exercise choice in areas such as intimate care and clothing; that residents' requests for privacy are respected when receiving personal care; and that continence care is provided in a timely and dignified manner³.

The provision of appropriate, dignified, and timely personal care is crucial to residents' experience of nursing home care and how they view their quality of life in the home. Much of the literature on nursing home care emphasises the importance

of respecting residents' choice, privacy, and dignity when attending to their personal care needs, and yet there are many examples that this is not always the case in practice^{4, 8, 9, 11, 14}. A number of reviews of nursing and residential home care in England carried out by the CQC have found instances of staff failing to ensure privacy when providing personal care to residents and staff not asking about or following residents preferences in relation to personal care^{8, 14}. In one report, the CQC found that a quarter of the 386 care home residents[†] they spoke to did not feel they were offered a choice of male or female staff to help them use the toilet¹⁴. The NIHRC also reported this as an issue, where it was noted that male members of staff regularly provided intimate personal care to female residents even though this caused the resident considerable distress⁹.

In 2014, the RQIA carried out an independent review of actions taken in respect of concerns raised about Cherry Tree Private Nursing and Residential home in Carrickfergus. This was initiated from whistle-blowing allegations by staff to external bodies, complaints raised by families, and concerns raised by the NHSCT during the period 2005 to 2013. Personal care in respect of individual residents was one of four areas of concern identified in the review, within which poor care standards and untimely and inappropriate continence care were recurring complaints¹⁵.

Issues around continence care emerges as a particular concern in literature on residents' experience of nursing home care in Northern Ireland^{2, 4, 9, 15}. The PCC and Age NI identified a number of issues around continence care from engagement discussions with residents and relatives/carers of residents in nursing homes. Concerns expressed by some residents and their relatives include; residents waiting lengthy periods of time before staff assisted them to the toilet; residents risking falls trying to go to the toilet unassisted because no staff were available; residents who are still able to use the toilet being forced to use incontinence pads due to time constraints on staff; and residents being left for long periods of time in soiled or wet incontinence pads before being changed^{2, 4}. The NHIRC report also found that personal care is often rushed due to inadequate staffing levels and residents regularly wait lengthy periods before a member of staff is able to assist them with

[†] 81 care homes took part in the review of which, 27 were nursing homes, 27 residential homes, and 27 were care homes for adults with a Learning Disability

continence needs. The report suggested that as a consequence some residents are asked to use, and potentially become reliant on, incontinence pads⁹.

4.1.4 Healthcare

People who live in nursing homes usually have high level, complex healthcare needs. Cognitive impairment, mobility problems, incontinence, mental ill health and depression, pain conditions, and dietary and feeding complications are common amongst nursing home residents. Many residents require multiple medications on a daily basis and access to a range of health and social care services outside the home. A central message of the literature is that people living in nursing homes should have equitable, timely access to good quality health care that helps to support both physical and mental wellbeing and enhance quality of life^{7, 9, 14, 16}.

Older people, regardless of where they live, have the right to health care that is accessible and of a quality equal to that available to the general population⁹.

In 2006, the National Care Homes Research and Development Forum undertook a literature review on quality of life in care homes. It identified a number of healthcare issues where improving services for people in care homes must be made a priority: mental health; depression; dementia; pain; nutrition; falls; continence care; and medication¹¹. These areas of care continue to be key issues in the literature about residents' experiences of health care in nursing homes.

As so many nursing home residents have complex medical needs, appropriate access to a full range of health and social care services and good medicines management are identified as vital to the quality of care residents receive in nursing homes. However, a number of reports suggested that better management of medications is needed in nursing homes^{11, 12, 14}. For example, one CQC report found that 35% of the care homes inspected 'sometimes' had problems getting medications to residents on time¹⁴. The same report also found that less than half of the residents (44%) they spoke to had routine visits from a GP¹⁴. Timely and appropriate access to GP services and other health care services was identified as an issue in various

reports. The main concerns being lack of consistent and regular reviews of medication by GPs; lack of regular reviews of mental and physical health of residents by GPs and other health care professionals; and transport issues when attending healthcare appointments outside the home^{4, 9, 14, 16}. The NIHRC report also expressed concern about nursing home residents' access to health care professionals such as dentists, physiotherapists, and chiropodists⁹.

A number of reports suggest that there is a level of unmet need amongst nursing home residents with a diagnosis of dementia^{7, 12, 17}. In 2014, inspectors visited 129 care homes in England to look at quality of care for people with dementia. As part of the inspections, they asked residents and their families about their experiences of care and what was most important to them. The review found that the quality of care for people with dementia varies greatly. For example, in just over a quarter of homes inspectors found aspects of variable or poor care in how residents' needs were assessed and in how information about residents' needs was shared between services. In around a third of homes, inspectors found aspects of variable or poor care met people's physical and mental health and emotional and social needs¹⁷. A number of reports have recommended that all health and social care staff involved in the care of people with dementia need to have the necessary training and skills to provide them with dignified care^{4, 7, 14}.

People with dementia and their families told us that staff who understood their needs was the most important thing¹⁷.

End of life care in nursing and residential homes has been highlighted as an issue of concern in some of the literature. One report suggested that 'equal value needs to be given to living and dying well in care homes'¹¹. A common recommendation is that residents should be enabled to exercise choice. Furthermore, residents and, where appropriate, their families should be given the opportunity to discuss end of life care with nursing home staff, including where they would like to receive care and decisions about resuscitation. Residents' preferences for end of life care should be recorded in their care plan^{7, 11, 14, 16}.

4.1.5 Food and nutrition

According to Age UK, dehydration and malnourishment are two of the most frequently cited examples of poor care of older people in care homes and hospitals¹⁸. A 2011 nutrition screening survey in the UK and Republic of Ireland found that more than 1 in 3 people recently admitted and screened in care homes in the UK had medium or high risk malnutrition (41% were malnourished, 25% of which were high risk). In the Republic of Ireland, about 1 in 5 recently admitted to care homes were found to be at risk. The survey also reported that the prevalence of malnutrition was greater in nursing homes than in residential homes¹⁹. The Commission on Dignity in Care recommended strongly that the nutritional status and needs of new residents must be identified on admission, that food intake must be constantly monitored, and that action must be taken to ensure that every resident has enough to eat and drink⁷.

There is some evidence in the literature that this is not always the case in practice. A CQC inspection programme of care homes found that residents in one in six of the homes inspected were not always supported to eat and drink sufficient amounts. Furthermore, about half the homes that were not meeting residents' nutritional needs were also not meeting the standard about staffing⁸. A call for evidence as part of the NIHRC review of human rights of older people in nursing homes received 15 reports that residents were admitted to hospital for dehydration; in 8 of these cases, it was the caller's view that this was because the home failed to provide residents with enough to drink. The report recommends that residents should have adequate access to both food and water, both night and day⁹. Poor nutrition and dehydration were identified as recurrent complaints in the RQIA review of concerns raised about the care delivered at Cherry Tree House nursing and residential home¹⁵.

The NIHRC report also recognised that eating and drinking have a social significance for most people, as well as nutritional importance. It is important that mealtimes are not rushed and that residents should be supported to enjoy a dignified dining experience, even if they require assistance with eating and drinking⁹. Various reports have highlighted the importance of offering residents' a degree of choice and flexibility as regards food, drink, and mealtimes in nursing homes^{2, 4, 9}. Age NI found

in discussions with residents that restrictions around food and mealtimes in the nursing home, such as not being able to eat what and when they like, have occasional takeaways, share mealtimes with family, or even make a cup of tea for visitors, could impact on their sense of identity and increase feelings of loneliness and isolation².

4.1.6 Safeguarding from abuse

The publication of the Francis Inquiry report (2013) into the causes of the failings in care at Mid Staffordshire NHS Foundation Trust between 2005-2009, brought issues of patient safety and quality of care to the public's attention more than ever²⁰. Patient safety and protection from abuse and neglect for residents of nursing homes is an important issue in the literature on nursing home care^{9, 14, 15, 21}. 'Abuse' has been described as a 'single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to another individual or violates their human or civil rights'²². 'Neglect' occurs when a person deliberately withholds, or fails to provide, appropriate and adequate care and support which is required by another adult²².

The NIHRC report concluded that 'there is a risk of multiple forms of human rights abuse' of older people in nursing homes in Northern Ireland⁹. These abuses could be found across a wide range of areas such as: the provision at all times of dignified personal and nursing care; access to healthcare services outside the home; appropriate and timely assistance with continence care; access to the outdoor environment of the home; and adequate access to food and water. The NIHRC report also examined how restraint is used and understood in nursing homes. It concluded that residents' freedom of movement may at times be restricted in nursing homes due to physical measures of restraint, such as bedrails, or the use of medication with sedating effects. The report found that concerns about the use of restraint in nursing homes in Northern Ireland are compounded by the lack of a statutory definition of restraint and the absence of formal guidance that draws on international human rights standards⁹.

A CQC review of healthcare provision in care homes found that homes caring for people with dementia were less likely to be meeting the standards relating to respect and safeguarding of residents¹⁴.

Older people, including those living in residential or nursing home settings, are a group at increased risk of abuse or neglect. In recent years, the Commissioner for Older People for Northern Ireland (COPNI) has called for adult safeguarding legislation to ensure improved protection for older people from harm or abuse²¹. In 2015, the DHSSPS and the Department of Justice (DOJ) jointly developed and published 'Adult Safeguarding – Prevention and Protection in Partnership' on behalf of the Northern Ireland Executive. It aims to improve safeguarding arrangements for adults who are at risk of harm from abuse, exploitation, or neglect. The policy document sets out how the NI Executive intends adult safeguarding to be taken forward across all Government Departments. The key objectives are to reduce the incidence of harm from abuse, exploitation or neglect of adults and to provide them with effective support²². It is one of the policy documents now used by the RQIA when carrying out inspections of nursing homes⁵.

4.1.7 Making decisions about care

Involving, supporting, and enabling residents to make decisions about their own care is a key theme across the literature on nursing home care experience^{2, 4, 7, 9, 11}. The National Care Homes Research and Development literature review found evidence to suggest that many older people in care homes desperately want to be involved in decisions that affect them and that enabling and empowering residents to exercise choice is essential for quality of life¹¹.

The NIHRC report concluded that participation in decision-making is a human right in itself and integral to all the themes identified in their report from quality of life to personal care, to choices around medication and health care⁹.

The nursing home environment should be built around enabling older people to make meaningful decisions about their lives⁹.

It is clear from the literature that involving residents in decisions about their care and daily routine, where possible, can make a big difference to how they experience life in the nursing home^{2, 4, 7, 9, 11}. This involvement should extend to all aspects of daily life, from decisions about healthcare and personal care, to choices about activities, outings, food, mealtimes, and the indoor and outdoor environment of their home.

Age NI suggested that enabling residents to 'have your say' can not only improve quality of life, but also increase feelings of self-esteem, dignity and pride amongst residents².

It was apparent from conversations that having a voice or 'say' in their life in the home can make an enormous difference in their feelings of self-esteem, self – fulfilment and participation. Not having any control over what happens to them leads to apathy, sadness and isolation².

The Commission on Dignity in Care recommends that care home managements have robust processes in place to collect feedback and complaints from residents and their families and that they must act on this information⁷. There is evidence in some of the literature that residents can be reluctant to complain or speak up about their preferences in case it might impact on their future care or their relationships with staff^{2, 4, 9}. Independent advocacy services have been identified as an important aid in helping people in nursing homes overcome some of the barriers to making a complaint or providing feedback on experiences of care in the home^{7, 9}.

In recognition of this, the PCC developed a toolkit to promote and sustain advocacy in care homes. It aims to help staff working in care homes to develop skills to become more proactive and responsive advocates²³. A recent RQIA review of advocacy services for children and adults in Northern Ireland found that existing provision continues to be variable across services for older people and for specific conditions such as dementia and Alzheimer's disease²⁴.

4.2 Review of PCC Complaints Support Service data

There is quite a body of evidence highlighting important areas of consideration in the provision of nursing home care. Nonetheless, the PCC is not aware of any published reports exploring the experience of nursing home care within Northern Ireland since the revised nursing home standards in 2015.

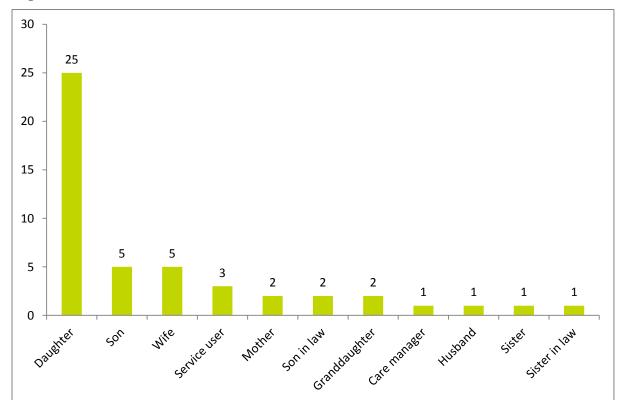
The PCC Complaints Support Service has important intelligence on key issues experienced by patients and the public accessing Health and Social Care services. As such, a review of complaints cases was undertaken in an effort to explore current issues or concerns experienced in relation to nursing home care in Northern Ireland.

It is acknowledged that complaints and concerns raised by residents and their families provide only one aspect of patient and family experience of these services. However, complaints - and the actions taken by nursing homes to resolve them – are an important means of understanding and reflecting upon service user experience. Management of complaints when they do arise is also an important indicator of the quality of any service.

A review of 2015/16 and 2016/17 PCC complaints data was undertaken to identify cases relating to nursing home care; 65 cases were initially reviewed. Of these, 17 cases were excluded and 48 cases were included in the final analysis. The reasons for exclusion were: there wasn't enough information recorded within the complaints database to ascertain the core issue/concern (N=9); the subject of complaint was a resident in a nursing home but the complaint was not about nursing home care (N=5), and the subject of complaint was a resident in a care facility but not a nursing home e.g. a fold (N=3).

4.2.1 Clients of the PCC Complaints Support Service

In the majority of cases, the individual who contacted the PCC Complaints Support Service regarding nursing home care was not the resident of the home. In 44 cases, the client was a family member of the resident and a care manager brought one case on behalf of the resident. There were only three cases between 2015/16 and 2016/17 where a service user raised a complaint themselves.





4.2.2 Profile of residents in nursing home cases

The age of the nursing home resident (subject of complaint) was known in 32 cases (N=32/48). Of these 32 cases, 75% concerned individuals aged over 80 years of age (80-89 N=13/32; 40.6%; 90-99 N=8/32; 25.0%). There was a balance in terms of the gender of residents [male (N=21/48; 43.8%) and female (N=27/48; 56.3%)].

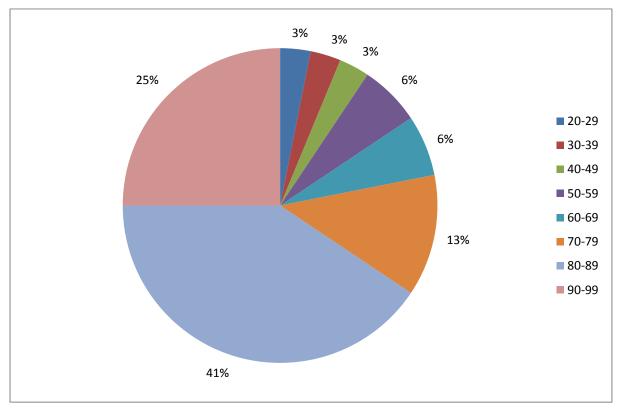


Figure 2: Age of residents

In 17 cases, the resident was deceased at the time their family member raised the case with the PCC Complaint Support Service or they died during the complaint process. In 14 cases, the resident was identified as having dementia and in six cases residents had a particular condition of note ranging across physical disability, mental health issues, learning disability, sensory disability and neurological conditions.

4.2.3 Complaint cases by Trust area

As the PCC Complaints Support Service is a regional service, cases were spread across the Trust areas.

Trust area	Number of cases	%
Belfast	16	33.3%
Northern	10	20.8%
South Eastern	10	20.8%
Southern	7	14.6%
Western	5	10.4%
Total	48	100%

Table 2: Complaint cases by Trust area

4.2.4 Nature of issue/concern

While cases often raised more than one issue or concern, cases were reviewed to determine the core problem. The top five most common issues/concerns are outline in Table 3.

 Table 3: Top five issues/concerns in nursing home complaint cases

	Top 5 - Nature of issue/concern	Number of cases	%
1	Medication and health care	10	20.8%
2	Personal care	8	16.7%
3	Capacity and capability of staff to meet the needs of residents	6	12.5%
4	Financial issues	4	8.3%
5	Decision making	3	6.3%
	Social contact and stimulation	3	6.3%
Other (N=14/48; 29.2%): falls, nursing home closure, staff attitude, admission/discharge arrangements, eating and drinking, assault, communication around an incident, record keeping, security of the environment.			

Medication and healthcare

Within this category, there were a number of issues raised. In five cases clients felt that poor quality healthcare hastened the death of their loved one. An example of this was a case where a client raised a complaint because their loved one had died from cancer. The client believed that their loved one could have been diagnosed earlier. The client explained how the family had highlighted the resident's deterioration to nursing home staff but felt their concerns were disregarded. Only after persistent efforts by the family to have their concerns acted upon were medical investigations carried out. These revealed the presence of an advanced cancer, which proved terminal in this case. In another case a client relayed how they had had to insist that nursing home staff call an ambulance for their relative. The client believed that the delay by staff meant that their relative was in unnecessary distress at the end of life.

In two cases clients felt that poor healthcare provided to their relatives resulted in their significant deterioration. The residents in both these cases had serious falls and required admission to hospital. In one case, the resident sustained a serious injury during the fall and passed away shortly after admission to hospital.

Apparent mismanagement of medication was the primary cause of concern in two cases. In one of these, nursing home management had explained to the resident's family that medication had been incorrectly provided on three occasions. The family accepted this but it was the way this news had been conveyed to the family that the client had issue with. The client felt that the information was relayed in an abrupt and unapologetic way by the nursing home manager. This led to a breakdown in relationships between the family and the member of staff at a time when the resident was nearing end of life. This meant that this period was even more stressful for the family.

In the final case within this category a complaint was raised by a client because the nursing home staff failed to call a GP to assess their relative after they had wandered from a secure unit for a substantial period of time. Due to the medication that the resident was on and the fact that they had been complaining of pain on their return to the unit, the family felt that a GP assessment should have been required.

Personal care

In five of the cases where the primary concern was about the personal care afforded to a resident, the complaints came from families whose relative had been in a nursing home for a period of respite. In four of these cases the resident had developed a pressure sore(s) during their stay and the clients in these cases believed this to be due to inattention to personal care, particularly hygiene.

In the other three cases, clients sought support from the PCC Complaints Support Service because they had raised relatively minor issues with nursing home staff but their concerns escalated due to unsatisfactory responses from staff. For example, in one case a client had asked nursing home staff to change an incontinence pad for their family member but staff maintained they had already changed it. This was despite the relatives knowing this could not have been true as they had been with the resident during the period when staff were claiming they had carried out the activity.

Capacity and capability of staff to meet the needs of residents

In three of these cases clients felt that the nursing homes in question were unable to meet the needs of residents due to an inadequate staffing ratio. Clients highlighted how this resulted in issues such as: delays in toileting; delays in residents getting meals as there were no staff available to assist them to eat; residents left long periods before being brought to bed; safety concerns due to residents being left unsupervised; and little opportunity for staff and residents to interact due to the pressure on staff to fulfil other duties.

The other three cases centred on the issue of nursing home staff being unable to meet the complex care needs of patients. In two cases, the residents had dementia. The client in one of these cases raised their concern because they felt staff in the dementia unit did not have the necessary training or skills to care for people with dementia. In the other case the client raised their complaint after their loved one had been accepted to a nursing home. However, after a period of a couple of weeks the client was being told to seek an alternative placement for their family member as the home was not able to provide the required level of care. In the last of these cases,

the client raised their concern after their loved one, who had a progressive neurological condition, passed away after being admitted to a nursing home for a short period of respite. The client felt that the inability of staff to attend to their family member's complex needs led to their significant decline and subsequent death.

Financial issues

Four clients approached the PCC Complaints Support Service with issues about the management of financial aspects of nursing home care. Three of these clients were querying or disputing how the fees apportioned to the resident had been decided. One of these clients was being billed for a substantial sum for the care of a deceased relative. The client's issue was why the outstanding payment had not been addressed before the death of the resident.

Finally, a client wanted to know how funds allocated for extra services in a nursing home were managed and disbursed. This is because they had noted a reduction in the activities for which this fund had previously been used. The client described how the residents used to go on trips and have activities that were covered by the comfort fund but explained how these had become much less frequent. The client wanted support to raise this issue with the nursing home anonymously.

Decision making

The three cases where the primary issue was regarding decision making were quite different in nature. However, at the heart of each was why the service user or family had not been fully included in the decision making process.

In the first case a concern was raised by a service user who had been admitted to a nursing home for a two week period of step down care after an operation. Due to difficulties in securing an appropriate domiciliary package, the service user remained in the nursing home for an additional number of weeks. The client was now facing a bill for this additional period despite being told the cost would be significantly less. Their main concern was why they had not been fully involved in the care planning process and enabled to determine whether the nursing home in question would have been a suitable placement given that they felt they had received a poor quality of service.

A family member raised the second complaint; they wanted to take their family member home to live with them as they felt the nursing home was not providing adequate care. Due to the residents needs it was felt that they required 24-hour care. A decision was taken not to allow the resident to be discharged into the care of the relative. The client was querying their role as next of kin in the decision making process.

In the final case, the client raised a concern that their family member was admitted to a nursing home for a period of respite against their wishes despite being deemed to have capacity. The resident subsequently died in the nursing home during the period of respite. The client had been told that normally a multi-disciplinary team would have assessed an individual if they were to be admitted permanently. However, as the initial admission had only been for respite care this had never happened. Another family member had instigated the admission. The client was querying how the decision was taken without consulting the resident and other members of the family.

Social contact and stimulation

This last category of complaints were perhaps the most complex. In three cases, clients were raising complaints after restrictions were placed on their ability to visit their family members in a nursing home.

In each of the cases, there had been some level of verbal confrontation between the client and nursing home staff. As a result, the clients had been restricted in their visiting times or had to be accompanied during their visits. It was apparent these decisions had been taken because of the zero tolerance policy of abusive behaviour towards staff. However, each of the three clients were arguing that they had been unfairly treated as a result of raising concerns with nursing home staff. The clients in these cases were raising their concerns in order to having normal visiting arrangements reinstated.

4.2.5 Complaints processes in nursing home cases

It is usual for any complaint about a nursing home to be made direct to the manager of the home in the first instance. The relevant Trust will get involved if the client is dissatisfied with the response or if the complaint raises an issue that requires investigation under another Trust led process – for example, A Vulnerable Adults' Investigation.

If the client remains dissatisfied once the complaints' process is exhausted they have the right to ask the Ombudsman to investigate. The PCC Complaints Support Service offers continuity of support throughout and also should the client choose to make a complaint to a regulator. The only exceptions to this continuity are police and legal cases.

Safeguarding or serious adverse incident investigations were involved in eight (N=8/48; 16.7%) of the new cases raised with the PCC Complaints Support Service during the period of 1^{st} April 2015 – 31^{st} March 2017.

Table 4 highlights the number of cases where an organisation outside of the nursing home was involved in the complaint case. For a number of complaints, there were multiple organisations involved in the case. It is worth highlighting that the PCC Complaints Support Service does not see every complaint through to closure. Clients often opt to continue with the process themselves once it has been escalated. Some of the cases reviewed may have proceeded to other processes but this information is not known by the service.

Organisations involved in complaint cases	Number of cases
HSC Trust	36
RQIA	21
Ombudsman	4
Older Peoples Commissioner	4
Human Rights Commission	1
Law Centre	1
Nursing and Midwifery Council	1
Police Service of Northern Ireland	1

4.2.6 Outcomes for clients

As highlighted previously the PCC Complaints Support Service does not see every complaint through to closure. This means that often the outcome of the case is not known by the PCC Complaints Support Service. Some positive outcomes are highlighted in Table 5 and examples are provided.

Table 5: Outcomes achieved in nursing home complaints cases

Outcome for client	Number of cases
Apology and explanation given	7
Learning/retraining/reminder for staff	7
Treatment and care reviewed with client	2
Policy change resulted	2
Service change resulted	1

Examples of outcomes include:

- The creation of a post falls questionnaire to be completed by staff in the nursing home after any incident. One aspect of the questionnaire was to ensure that in response to any incident the family of the resident would be informed immediately.

- A process outlined which stated that should any resident leave the nursing home unaccompanied they would have a visit from a doctor for a check-up regardless of symptoms.
- Client's permission sought by the nursing home to use their complaint case as an example to be shared with staff as a learning exercise.
- An assurance that the nursing home would review its arrangements regarding the provision of podiatry appointments.
- Policy change with regards how the service provider advises clients of notice to terminate residency. The new wording of the policy stated that four weeks notice of termination of contract would be given. Further, should a decision be taken to terminate the agreement, the resident and/or their representative would be notified of the specific reasons for termination in writing.
- Quality improvement plan for nursing home put in place by RQIA.
- Admission and apology from nursing home staff regarding their behaviour. As a result training to be arranged by the nursing home for all nursing and care staff to ensure they will manage such situations appropriately in the future.

5. Points of learning from complaints

The results from the review of PCC Complaints Support Service cases relating to nursing homes mirror many of the findings from the review of published literature. In particular, the issues that residents can face in relation to medication and healthcare, personal care, the ability of staff to meet the needs of residents, financial issues, decision making, and social contact and stimulation. The focus in preparing this report was to identify learning from complaints that could be applied in order to improve the quality of nursing home services. Therefore, a set of learning points and recommendations for key stakeholders have been produced:

5.1 Termination of contract

Learning point 1

In three of the cases reviewed there had been a 'termination of contract' notice issued. In two cases, the decision was overturned and in the other case the resident was admitted to hospital and did not return to the nursing home. In two cases, the reason for termination was highlighted as 'intimidation of staff' and in the other case the reason was that the nursing home was 'unable to meet the high expectations of family'.

It is clear that a 'termination of contract' notice would only be issued in serious circumstances but for all three clients in these cases the notice came as a shock. They believed the notices had been issued as a result of them raising concerns over the care provided. The fact that in two of these cases the decision was overturned demonstrates that with additional intervention the situation was able to be deescalated.

Recommendation 1: Residents and their families need to be assured that simply making a complaint will not lead to a request to leave the nursing home. In all instances where a decision is made to terminate a contract the route to this decision should be documented. The resident and their family should be informed and involved in the process. The resident and their family should be given the option to

raise objections in advance of the decision and to appeal the decision after it has been made.

Recommendation 2: It would seem necessary for a review of 'termination of contract' clauses in nursing homes contracts to be undertaken by the HSC Board and HSC Trusts. This would ensure that these notices cannot be used to unfairly discriminate against people, particularly those who raise issues or concerns.

5.2 Facilitating people to raise issues/concerns

Learning point 2

It is right that nursing homes should seek to resolve issues or concerns raised by clients at a local level before they are escalated to the HSC Complaints Process. However, this process can add an extra layer of complexity for clients raising complaints. In most of the cases reviewed for this report by the time the client contacted the PCC Complaints Support Service they had already raised concerns informally with nursing home staff and were not satisfied with the response.

The current standards and guidelines for complaints in Health and Social Care state that 'complaints relating to contracted services provided by independent sector providers [including nursing homes] may be received directly by the independent sector provider or by the contracting Trust. The general principle in the first instance would be that the independent sector provider investigates and responds directly to the complainant'. The document also states that should the investigation be conducted by the independent sector provider their written response 'must advise the complainant that they may progress their complaint to the Trust for further consideration if they remain dissatisfied.' It is also required that 'the complainant must also be informed of their right to refer their complaint to the Ombudsman if they remain dissatisfied with the outcome of the complaints procedure.'

There were two primary reservations clients had about submitting a formal complaint to the nursing home where this was not done through the formal HSC Complaints Process. First, clients believed their case would not be dealt with objectively, especially in cases where the issue or concern involved the nursing home management. Second, in cases where the subject of the complaint was still a resident in the nursing home, clients were concerned that their care may be negatively impacted.

Recommendation 3: Clients need to be given written assurances as to how their complaint was objectively investigated. For example, copies of any documentation that was reviewed (where appropriate) and a guarantee that the staff member(s) responsible for the investigation conducted it in an objective manner and reviewed all appropriate evidence. Clients also need to be confident that their complaint will be handled in a confidential manner.

Recommendation 4: The nursing home complaints procedure should make residents and their families aware that they can raise a formal complaint with the HSC Trust in the first instance if deemed necessary.

Learning point 3

The vast majority (N=44/48; 91.7%) of the clients who contacted the PCC Complaints Support Service during 2015/16 and 2016/17 regarding nursing complaints were family members of a resident. This reflects the fact that residents in nursing homes are often unable to raise issues or concerns on their own behalf due to a lack of capacity. Processes need to be in place to ensure that residents and family members are aware of ways in which they may make their concerns known. Often clients contacting the service did not know whether to bring their complaint to the nursing home or to the HSC Trust. In addition, it was reflected in many of the cases that clients were not in contact with nursing home managers and were relying on other staff to pass on their issue.

A section on complaints is contained within the nursing home standards for Northern Ireland. The standards outline that: arrangements for dealing with complaints including details of independent advocacy services are publicised; a copy of the complaints procedure is provided on admission to every resident and to any person acting on their behalf; the complaints procedures includes a step-by-step guide to making a complaint; the procedure includes the details of the PCC and an overview of their role in assisting with complaints; and, advice is provided to residents on how to make a complaint and who to contact outside the home if they remain dissatisfied or require support services.

Recommendation 5: Nursing homes should review their complaints procedures to ensure they meet the criteria set out in the nursing home standards for Northern Ireland and that all residents and family members are aware of the complaints procedure.

Recommendation 6: The nursing home staff directly involved in the management and investigation of complaints should be trained and supervised in the application of the complaints procedure as outlined in the nursing home standards.

Learning point 4

There was evidence within the cases reviewed that communication flow within nursing homes complaints is complex. In cases where there was involvement from multiple representatives (e.g. nursing homes manager, regional nursing home manages, care manager, Trust complaints department) it was clear that poor communication flow was detrimental in achieving a resolution.

Recommendation 7: There should be a designated point of contact in nursing home complaints with whom clients can liaise. It should not be the responsibility of the client to follow-up responses from multiple sources.

5.3 Openness and transparency in dealing within issues and concerns

Learning point 5

On first review it could appear that a number of complaints raised by clients in relation to nursing home care are less serious in nature. However, it was the way in which staff had reacted to the concern being highlighted that was the issue for the client. In these cases clients felt that staff had demonstrated a lack of honesty and defensiveness in relation to the client highlighting their concern. These clients believed that staff who would act in this way could not be trusted in the care of vulnerable residents and as a result escalated their concern to a formal complaint.

Recommendation 8: Designated staff responsible for complaints in a nursing home should provide support to all staff in order to encourage an open culture in relation to complaints.

5.4 Management of expectations

Learning point 6

In some cases where residents had been newly admitted to a nursing home or where they had been admitted for a period of respite there was some evidence that clients had the expectation that the nursing home would meet the standard of care that had been provided to the resident by their family. When this expectation was not met this led to clients raising complaints about the standard of care.

The nursing home standards contain detailed information on processes that should be conducted before an individual is admitted to a nursing home. One of these requirements is to have an individual written agreement which contains information on what a resident can reasonably expect in terms of care and treatment.

Recommendation 9: Agreements should be reached between the nursing home, the resident and/or their family members pre-admission so that expectations of care are managed. Residents and their family should be provided with a clear statement from the nursing home on the standards that they can expect.

5.5 Dealing with the complexity of next of kin issues

Learning point 7

In five nursing home complaints raised with the PCC Complaints Support Service issues with regard to next of kin complicated the cases. In each of these cases, the client raising the concern was not identified as the next of kin but was an immediate relative of the resident i.e. they were a child of the resident. The clients in these cases felt that the nursing homes had used the fact that they were not next of kin to disregard their concerns and not engage with them to find a resolution. One of these cases was able to be resolved informally due to the nursing home arranging a meeting with all family members and agreeing a process by which relevant members

of the family would be notified and consulted regarding the residents care; this satisfied the client.

Recommendation 10: On the admission of a resident, the nursing home should ensure clarity of next of kin and family liaison arrangements. The fact that an immediate family member is not the identified next of kin should not necessarily prevent them from being able to raise an issue or concern of behalf of the resident.

5.6 Complaints are not representative of everyone's experience

Learning point 8

The issues that have been highlighted within this report are not representative of everyone's experience. Indeed, even within the complaints cases reviewed, clients are often at pains to highlight the positive aspects of their experience. For example, one client included within their complaints letter "I have been incredibly impressed by all the nursing staff and the attention and loving care that they individually showed".

Nonetheless, complaints are a valuable source of intelligence when they are used to identify learning. The nursing home standards outline that nursing homes should be able to evidence that complaints are used as a learning experience and are used to improve the quality of services.

Recommendation 11: The designated complaints lead should ensure that where learning from complaints is indicated, that the necessary actions are followed up and that record is kept of this and that it is available for inspection.

6. Conclusion

The review of recent literature on residents' experience of nursing home care was undertaken. A key theme running throughout all the literature reviewed is the importance of ensuring that people living in nursing homes are given the opportunities and support necessary to enable them to live a full and dignified life. The central message is that care that is shaped around the resident's needs and wishes and supported by strong relationships with compassionate staff can result in more positive experiences of nursing home care.

Other areas that were discussed within the literature were factors impacting quality of life, such as: meaningful recreational activities and social activity; the provision of appropriate and dignified personal care particularly continence care; the need for equitable and timely access to a full range of health care services; access to appropriate health care; the importance of food and nutrition; the safety of residents and their protection from abuse and neglect; and, the need to support and enable residents to make decisions about their own care.

The review of PCC Complaints Support Service cases relating to nursing homes highlighted particular issues that residents can face in relation to: medication and healthcare; personal care; the capacity and capability of staff to meet the needs of residents; financial issues; decision making; and social contact and stimulation. These findings further substantiate the findings from the literature review.

As a result of undertaking this project the PCC has produced a set of learning points and recommendations. These focus on ensuring that residents and family members are supported to raise their issues and concerns around nursing home care taking into consideration the vulnerable nature of this client group. The PCC has recommended that nursing home complaints procedures are reviewed to ensure they meet the revised nursing home standards. Furthermore potential complainants should be made aware that they may raise their case directly through the HSC complaints process. Of particular concern are the current processes around 'termination of contract' notices and the need to ensure that these contract clauses are not used to unfairly discriminate against people, particularly those who raise issues or concerns.

It is hoped that the learning points and recommendations identified in this report can be used to improve the quality of nursing home services and people's experience of nursing home care.

References

- 1. Department of Health, Social Services, and Public Safety. *Statistics on community care for adults in Northern Ireland 2016/17*. Belfast: DHSSPS; 2017
- 2. Age NI. Review of minimum standards in nursing homes. Engagement with residents in nursing homes. Belfast: Age NI; 2014
- **3.** Department of Health, Social Services, and Public Safety. *Care standards for nursing homes.* Belfast: DHSSPS; 2015
- **4.** Patient and Client Council. *Consultation engagement on the review of minimum standards of nursing homes.* Belfast: PCC; 2014
- 5. Regulation and Quality Improvement Authority. RQIA provider guidance 2016-17
 Nursing homes. Belfast: RQIA; 2016
- 6. The United Nations Principles for Older Persons, adopted by the General Assembly of the United Nations resolution 46/91 of December 1991 <u>http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx</u> [accessed 17/01/17]
- Commission on Dignity in Care. Delivering Dignity: Securing dignity in care for older people in hospitals and care homes. London: Commission on Dignity in Care; 2012
- **8.** Care Quality Commission. *Time to listen. In care homes. Dignity and nutrition inspection programme 2012.* CQC; 2012
- **9.** Northern Ireland Human Rights Commission. *In Defence of Dignity. The human rights of older people in nursing homes.* Belfast: NIHRC; 2012
- 10. Age NI. Agenda for later life 2015. Public policy for later life in Northern Ireland. Belfast: Age NI; 2015
- **11.**National Care Homes Research and Development Forum. *My Home Life: quality of life in care homes literature review.* London: Help the Aged; 2007
- **12.** Joseph Rowntree Foundation. *Improving care in residential care homes: a literature review.* York: JRF; 2008
- **13.** Joseph Rowntree Foundation. *My home life. Promoting quality of care in care homes.* York: JRF; 2012
- **14.**Care Quality Commission. *Health care in care homes. A special review of the provision of health care to those in care homes.* CQC; 2012

- **15.**Regulation and Quality Improvement Authority. *Independent review of the actions taken in relation to concerns raised about the care delivered at Cherry Tree House, Carrickfergus.* Belfast: RQIA; 2014
- 16. British Geriatrics Society. Quest for Quality: British Geriatrics Society joint working party inquiry into the quality of healthcare support for older people in care homes. London; British Geriatrics Society; 2011
- **17.**Care Quality Commission. *Cracks in the pathway. Our review of dementia care.* CQC; 2014
- **18.**Age UK <u>http://www.ageuk.org.uk/home-and-care/improving-dignity-in-care-</u> <u>consultation</u> [accessed 17/01/17]
- **19.**Russell CA, Elia M. *Nutrition screening survey in the UK and Republic of Ireland in 2011.* Redditch: British Association for Parenteral and Enteral Nutrition, 2012.
- 20. The Mid Staffordshire NHS Foundation Trust Public Inquiry Chaired by Robert Francis QC. Feb 2013. Available at <u>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/27</u> 9124/0947.pdf
- **21.**Commissioner for Older People for Northern Ireland. *Protecting our Older People: A call for adult safeguarding legislation in Northern Ireland.* Belfast: COPNI; 2014
- 22. Department of Health, Social Services and Public Safety and Department of Justice. Adult Safeguarding – Prevention and Protection in Partnership. Belfast: DHSSPS; 2015
- **23.** Patient and Client Council. Someone to Stand Up for Me. A toolkit to promote advocacy for older people in the independent care home sector. Belfast: PCC; 2012
- 24. Regulation and Quality Improvement Authority. *Review of advocacy services for children and adults in Northern Ireland.* Belfast: RQIA; 2016