

Patient and Client Council

Submission to the Health Committee Inquiry into the Impact of COVID-19 on Care Homes in Northern Ireland

October 2020

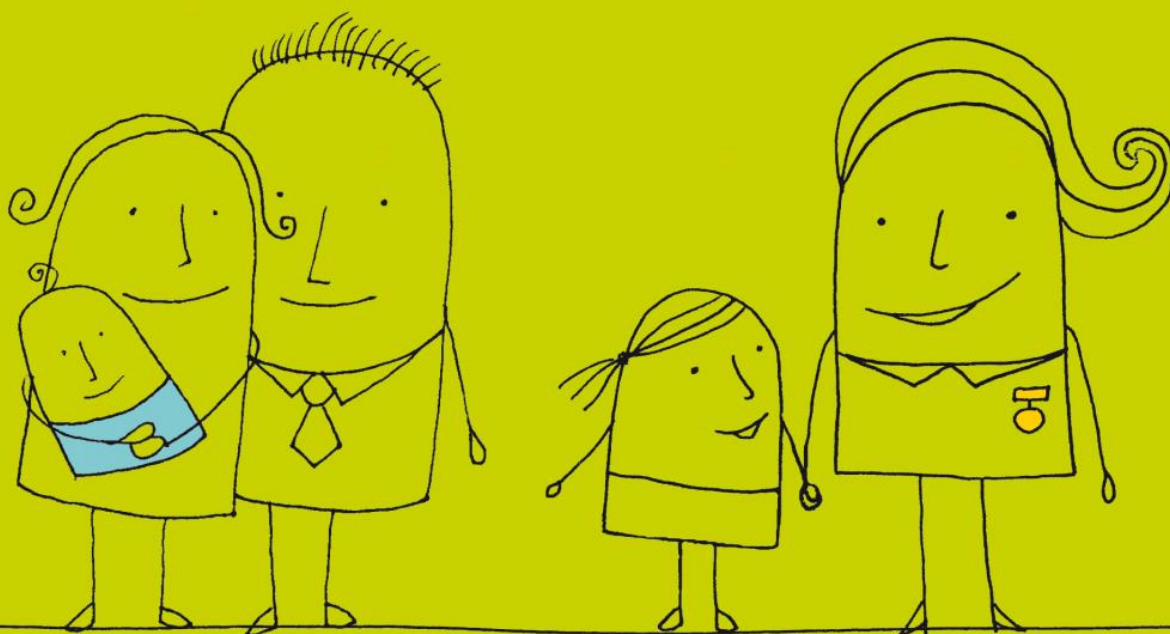


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Patient and Client Council

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October 20th 2020

Dear Mr Gildernew

Thank you for your invitation to contribute to the Inquiry into the impact of COVID-19 on Care Homes in Northern Ireland.

The Patient and Client Council is an Arm's Length Body established by the Health and Social Care (NI) Act (2009). The Patient and Client Council has five statutory responsibilities to the public and these are:

- Representing the interests of the public;
- Promoting involvement of the public;
- Providing assistance (by way of representation or otherwise) to individuals making or intending to make a complaint relating to health and social care for which a body to which this section applies is responsible;
- Promoting the provision by bodies to which this section applies of advice and information to the public about the design, commissioning and delivery of health and social care
- Undertaking research into the best methods of consulting people about, and involving them in matter relating to health and social care.

The Client Support Service of the Patient and Client Council is the primary means by which this organisation discharges its responsibility to provide assistance *'to individuals making or intending to make a complaint'*. The organisation also has an Involvement function and a Research function, both of which primarily focus on *'representing the interests of the public'*, *'promoting involvement of the public'* and promoting the *'provision of advice and information to the public about...health and social care'*.

The evidence we present here in response to your request is based on the work of all three of these staff teams, and specifically draws on:

- The Client Support Service database, a confidential repository containing details of all clients to whom our Client Support Officers provide support in resolving issues, concerns or formal complaints about health or social care.
- Records of contacts received by phone or email between 20th March and 28th September 2020 from members of the public seeking information or advice about – or wishing to report issues with – their health or social care;
- A survey conducted during June and July 2020 which aimed to record the experiences, opinions and suggestions of people who were asked to ‘shield’ due to COVID-19 between March and July 2020;
- A project carried out during August and September 2020 which involved online engagement with family members of people living in group living settings, to explore the impact of Covid 19-related restrictions on residents and their families.

By comprehensively searching / reviewing these sources, we have sought to address your request to provide, by 19th October 2020, proposals on *‘the steps required to minimise infections in care homes and care for those infected, while prioritising the care and wellbeing of all residents in the broadest sense as well as the wellbeing of staff’*.

I hope that that the information in these documents is of use to the Inquiry and provides assurance that best efforts have been made to discover relevant information, and to translate this information into practical, evidence-based recommendations.

You will note in our submission the reference to a ‘Temperature Test – Constant Conversation’ (Section 4.1) that we are in the process of developing and implementing along with partners. This relates to monitoring the ongoing impact of Covid-19 in care homes and we would be happy to have continuing engagement with the Committee in relation to material arising from this that might be relevant to its work.

Lastly, The Patient and Client Council are happy to discuss this report in more detail if this is required or if it would be useful to the Inquiry’s work. If you do have further questions, please contact Dr Colm Burns by phone on 028 9536 1704 or 07867528309 or by email at colm.burns@pcc-ni.net

Yours sincerely

Vivian McConvey
Chief Executive

1 Summary of evidence and proposed steps

Most of the Patient and Client Council's evidence has come directly from care home residents' family members so the impact of visiting restrictions is naturally the dominant theme.

Across a large majority of the contacts and cases reviewed, there was significant concern for the short and long-term impacts of isolation on residents' emotional and physical wellbeing. The reported effects on residents living with dementia were particularly severe. The most extreme accounts related to the lockdown period but deep concern about visiting arrangements persists.

Given the potential need to tighten visiting restrictions again in the near future, some key proposals for the Department of Health based on the evidence include:

- Replace top-down decision-making on visiting restrictions with a creative ongoing engagement strategy, so that the perspectives of residents and their families are central in planning visiting arrangements which are safe, humane and acceptable to all stakeholders. Whilst we recognise that decisions are having to be made at pace, an integrated engagement plan would ensure that residents and families can share their experience, insights and suggestions as we progress through the pandemic. This would also go some way to address the feelings of 'powerlessness' expressed by family members.
- When issuing or updating care home visiting regulations, clearly communicate to the public and to residents' families that this guidance is advisory only for independent sector care homes, i.e. that these are private businesses; and that decisions about visits are at the discretion of care home management and not the Department of Health. Doing so may reduce confusion and frustration around the inconsistency in visiting arrangements between sectors, and between care homes.
- Related to the above, steps to increase consistency – across and within sectors – in how care homes interpret, implement and adhere to visiting advice would be welcome. This could be through more proactive communication and engagement with providers at the point of issuing guidance.
- Provide information on the rationale for decisions as visiting guidelines are announced or updated so that care home providers, residents and their families can understand policy decisions.
- Explore and facilitate shared learning on good practice and successful visiting arrangements between providers within Northern Ireland and across the other four nations, England, Scotland, Wales and the Republic of Ireland.

For care home providers, suggestions for new or improved practice include:

- Develop innovative visiting arrangements (again in collaboration with residents and their families) which adhere to guidelines but which strike a balance between protecting staff and residents from COVID-19 and maintaining residents' quality of life and wellbeing. Such steps could ideally be tailored to individual residents, and are especially important for residents living with dementia or approaching the end of life.
- Create and sustain ongoing regular engagement and communication with residents and families. This is critical to working together and successfully managing the pandemic. Steps for care home providers should include:
 - Provide information on the rationale for changes to visiting arrangements so that residents and their families can understand decisions.
 - Give family members regular updates about each resident during periods of restricted visiting or contact, including information on health status but also qualitative updates on how the resident is coping. Again, this is especially important for residents living with dementia or approaching the end of life.
 - Regularly update residents and family members about the incidence and spread of COVID-19 within their care home.

Specifically in relation to **steps required to minimise infections in care homes and care for those infected**, consideration should be given to routine testing of individuals (including staff, residents, visitors and loved ones) at 'transition points' i.e. upon entry into and exit from care within care homes, hospitals; and community care settings, including domiciliary care.

- Whilst policies exist in relation to testing, they do not cover all settings. In order to minimise infection spread, consideration should be given to the extension of these policies to support routine testing at 'transition points', where individuals are moving from one setting to another. Of particular concern is the transition between hospital and domiciliary care. This has been tragically highlighted in the case of a family in the NHSCT (where both parents died within 4 days of one another), and which is currently the subject of a Level 3 SAI (Significant Adverse Incident). In this case, the lack of testing when one parent moved from an acute hospital setting into a domiciliary care setting, coupled with the lack of routine testing of domiciliary care staff, has been highlighted as a significant concern by the family, particularly in relation to minimising infection spread. The lack of routine testing at such 'transition points', and of domiciliary care staff, remains an ongoing issue.
- Testing is only as effective as the coverage it provided across settings. With the current challenges in HSC workforce and in the care home sector;

including the transience of staff across settings, the use of agency staff across services and the ongoing regulation regime implemented by RQIA which necessitates visits into care homes by RQIA inspectors, routine testing of individuals at 'transition points', on exit and entry to services is critical in minimising infection and spread of Covid 19.

A final theme to cut across the evidence we reviewed was the appreciation and gratitude of residents and their loved ones for the work of operational care home staff during the COVID-19 pandemic. They repeatedly expressed understanding for the difficult work of the care providers during lockdown, and were thankful for their efforts.

Mini Inquiry – Impact of COVID

The Patient and Client Council (PCC) engaged with a number of families of residents from care homes in order to support the Health Committee's Mini Inquiry – Impact of COVID-19 on 14th October 2020. The event provided an opportunity for individuals to share their experiences, specifically in relation to the impact of COVID-19 within care homes where their family members reside.

The PCC engaged with families to discuss how best to support the event to ensure that their lived experience shaped the discussion. As such, a virtual preparatory meeting was facilitated by PCC on Tuesday 13th October 2020 in readiness for the meeting. The meeting framed dialogue around experiences, key areas of focus and to provide peer support to families in readiness for the meeting. As a result, the engagement opportunity provided a full understanding of the plethora of challenges and complexities that many individuals are currently experiencing which were presented in full by families who attended the mini inquiry.

Families welcomed the opportunity to have their experiences heard by policy makers; this was reiterated by all who were engaged within the process. The impact of restrictions and the presenting challenges of COVID-19 cannot be underestimated nor too can the direct correlation between current measures implemented and patient experience in terms of social, emotional and psychological impact of limited visitations, contact and communication. Families were vocal of their experiences thus far; during the inquiry meeting we were able to frame the feedback into the following key areas;

1. Visitation;
2. Communication;
3. Care;
4. Infection Control and prevention

Visitation

Restrictions have been detrimental especially in those cases where a resident has communication / cognitive challenges. The frequency of visiting has been dependent on the testing within the homes and the turnaround of respective results therefore impacting upon frequency of visitation.

Moreover, the twenty minute weekly visits are not long enough; many families cited that the actual interaction time is impacted by the processes to enter the home, temperature checks, donning PPE and transferring patients to isolated areas.

Due to the current arrangements, visits are distressing for residents and also the family. They are not conducive to providing meaningful engagement with residents: participants widely cited infringement of human rights and abuse of vulnerable adults.

Concerns were highlighted around designation of particular individuals as care partners and the impact that it has on families especially those larger in numbers.

Across all client groups visitation was the most topical issue. Families were unanimous in outlining that there has been no constant provision for visitation and the ad hoc approach is detrimental to residents and families longer term. Visits were cancelled or rescheduled without clear guidance as to why; often leaving families wondering not *when* but *if* they would see their family member again. This was most prevalent in the cases of those living with degenerative or cognitive conditions and those older in years. In particular, one family member displayed two comparable photographs of her recent visits with her mother who was 92 years of age. The photographs conveyed how her health had declined between the two visits that the family were permitted over a six week period. More importantly, the visit was through a Perspex screen which does not lend itself to any form of tactile connection, a connection that her mother whom has cognitive issues needs to reassure her. Visibly upset, several other families confirmed that this example resonated with their own experiences thus demonstrating the impact not only on the individual but on the wider family networks too. In this scenario, the family outlined how they had brought presents to celebrate her mother's 92nd birthday and were unable to do so fully, they had to pass gifts and greetings cards through a window during the 20 minute visit. Additionally, at what should have been a time of celebration, they were asked to sign a Do Not Resuscitate order for their mother, highlighting how the experiences are often marred by ill thought through bureaucracy.

The impact of visitation was further evidenced by a family whose mother, in her mid-sixties with end stage dementia, also has a hearing impairment. The family member conveyed that she was unable to communicate with her mother as she had to wear a mask when visiting, her mother was unable to lip read or pick up on social cues, therefore the current restrictions and measures impacted profoundly on interaction. Additionally, her mother recognised her and was very upset reaching out, trying to

hold her daughter. In this scenario, contact would have allayed the mother's distress and re-instated a positive connection between the resident and her family. The family members lasting memory of this visit with her mother was one of her being upset and in distress, and feeling utterly powerless in the scenario. The daughter cited that her 35 mile return journey home was filled with emotion and upset and questioned *'Would this be my last memory of Mummy?'*

This prompted discussion around the fact that there is no reassurance given to the family that a resident's emotional wellbeing is supported.

Care

One family highlighted that they could each visit their mother once every five weeks on account of the size of the family circle, this cycle of visitation provided twenty minutes of contact time to each every five weeks. The group were unanimous as to how precious this time is and often it was absorbed with internal processes, thus consuming the actual time with the resident.

Another family outlined that their mother could be settled with soft fabric materials being draped around her neck, this would often give comfort in times of distress or uncertainty. The restrictions and sanctions from the home warranted the prohibition of such items. As a result the lady would have her comforts removed, without her comprehension. Her cognitive abilities do not allow her to relate to the world outside or to understand the pandemic. This too was a common theme.

Families evidenced that they know their loved ones intuitively, their likes, dislikes and comforts – this social care element is integrated into the broader health care needs and needs acknowledged. In the case of a patient who cannot communicate, has an audio impairment and degenerative condition the family contacted the home to see how the resident was keeping. The home stated *'We have put the radio on in her room for her'*.

Families explained that updates on residents are dependent on who answers the phone and the levels of busyness within the home. During much uncertainty the need for compassion and reassurance is paramount. A number of similar examples were shared by families.

Communication

A common theme across all groups was the lack of communication from the residential settings to families.

External communications to families has been limited and in some cases non-existent. An example was given whereby a resident had been in contact with her family stating that there had been a death within the home, a message that was shared with the media in the first instance and not the residents and families. It was

heavily reported that information was given to the media in the first instance; or that communications were second and third hand from other residents' families.

On another occasion, a family was not told about an outbreak within the home and had to hear it from the media. This claim was confirmed by another carer, highlighting that families are not given a true indication of prevalence and outbreaks. In comparison, a further case highlighted that there was no sharing of information where homes were COVID-19 free and when it would be permissible to visit.

In relation to communication with families, there was an alarming body of evidence that highlighted that residents were unable to interact with families through technological aids such as iPads, video calling or virtual platforms. Whilst funding was provided by the Department of Health to support this initiative, it is patchy at best. Examples were given whereby relatives were not supported to use the device, staff were present during the calls or where the video or audio did not work. There appears to have been little thinking about the complexities of communication, especially with elderly and sometimes cognitively limited people; and the restrictions imposed by e.g. Bad Wi-Fi or poor internet connectivity. . Whilst there has been financial investment by Department of Health into these resources, assurances and accountability as to the quality of the experience needs to be at the fore.

Processes:

'Families have been locked out, yet COVID-19 hasn't – the equation doesn't add up'.
'If PPE is suitable for staff to protect people and staff it could be used by families.'

It was strongly implied that the guidance is subjective - individuals are not subjects – there needs to be mandatory guidance / policy to ensure that people are connected, supported and effectively cared for. Families are willing to comply, to go above and beyond requirements; yet are closed out of the inner workings of the processes.

Infection Control and Prevention:

A number of families were asked if there had been a COVID-19 outbreak in the home.

Several of the group confirmed that there had been outbreaks in the home and highlighting that this was attributed to PPE as an issue. Many asked '*Why can't the HSCT train families in the use of PPE to support visiting and infection control?*'. Families were willing to wear full PPE in order to visit residents, yet this has not been put forward as an option.

When asked if an outbreak occurred, would they support their family member being moved to an isolation area or alternative facility? A number of participants outlined that in most cases they would, if the person was mobile and not ill. Risks would need to be assessed and in consultation with the family. Others highlighted that a move would be detrimental to their relatives' condition and the logistics of moving would be

very difficult to implement. It was highlighted that for those with dementia and cognitive difficulties in particular this would be very distressing.

Summary:

The lived experience outlined during the mini inquiry conveys the real impact that of COVID has had on care residents and their family members. The gravity and emotional impact was evident. Key findings from the inquiry suggest the need to implement and endorse:

- Clear mandatory guidance on arrangements and the rationale for them
- Effective communication internally and externally
- Recognition of care and communication needs
- Lived experience needs to be at the heart of all elements of public and policy discourse.

Both of these initiatives are part of a wider objective to develop an engagement platform related to Care Homes, supporting care home residents and family members to be part of an ongoing conversation with providers and policy makers. Further information in relation to this is detailed at Section 4 of this submission. This would be an avenue for the Committee for Health to have an ongoing relationship with the Patient and Client Council to understand the experience of families as we move forward.

2 Appendix A: Evidence sources and methods

2.1 PCC Call Answering Support Service contacts (N=159)

The PCC Call Answering Support Service deals with contacts received through the PCC Freephone number, emails to complaints.pcc@pcc-ni.net or to info.pcc@pcc-ni.net, and COVID-19 related emails from the public forwarded by the PHA.

From 20th March to 28th September 2020, the PCC Freephone received 4,156 contacts.

159 of these contacts were related to COVID-19 and care homes.

Contact records were downloaded in MS Excel and filtered / searched in order to identify all contacts potentially related to COVID-19 and care homes. These contacts were reviewed to confirm their relevance and to identify clusters of COVID-19 / care home contacts, based on what the enquiry or issue specifically related to.

2.2 PCC Client Support Service Cases (N=15)

The Client Support Service of the Patient and Client Council is the means by which this organisation discharges its responsibility to provide assistance 'to individuals making or intending to make a complaint'. Details of all clients to whom our Client Support Officers provide support in resolving issues, concerns or formal complaints about health or social care are held in the Client Support Service database.

A comprehensive search was conducted of all new cases logged from March 2020 until September 2020 to identify any formal complaints, issues or concerns relating to COVID-19 and care homes. The search involved filtering cases based on Programme of Care / service areas – as well as searching for key words – to identify all relevant cases. Documentation on these fifteen cases was then reviewed in detail and typed up into summaries which were then incorporated into the response.

2.3 Shielding Engagement Survey (N=38)

During June and July 2020, the Patient and Client, in partnership with the Department of Health, carried out a survey of Northern Ireland's shielding population. The aim was to understand the impact of shielding on people's lives, the types of support they were already receiving or from which they could benefit, and the ways in which their experience could be improved. The survey was predominantly online but with options to respond over the phone or via post or email. Some questions were categorical / scale format but most were open ended free text. Over 3,500 responses were received.

Response data was downloaded in MS Excel and filtered according to respondent category and reason for shielding, in order to identify responses from care home

staff, residents or their loved ones. A key word search was also carried to ensure no relevant response data were missed. These 38 responses were reviewed to confirm their relevance and to understand the common themes around COVID-19 / care homes.

2.4 Group Living Engagement Project

During August and September 2020, the Patient and Client Council carried out a series of virtual group engagement sessions and interviews with family members of people living in group living settings, to explore the impact of shielding restrictions on residents and their families.

A summary report of this work, setting out recurring themes and proposed actions, is currently in draft form. The draft report was reviewed and key issues relating to COVID-19 in care homes, including the challenges faced by residents and their loved ones and perceived areas and suggestions for improvement, were identified

3 Appendix B: Detailed evidence

<i>3.1 Discharge from hospitals to care homes</i>	
<u>Call Answering Support Service Contacts</u>	<p>There were a very small number of contacts to the Service specifically relating to discharge from hospitals to care homes; there were a small number of contacts more generally around movement of residents into and out of care homes. All contacts of this nature were in the earlier stages of the COVID-19 pandemic.</p> <p>These contacts tended to involve family members concerned about residents being returned to their care home or reporting delays in getting residents back into their care home. The negative impact on people living with dementia of moving into and out of care homes was raised by several clients.</p>
<u>Client Support Service Cases</u>	<p>Two cases relating to issues with movement into and out of care homes were identified in the Client Support Service database. Neither had been escalated to a 'formal complaint'. One was from a family member questioning the decision to move her father out of his care home into a COVID-19 ward after a positive test. The other involved a resident being asked to move back home from a COVID-19 free care home after a suitable care package had been put in place. Their family member successfully challenged the decision.</p>

<i>3.2 Access to PPE</i>	
<u>Call Answering Support Service Contacts</u>	The volume of contacts to the Service about care home staff's access to PPE was very low and these pre-dated PPE being made compulsory in care settings. A small number of other contacts were from family members reporting that guidance on the use of PPE was not being adhered to by care home staff while visitors were required to wear full PPE.
<u>Shielding Engagement Survey</u>	Several respondents mentioned PPE in care homes. These responses were received during the period when the guidance for care homes prevented face-to-face visiting, and were from people who felt that visits in person should be allowed as long as everyone wore adequate PPE. Again, the number of such responses was relatively very small.

<i>3.3 Testing in care homes</i>	
<u>Call Answering Support Service Contacts</u>	COVID-19 / care home contacts about testing have been the second most common theme and have increased during August and September. However, very few of the contacts were from people raising issues or concerns. Many of them were requests from care home staff for clarification on how to arrange testing, on the required frequency of serial testing for residents or staff and on what steps to take in the case of a positive test in the home.
<u>Client Support Service Cases</u>	There was one case which referenced COVID-19 testing in care homes: a family member of a resident asking why her father had not been re-tested when returning to his care home after being moved to a COVID-19 ward due to a positive test.

<u>Group Living Engagement Project</u>	There were some suggestions from residents' family members that more visiting could be allowed in care homes based on testing residents and their visitors in advance to confirm that they are not infected with COVID-19.
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3.4 Funding and increased costs for care homes

No relevant evidence

3.5 Staffing issues and levels

<u>Call Answering Support Service Contacts</u>	Staffing issues and staffing levels were one of the main themes among COVID-19 / care homes contacts. Aside from a number of employment-related enquiries from care home staff (e.g. relating to return to work after shielding or travelling), several people raised concerns about high sickness and absenteeism among care home staff, as well as excessive workload. One contact reported having to cut corners on a regular basis and being worried that something was going to go 'badly wrong' in the home in which he worked; another suggested that understaffing had left staff with no option but to work across units with little regard for infection control.
<u>Shielding Engagement Survey</u>	One survey respondent (the sister of a care home resident) referred to the impact of staff shortages. Her sister tested positive for COVID-19 and was moved to a 'quarantine wing' of the care home along with some other residents. Due to staff shortages, agency staff had to be brought in to care for the resident during quarantine. She also then had to remain in the quarantine wing because there were no staff to deep clean her room to allow her to move back in.

<u>Group Living Engagement Project</u>	There was no evidence on staffing issues and levels in care homes from the group living engagement project. However, it should be noted that participants were unanimous in their praise for the care home staff looking after their relatives. There was great appreciation for how difficult the working conditions were in care homes, and gratitude from participants for staff members' efforts. This also came through strongly in shielding survey responses.
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3.6 Staff pay and conditions

No relevant evidence

3.7 Visitors

<u>Call Answering Support Service Contacts</u>	<p>Visiting has been by far the largest and most consistent theme in contacts to the Service around COVID-19 and care homes, and these contacts are also much more likely to be critical or negative in nature.</p> <p>There has been clear variation over time, with contacts prior to the relaxation of care home visiting advice tending to come from family members who were frustrated and concerned at not being able to visit or, in many cases, even see or speak to their loved ones. It was common at this stage for people to be seeking updates on when the visiting guidance would be reviewed and potentially eased.</p> <p>After the restrictions were eased in July, visiting contacts remained the most common theme around care homes but the nature of contacts changed. Some people were confused and frustrated about the continued inability to visit their loved one despite the changes in guidance. There was an explanation</p>
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3.7 Visitors

	<p>for this in some cases (e.g. care homes awaiting delivery of marquee equipment to enable outdoor visiting).</p> <p>More commonly, contacts were from family members who were unhappy with the measures put in place to enable visits. These often involved residents with dementia whose family members were concerned that visiting conditions were detrimental to their emotional wellbeing. For example, seeing family members wearing PPE, behind screens or outside in a 'freezing cold tent' had caused confusion and distress for residents with dementia. One client described her visit with her father as like a 'prison visit'.</p>
<u>Client Support Service Cases</u>	<p>Visiting was also the dominant theme in Client Support Service cases relating to COVID-19 and care homes. There were eight cases involving care home visits, though none of these was a formal complaint. Six of the cases were raised in March / April 2020 and the remaining two were from September 2020.</p> <p>The earlier cases were from people who were either seeking confirmation that the Department of Health had advised a total cessation of care home visits, or taking issue with this advice because they felt that their loved one could not cope without contact from their family. Several of these clients complained about the lack of effort from care home staff to facilitate remote contact with their loved one. For example, two stated that their care homes had declined to allow visiting at a window and one that the care home had not facilitated video calls when asked. These cases date from the very early stages of the COVID-19 pandemic, potentially before care homes had planned their response or put measures in place.</p> <p>The more recent cases were issues / concerns about lack of flexibility in visiting times and about changes to visiting arrangements being poorly communicated to a resident's family.</p>

3.7 Visitors	
	<p>Two of the cases involved residents with dementia. One of these clients reported that her father would cry when she visited at the window and questioned the discrepancy between the blanket ban on visiting in private care homes and the allowance for one visitor to residents of Trust care homes.</p>
<p><u>Shielding Engagement Survey</u></p>	<p>Again, a very large majority of the relevant responses to the Survey were about visits or, more specifically, about the negative impact of the visiting restrictions. These were primarily related to the effects on residents' quality of life and emotional wellbeing of long-term separation from their loved ones. When asked about the impact of shielding restrictions, responses (in June / July 2020) from care home residents and their family members included:</p> <p>'Not seeing your loved one and being confined to your room is affecting [my husband] mentally as he misses seeing us and our dogs. He has an upstairs room so it was not always possible to see him downstairs through a window. His appetite has been affected and he has lost weight'.</p> <p>'I am very lonely and miss my family visiting. I worry about them and I worry about myself and the possibility of getting coronavirus. My mental health is deteriorating and I am becoming more confused in time and place'.</p> <p>Others provided insight into the often severe consequences for residents' family members of not being able to visit their loved ones in care homes:</p> <p>'Our granny went into a care home at start of March. It was the last time we got to hug her and talk to her and we couldn't visit our granny as she was dying. She passed away in May'.</p> <p>The impact of visiting restrictions on residents living with dementia and their families was a recurring theme in the Survey responses but there was variation in the reported impacts. One respondent said</p>

3.7 Visitors

	that her mother was 'devastated' while another stated that 'I don't think he will miss me as we were getting to a stage where he did not always recognise me, but I worry about him as he is very frail'.
<u>Group Living Engagement Project</u>	<p>The pause in visits and subsequent visiting restrictions were also a dominant theme in the engagement with family member of group living residents. The loss of free access to visit care homes had given participants a sense of having 'lost control' over their contact with their loved ones and over their care. Much of the discussion related to the implications of this for family members but primarily for residents.</p> <p>In addition to missing their company and physical contact, the inability to monitor the wellbeing of their relative and to care for and reassure them during such a difficult time was challenging for participants:</p> <p>'I now am permitted one visit per week for twenty minutes. This leaves me feeling as if I have no say in his life and I also am left feeling very removed from him. We have been married for fifty one years, and it was bad enough having to make the decision that I couldn't look after him anymore but I now feel that I have abandoned him'.</p> <p>Levels of concern for residents themselves were profound in the interview and focus group evidence. Almost all study participants expressed significant concern over the impact on their loved ones' physical and mental wellbeing of isolation as well as the lack of mental stimulation :</p> <p>'You cannot just leave people sitting doing nothing. I actually think it's against their human rights as people... The reality is you can't deprive people of everything in their lives just to keep them safe'.</p> <p>Again, there was particular concern for the wellbeing of relatives with diminished mental capacity. These individuals were deemed especially vulnerable due to difficulties with verbal communication (limiting the benefit of phone and video calls), with adjusting to even simple changes in their routine, and with not understanding what is happening:</p>

3.7 Visitors

‘When he got a urinary tract infection and became confused – refusing to take the antibiotic and his other medications – I had to try and persuade him via facetime several times a day and this was heart breaking to see him so confused and fearful’.

‘My sister had deteriorated mentally and was confused about my appearance – I was wearing a mask, sitting at least ten feet away and there was no physical touching. She no longer talks about other family members and had no idea of when we last met’.

The evidence also suggested that residents approaching the end of life were more acutely impacted by visiting restrictions:

‘The thought of [my father] dying with a lack of family support is worse than the thought of him getting COVID-19 to be brutally honest’.

Aside from the actual removal or reduction of visits, several participants were dissatisfied with the lack of family member involvement. There was frustration at not having been consulted or involved in developing an approach to visits that balanced residents’ safety with their quality of life and wellbeing. There was also a sense that those making these decisions did not understand the situation in care homes and that, as a result, policies had not been tailored to the unique needs of care home residents:

‘You just feel like you have no say in anything at all. Everything was ‘This is what’s happening and tough’, and it was just like you just feel so helpless’.

Some participants also expressed frustration that the scientific rationale for visiting arrangements was not communicated, beyond being told that it was necessary to keep their loved one safe.

<i>3.8 Regulation</i>	
<u>Call Answering Support Service Contacts</u>	RQIA was referenced in around one third of all contacts relating to COVID-19 / care homes. During April and May 2020, members of the public calling RQIA were being transferred to the PCC Freephone service. This caused confusion for some callers, who wished to get through to a Home Inspector or the Duty Inspector. There is no evidence about RQIA's role in regulating care homes during COVID-19.
<u>Client Support Service Cases</u>	RQIA was mentioned in around half of all new cases relating to COVID-19 and care homes. In most cases, RQIA were contacted for clarification on visiting guidance or clients were signposted to RQIA when they wanted their concern investigated. Several of these clients objected to the inconsistent application of visiting regulations, and questioned why visitors were still allowed in Trust-run care homes while they were unable to visit their loved one in their independent sector home.
<u>Group Living Engagement Project</u>	<p>Some participants strongly questioned the 'leeway' given to independent sector care homes in interpreting and implementing government advice on visiting during the COVID-19 outbreak. Perhaps unsurprisingly, the lack of consistency in visiting across different care homes was universally cited as a significant source of frustration for families. People highlighted the 'lack of continuity and standardisation' between Trust-run and independent sector care homes in this area but also the inconsistency 'even within a specific group of private providers'. Some saw it as a sign of inequality and unfairness in the system:</p> <p>'The whole key thing to it all would be consistency so that you don't have my sister's home does this in Comber and somebody else's home in Bangor does something different'.</p>

<i>3.9 Medical care within care homes and advance care planning</i>	
<u>Call Answering Support Service Contacts</u>	A small number of contacts related to medical care within care homes. The contacts were varied – one case involved a situation where a family member had passed away in a care home and the family had

	not been notified for four hours, which had caused significant upset to the family.
<u>Client Support Service Cases</u>	Two very serious cases related to medical care within care homes during the COVID-19 pandemic, both of them formal complaints. One involved a resident who had contracted COVID-19 while in a care home and subsequently died. The other related to a resident whose discharge from a nursing home was delayed due to COVID-19. She choked and was taken to hospital where she later died. The resident's husband was confused about the chain of events and cause of death, and wished to raise a formal complaint.
<u>Group Living Engagement Project</u>	<p>There was no evidence from the group living engagement project directly relating to medical care in care homes. However, the ability to obtain up to date information on residents' health status and on the incidence of COVID-19 in their care home was a very high priority for participants, particularly in the absence of regular visits. Some felt that care homes had put insufficient effort into providing such updates, that 'they won't tell me anything and I don't know'. This was a source of stress – and in some cases distrust – among family members:</p> <p>'It was as if things were being hidden from you, but you knew from speaking to others they were probably in the same boat but you just wanted to know what exactly was going on. What provision was being made, and sometimes you just couldn't find out'.</p>

3.10 Preparedness within the HSC and in care homes

<u>Call Answering Support Service Contacts</u>	There was a very small number of contacts relating to preparedness and planning for COVID-19 in care homes and in the wider HSC system and these were enquiries as opposed to issues or concerns.
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<u>Client Support Service Cases</u>	<p>Several cases alluded to preparedness for COVID-19. There was no consistent theme in these cases and they included clients reporting poor adherence to social distancing, lack of provision for remote contact with residents and inadequate facility for testing residents.</p>
<u>Group Living Engagement Project</u>	<p>There were no direct references from the group living engagement project to preparedness in care homes (or a lack of preparedness). However, several participants suggested that more balanced and humane visiting regulations could have been developed had more thought, planning and consultation gone into the decisions:</p> <p>‘I know that we have to sort of realise that this is very strange circumstances, but I think there is nothing in life that is risk-free and I think we can be more proactive in managing risk’.</p> <p>‘They need a hug from a loved one. Surely it is not impossible to facilitate this basic human right’.</p>

4 Looking Forward

4.1 Temperature Test – Constant Conversation

The Patient and Client Council is proposing to work in partnership with Public Health Agency, residents and relatives to establish a COVID-19 and Care Homes **‘Temperature Check’**. The proposed methodology will be a longitudinal survey that will establish a constant conversation with residents and family members. The aim is to send the same set of questions directly to the same group of people that is, residents and family members of care home residents, on a bi-monthly basis. Starting small, we aim to build a recruitment campaign which will be open to the public with the invitation to participate promoted widely online (HSC social media, HSC websites), and in a more targeted way through key stakeholders in the care home sector.

Care home residents and family members will be invited to engage in a constant conversation about their opinions, experiences and ideas around the response to COVID-19 in care homes. This will allow relatively robust tracking over time of the perspectives and experiences of people whose loved ones are living in care homes under COVID-19 restrictions. The data gathered would be shared widely to inform and influence the development of policy, guidance and practice within care homes.

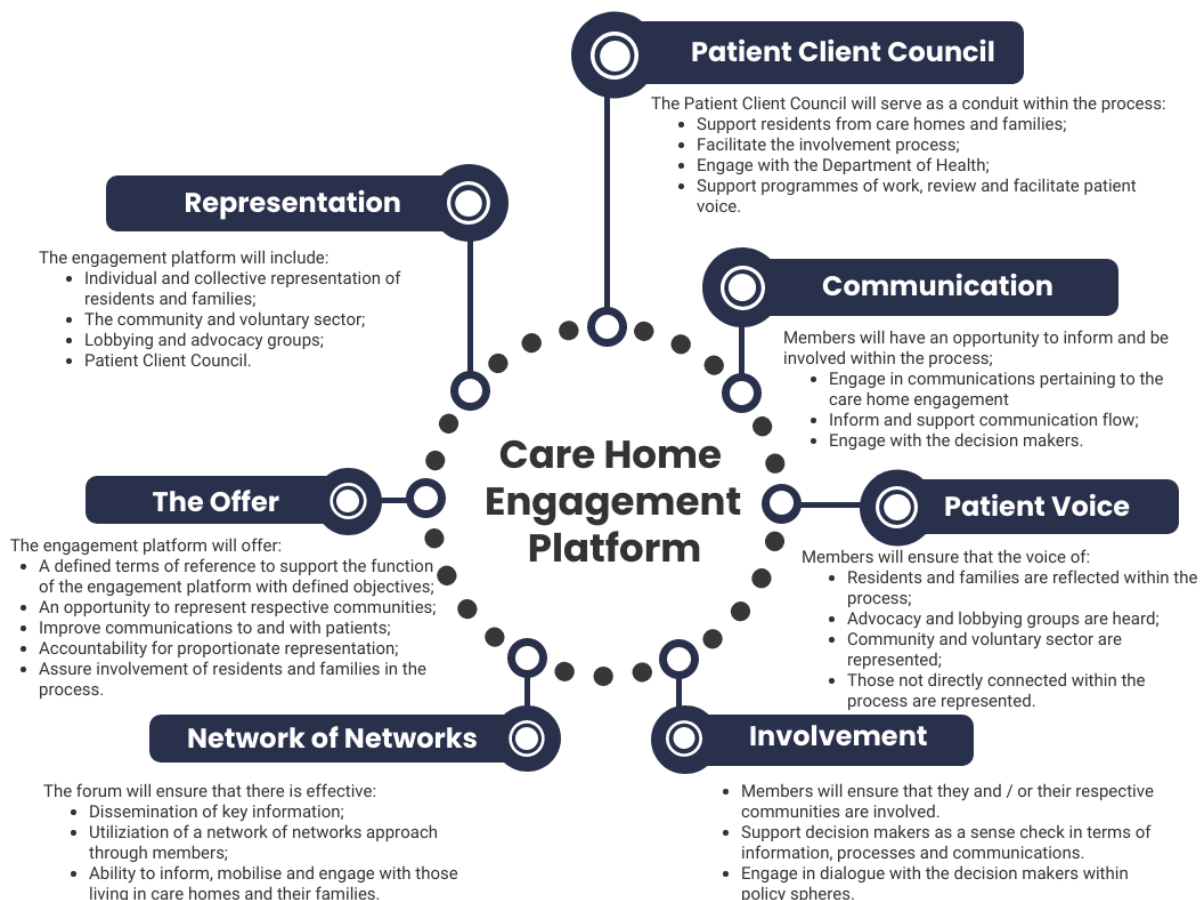
The first target area of conversation would be to explore the experience of visiting and maintaining ongoing contact with loved ones. The initial priority would be to develop questions that are generic enough to remain relevant, as the current circumstances as we understand them, evolve. Once established as an engagement process, we would also leave open the option to add additional survey questions, e.g. where new or significantly different guidance or restrictions are introduced.

The suggested areas on which the survey will focus are under discussion and may include measures of:

- How satisfied family members are with the provision for visits in line with Departmental Guidance?
- What provision has been made for alternative means of seeing and talking to their loved ones face to face?
- How informed family members feel about the COVID-19 situation in the respective care home and about the status of their loved one?
- How confident family members feel about the response to and management of the COVID-19 pandemic in the respective care home?
- Family members’ perceptions of the extent to which COVID-19 is impacting the quality of their loved one’s care in relation to quality of life, physical and emotional wellbeing?

4.2 Engagement Platform

The Patient Client Council are keen to identify and establish a Care Home Engagement Platform composed of residents and families, community and voluntary sector, individuals, lobbying and advocacy groups. This platform will serve as a central point for communications, engagement and information to ensure that everyone receives the right information at the right time. It will use a network of networks approach whereby key representatives will cascade information to their members, overcoming the current problem that information is not being communicated. Initial discussions will be framed with other organisations and we hope that this will strengthen the public voice in the Care Home discussions.



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