TEN THOUSAND MORE VOICES

CARE HOMES & COVID-19

-THE LIVED EXPERIENCE OF CARE HOME RESIDENTS, THEIR RELATIVES AND STAFF DURING FIRST WAVE OF COVID-19 PANDEMIC

September 2020

Share your story, shape our service

"We are a hidden treasure ... and
unfortunately no one is looking for us"

- Words of a Care Home Resident
(December 2019)

Foreword

We are delighted to present the 10,000 More Voices Project on the experiences of Residents, Relatives and Staff of Care Homes during the first wave of the COVID-19 Pandemic. It is widely recognised the pandemic has had a significant impact upon the health and wellbeing of residents in Care Homes, including the necessary but painful decision to restrict visiting. This in turn has been an extremely challenging time for the relatives with reduced the opportunity to be a physical part of the resident's life and for staff who have had to deliver care in such times of rapid change and competing pressures. This project encompasses the impact of the pandemic for residents, relatives and staff of Care Home, presenting a spectrum of experiences. The analysis highlights how Care Homes have responded and adapted to support the residents and relatives , but also recognises a time which has been painful and traumatic and further work is required to ensure support throughout and beyond the pandemic. The key messages presented ensure the voices of residents, relatives and staff are heard and can inform the developments in the Care Home sector.

As a system it is crucial we engage with residents, relatives and staff of Care Homes to support decisions which are coproduced and underpinned with strong enduring relationships. We would like to personally thank everyone who contributed through the 10,000 More Voices survey and for all of whom openly shared with us their story. Each story is valuable, each story matters. We commit to using the experiences we have heard to shape the planning, commissioning and delivery of services within our Care Homes and for the wider Health and Social care system in Northern Ireland. Never before has our Health and Social Care system experienced such demand and challenge. Never before has it been more important to listen and learn from the experiences of the people of Northern Ireland.

Mrs Marie Roulston
(Director of Social Care & Children's Services, HSCB)

Mr Rodney Morton
(Director of Nursing & AHP, PHA)

Mrs Michelle Tennyson
(Assistant Director of AHP, PPI & PCE)

ABBREVIATIONS

BDA	British Deaf Association
BHSCT	Belfast Health and Social Care Trust
DOH	Department of Health
HSC	Health & Social Care
NHSCT	Northern Health and Social Care Trust
NISCC	Northern Ireland Social Care Council
PCC	Patient Client Council
RCN	Royal College of Nursing
RLI	Rapid Learning Initiative
RQIA	Regulation and Quality Improvement Authority
SEHSCT	South Eastern Health and Social Care Trust

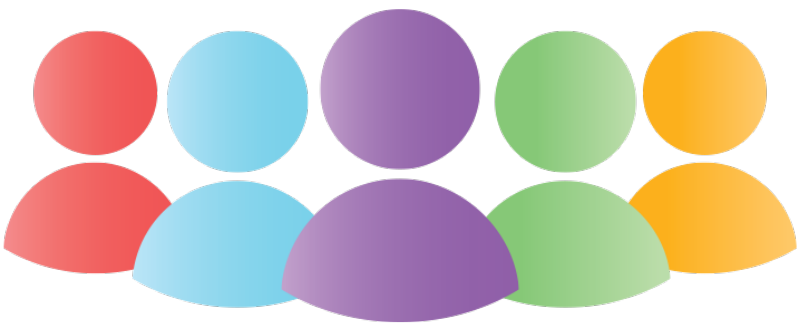
ACKNOWLEDGEMENTS

The Public Health Agency would like to express their heartfelt thanks to the many agencies involved in the design, promotion and completion of this project. Without the support of Department of Health (DOH), Health & Social Care Trusts (HSC), The Regulation and Quality Improvement Authority (RQIA), Royal College of Nursing (RCN) and Patient Client Council (PCC) it would have been impossible to have reached so many in such a short time.

A sincere thank you also to the many residents, relatives and staff who submitted their personal experiences of the first wave of COVID-19 pandemic. We are aware that this may not have been easy, however the valuable contribution of so many has enabled this report to be rich and comprehensive. The findings detailed in the report have influenced and guided the work in Care Homes during Wave 2 and continues to do so as the pandemic progresses.

Many extracts from the stories & free text questions have been included throughout this report, some of which have been edited to ensure anonymity of respondents. If you are interested in discussing any of the information presented you can email 10000morevoices@hscni.net.

"... I am struggling to identify what went well.....My staff accepted the challenge and got the residents through the pandemic. They are the real heroes and heroines and they should be rewarded for their bravery, dedication and commitment through the pandemic. Many more would have died had it not been for them..."
(Words of a Care Home Manager)



EXECUTIVE SUMMARY

10000 More voices launched a project on 24th June 2020 to explore the lived experiences of Care Homes residents, their relatives and the staff during the first wave of the Covid-19 pandemic. The preliminary findings informed the Rapid Learning Initiative into the Transmission of COVID-19 in Care Homes in Northern Ireland (RLI) as led by the Department of Health. The full 10,000 More Voices project closed on 31st August 2020 with 744 responses received (519 Care Home residents, 109 relatives and 116 staff).

There was a wide variety of experiences shared, from residents who were unwell and diagnosed with COVID-19 to residents who were mainly impacted by the response to protect them during COVID-19. Similarly many relatives reflected upon the experience of the impact of the response to the pandemic in the Care Home with a small number sharing the painful experience of their relative dying during this time. Staff also shared their experiences of supporting residents at end of life care and the challenges they faced to support residents and relatives to stay connected during the first wave of the pandemic.

Each return was analysed through the Sensemaker® programme to explore and identify key themes shared by residents, relatives and staff. These key messages demonstrate both the positive experiences in the Care Homes and the elements which need to improve as we face further waves within the COVID-19 pandemic. Many of these are echoed in the RLI report and reflected in the work which is ongoing and helps to show the progress which has been made since the first wave of the pandemic. The following summarises the key messages.

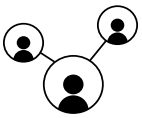
Technology: Residents and relatives both reflected upon the importance of staying connected throughout the pandemic. Technology has been an important resource to support the Health and Wellbeing of residents of Care Homes to remain connected with relatives and the wider community during wave 1; however for some relatives and residents technology can also be a barrier for people with more complex communication needs and does place a demand on staff. It is important methods of engagement are tailored to the needs of the resident and staff in Care Homes are supported to facilitate the technology as a key part of their role.

Channels of communication and flow of information: Care Home Managers raise the importance of communication which is consistent, efficient and robust to support them to manage large volumes of information and provide clear direction to residents and relatives. It is important the channels of communication are simple and efficient to strike a balance between the importance of information sharing and the daily challenges of leading in a Care Home during the pandemic

Relatives also highlight the importance of an available channel of communication with the Care Home. This should be built upon an open and trusted relationship between relatives and Care Homes managers to facilitate relatives to stay informed and continue to support and inform decisions where appropriate. Relatives are an important partner in supporting the health & wellbeing of residents and it is crucial they remain connected through open and transparent communication .

Health & Wellbeing: Residents reflected upon the importance of input from external services such as primary care and allied health professionals, in the management of their health and wellbeing – including acute illness, long term conditions and to support rehabilitation. Recognising the need to support safe practices residents highlighted the need to stay connected with these services. Equally so Health & Wellbeing of Care Home staff has been impacted by the ongoing pandemic. From staff experiences there is limited opportunities of support for staff highlighting the importance of developing strategies which will build on coping mechanisms and resilience of staff and also to offer practical support in relation to rest and hydration during shifts.

Safe & Effective Care: The pandemic highlighted the need and opportunity for staff to train in additional areas relating to working within the Care Home. The provision of training has been a positive response to the management fo COVID-19 and supported staff to develop. It is important such opportunities continue and even extend to support staff to embed new skills and knowledge into their daily work.



Working in Partnership : For staff compassionate leadership and teamwork are essential elements to the pandemic response – offering important emotional support and practical guidance during times of crisis and loss. Care Homes are a community which uphold each other and it is recognised the need to support leaders in Care Homes to refine these skills and embed the values into practice.

Reflective throughout all the key messages is the importance relationship building between all strategic organisation and the Care Home sector to develop forums to engage and consult on policy & guidance - Ultimately a partnership approach is essential, to include the voice of residents & relatives, so that in the delivery of safe and effective care the residents health & wellbeing is paramount.

Next steps

Many of the key messages included in this report have been woven into the recommendations of the RLI into Transmission of COVID-19 into Care Homes (DOH, 2020). This work is led by the DOH and supports multi agency response informing the actions for future waves of the pandemic. It is recognised the importance of maintaining an ongoing channel of feedback to continue to learn from the experiences of residents and relatives of Care Homes. The work will be taken forward through the Regional Surge Plan for the NI Care Home Sector Operational Group, which is representative of DOH, PHA, HSCB and RQIA. It is the ambition of the 10,000 More Voices team that this project supports ongoing conversation and challenge about how we can continue to make positive changes to support the health & wellbeing of the residents during, and in the years after, the pandemic.

PROJECT OUTLINE

1.0 INTRODUCTION

At the request of the Minister of Health, the Chief Nursing Officer established a Task and Finish Group during the first wave of COVID-19 pandemic to explore the Transmission of COVID-19 in the Care Homes. This Rapid Learning Initiative (RLI) adopted a collaborative approach between HSC organisations, the independent sector and residents and their families to produce knowledge as quick as possible over a defined 3 month period to identify recommendations for action. The initiative 10,000 More Voices was the core methodology embraced to collect the narrative of relatives, relatives and staff to inform the RLI report and influence change at a strategic level.

The 10,000 More Voices Initiative has been commissioned and funded by the Health and Social Care Board (HSCB) and the Public Health Agency (PHA) to provide a person centred approach to improving and influencing experience of health and social care services. Embracing the principles of Co-Production, Patient Client Experience (PCE) is both a driving force for service improvement and also a quality indicator of service improvement. Led by the Public Health Agency the RLI Experience group was representative of key stakeholders in the Care Home sector (Appendix 1). This multi agency group sought to explore & understand the experience of the residents, relatives and staff. The findings are woven into the DOH document "The Rapid Learning Initiative into the Transmission of Covid-19 into and within Care Homes in Northern Ireland" which can be accessed through www.health-ni.gov.uk/publications/rli-final-report. The following report outlines the analysis and evidence supporting the current work in supporting Care Homes during COVID-19 pandemic.

2.0 PROJECT AIMS & OBJECTIVES

2.1 Aim

The aim of the project was to explore learning from the experience of everyone, the resident, the relative and the staff, who engaged with Care Homes during the COVID-19 pandemic through bespoke surveys.

2.2 Objectives

1. To support residents, relatives and staff to share their experience through narrative and robustly analysed qualitative data.
2. To understand the personal impact of COVID-19 on residents, relatives and staff.
3. To explore the impact of COVID-19 in relation to the delivery of care – including communication, partnership working and information sharing.
4. To highlight the positive experiences of residents, relatives and staff during the COVID-19 pandemic – to be celebrated and explored at a regional level.
5. To identify areas of improvement as suggested by residents, relatives and staff and inform actions of improvement as part of Surge 2 planning in Care Homes.

2.3 Definitions

The definition of Care Homes for the purpose of this project and the RLI:

-Any Care Home registered with the Regulation and Quality Authority as a nursing home or residential Care Home, in accordance with the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003.

3.0 METHODOLOGY

3.1 Survey Design

In line with Experience Based Co-Design (EBCD) 10,000 More Voices promotes the principals of Co-production through engaging service users in the design of the survey at the start of each project; however in light of the restrictions during the COVID-19 pandemic it was not possible to undertake a design workshop. Therefore the design of each survey was informed by previous projects which had been co-designed with peer facilitators for AgeNI and supported the identification of key concepts and tested data collection tools. Also to support collection of experience in residents and relatives easy read versions of the surveys were developed in collaboration with BHSCT.

3.2 Engagement

Promotion of the project was led by the PHA in collaboration with the DOH, RQIA and HSC trusts. A variety of approaches were adopted to engage each group for the project and outlined in an infographic and social media announcement (Appendix 2). The following is the approach for each group:

1. Residents of Care Home: Each Care Home in Northern Ireland (483 in total) received 10 copies of the resident's survey with stamped addressed envelopes. Care homes could request more copies through the Regional Office. Surveys could also be completed through telephone consultation or video conference.
2. Relatives of a resident in a Care Home: Relatives were invited to share their experience via an online link promoted on social media or by requesting a printed survey via the regional 10,000 More Voices office. This was promoted through NISCC and RQIA. Relatives from Deaf community were also engaged through zoom calls facilitated by the British Deaf Association (BDA).
3. Staff working in a Care Home: All staff were invited to share their experience via the online link. Staff could also request an interactive pdf version which could be returned by email or printed and return by post. This included staff from HSC trusts who were redeployed to support Care Homes during the first wave.

3.3 Data collection

Each data collection tool was piloted with a small defined group to ensure the tool was effective and upon approval the project launched on 24th June 2020. All data collection was anonymous with no personal identifiable detail recorded. All raw data was collated and entered onto the Sensemaker® Analyst Online programme by 10,000 More Voices teams to support the analysis and identify key themes shared by residents, relatives and staff. Data was managed in line with Data Management Guidelines for 10,000 More Voices. Surveys also signposted respondents to the relevant service if they wished to raise a concern or escalate a safeguarding issue.

Data was analysed on 15th July 2020 to inform RLI report however as data returns continued after this date it was recognised the importance of supporting residents to continue to share their experience. Therefore the project as extended to 31st August 2020 and further promotion work undertaken.

3.4 Survey Design

The following outlines the concept of Sensemaker® with particular reference to the analysis tools known as Triads & Dyads.

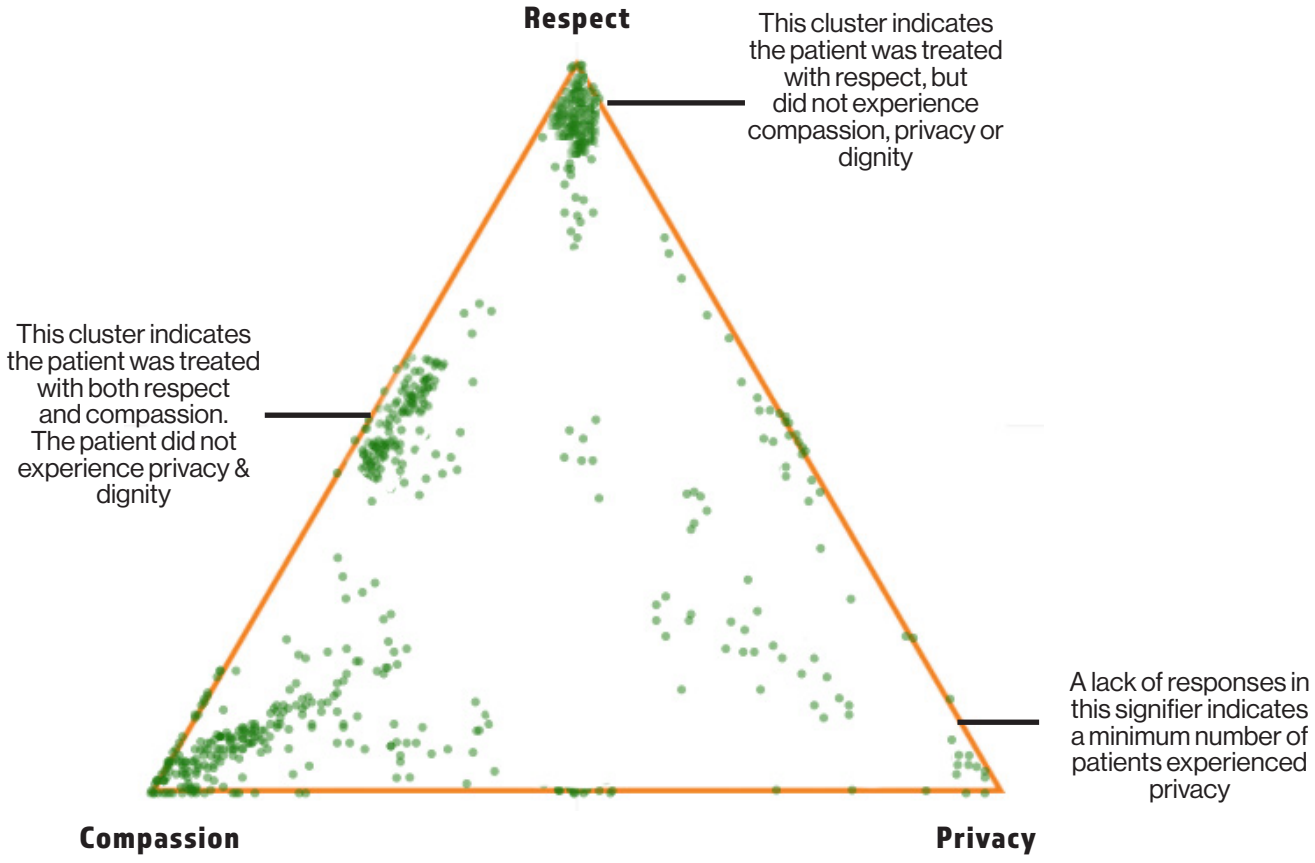
Using Sensemaker®: Understanding the responses.

When completing the survey all respondents were asked to describe their most memorable experiences of Care Homes during COVID-19 pandemic. The second section contained a number of statements to support the respondent to reflect deeper on their experience. These responses are recorded in Sensemaker® in the form of a Triad (triangles) or Dyad (linear sliding scale) and are included in Sections 4 to Section 6 of this report.

Triads illustrate pattern formation and clusters of response to each statement. In relation to triads the dot was plotted according to the relevant answers selected; if none of the responses applied the respondent could tick "this does not apply to me". Each dot within the triad represents an individual experience of the resident, relative or staff, with each individual story accessed through the analysis software. A high concentration of dots in a specific area identifies an emerging pattern in relation to the answer. An example of responses to a triad is demonstrated in Figure 1.

Figure 1. Example of a Triad

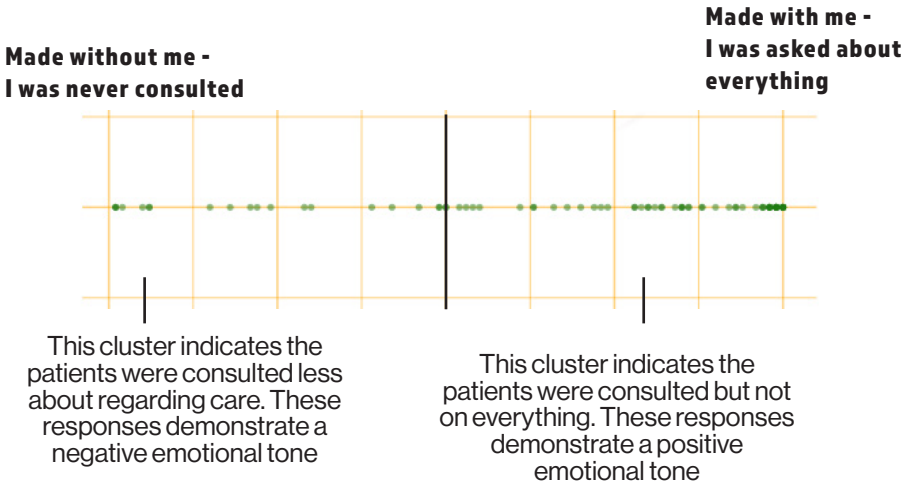
Responses to statement: In my experience I was treated with...



The same principles apply for dyads, which demonstrate two extreme responses to a statement/question, moving from negative emotional tone to a positive emotional tone. An example of a Dyad is illustrated in Figure 2.

Figure 2. Example of a Dyad

Responses to statement: Decisions regarding my care were...



3.5 Limitations

- Survey design with Sensemaker® is an academic data collection tool requiring a level of understanding around concepts such as triads & dyads. To support engagement and understanding with as many residents and relatives as possible, the methodology was adapted to support easy read versions and still support data analysis through Sensemaker®

- It is recognised resident returns are representative of residents with the cognitive ability to share their story and complete the survey. The design of the survey would limit returns from residents with cognitive impairment (for example dementia). In further studies consideration should be given to methodologies such as "Talking mats" to support someone with cognitive impairment to share their experience.

- Sample selection for the study was opportunistic in a short rapid process of data collection. Although numbers are not statistically representative of over the vast numbers of residents, relatives and staff it is recognised every story counts and learning can be identified in each experience.

- Methods of engagement with relatives relied on communication through Care Home managers and social media advertising. It is recognised Care Home managers were receiving a large volume of information at this time by email and may have had limited opportunity to promote with families. This may account for the low number of relative responses and additional promotion would be sought in future projects in Care Home sector.

- Staff responded to the wider project called "You and working during COVID-19 Pandemic" which was designed with staff and was directed to all staff who worked with patients/clients at this time. Therefore this survey was not specific to the Care Home setting but the wider health and social care setting. The broad concepts explored are presented and filtered to responses by staff in Care Homes. Further engagement with professions who normally conducted visits in the home for healthcare needs would be an area of focus in further projects.

4.0 FINDINGS & ANALYSIS

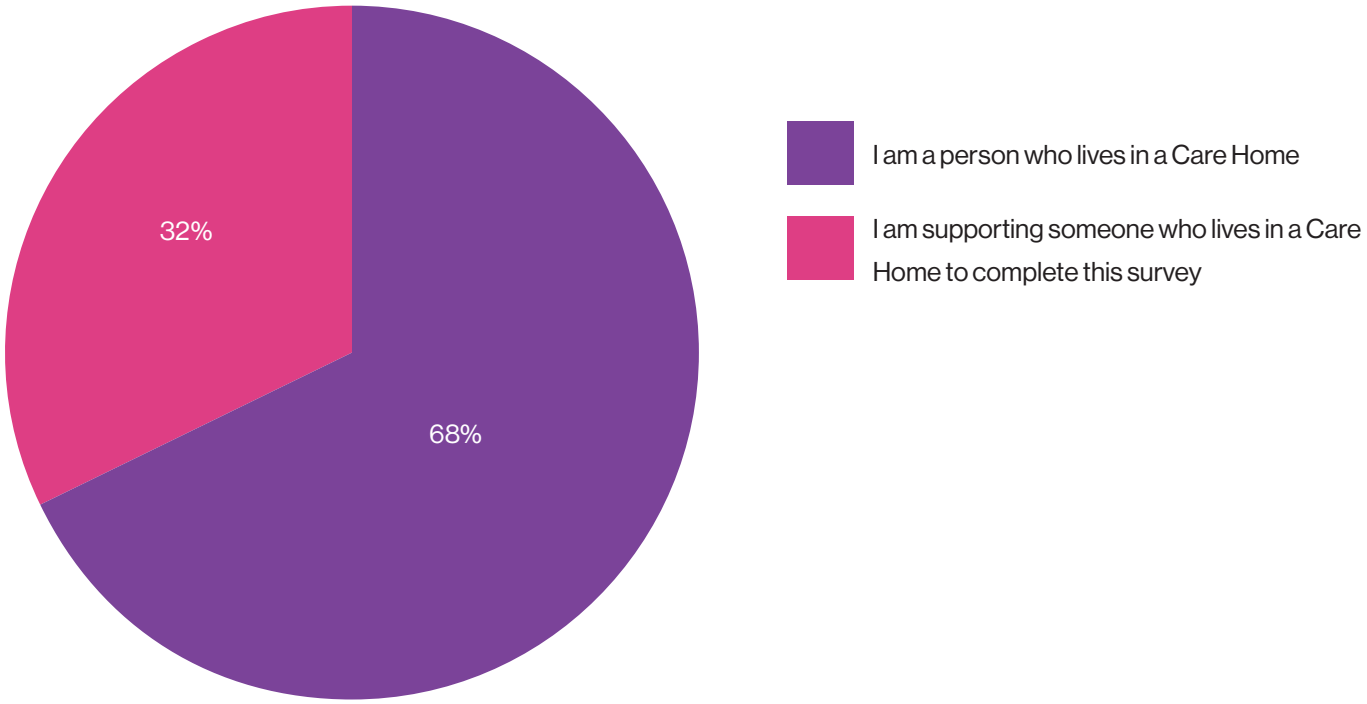
- The Resident's Voice

4.0 FINDINGS & ANALYSIS - The Resident's Voice

4.1 Overview of Returns

From 24th June 2020 to 31st August 2020 a total of 519 residents of Care Homes returned completed surveys sharing their experience of COVID-19. The first step of the survey was to build context around the experience through a small number closed statements as illustrated in the following figures.

Figure 3. Statement 1. Please tell us who you are: (n=519)



In relation to 32% of responses being facilitated, residents were supported by Activity Nurse and Care Home Staff to tell their story and return the survey.

Figure 4. Statement 2. How long have you lived in the Care Home?

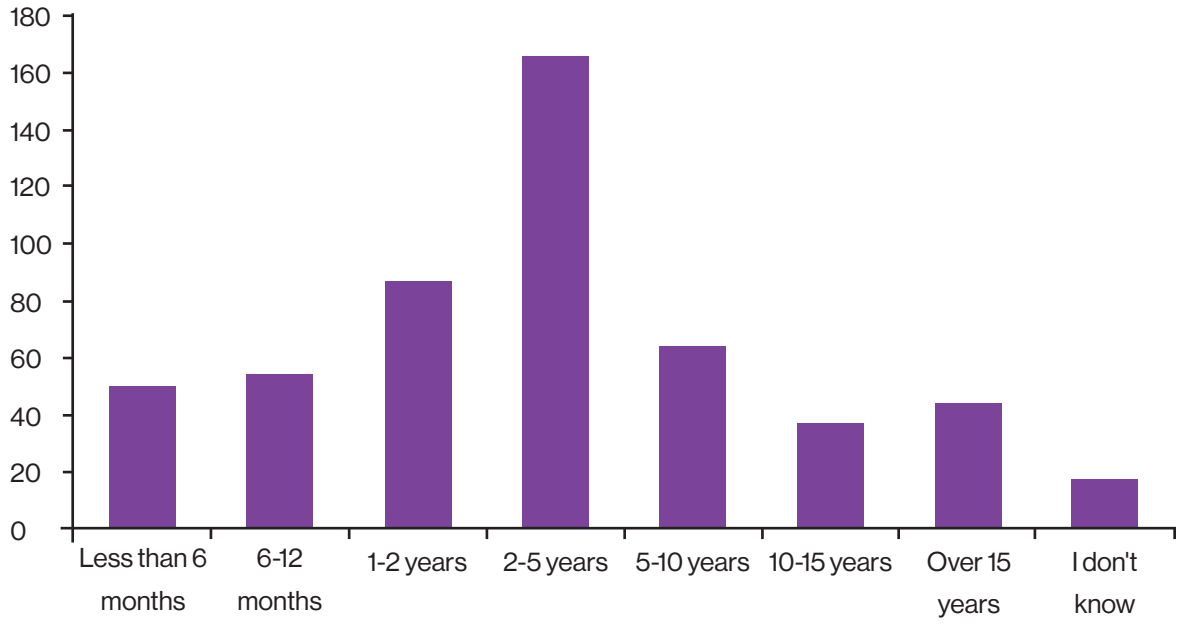


Figure 5. Statement 3. Have you tested positive for the virus?

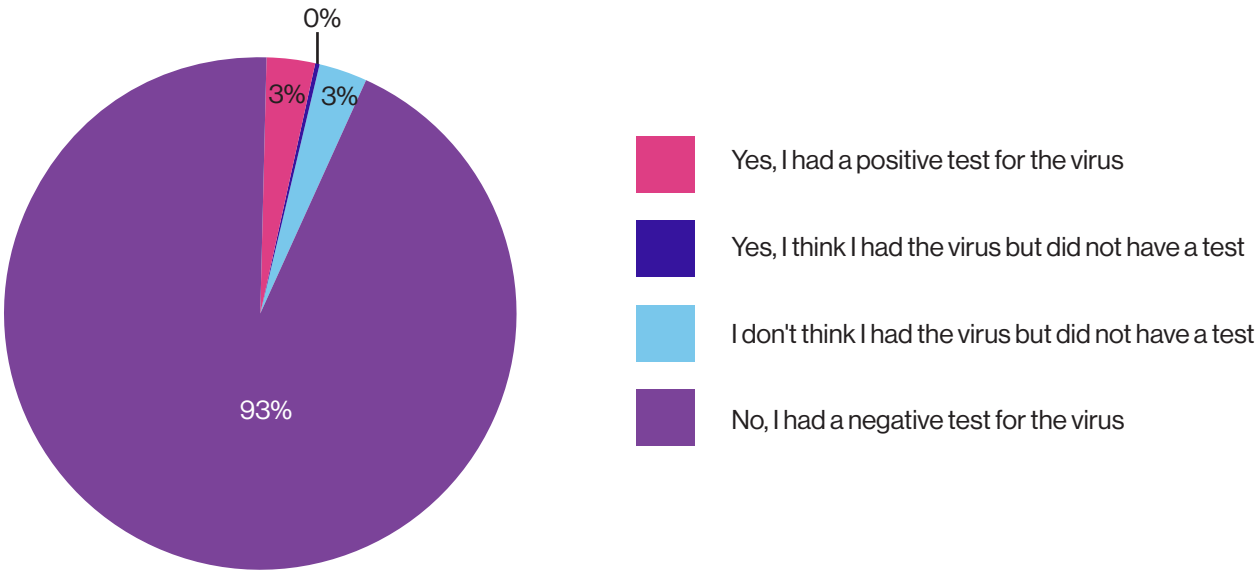


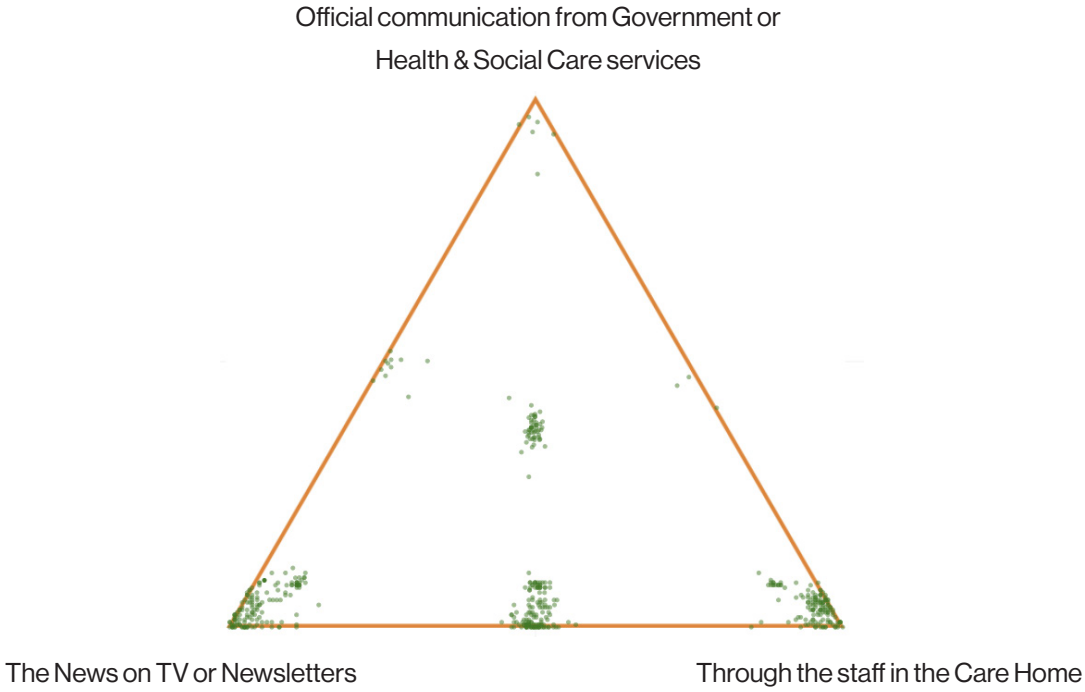
Figure 5 demonstrates that the majority of responses were from Care Home residents who did not contract COVID 19 during the first wave and have been tested. A small number of responses were received from patients diagnosed with COVID-19.

The following section presents an overview of the findings of the core concepts included in the residents survey. These are further enriched and illustrated through the words of the residents. It is important to acknowledge each of the above context statements can be used to filter the data and inform deeper understanding of the experience of a particular context (for example briefing paper on the lived experience of residents admitted to a Care Home during the pandemic). The following analysis supports the understanding of the data as a collective.

4.2 Source of information about COVID-19

Figure 6 illustrates the responses of residents in relation to the source they accessed information regarding COVID-19. The signifiers explore if the information was accessed through official communication, media or through the staff. It is evident there are three prominent clusters to the bottom border of the triad indicating a majority received information from TV or Newsletters (28%), through staff in the home (29%) or both (28%). Only 15% of responses acknowledged they received official communication from the Government or Health and Social Care services.

Figure 6. Triad 1. (n=490) "I heard about the virus through..."



"...Soon after the virus 'shut-down' I had a letter from the Health Department saying I was among the vulnerable people and needed to shield. At that time a lady in our home was affected by the virus so the staff made many changes to our routine..."

"I don't know much about virus just what I hear on TV and read in newspapers... I know that it's very infectious and we must be careful"

"At present we are still in lockdown but things are gradually becoming more normal. At first I found the information rather slow in detail. I blamed the DHSS trying to deal with a situation which they had no plans for. We were put on isolation and had to spend all day and night alone - this was a very stressful and lonely time."

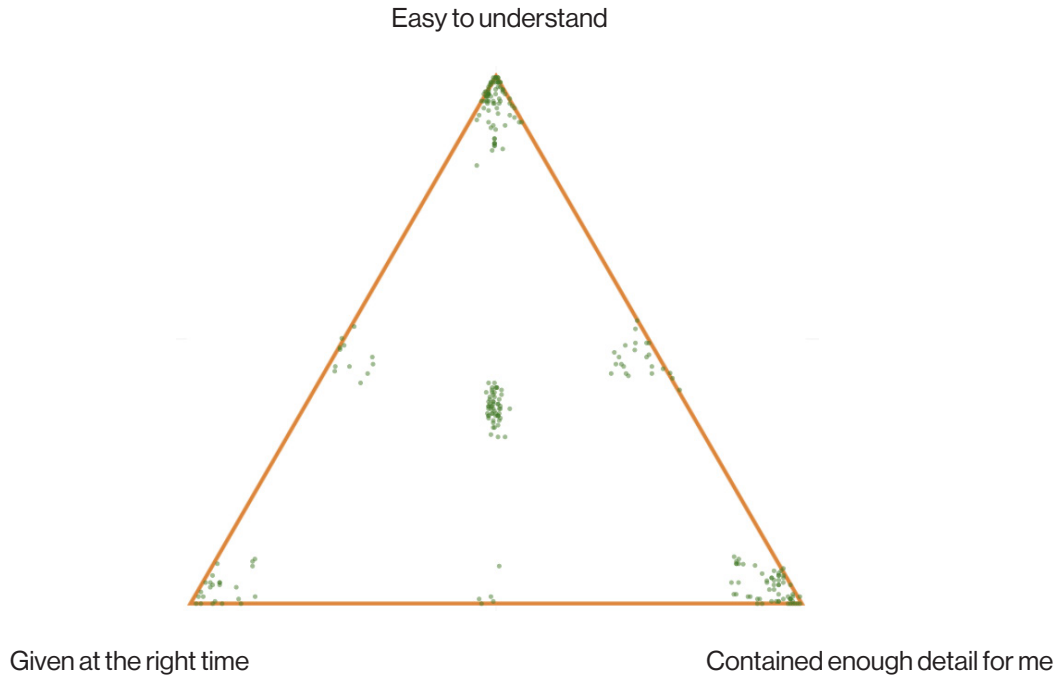
"I was not scared because I knew I was safe, I was told about the virus from staff and the news. At some time I was scared when watching the news that I had the virus. The staff helped me when I was scared and I got to do a lot of activities..."

A key message in the narrative is the need for residents to receive information direct from the government and health care sources and to support them in understanding the decisions being made. This also presents challenges regarding the chain of communication during a pandemic to ensure that communication about the resident is communicated with them and that it is easily understood (refer to section 4.3).

4.3 Quality of Written Information Received

Triad 2 explores the quality of any written information received during COVID-19 regardless of the source. The signifiers consider if the information was easy to understand, timely and comprehensive. Only 50% of returns reflected upon the quality of written information.

Figure 7. Triad 2. (n=263) "Written information I received about the virus was…"



The main signifier (66% of responses) indicated any written information received was easily understood. However it is also important to highlight in the absence of a response to the triad there is counterbalance message highlighting a lack of good quality written information. This is highlighted in the narrative of the responses highlighting the issue of information which was always changing and ensuring the information is accessible to all, in particular for people with more complex communication needs.

"I am a resident who is Deaf and I talk through British Sign Language, but I can lip read… I have the advantage that I have a good command of written English so can follow a lot of the information that comes out in the press, most other Deaf Sign language users do not"

"…Atmosphere in the home is not as relaxed as it was… Different information almost every day…"

Timeliness was the response least identified with (13% of responses) once again reinforcing the challenge of how timely information is generated and subsequently engaging and sharing effectively with the residents.

"...I still don't understand why they have done this to us... I feel like I have no rights and no voice. Was I not important enough to be asked about the plans they made on my behalf or even to tell me? ... "

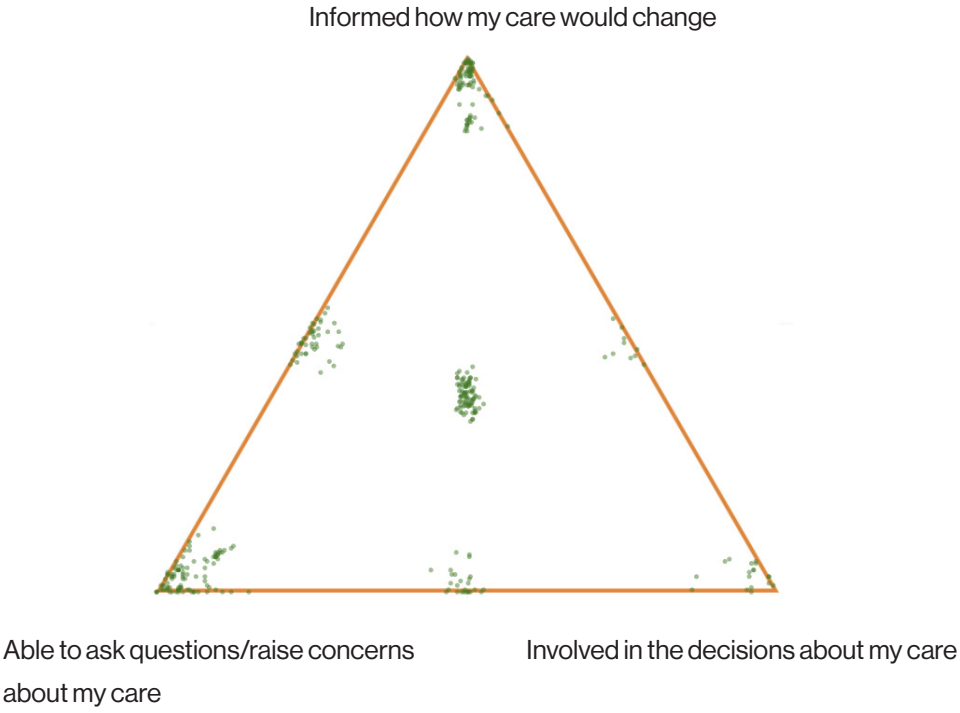
"...It would be nice to have something in writing to see what is proposed"

A key message is to highlight the importance of residents receiving the information in a timely and accessible manner and to support residents with complex communication needs to access and understand the wider decisions being made regarding their home.

4.4 Consultation in Changes to Care

Triad 3 considers the communication around the changes made to each resident's care, exploring if they were informed, could they ask questions and were they involved in the decisions. 72% responses reflected upon this triad, with 28% indicating the signifiers were not applicable to their experience. This may be that they did not identify any changes as outlined in their narrative or that the changes were not communicated; however it was widely indicated that residents were informed of changes (included in 60% responses) and were able to ask questions (included in 39% responses). The central cluster (25% of responses) included all three signifiers. The response indicated least was being involved in the decisions about my care.

Figure 8. Triad 3. (n=374) "Regarding changes to my care I was..."



"...Staff was very good at looking out for me, keeping me safe... I now believe I cope better now that I understand things. Staff are always here to answer my questions and here to keep me safe..."

"....Having spent 3 weeks in hospital with virus in March-April I was pleased to go to (name removed) Care Home for rehab before finally getting home. It gave me time to strengthen and recover more so that I would be better able to cope with home life... I was as happy as I could be besides being at my own home. The staff were pleasant, caring and lovely. They were more than helpful ...took good time to explain process of recovery very well, I have continued to improve and strengthen at home and I'm back to myself again..."

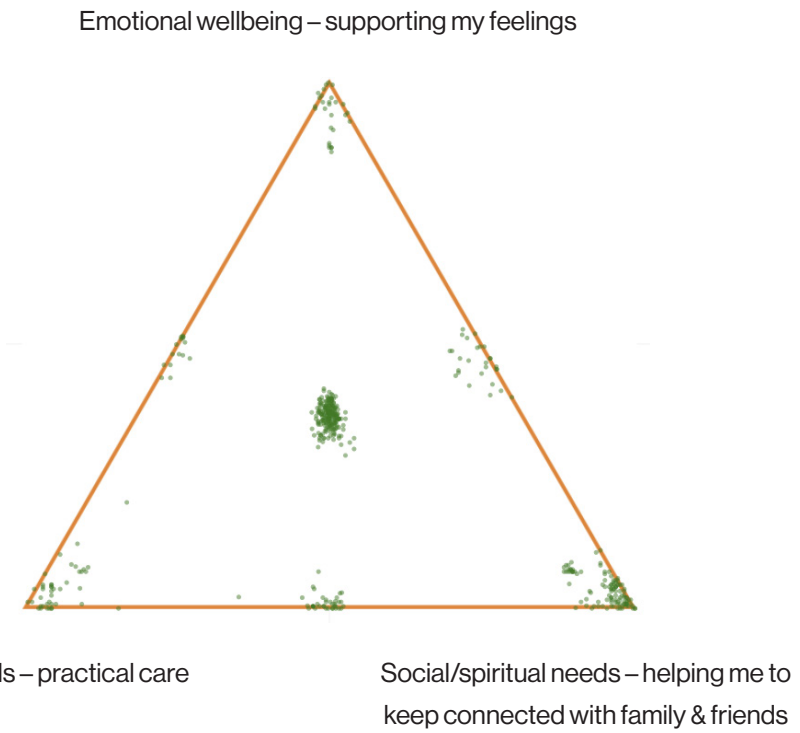
"...You couldn't say a bad word about the staff they are great at their job - if you had a minute of pain you just had to go to the nurses and they would sort it out. It's always 'hello good morning how are you, anything for us to do for you today'...If you have any problems you only have to go to them..."

From the narrative around this triad the key message is the importance of the relationship and communication between the residents and staff in the Care Home, supported through open dialogue. Residents reflected upon the importance of being informed and staff being responsive to their concerns or queries – the challenge however is supporting residents to feel they are part of the decisions made in relation to their care.

4.5 Holistic Care

Triad 4 considered if the resident received care to support physical, emotional and social needs, as illustrated in Figure 9; 92% returns reflected on this triad.

Figure 9. Triad 4. (n=480) I received care for....



Central responses equated to 46% of responses which acknowledged they received holistic care on all three signifiers. The signifier, social and spiritual needs, equated to 81% of responses and reinforced the measures taken within Care Homes to support residents to stay connected.

"The virus has changed how I see my family. It has been hard but staff have been great looking after me. Having video chats and doing activities has helped me. My care hasn't changed; staff have been great and will answer anything we need to know..."

"During lockdown we were unable to do activities but we came up with other activities to do at home. So we walked every day, we enjoyed gardening, growing peas, tomatoes, strawberries, lettuce etc. We enjoyed games on the Wii. It was sad not seeing family but we felt well supported by staff, were able to social distance through the window and communicate with family over the phone. Lock-down brought different new activities such as themed nights - China, Mexico. Every Thursday we enjoyed clapping for the NHS"

"I have been very fortunate in being able to use the telephone and my I-Pad in keeping in contact with my family members. All staff members have been excellent in making the lock-down more bearable"

"All I can say is the care home has been marvellous. All the care in the world. All I have here is wonderful care and attention. Nothing was ever too much trouble and the staff take time to talk to me and it kept my mind off things and kept me active"

It is important to note that 9% of responses indicated only their physical needs were addressed. When exploring the narrative it is evident there were a number of factors which impacted upon the resident's emotional and social needs. There is clear indication of the importance of mechanisms to support residents to stay connected with social network – including family, church and social groups, to help residents remain part of their community and cope with the impact of COVID-19.

"As a resident who is 90 years old, in a well-managed residential home, I find the 'locked in' situation restricts greatly contact with the outside world. With all next of kin in GB, I appreciate the security of the home. I rely on visits from friends, booked us for 30 minutes by appointment, whereas I was previously drive myself to church activities and other social events, invitations to meals , meetings of organisations to which I belong, and shops to replace clothing etc. I find the telephone in-dispensable for contacts with family and friends..."

"...I've also lost all access to my Church during COVID and my faith is not being nurtured. Whilst other people can listen in to broadcast services, I cannot [communicates through British Sign Language]. I have been able to connect with family and friends on my tablet but Homes need to invest in better Wi-Fi because this is what we have been relying on to keep in contact with people..."

"...Isolation is doing my head in and I have no contact with family on the outside. Apart from that it hasn't changed much. I felt very scared because it was new and unfamiliar. I felt very anxious for my friends and family outside especially my uncle..."

"...to mention the great support received from my church. Sunday service available on my computer. Literature concerning behind the scenes of the service being provided to the community by fellow members visits by appointment (only 30 minutes) by fellow elders and my wonderful minister. Phone calls from fellow members etc....."

"...was able my own churches services because the tablets were donated. Apart from that there wasn't much good about it..."

"...I know it was a good thing to keep everyone separated but I was mad, I was also mad that I had to talk to my husband through a window and he wasn't too well at the time. I was worried about him as well as myself..."

Residents also reflected upon their social network within the Care Home and the importance of staying connected and challenge in maintaining friendships within the community of the Care Home.

"...I feel I have made a closer friend during this time as we go walks around the home and spend time together as we don't see our family and friends..."

"...I am 94 years of age... and up to the beginning of coronavirus I was reasonably happy accepting life would be different [since moving to the Care Home]. However, I met a retired gentleman, in all aspects of the word and we enjoyed each other's company very much but he was taken ill last Christmas and when he was allowed home from hospital, I knew he really was not well but he never complained and I was not aware what he was suffering from. On XXXX [date removed] I was amazed to see my friend going to hospital by ambulance and he sadly died- I can only assume it was the virus which caused his death as it was at that time which proved I had the virus but was not taken to hospital..."

"..I personally still seem to have a relatively decent level of cognitive ability. Regrettably those of us who could play board games like scrabble are prevented by need to maintain a safe distance with each other..."

"...Being in my own room not being able to socialise the same. More tired than normal but just cause I miss the craic with my fellow residents..."

The key messages highlight the importance of supporting residents to stay connected and develop strategies which are effective for the individual resident to remain part of their family and community networks. This is also further explored in Section 4.6 – The Challenges

4.6 The Challenges

Figure 10 explores the greatest challenges for the residents during COVID-19 pandemic, exploring three signifiers – the wearing of masks & PPE, missing friends and families and the lack of stimulation during lockdown. The main signifier highlighted by the residents (89% of responses) highlighted how much they deeply missed their family and friends.

"...Although the care home staff have all been fantastic and my welfare and healthcare has been looked after to an extraordinary high standard I have felt really lonely. I missed the regular visits of my friends and family even though I've been surrounded by the other home residents daily..."

"...Being in my room a good bit, and not seeing friends and family. I can see them now but it's so hard not being able to hug people or kiss them. When they visit they have to wear a mask so it's hard to hear what they're saying. It's so different to how it used to be and I just wish it was all over..."

"... I do not know when I will meet my new granddaughter ... I can't even hold her or give her a cuddle... I just want to hold her..."

Figure 10. Triad 5. (n=479) The part I found the hardest was...

Lack of activity or stimulation is identified in 21% of the responses. Within the narrative residents shared about the activities they missed due to lockdown and reflected on the loneliness they experienced being restricted to their rooms.

"I felt quite 'low' staying in my room for two weeks but I knew I had to stay safe and keep everyone else safe. I missed my family and it was great when they were able to visit. Staff cared for me well."

"Confined to room, I like getting out & about, feel trapped a lot of the time, I know it's for my own good... No socialising with others, no activities, I miss eating in the dining room with other clients. Miss seeing the kitchen staff"

"Staff was very good at looking out for me, keeping me safe. I found it hard because before Coronavirus I could go into the town independently. I miss my swimming and going out for meals. Hopefully they will resume in August"

Conversely there were larger numbers of stories outlining the additional measures by Care Home staff to support and stimulate the residents at this time.

"...The staff tried to keep us all happy. I missed visitors, Church Services and entertainers. Meal times were always specials when we could all sit together and have our meals. The staff still encouraged us to come to the dining room but we had to social distance and I missed the chat. I enjoyed receiving letters, notelets and parcels from family and friends. The staff did a great job!"

"...we put up bird feeders and learned about all the different birds in the garden. I felt protected and I'm happy here and feel grateful for everything the staff have done for me..."

"...I felt safe and cared for, we had good fun playing bingo. I adopted a donkey for a year - I saw on TV that he needed help during the virus. Staff here helped me to do this and I felt happy to help others. Staff shopped regularly for treats for me..."

"....The staff playing games, colouring rainbows with me and singing my favourite songs. My best days were sing songs with the staff...."

"...As I was in my room all day I learned how to knit little hats for premature babies in hospital. I have completed over 150 hats and now I am trying to teach my good friend how to knit little bags for gifts. It's been good to take my mind off it all..."

Staff wearing masks and aprons accounted for 45% of responses. Residents reflected upon the challenges of the communication and being unable to see the staff faces; however there was also a wide acknowledgement of the importance of PPE and an appreciation it was to keep residents and staff safe. The issue in relation to communication was identified as a particular issue for residents who are hard of hearing or deaf and rely on lip reading.

"...The staff have to wear face masks and visors therefore it makes it hard for me to know who they are and also hard to hear what they are saying. I do not get to see my family..."

"....What I miss most is the lovely smiling faces of the staff; instead I see masks and not expression..."

".... One of the biggest frustrations is staff now have to wear masks, making lip-reading impossible. They presume that, because I use speech with them, that I can hear them through their mask and have not realised that I have been lip-reading them. Some staff have removed their masks at a distance, others haven't. It's worse in the evening and night, when lip-reading is particularly difficult at a distance and in poor light... If we are at risk of a second wave, I think staff need Deaf Awareness training to learn how to adapt to Deaf Sign Language Users needs during COVID. As a Deaf resident, Homes need to be looking at the wellbeing of Deaf residents in terms of company."

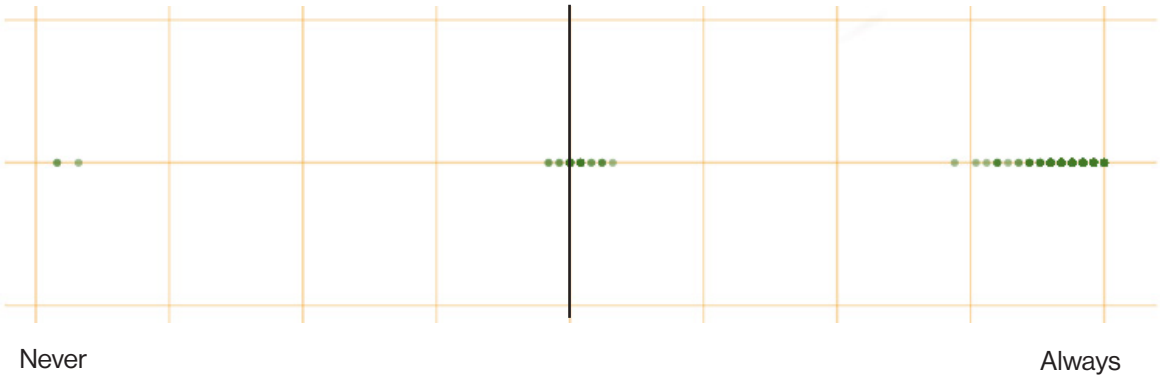
Reinforcing the previous key message in 4.5 the visits and engagement with families is vital to support the residents and was recognised as a major challenge in Care Homes when guidance on visiting was implemented. It was recognised that many staff made extra efforts to stimulate the residents and support activity during lockdown. A second key message in this triad was the impact of PPE had on communication with residents, in particular for residents who are deaf or with hearing loss.

The next five sections presents the responses of residents plotted on dyads, discussing topics in relation to safety, engagement, emotional wellbeing, personal needs and additional clinical needs.

4.7 Safety

Figure 11 illustrates responses in relation to feeling safe and protected. The main cluster of responses represents 92% always felt safe and protected. In the narrative this is attributed to the dedication of the staff in the Care Home and recognition of the restrictions in relation to visiting and social distancing.

Figure 11. Dyad 1. (n=504) "I felt safe and protected from COVID-19…"



"…I am not worried about virus and feel safe as staff are wearing aprons and masks. I am 95 years old and have lived through Spanish Flu and the war so I have seen a lot in my life…"

"….I found the fact that I had to stay inside very frustrating- limited to where I could go. But I found that the staff in the home were amazing and controlled the virus very well, keeping everyone safe in their own restricted area and keeping everyone separate. I feel the staff gave us great one to one attention and the home was kept amazingly clean and staff kept on top of absolutely everything. I understand the staff were very restricted in their private life too, that kept us all safe…"

"… At first it was a shock but we were put at ease and I felt safe and glad that I was in such a wonderful home…"

"…. I hate the staff having to wear masks because I can't hear what they're saying. I hate the fact we can't go outside or to the shop next door. It has been like prison in some ways but I know it's for our own safety and protection…"

There was only 1% returns indicating they felt unsafe and only one story shared – this story reflected upon fear for the resident's family outside of the Care Home and also a journey through from hospital to the Care Home.

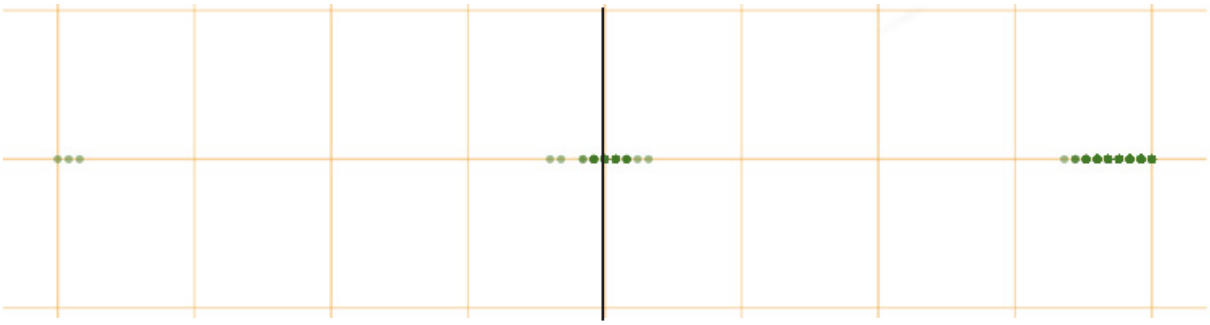
"… I was admitted from the hospital to xxx [name removed] for rehab following surgery. Whilst in home- pandemic striked- COVID 19. I was very frightened; scared for my life. I was deeply concerned for my family, my sons… Youngest living with his brother when it broke out. Worried about him as he is autistic and how this was to effect. I call this the 'invisible killer'. I had someone sharing the room with me and she left, this made me feel more lonely and insecure. Then I had to be moved again to the xxx (name removed) as my rehab was completed and yet again I had to go to isolation for another 14 days and this made me worse than 'mad'. I will never do this again!!…"

A key message is the recognition by residents of the measures to be kept safe and the dedicated staff who supported this.

4.8 Engagement

Figure 12 presents resident responses in relation to engagement with staff. The main cluster, 87% of responses, reflected that staff always talked and listened to the residents. This reinforces previous messaging on the value of the relationship between staff and residents.

Figure 12. Dyad 2. (n=499) "Staff talked to me and listened to me…"



Never

Always

There was a minor cluster of 12% who responded the staff engaged some of the time. The narrative highlighted the sense of isolation related to being kept within their rooms. Also some residents commented their experiences hadn't changed due to COVID-19, inferring lack of engagement with staff may have always been an issue in the Care Home.

"….I don't feel that it made much of a difference really. I felt cut off when we were isolated in our rooms…"

"…Made me feel isolated, restricted, lonely, cut off from family and friends…"

"…We are supposed to go to the dining room for all meals but now we stay in our rooms and then staff bring food. Isn't too bad with TV and books to read. There is no activities- being more or less confined to our rooms - All Day!"

"I feel nothing because nothing has changed…"

The key message is the importance of the role of staff in engaging effectively with residents, in particular during periods of isolation in their room.

4.9 Emotional Wellbeing

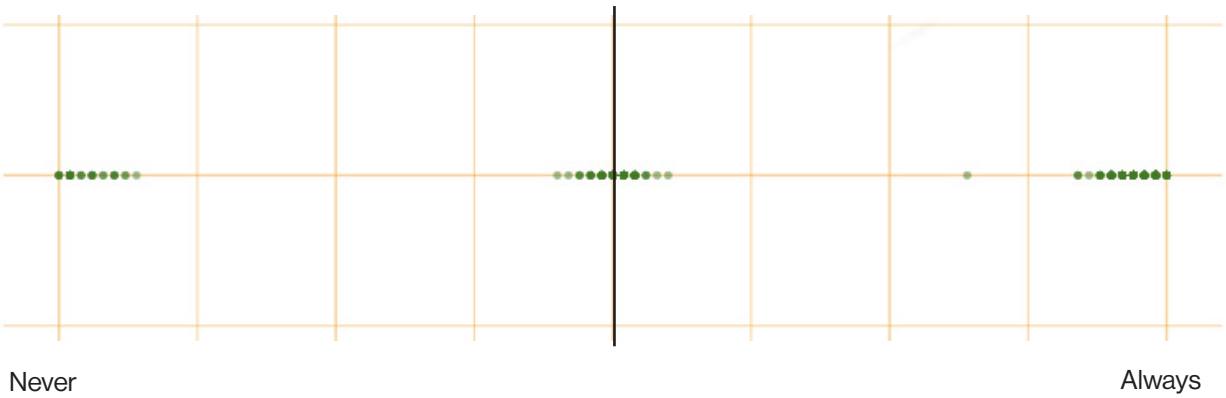
Figure 13 explores the emotional impact of the pandemic on the resident using a statement of positive emotional tone. 50% of responses related to always feeling happy, positive and hopeful every day. In the narrative behind the responses it was recognised the importance of the staff but also the importance of measures taken to support residents to connect with families.

"...A lot has changed from what it used to be. We just have to bear with it. I miss my family coming in to visit, though we now have a visiting pod and I kept in touch with my family through phone WhatsApp video call..."

"...My carers talked to me and reassured me there was nothing to be scared about. I started to feel happier and wasn't scared anymore. If I felt lonely, the carers would sit with me and hold my hand..."

"...I always feel like I'm at home. Whoever devised this place it's a fantastic thing. They love us and we love them. Everybody is quite happy thank goodness it's a good thing. There's no unhappiness. You couldn't say a bad word about the staff they are great..."

Figure 13. Dyad 3. (n=501) "I felt happy, positive and hopeful everyday..."



Conversely 38% reflected this statement was only relevant sometimes and 12% stating they never felt happy, positive and hopeful. In the narrative words with negative emotional tone (such as sad, low etc.) related to missing friends and activities and in essence yearning for life before COVID-19. Also residents in this group reflected on the inability to connect with family due to a lack of arrangements.

"...No family visits any day care in the centre, no trips out, shopping, meals out etc. I got very sad/low - needed medication changed/ new meals I would not eat well, wanted to stay in bed a lot and got very upset sometimes I shouted..."

"...I felt quite 'low' staying in my room for two weeks but I knew I had to stay safe and keep everyone else safe. I missed my family and it was great when they were able to visit. Staff cared for me well..."

"...Lockdown has felt like a lock in - for a period of time I was quarantined to my room. I've felt frustrated as I have wanted internet in my room but as members of the public aren't allowed in so it can't be put in yet. This has not been a positive experience for me..."

"...My happiness could have been improved by more activities each day. It would be great to have more games in the care home..."

"...I miss everything ... but especially I miss pet therapy..."

"...I don't seem to have any rights anymore, always told to stay in room. I feel no one is listening to me and no one cares. The situation has affected my mental health. My daughter gets into see me twice a week in PPE but she can't come to my room. I am very depressed and just want to die..."

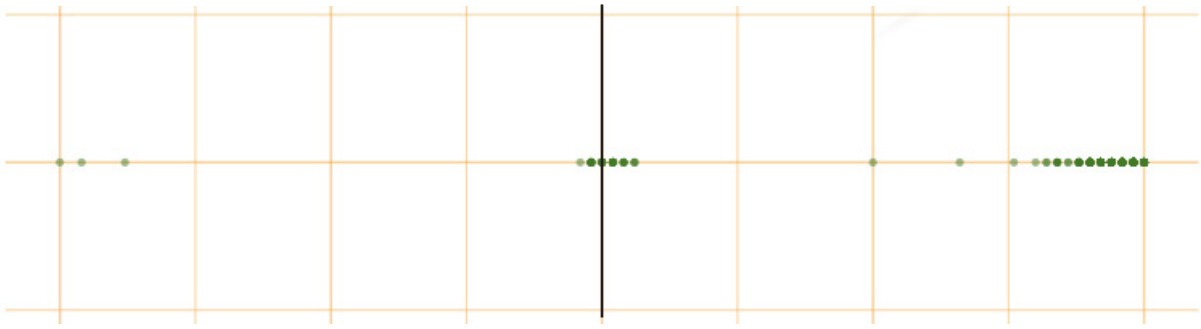
The key message reinforces the importance of supporting residents to stay connected with their family & community network to support them emotionally during the pandemic.

4.10 Personal Needs

Figure 14 outlines responses in relation to how well the Care Home met the needs of the resident. 90% of responses reflected their needs were almost always met, giving very positive reflections on the dedication of staff.

"...I was lonely at home. In this care home I have company and all the activities. I have friends and enjoy all games and sing along. The care staff help me daily. My family book visits and I look forward to that...."

Figure 14. Dyad 4. (n=501) "The staff in the Care Home were able to meet my needs..."



A minor cluster of 9% indicated needs were only met some of the time. The narrative in this group reflected upon elements of their care which were limited due to restrictions.

"...Difficult getting used to a change in my normal life. Missed not having hairdressers etc. but the staff tried their best to help me with whatever I want..."

"...I was not able to go out on bus outings and go to shops. I felt disappointed. We had a tuck shop in the home which I liked. I bought my DVD's from Amazon..."

"...The worse thing is not being able to see our loved ones as often. Time can be monotonous - change of way of life and wondering will life ever be the same again - fear of the unknown. My sister died in hospital. This was a hard time - family unable to come into home to talk with me. Taking 1 day at a time..."

Within the 1% of responses stating their personal needs were never met residents reflected upon moving into the home during COVID-19 and difficulty adjusting to the restrictions.

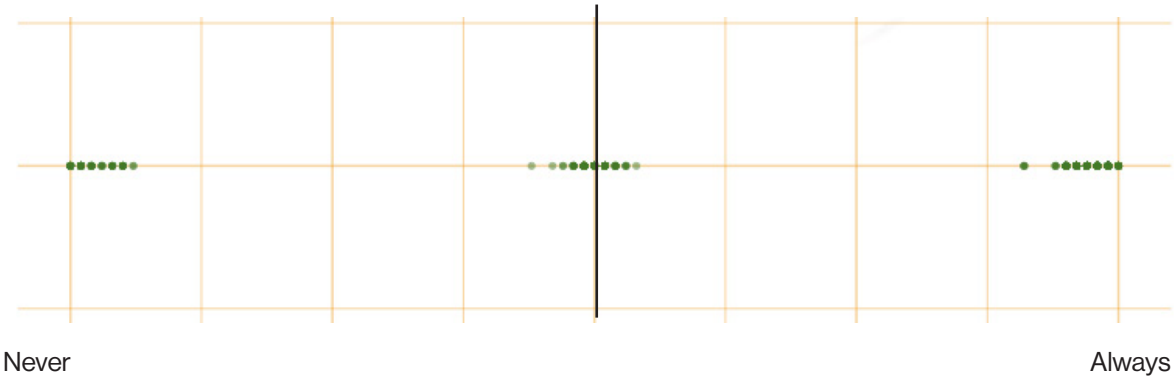
"... I find it very hard to adjust. I came into this care home due to the virus. I lived in a neighbourhood where neighbours would've just called in as they pleased, so kind, lovely, pleasant people. Now I'm in a Care Home with people who try not to come close, masks always (can't see a smile). Very isolated, I felt very emotional, I can't describe it. It's too big of a change in a bad way. I miss my family terribly..."

"...I felt bad & fed up talking about coronavirus. I couldn't do much apart from go for walks. I was bored. I couldn't & still can't go to work. I miss my parents. I miss going to church..."

4.11 Additional clinical needs

Figure 15 explores the residents experience when additional clinical needs arise, requiring intervention from other healthcare professionals outside of Care Home setting. The main cluster represented 58% of respondents who stated other healthcare professionals were always able to meet their needs. 22% stated other healthcare professionals met their needs some of the time, with 20% saying these need were never met.

Figure 15. Dyad 5. (n=488). "Other healthcare professionals (for example my GP) were able to meet my needs"



In relation to the narrative around responses with a negative emotional tone ("sometimes" or "never") residents reflected upon the importance of seeing healthcare professionals such as their GP, physiotherapy, podiatry or alternative arrangement put in place to support their healthcare needs.

"...I only came to Care Home in the beginning of the pandemic. It changed my life a lot - not being able to see my family and friends, I wasn't able to get through physiotherapy treatment because of restrictions of visitors (medical staff). All that just makes me feel sad also not able to have any social life apart from calling..."

"...No GP visit face to face- Went to hospital A&E instead. Otherwise all care as normal, Nurses still come regularly. Had to wait longer for podiatry appointment but was seen yesterday..."

"...GP appointment to home being withdrawn impacted most as unable to get response/treatment to some health issues..."

"...GP wouldn't come in to see me when I was sick. I ended up in hospital and mum and dad couldn't spend time with me..."

"... I needed to see the physiotherapist but they weren't allowed in... I believe the home could have been trained to help me exercise... I used to walk around the Care Home ... now I can hardly move without pain".

The key messaging is the importance of ongoing provision of services into the Care Home to support healthcare, including acute illness, management of long term conditions and rehabilitation.

5.0 FINDINGS & ANALYSIS

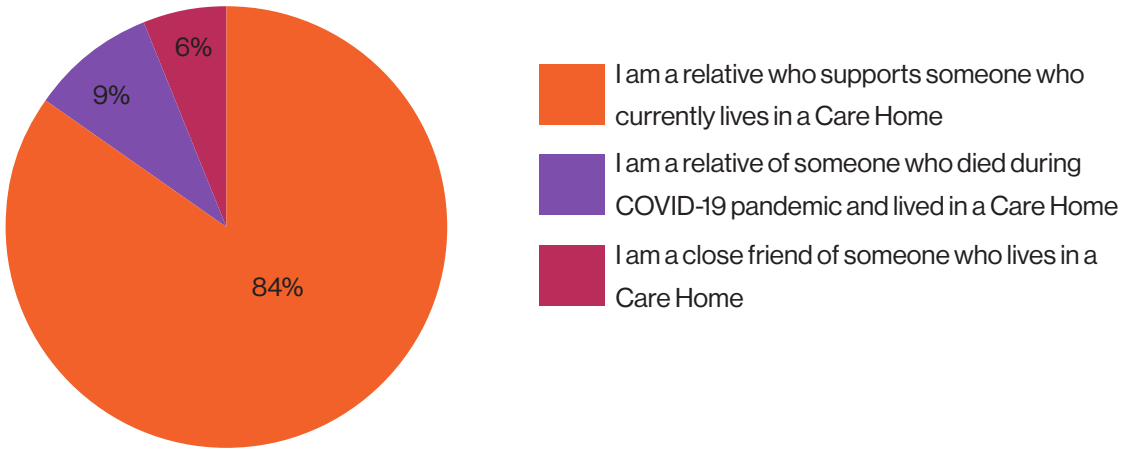
- The Relative's Voice

5.0 FINDINGS & ANALYSIS - The Relative's Voice

5.1 Overview of Returns

From 23rd June 2020 to 31st August 2020 a total of 109 relative surveys were completed sharing their experience of Care Homes during Covid-19. The first step in the survey was to build context around the experience of the respondent and their relative living in the Care Home, through a small number of closed statements as illustrated in the following figures.

Figure 16. Which of the following statements best describe you? (n=109)



In Figure 16 the tab "Other" accounts for representatives from BDA who engaged with the project through a zoom workshop to share the experience of the Deaf community. Figure 17 breaks down the relative who responded to the survey.

Figure 16. Which of the following statements best describe you? (n=109)

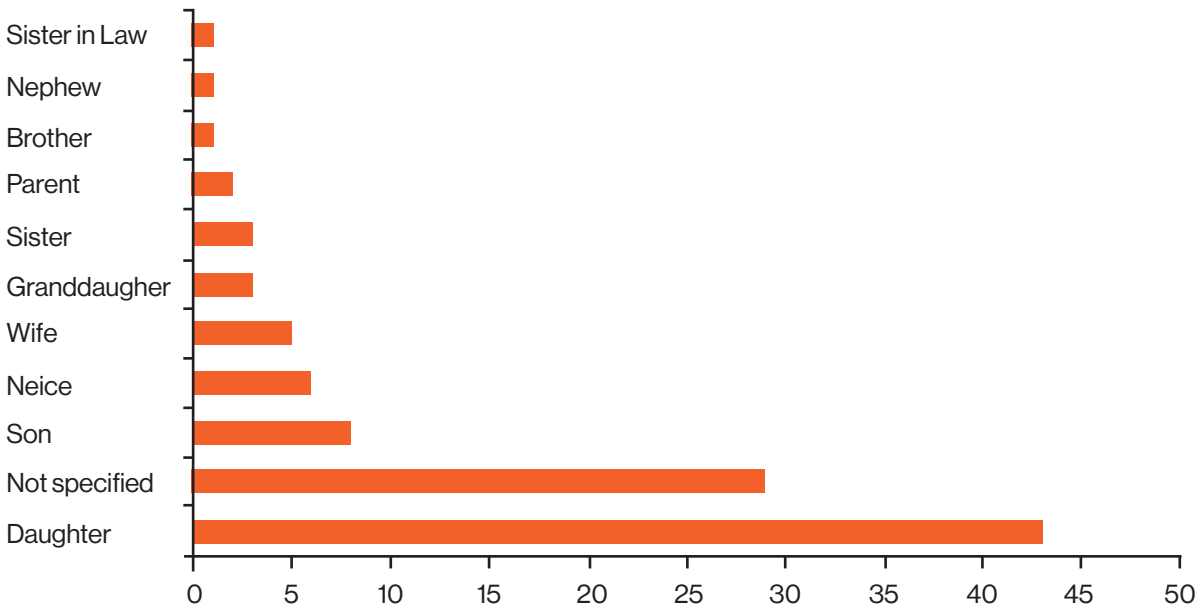
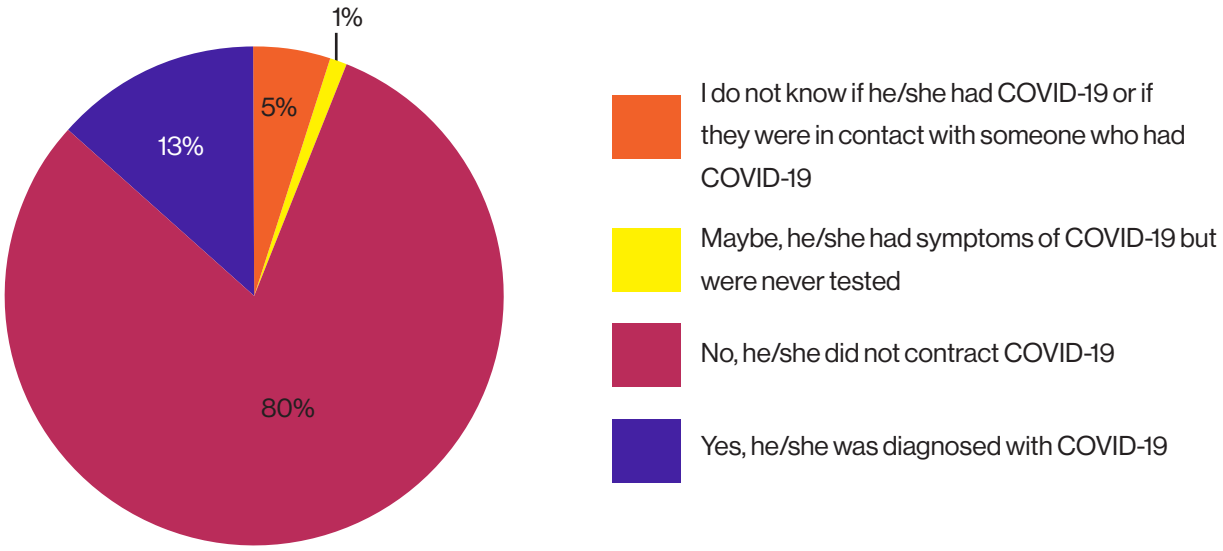


Figure 18 details if the respondent's relative was diagnosed or exposed to Covid-19 during the first surge of the pandemic.

Figure 18. During Covid-19 pandemic was your relative diagnosed or in contact with Covid-19?



The following section presents an overview of the findings of the core concepts included in the relative survey. These are further enriched and illustrated through the words of the relatives. It is important to acknowledge each of the above context statements can be used to filter the data and inform deeper understanding of the experience of a particular context (for example briefing paper on the lived experience of relatives who were bereaved during Covid-19 pandemic).The analysis in this section supports the understanding of the data as a collective exploring the following concepts

1. Communication
2. Changes in Care
3. Safety
4. Connection
5. Confidence

To support the context of the stories relatives were asked to share three words which describe their experience. The emotions shared by residents are reflected in the word cloud, giving cognisance to range of emotions that relatives experienced at this time.

Figure 19. The emotions of relatives experienced during the Covid-19 Pandemic

5.2 Communication about COVID -19

Figure 20 explores how the relatives learned about changes in the Care Home during the first wave of the COVID-19 pandemic. The signifiers outlined communication from the Care Home, news & social media and official communication from Government or Health & Social Care. Responses represent 85% of returns with 15% stating the signifiers were not part of their experience.

Figure 20. Triad 1. (n=93) "I learned about the changes within the Care Home (for example visiting arrangements, changes to activities, living arrangements) through…"

The signifier with most responses (84%) indicated communication came via the Care Home. There is also a minor pattern formation towards the news and social media, with minimal reference to official communication from the Government/Health & Social Care services. In the narrative relatives discussed the timeliness and approach in the communication from the Care Home.

"…Communication with the care home & knowing everything was being done to a high standard to keep my relative & everyone in the home safe & well…."

"… the day the Care Home was to lockdown the manager rang me. I appreciated that she took the time to tell me to come in and see mum as she didn't know what the following weeks would be like. We were both very emotional…. I guess it was as hard for her to break the news but I appreciated the call instead of a standard email or letter.."

"… the home was great and they did their best to keep me informed – it wasn't easy for them to know what to communicate – afterall the guidance kept changing!"

It is important to highlight relatives did not always reflect positively on the communication with the Care Home, particularly when the communication was limited or not delivered with empathy.

"...There was very limited communication with the home - they called me to say a resident had COVID 19, there was then a news story on UTV about the care home reporting more deaths but no response from the home (the story appears to have been inaccurate) but this lead to loads of rumours..."

"....Probably the biggest negative in terms of how the home handled things was when the nurse in charge called me at work to tell me that they were locking down with immediate effect and no visitors would be allowed. This was in mid-March, and - while I understood the reasons - I thought at the very least the communication could have been handled more sensitively. The manner in which the message was conveyed was very abrupt and there was no room for discussion. The individual hung up before I'd really had a chance to process the information. Since then though, communication has been ok. I received a letter to inform me that COVID had unfortunately entered the home..."

"... The last day I saw my mum in March I left feeling like my mother was on death row... I knew nothing, I was told nothing and no one answered my questions... I feared for my mum's life and I heard nothing for weeks even though I tried ... I never knew when I would hear from them..."

"Shock at getting an email to say the home had closed to visitors. I understood no notice could be given, for obvious reasons, but it was troubling..."

"kept in the dark"

"Calls were not returned and we were blocked from getting through to Mum's Unit to speak to staff. Reception started to take all calls. The phone link to Mum's Unit was left broken throughout the period and at night you had to speak to another Unit to get any contact with Mum's Unit. We first learned of multiple deaths in the Home via the media. To this day we have never been told how many died in the Home. Only after media exposure did we get a letter re the deaths from the Management. We got a second letter that things had worsened and this was the first we heard Covid was in Mum's Unit. We were phoned to be told it was in the Home on 1 April. ..The lockdown was introduced very early without communication and contrary to PHA advice at that time and when challenged in that first week, we were callously told by Management that we could get Mum moved to another Home."

The key message is the need for open and transparent communication with the Care Home – communication which is both pragmatic and empathetic. Where there was an absence of communication relatives were both isolated and scared for their family member in the Care Home. Similar messaging is apparent in the next section.

5.3 Communication about your relatives' care

Figure 21 considers communication with relatives about the individual resident's care – exploring if relatives could ask questions, were informed about a change in their health or wellbeing and being involved in decisions about care, identifying with the concept that relatives are important partners in the delivery of care. In total 80% of returns reflected upon this triad. 20% stated the signifiers were not part of their experience, suggesting a lack of engagement by the Care Home in relation to care delivered during lockdown.

The most common signifier identified that for 82% of responses the relative was able to contact the Care Home and to ask questions. In the narrative it is reinforced in the words of the relative's the importance of two way engagement with the Care Home.

Figure 21. Triad 2. (n=87) "During Covid-19 pandemic I was…"

"….This home has went above and beyond to keep everyone safe during this time. There hard work and dedication is like no other. They have went to so much effort to keep in contact, keep everyone safe and entertain everyone when visitation was not permitted…"

"…I phoned regularly for updates on how she was doing. There was a period of about 4 weeks when she was unwell and her general condition had deteriorated so not being with her was so hard to bare. I have always had faith in the quality of care my mum receives and initially this was reassuring but as time went on i just wanted to be with her to see that she was ok…."

"…Giving me quality time with mum the day before the home locked down. Keeping in touch throughout with staff and speaking to mum on the phone. She has Alzheimers so face time would have been difficult. They were very transparent about what was happening.."

"…I received a phone call each week to let me know how my father was and also a generic email was sent each week…"

It is evident in Figure 21 that the concept of partnership with relatives was compromised during the lockdown with only a small number of responses indicating they were involved in decisions about the resident's care. In relation to the changes in the resident's health or wellbeing there was concern raised at the lack of information shared with the relative or a complete absence of any contact, devaluing the role of the relative in the resident's care.

"...The home did not keep in contact. They did not offer any type of reasonable engagement with my grandmother. I was not allowed to leave anything in to the home from treats through to new knickers. Official complaint lodged with Social worker and Key worker. regarding the homes unwillingness to help family member keep in touch. At one stage it was said I would not see my grandmother until there was a cure..."

"...15 people died in the Care Home in XXXX [detail removed to protect anonymity]... No engagement or reassurance was offered by the home to any of the residents families who survived the virus. My mother-in-law has thankfully survived..."

"...Unfortunately my memorable moments are filled with anger and sadness. Not once did the care home contact us to update us on our relatives health and wellbeing until they became poorly; end of life poorly! We attempted to keep regular contact with the care home via telephone call for updates on our relatives health and wellbeing - sometimes we were unable to get through and the times when we did speak with someone they advised that our relative was 'keeping well and doing good' unbeknown to us that this was far from the truth..."

The key message is that relatives remained key partners in the health & wellbeing of the resident. There is a need for ongoing communication between the Care Home and the relatives, particularly during the period of lockdown when relatives are unable to visit and support care.

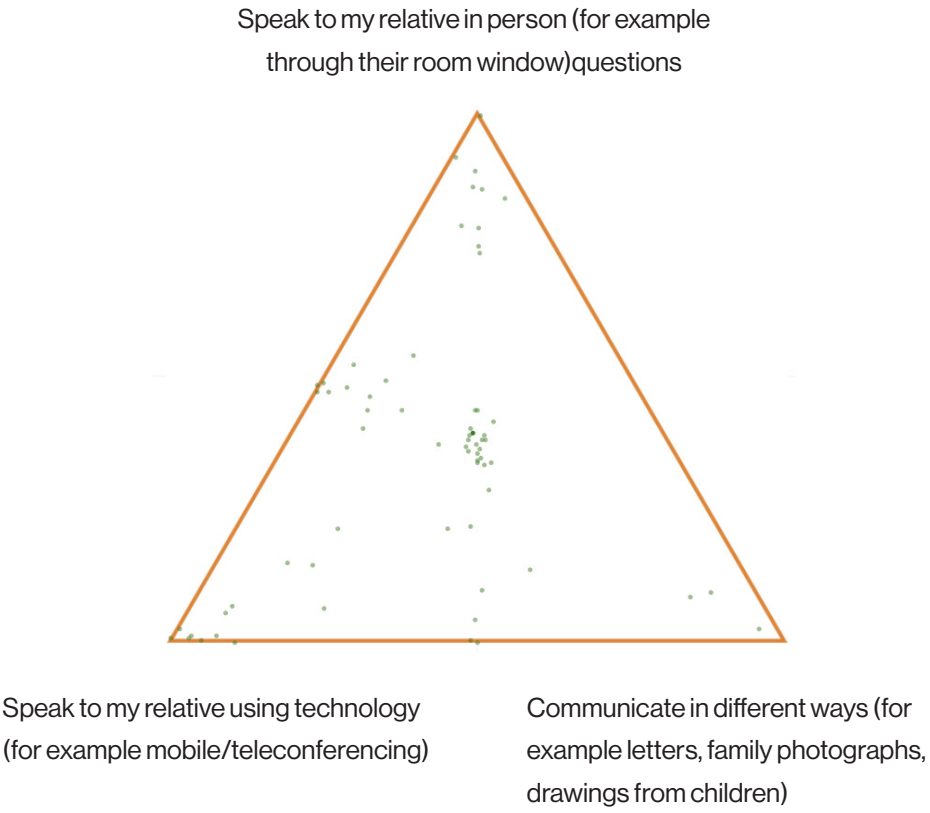
5.4 Support

Figure 22 explores measures implemented by the Care Home to support relatives to connect with the resident. It explored the use of technology, measures to support visiting at a distance and creative measures to keep the relatives connected (for example letter, photographs). In total 80% of returns reflected upon this triad ; 20% of returns indicated the signifiers were not part of their experience suggesting they were not supported to connect with the resident. The following words of resident expresses the anger when support was not made available by a Care Home.

"Horrible, not able to see father for 15+weeks. Absolutely disgraceful. No window visits, no videos sent to family. Home seemed very slow to find new ways of patients interacting with their families, yet the Home has mobile phones, computers and I-Pads and could very easily have introduced virtual visits. Window visits commenced after 17 weeks but were not successful. Still unable to be in a room with father on 8th July - last time we were sitting with him was 21st March - an absolutely awful way to treat elderly, vulnerable people..."

79% of responses in the triad indicated the relative was supported to engage using technology. There is also a strong pattern formation toward support to speak to the relative in person, indicated in 64% of responses. In the narrative relatives reflected upon the importance of these measures particularly the value in technology, however some relatives reflected openly on the complex challenges in engaging with the resident in this way, in particular for residents with cognitive impairment (for example dementia)

Figure 22. Triad 3.(n=87) During COVID-19 pandemic the Care Home supported me to:



"...I will always remember the speed with which the home got Wi-Fi up & running and purchased iPads at the start of lockdown, so that their residents could keep in touch with their families...The help the staff gave to my mum in setting up her new iPad so that we could FaceTime each other during lockdown..."

"...The home made provision for WhatsApp video to each resident if required. Fortunately my mum at the age of 92 is high tech with her iphone so the family were able to see and talk to her. I phoned/videoed her each day and she was able to tell what precautions the home was making with daily temperature checks and eventually COVID 19 tests for all..."

"...The home quickly put us at ease by setting up video calls. My aunt had never used this technology in her life but with a large ipad she was just delighted to be able to see us as she talked to us. This provided us with so much reassurance and we knew she was happy and could talk to her as much as we wanted. As restrictions lifted we got to visit her outdoors if the weather was good and we spent a lovely afternoon outside on a picnic bench at a 2metre distance. We could also speak to her through her bedroom window and were provided with cleaned garden furniture to facilitate this..."

"...on a couple of occasions they took the phone to Mum for me to say hello but it really upset her, she cried and was pleading with me to come to see her. I came off the telephone in tears and upset that she was so unsettled.. The Home arranged Whatsapp but Mum is 93 and has Lewy Body Dementia, she didn't know what to do, where to talk into, everything had to be relayed by the receptionist who was holding the phone. Sixteen weeks later we got window visits which were better, maybe more so for us rather than Mum.."

"Watching my mother of 83 cry as I looked at her through a window"

"My most awful moment was when the care home manager told me I wasn't allowed to phone my mum sitting in her usual place in the room while I stood outside the building looking at her through a closed window - that I had to make an appointment to do that and that they were not willing to accommodate appointments after 3.30pm each day. I am an NHS worker and only get home around 6pm. Manager said that I could just 'wait until the weekend'. It just didn't make any sense from an infection control point of view or any point of view. The nursing home seemed to make care very process driven and inflexible, not centred around the residents, and not at all recognising that contact with relatives is also a central part of the wellbeing of the resident..."

In the narrative relatives also reflected on times when the support they received was beyond expectation and the relative recognised the dedication of the staff in the Care Home.

"...We had a lovely family experience during COVID-19 restrictions. It was mums birthday in June and a party of 6 family members were particularly keen to see mum on her birthday. We had pre-arranged our visit with one of the Senior Care workers, excellent member of staff, to visit the care home. (name removed) went out of her way to facilitate tea and cake for us all in carefully arranged seating in an outdoor area. It went wonderfully well.."

"...The wonderful caring support she received and her personal resilience to face down and defeat the condition. Facetime contacts facilitated by the staff where delightful and we will be forever be grateful to the care staff/ home for enabling us to have a social distance 93rd Birthday party for her and her singing for us..."

The key message is that families need to be recognised as essential network for their relative in a Care Home and must be supported to connect in the best possible method for the individual. In many cases the family provide valuable stimulation for their relatives, supporting their mental health & wellbeing.

The next five sections presents the response of relatives plotted on dyads, discussing topics in relation to safety, engagement and staying connected.

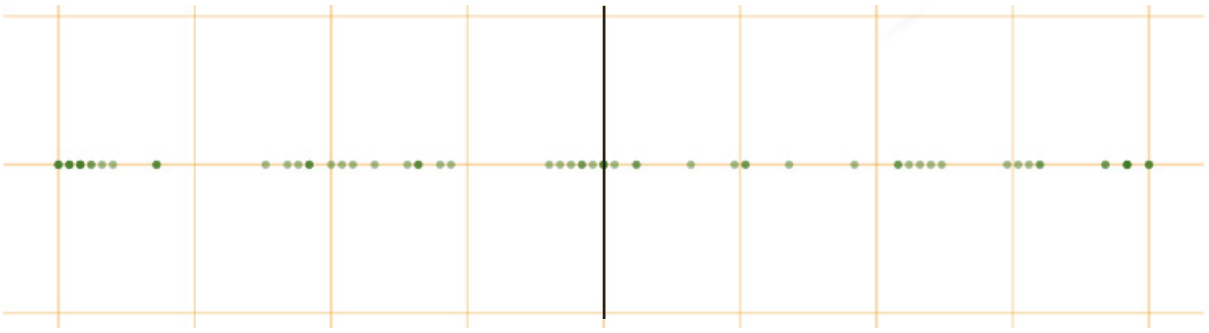
5.5 Safety

Figure 23 illustrates responses regarding the safety of the resident in the Care Home and concerns about contracting COVID-19. 77% (n=84) of returns completed this statement. When considering the extremes to the statement "In relation to my relative's safety I was..." 28% stated they were confident their relative was safe and protected from COVID-19. The narrative reflected trust in the Care Home processes and a good relationship with the Care Home manager.

"... these are unprecedented times – I could not say enough praise for the Care Home. It closed before the government instructed and I for one was relieved. Really difficult days but I knew the Care Home manager had my mum's and the other resident's interests at heart... I knew mum was safer in there than out in the madness this world..."

".. When the nurse rang to say they were moving to shut down it was so emotional for both of us... she promised she would do everything for dad and I knew she would..."

Figure 23. Dyad 1.(n=87) During COVID-19 pandemic the Care Home supported me to:



Extremely afraid they would contract COVID-19

Completely confident they were safe and were protected from COVID-19

Regarding the more negative emotional tone 36% raised concerns for the safety of their relative in the Care Home, with 11% stating they were extremely afraid. The narrative indicates a lack of communication regarding outbreaks of COVID-19 between the Care Home and the relatives, leading to a lack of trust. There was also concern there were no independent professionals able to attend the Care Homes such as RQIA or GP, causing a level of concern regarding safety.

"15 people died between 26th March and 10th May at XXXXXXX [names removed]. No engagement or reassurance was offered by the home to any of the resident's families who survived the virus..."

"... I heard it on the news the Home had COVID-19... Total disgrace that I have to learn that my dad is at risk through BBC Newsline....I rang and begged them to tell me if mum was at risk... I was told – No news is good news... I was so scared that every time the phone rang I was convinced it was them to say Dad had COVID-19 and I would lose him..."

"...Secretive, could not trust what being told, didn't know how loved one was being treated and if being neglected, saving lives of the elderly and vulnerable didn't matter to care home management, authorities which are meant to help, GP and medical services and RQIA would not go near a care home...."

"...we have had good experiences to date and trust the staff in the care home to look after my mum, but part of that trust is built through first hand evidence, something I personally didn't have over the last 4-5 months. The next best thing would have been the knowledge that the system (through RQIA) would have been monitoring my mum's care but I understand those inspections were suspended during this period..."

For responses which were more neutral (centre of the dyad) there was a recognition of the importance of the lockdown for safety however mixed emotions due to the impact on their relative's health & wellbeing. The narrative reflects these competing emotions.

"The care home was excellent. They used their own staff, no agency staff. Not being able to visit my dad was tough, but kept him safe. We did FaceTime. This was difficult but better than nothing. Unfortunately his dementia declined quickly. Being isolated in his room kept him safe, but my dad paid a cost...."

"I knew Mum was safe and the Home was protecting her from the virus but it really felt like she had died. There was no contact with her, when we rang into the Home asking about her, on a couple of occasions they took the phone to Mum for me to say hello but it really upset her..."

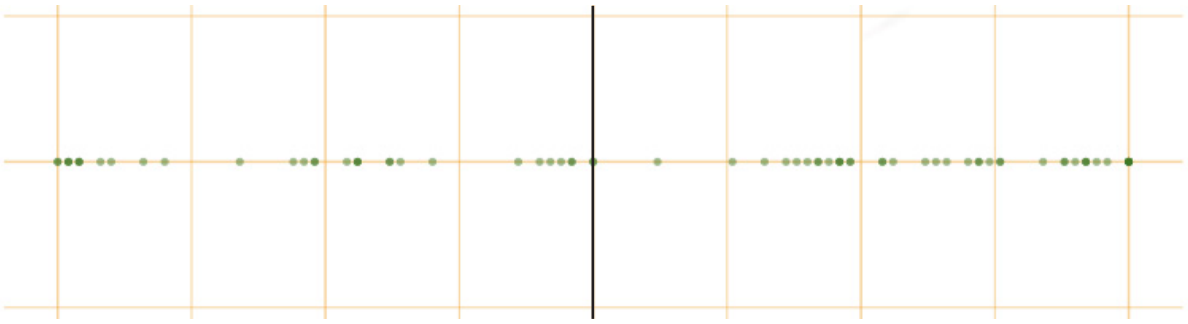
"...The home has been brilliant. Mum is safe & content but I believe she has deteriorated without the stimulation of activities & visitors and of course in her own way she experiences the loss of my Dad who was with her every day. I appreciate all the home has done.."

The key message is the importance of the relationship between the Care Home and the relatives to; it is crucial that Care Homes are open and transparent about their processes (for example infection control measures) to instil trust and also about new case/risks to the residents to help relatives manage anxiety when they are not physically able to be in the Care Home. Relatives also indicated the importance of the input of other organisations/professionals such as RQIA & GP to support the safety of their relative.

5.6 Connection

Reflective of section 5.4 figure 24 illustrates if the relative felt connected. There is an even spread across the spectrum with 51% with a positive emotional tone (from midpoint of dyad) stating they were connected and 49% with a negative emotional tone implying disconnected.

Figure 24. Dyad 2. (n=84) In relation to connecting with my relative I was...



Completely disconnected, I was never able to speak with them

Completely connected and engaged with them regularly

Supporting the messaging from section 5.4 the narrative demonstrated the importance to staying connected – For stories with negative emotional tone the narrative shows the distress caused by the inability to visit and limited communication by the Care Home.

"...Prior to COVID-19 my grandmother had a relative with her everyday who typically fed her one of her core meals. We also took care of all her washing and ironing. During COVID this all stopped and the care home closed its doors 3 weeks before lockdown. They did not inform us of this until the evening before it was closing. For my Grandfather who has been married to his wife for 60+ years this was very distressing and emotional. At the beginning we got little to no update on granny. Then on Easter Sunday we got all call to say Granny was COVID-19 positive. We then had to wait almost 48 hours before an update on how she was..."

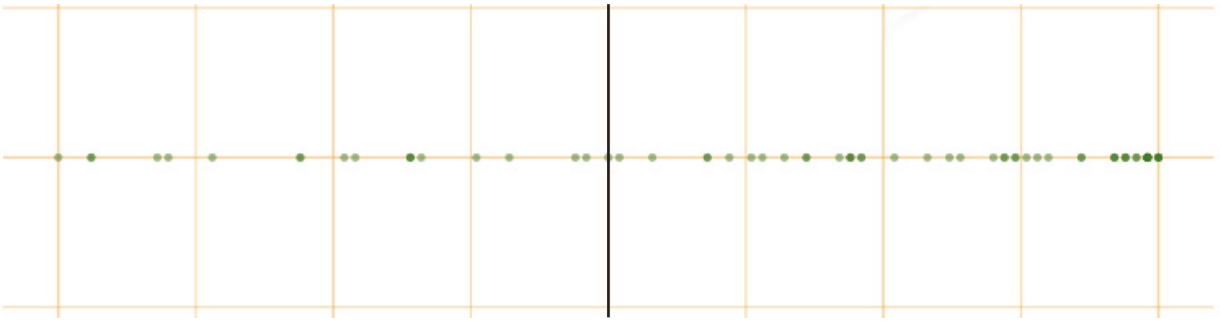
"....My father went into the care home about 6 weeks after lockdown started... .It broke my heart to wave him off at the door and not be able to help him unpack his belongings and settle in and it continues to hurt every time I have to wave to him through the window and not be able to hold his hand or hug him. His communication difficulties mean that, even though we can visit him from behind a perspex screen at a 2m distance, I can have very little interaction with him. I still get very emotional... I was able to see him through his window and wave to him every day. For me, this meant that I could reassure him that I had not just abandoned him and got on with my own life... The staff appear to be very caring and they keep me well informed of any changes in his condition or care. I do still feel VERY cut off from him and reliant on others to assess his day-to-day condition..."

The key message is the utmost importance to keep relatives and residents of Care Homes connected; connection is also essential between the relative and the Care Home as the key network for the residents of the Care Homes.

5.7 Confidence

The final statement in the survey explores the relative's confidence in care received by their relative in the Care Home. Figure 25 illustrates the responses – 85% of returns completed this statement.

Figure 25. Dyad 3. (n=93) In relation to my relative's care I had...



No confidence my relative was cared for during COVID-19 pandemic

Every confidence my relative was cared for during COVID-19 pandemic

50% of responses were in the very positive quadrant of the dyad indicating they had confidence in the care of their relative. Within the narrative of relatives reflected upon the open communication with the Care Home.

"...The home my brother was in gave us a daily update and regular photos of him enjoying activities organised by home... never once had to worry about his care..."

"...One thing I do know is that he is being really well looked after, which is such a relief as the last home he was in left a lot to be desired, to put it mildly.."

"...Giving me quality time with mum the day before the home locked down. Keeping in touch throughout with staff and speaking to mum on the phone. I contacted their MP to make sure they were getting all the support they needed..."

The remaining 50% of responses spread across the spectrum toward little or no confidence in the care delivered. In these cases the narrative highlighted relatives concerns or advice being ignored and lack of trust in the Care Home – in particular a number of stories reflected concerns about deterioration in the residents health and in particular the quality of care given at end of life.

"...It was and still is a terrible experience. The care home locked down without warning, which meant I could not explain what was happening to mum. The care home made no contact with me so I had no idea how mum was. Before lockdown the home were routinely transferring everywhere by wheelchair when they were told mum needed to keep active by walking with a frame as much as possible. They ignored this and now she is barely mobile. It was almost impossible to get through on the phone and when I did talk to someone they weren't remotely reassuring. I felt like I'd left her stuck in a prison..."

"...This entire situation has been a nightmare for me and my family. Kept in the dark and not allowed to visit. It also appears that none of the residents were offered a hospital bed for treatment and they were left to die in their rooms with no-one to comfort them. Perhaps 'no resuscitation orders' have been used as an excuse for this euthanasia. I dread to think what will happen if any future virus gets into this home..."

"....To suddenly have this [family] taken away from your loved one has been horrendous and detrimental to their life and health, (mentally and physically!)I can totally understand and be glad that safety of our loved ones should be priority but definitely needs rethought! My Mother from xxxxx [date removed] to present is in hospital and very ill and isn't it shameful that we have only been by her side since her admittance to hospital! Needless to say I personally think it might not have happened or definitely wouldn't be as critical if we had been allowed to visit as usual over the 3 month period of this ban and still ongoing. Being sensible, wearing full ppe I personally think access would have been achievable, instead of Skype and talking through a window! Now instead I am completing this survey beside my Mother's bedside in hospital at 4.00am, feeling very lucky and privileged that I can be with her as unfortunately so many people have lost their loved ones and have not been with them, totally devastating for all. In this world that we now live in the elderly have not been heard or respected the way they should be!"

"...Frustrating was how I/we as a family felt during the whole experience. We were getting mixed messages from the home depending on who was giving the information. We even wondered at times if they knew who the person was we were asking about. Even on the day she died the home caused additional anxiety which there was no need to do..."

The key messaging around confidence in care is the need for communication with the Care Home which is open and trustworthy. Also in relation to deterioration of a resident's health, it is important the relatives are informed at the early stages and measures made available to support the families to be together. There is also a clear message that assurances are required in relation to end of life care and the arrangements regarding "Do not resuscitate" orders.

6.0 FINDINGS & ANALYSIS

- The Staff Voice

6.0 Findings & Analysis – The Staff Voice

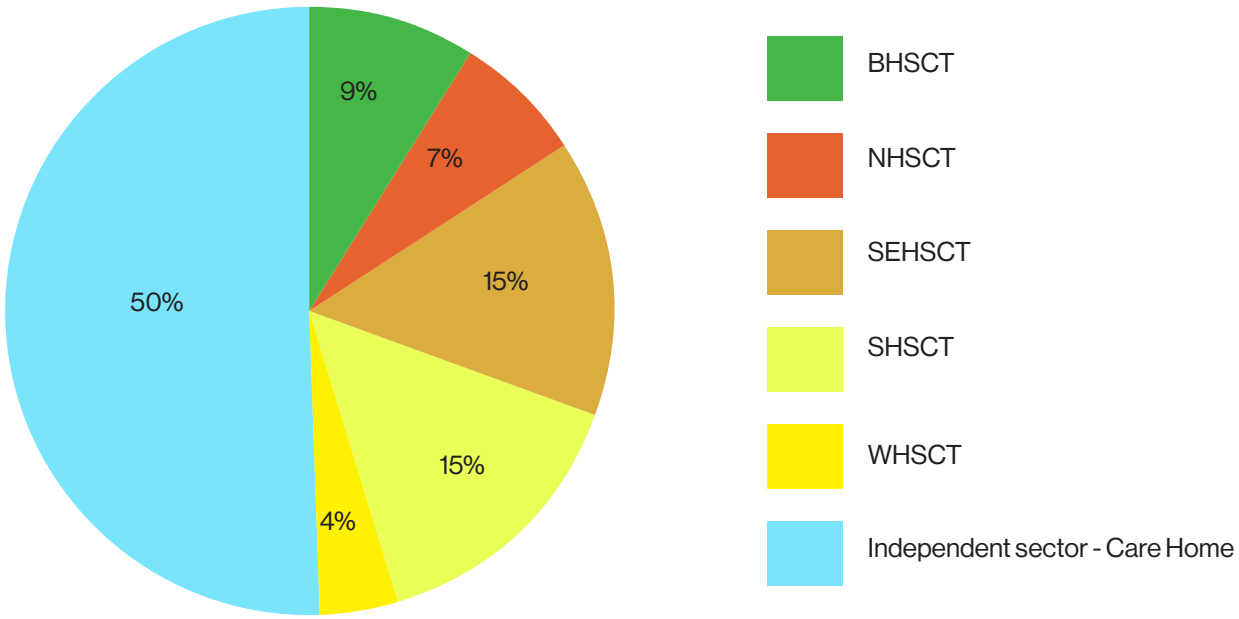
6.1 Overview of Returns

From 24th June 2020 to 31st August 2020 a total of 116 staff who worked within Care Homes returned completed surveys sharing their experience of COVID-19. This information has been gleaned as part of a larger project extended to all staff who worked on the frontline, entitled "You and Your Experience of Working during Covid-19 Pandemic". The following analysis only related to staff who worked within the Care Homes at this time.

The first step of the survey was to build context around the experience through a small number of closed statements as illustrated in the following figures.

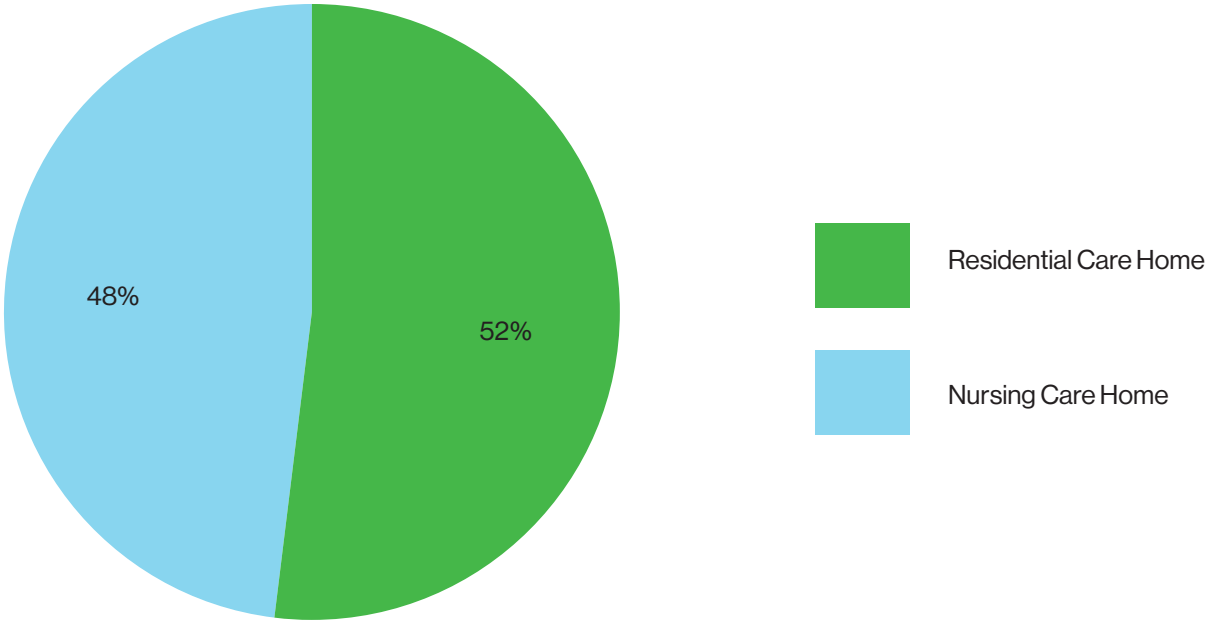
The first question explored the organisation to which the respondent was employed. From figure 26 it is evident just over 50% were directly employed in the Care Home (n=59); The remaining 49% (n=57) were staff indicated they were employed by a trust – this is reflective of staff who worked within statutory Care Homes, changes in their job role to support Care Homes (for example management, social work, in reach support) and staff were redeployed into the Care Home setting from the trusts.

Figure 26. Question 1a (n=116) Which section of the Health & Social Care are you employed by?



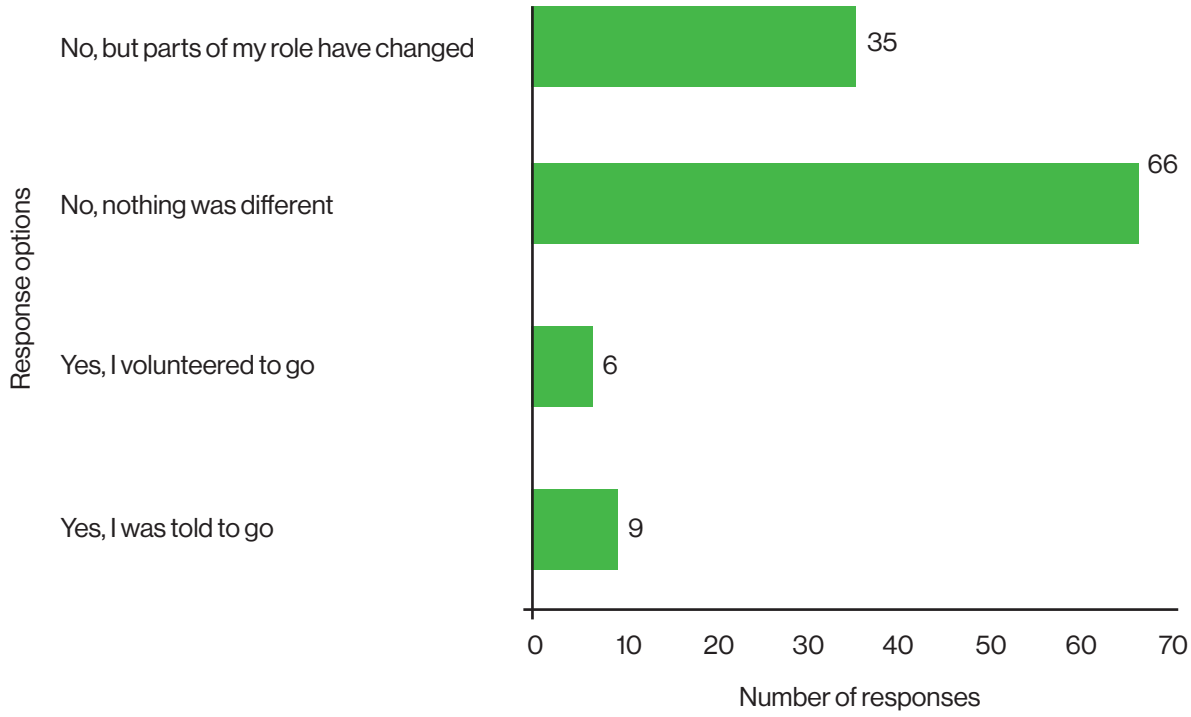
The next question explored the Care Home setting, asking the respondent to indicate the location of their place of work. This is illustrated in Figure 27, demonstrating a balance between resident and nursing care home settings.

Figure 27. Question 1b (n=116) At this time where is your place of work...



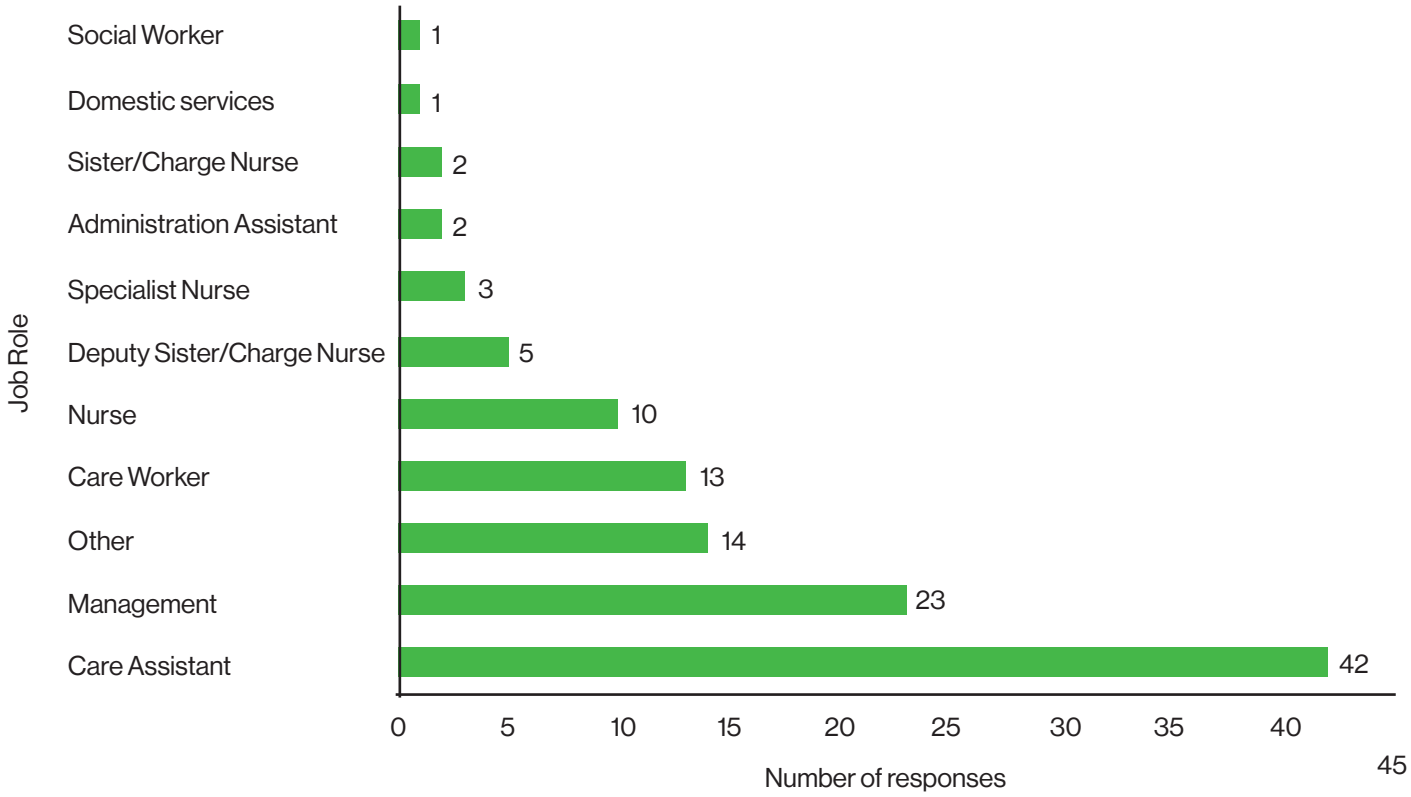
Respondents were also asked to reflect upon their current role in relation to redeployment/changes to their role. As illustrated in Figure 28 the greatest proportion of respondents indicated their job role did not change. There was a cohort of respondents who indicated they were redeployed into the Care Home setting (n=15). The majority of these staff were care assistants (n=12). 35 respondents indicated their job role had changed. The majority of this group of staff were senior care workers or staff nurses.

Figure 28. Question 1c (n=116) Have you been redeployed from your usual role/department...



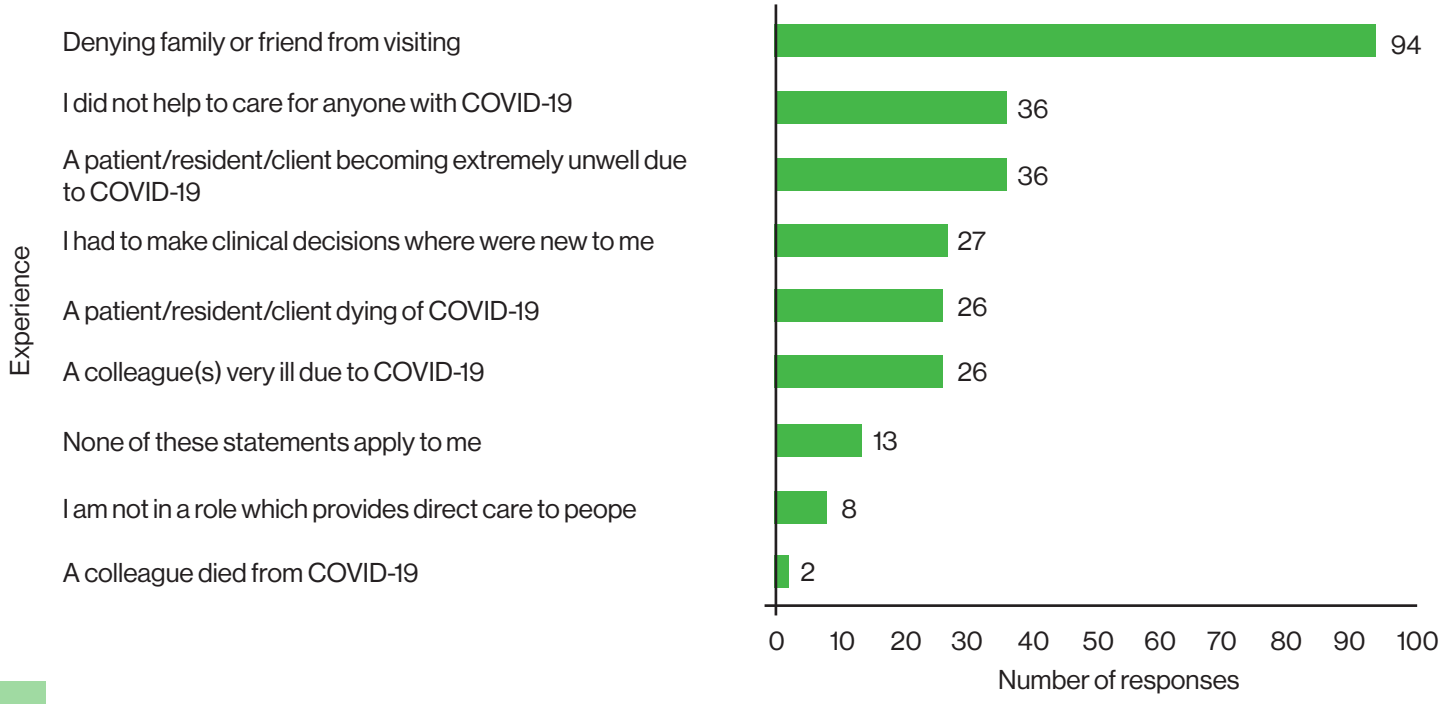
Staff responding to the survey were from a variety of job roles as outlined in Figure 29. The majority of responses were from a nursing care perspective – for example care worker or care assistant made up 47% of responses (n=55) and registered nursing profession (registered nurse, deputy/sister or specialist nurse) represented 17% (n=20) of returns. The category other includes kitchen assistants, psychologists and in reach support.

Figure 29. Q1d. (n=116) What is your job role during Covid-19



The final context question related to experiences unique to the COVID-19 pandemic and offer insight into the complex challenges faced by staff during the first wave, as illustrated in figure 30.

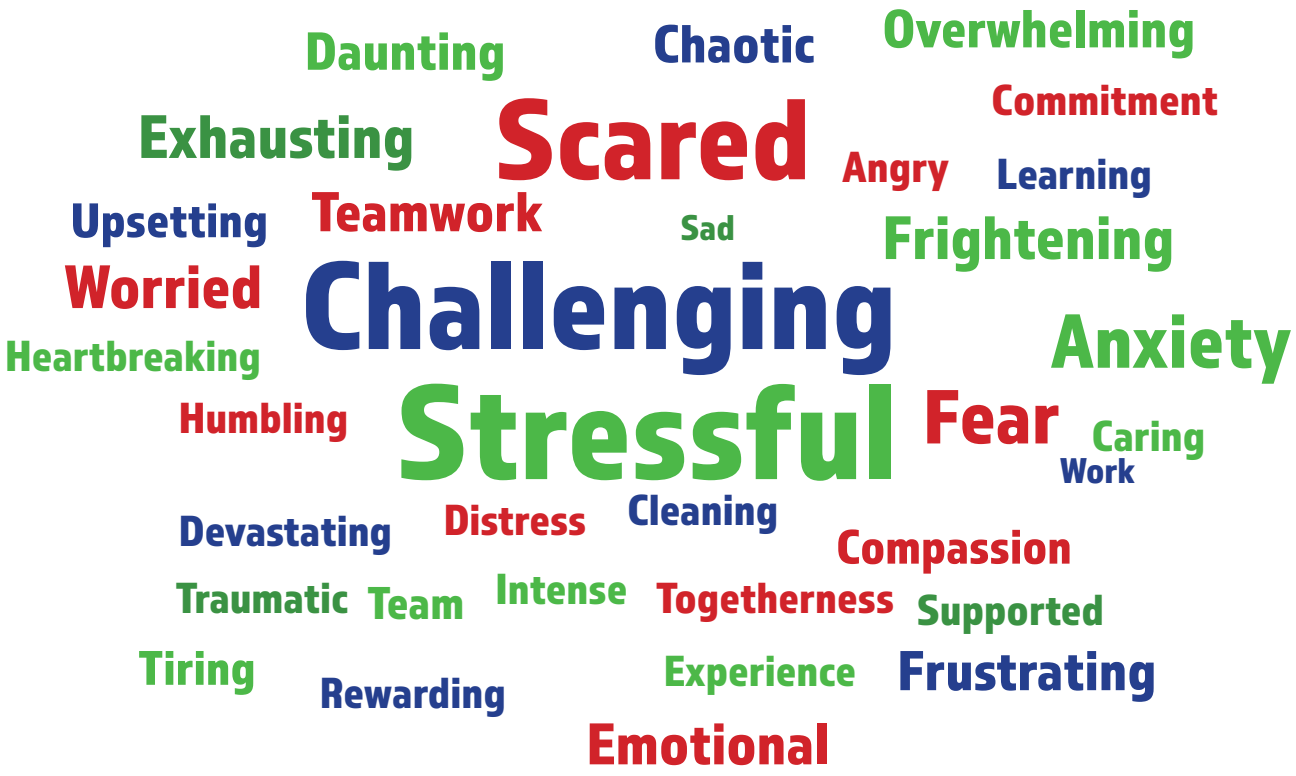
Figure 30. Q4f. (n=268) From the following list tick the statements you experienced during COVID-19



The experience/scenario indicated the most was "denying family or friend from visiting". Respondents who stated "None of these statements applied to me" roles related to support services such as administration or kitchen or staff who were considered "in reach" to the Care Home setting.
The following sections present an overview of the findings of the core concepts included in the staff survey. These are further enriched and illustrated through the words of the staff. It is important to acknowledge each of the previous context questions can be used to filter the data and inform deeper understanding of the experience of a particular context (for example briefing paper on the lived experience of redeployed staff or experience of bereavement in the Care Homes). The analysis in this section supports the understanding of the data as a collective exploring the following concepts:

1-Being in control
2-Being Prepared
3-Being challenged
4-Policy in Practice
5-Moving forward
6-Personal Impact including coping mechanisms, source of support.

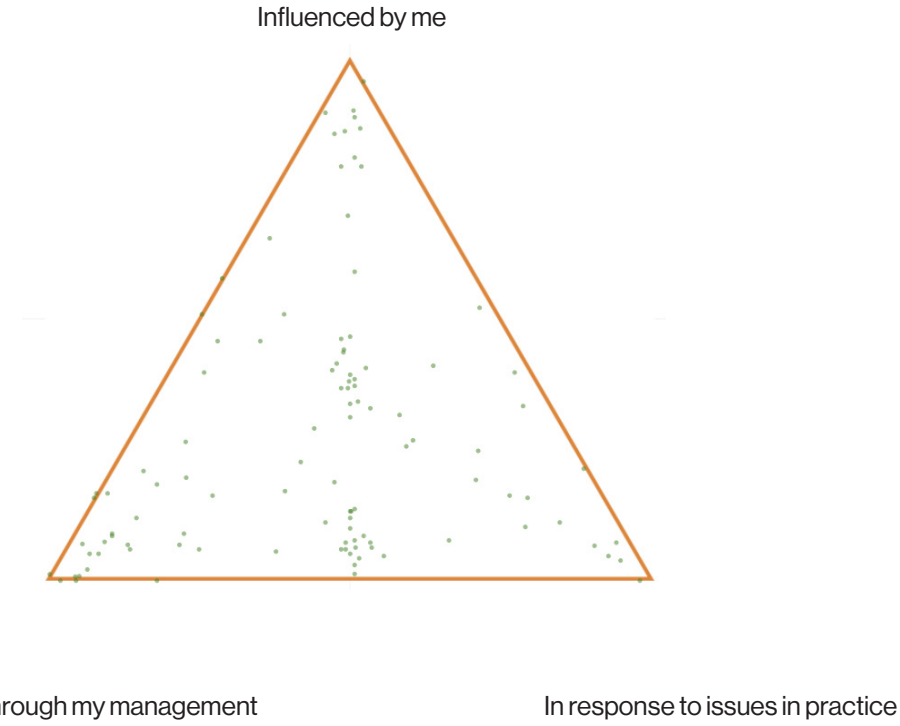
To support the context of the stories staff were asked to share three words which describe their experience. The emotions shared by staff in Care Homes are reflected in the word cloud, giving cognisance to range of emotions that staff experienced at this time.



6.2 Being in control

Figure 31 illustrates the response by staff working in Care Homes in relation to who was in control of the changes. The signifiers considered if the change was influenced by the staff, planned through management or in response to an issue. The dominant signifier, representing 67% (n=72) of responses, indicated change was planned through management. 53% (n=57) indicated change was also made in response to an issue in practice.

Figure 31. Triad 1. (n=107) In response to the COVID-19 pandemic changes in my role were...



In the narrative Care Home staff reflected upon making changes and decisions in the absence of clear guidance from regulatory or government bodies at the start of the pandemic– this particularly evident in stories where Care Homes made decisions around closing the doors early or clinical decisions. There is a sense that in the decisions about Care Homes the staff felt forgotten.

"...I was fearful and anxious most of the time. It was very unnerving at the start as there was no clarity, support or direction from regulators and other authorities regarding locking down care homes and new admissions. Messages in guidelines were conflicting depending on which authority you were speaking to. The measures were more reactive rather than proactive. We had to make our decisions regarding locking down the home which without the support of the authorities meant it was met with a lot of resistance which in turn increased the stress levels to staff..."

"...Plus the lack of support either from the company I work for and the Trust itself was ridiculous. Somehow someone decided that our elderly residents within the care home environment weren't meant to be treated and literally left to die! Receiving calls simply asking if my resident had a DNACPR and anticipatory drugs prescribed simply meant that their focus was not on us..."

"...A lot of emphasis placed on the NHS and Care Homes were neglected until it became apparent that the real struggle was within this sector so a bit of feeling that we were not as important..."

"...Feeling as if we didn't matter. No matter what we did we faced criticism. The overwhelming feeling of inadequacy at times due to how many of our colleagues were ill but also from people who never set foot in the care home but criticised from afar..."

"...Staff in the home (me included) felt unappreciated and worthless compared to the praise and appreciation shown to the NHS staff. From that point of view it was hard to keep staff motivated. The decision to stop families visiting affected me terribly as I was thinking of the impact this would have on the residents and of course the families particularly if they were to take ill and death was imminent..."

Only a small number of staff indicated they were part of the changes (31%/n=33) with the majority of staff holding a role in management or senior nursing roles. The key messages and the challenge moving into future pandemics/surges are to ensure that the Care Home staff are involved in the decisions about change. To ensure they are consulted and their expertise are an influencing driver to the change. There is also a need for change to be proactive and guidelines and directions to be clear, timely and supportive of decisions the Care Homes need to take to manage the risks.

6.3 Being Prepared

Triad 2 demonstrates the opportunities available to staff throughout the first wave of the COVID-19 pandemic. The signifiers explored if the staff worked within new teams, attended training for new skills or had the opportunity to practice new skills in the workplace. The dominant signifier – "Practice new skills in the workplace" was identified in 69% (n=63) of responses.

Figure 32. Triad 2. (n=91) At this time I have had the opportunity to...

In the narrative the skills reflected upon development of new processes, embedding infection prevention control practices and engaging in activities to stimulate the residents. This is also strongly linked with training on new skills with 43% (n=39) identifying this as an opportunity.

"...The greatest impact has been starting a new service from the beginning, getting processes set up and following them through and learning to adapt each day to make changes to ensure efficient running of the service..."

"...I had to learn to be a Care Assistant / Cook / Cleaner just in case of worst case scenarios..."

"...Their [the staff] willingness to adapt to very different working conditions and embracing training needs to ensure they could do their work to the high standard they set themselves..."

".... All training that was made available to the private sector through CEC has made a huge difference to my staff and I do feel that all training should be made available to us and should remain free of charge. Please don't forget that the nurses in the care sector can help to keep beds free in the hospital. Another thing that was a positive was the training available through Zoom. Staff completed training from their own home and they were safe..."

"...I was able to spend more time in the company of the residents I look after and get to know them better due to no visitors being allowed in. However, during this time it was difficult at points when residents started to miss family members and you had to console them but did not know when they could see them again..."

In the narrative it was evident that training was a challenge for some staff highlighting concerns regarding the effectiveness or relevance of the training or a lack in training during the first wave of the pandemic.

"...Training on PPE - All staff must complete mandatory infection control training, this training does not include the use of PPE in the on-line training modules. Residential Care Homes had not worn PPE to the extent prescribed in the Guidelines and this took a few days before it became second nature to the staff..."

".... We also never received PPE training and there was a lot of confusion as procedures kept changing..."

There is a minor cluster of responses indicating the experience of working within a new team (12%/n=11). This is reflective of staff who were redeployed during the first wave of the pandemic – either from Trusts or internally within the Care Home into a new team. In the narrative staff discussed the important aspects of redeployment – the new team was welcoming and supportive of the redeployed staff, the importance of communication regarding substantive post and communication with line manager, opportunity to develop and recognition of the impact of changing work patterns on the staff member and their family.

"... The staff and manager at the residential home I was redeployed to were very welcoming and helpful, I was made to feel part of the team. I felt unsupported by my own line manager who I only spoke to when I initiated contact. It has been demoralizing to hear my colleagues are returning to the day centre, when I have no contact from my manager and received no information in respect to my return..."

"...After finishing 3 months in this setting I found it extremely stressful. I felt resented by the present staff and always felt like the outsider. I rarely felt any job satisfaction, mostly felt that I was not given the opportunity to provide the best quality care to the young people I was assigned to..."

"...due to redeployment I have changed from working a full week mon-fri, to working 3 nights night duty, which have been a huge impact both on working and family life..."

"...coming into a new environment and being out of my comfort zone. But the manager and staff have been brilliant and i have enjoyed seeing the way a residential home works and meeting all the lovely residents..."

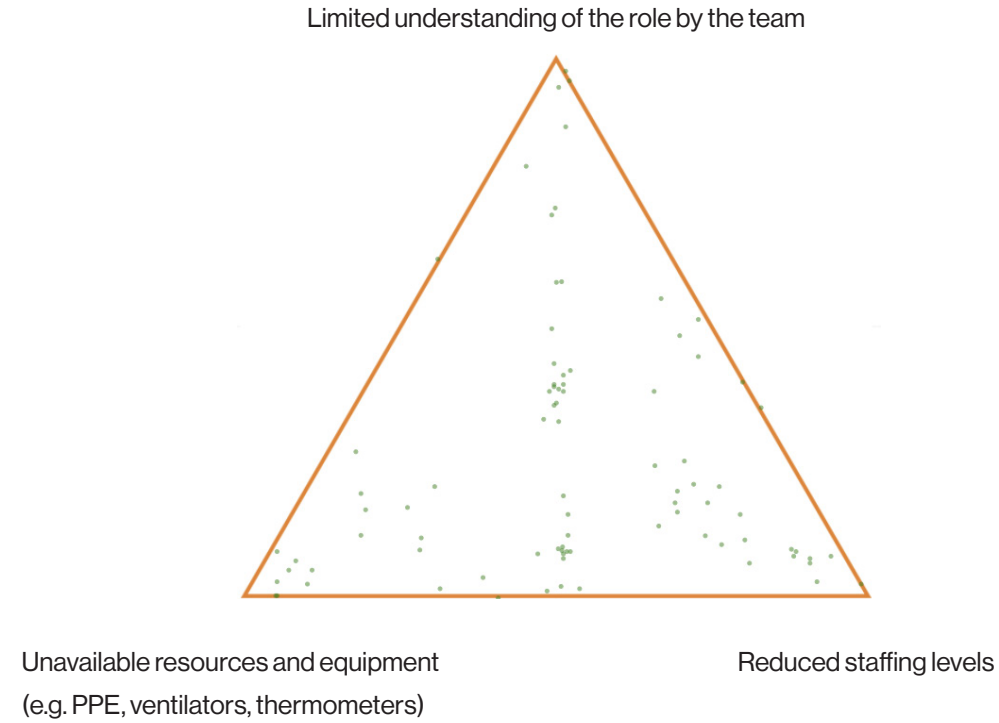
"...At the start, I struggled with the longer hours, and couldn't do any additional hours, because they didn't want to give them to us. Now they need us to cover their own staff it is okay..."

The key message in this triad was opportunities for training, application of new skill and working in new teams was part of staff experiences; however it is highlighted training needed to be accessible and relevant to the Care Home setting. There is also a recognition of the impact of redeployment into the Care Home setting and the importance of induction into the team, inclusion & support by the Care Home and ongoing communication with substantive line manager.

6.4 Being Challenged

Figure 33 illustrates barriers faced by staff during the first wave of the pandemic – the signifiers considered an understanding of the role, availability of resources and the impact of reduced staffing levels. The dominant signifier reflected upon the reduced staffing levels as a main barrier to staff fulfilling their role as indicated by 62% (n=53) of respondents.

Figure 33. Triad 3. (n=86) In response to COVID-19 the barriers to fulfilling my role in the work place were...



In the narrative Care Home managers reflected upon the difficulties faced to provide care in the context of reduced staffing levels due to sickness or isolation.

"...Staffing became more difficult with everyone working extra hours for first few weeks when some had self isolated..."

"...I returned in an expanded role taking on nursing duties while trying to organise the care staff and monitor critical patients. As more staff went off sick the trust sent me redeployed staff whom I was grateful for but most had never worked on a ward or care setting and this was a huge risk to patient safety with so many acute patients and a lot of patients with swallowing difficulties..."

"...On paper, there might be enough staff:resident ratio, but in reality, we are working with people who are only having contact with staff, are lonely and missing family, and as a result are more demanding of staff time. It is stressful when buzzers are going off, you are trying to attend to someone with dignity & respect, they are asking for you to do little things to delay you leaving their room, then you go to the next person requiring assistance, and they are upset because they have had to wait..."

"...Working 60 hour weeks, incredibly understaffed and unsupported.."

Staff reflected upon the importance of the team in times of staffing shortages and how teams pulled together. In the narrative it is evident Care Home staff undertook extra hours and made sacrifices to overcome the barrier of staffing shortages and ensure care could be delivered.

"...Living apart from my family. Worrying about my husband who is high risk and my daughter. People actually stopping to think of how good a job NHS and care home staff do..."

"...The positive reaction and dedication of staff to ensuring the health and safety of service users has to be one of the most satisfying and memorable moments despite having their own concerns, the impact on their lives, family etc.."

"...I had programmed myself in saying that my actions could kill one of my residents. I did not see my family for months except through a window. I was terrified to go out and get my essentials just in case I potentially got COVID-19 and infected one of my residents without realising..."

"...We had Day Care Staff redeployed to ourselves and after a very short period of time we became a solid team with everyone feeling valued and appreciated for the effort they made...."

The need to manage staff shortages also highlighted the challenge of engaging agency staff; in the narrative concerns were raised about agency staff as a source of spreading the virus and highlighted the need to cohort or block book agency staff.

"...agency staff should be tested more regularly, unless they have remained in one care home throughout, and wages should be paid to them for the equivalent number of shifts they lose. Block booking staff through agencies would reduce the number of new agency staff being brought in to work..."

"...Still have concerned about staff who work with us and then do agency shifts unable to control they maybe working with positive cases and carry to our home and then our vulnerable is exposed..."

There is also a strong pattern of responses for the signifier "Unavailable resources and equipment" as indicated in 53% (n=46). Staff highlighted in the narrative their concerns regarding the lack of PPE and delays in receiving the PPE in the first wave and also reflected upon the impact this had on the Care Home and the residents.

"...I had worry that the PPE our manager had ordered before the craziness started would not arrive and it didn't. Our orders were redirected and our PPE was limited. We managed..."

"...Having to purchase our own PPE at the beginning as our management kept saying COVID-19 was just media hype...."

"...We relied a lot on donations for first few months for hand sanitiser, antibacterial soap and homemade masks, which is ridiculous we would of had nothing if it wasn't for the support of our local community and churches..."

"...The community spirit was outstanding and the team work and commitment of my staff was and is outstanding. However the first week of lock down was frustrating being advised to travel 8 mile for PPE in the event of COVID patient. I felt we were of no great importance and treated differently from the trust..."

The key messaging in this triad was the importance of the teamwork in the Care Homes in facing the challenges of staff shortages and limitations in resources during the first wave. The challenge in this area is how to safely embed agency staff and redeployed staff into the workforce. Provision of PPE was a clear challenge in the early days of the first wave and the importance of a reliable and accessible supply going forward.

6.5 Policy & Practice

Figure 34 illustrates the challenge on how policy was translated and embedded into practice. The statement explored if the challenge was conflicting messages, rapid changes in guidelines or an apathy towards the guidelines. The dominant signifier "rapidly changing guidelines" is indicated in 75 % (n=78) of responses; however there is a strong pattern formation between this signifier and the signifier "conflicting messages from leaders" with the majority of responses evident in the left border of the triad.

In the narrative of these responses Care Home staff reflected upon the impact of the conflicting messages and changing guidelines upon the staff and upon the Care Home as a whole. Issues such as overload of information, lack of clarity in the guidelines and delays all resulted in a challenging and complex situation for the Care Home staff to work in.

"...At times there was a communication overload with a lot of information being forwarded and difficult to keep abreast of the current guidance...."

"...I was fearful and and anxious most of the time. It was very unnerving at the start as there was no clarity, support or direction from regulators and other authorities regarding locking down care homes and new admissions. Messages in guidelines were conflicting depending on which authority you were speaking to..."

"...My greatest reflection is how much we were in the dark. Every day rules and regulations were changing, the guidance differed depending on who was contacted and it was hard to know who to follow..."

"...What I can reflect on is the confusion and not knowing what to expect. Our work practices changing on a daily basis and getting different advice from many sources. Talking to colleagues who work in different homes and what they were doing was different from us..."

"...our team being very focused and determined. One other night at the begining of lockdown before my shift as senior in charge sitting at home trying to find latest guidance for care home and finding very little info was disheartening..."

Figure 34. Triad 4 (n=104) At this time the challenges to following COVID-19 related policies are...

The issue of information overload also impacted upon Care Homes in relation to informing central agencies such as RQIA or PHA with an increased demand on the Care Home staff to provide information. Monitoring processes caused an additional burden and challenge to inform how policy impacted upon practice.

"...I feel instead of the support we were supposed to be given we were given more work from extra emails to read or return, phone calls to take and paper work to fill out..."

"...Lots of initial single recording to different bodies which was unhelpful and added to the workload of trying to sort PPE and record use etc..."

"...Now the RQIA and PHA are becoming super efficient and demanding that policy be put in place regarding PPE, testing, cleaning and reporting numbers each day and it is placing great demand on organisations and making everyone's jobs really difficult. No one seems to be on the same page, their is no consistency..."

"... with every new guidelines comes a new monitoring demand... we are not being supported by government bodies... they do not listen to those who know what is best.. we are constantly being watched..."

The key message and challenge to embedding policy into practice is the need for consistent, timely clear messaging which consults with and embraces the voice of the Care Home teams. This requires a building of relationships between the Care Homes and central government bodies and a single point of communication to receive and share information.

6.6 Going Forward

Figure 35 explores what is required to facilitate Care Home staff to fulfil their role. The three signifers considered were the need for more resources, more information/training or more support from management. The responses in this triad are widely dispersed with some pattern formation reflecting the need for resourcing, training & information, as discussed in previous sections.

Figure 35. Triad 5 (n=86) To fulfil my role completely I require...

It is recognised in the narrative that issues regarding the provision of PPE, have mainly resolved as the journey through the first wave progressed. Identifying with key messages in the previous sections the challenge is to sustain the good work which has been embedded throughout the first wave of the pandemic. One of the key messages in the narrative was the importance of leadership in the Care Homes to provide information, guidance and direction to the staff as they deliver care to the residents.

"...We had a resident with COVID-19 at first it was a frightening experience. With changes of management and staff it really helped to overcome the fear. We were updated throughout every day which I really appreciated. We also have a WhatsApp group so we are constantly informed of any changes. The resident recovered and no other person in my work place got COVID-19 which I am really proud of; I believe this was due to fantastic management throughout and total teamwork..."

"...Very quickly due to good leadership and management within my work place we brought in safety measures rapidly and safely which allowed us to adapt. We pre-empted and implemented these measures quickly which I believe protected ourselves and our residents. Our community rallied around us donating much needed PPE and supplies and even treats and thoughtful gestures to the staff which really boosted morale and make us feel valued...."

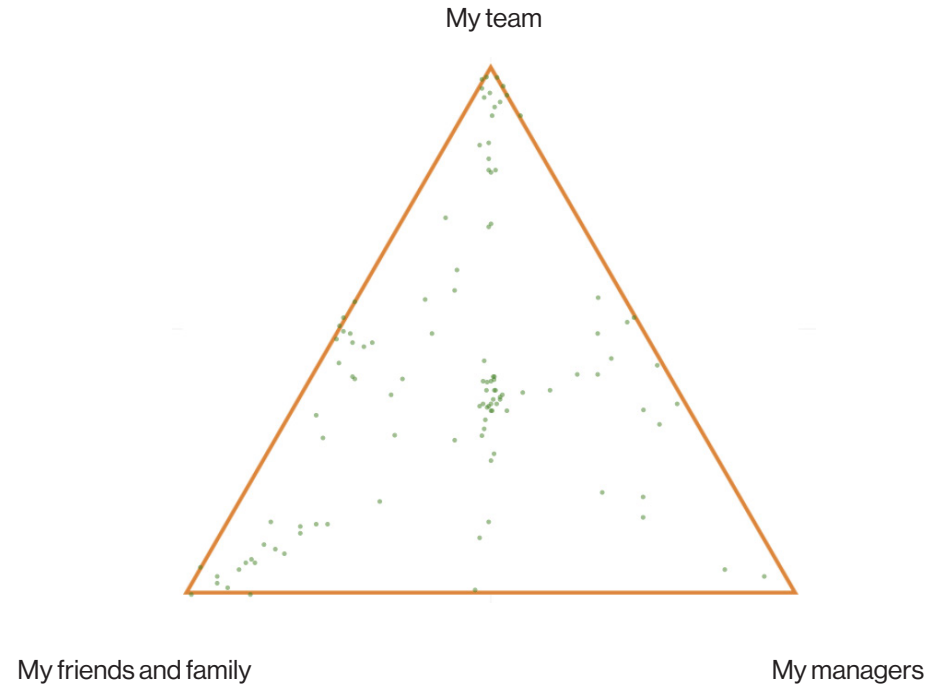
It is also important to recognise and value the vital role of Care Home staff in protecting the residents of Care Homes and to engage with the Care Home staff moving forward into further waves of the pandemic. A key message was the importance of the wider community in offering resources and encouragement for the staff at this time.

The following analysis (section 6.7 -6.11) considers the personal impact of Covid-19 pandemic on the staff working within Care Homes, including exploration of coping mechanisms and sources of support.

6.7 Support

Figure 36 illustrates where Care Home staff sought support when feeling anxious about their job role – the signifier explores if support was sought from the team, friends/family or management. There are two dominant responses – 63% (n=70) indicated friends and family as a source of support with 62% (n=69) highlighting the role of the team

Figure 36. Triad 6 (n=111) When I am concerned/anxious about my job role the people who support me are...



In the narrative the staff identify with the importance of the team in supporting them through the pandemic and in particular during difficult days such as the death of a resident. These reflections also relate to the team as being part of a family.

"...Looking back on my experience I think I learnt a lot that I will carry with me on my journey to become a nurse. The hardest part for me was watching a resident die from COVID-19. She was a quiet, able woman. She had mild dementia and was quite independent. Watching her go from walking with her rollator to bed ridden, in pain with no family around her was hard. It was hard having to accept that she was going to die... However I could not have gotten through this without the support of my staff and nurses. We were all in this together. We laughed together, cried together and mourned together. We were a family in this together. We were their family when they could not see theirs. We were there to hold their hands, sing with them and listen to their worries. My heart breaks for all those who lost their life. A life worth just as much as anyone..."

"...I felt my work colleagues became my closet friends as we were almost like a family as we worked through good and bad days together. My Manager was very supportive in both areas I worked. I am now coming into my retirement year and am quite sad how it has ended as this will be a year I will not forget..."

There is a lesser number of responses relating to support from management (42%/n=47). In the narrative staff reflect upon the role of management in supporting them during a personal diagnosis of COVID-19 or period of isolation; however in contrast a number of staff reflect upon the lack of support by management particularly when diagnosed with COVID-19 or lack of management support during redeployment.

"...I told management I had symptoms and was unwell but was told I was ok because I had no temperature, and was made to feel like I was being dramatic, I was in work the next day sweating and unwell struggling to work and was still not sent home, I got home that night I decided I had to phone in sick for the next day I was not taken seriously, I got tested and my test was positive for COVID-19..."

"... I never heard from my own manager after I was redeployed. I had no idea what was happening in my own job or when I could come back again..."

It is important to recognise that staff sought support from a range of sources however the challenge is to further explore the role of manager to support staff who are diagnosed with COVID-19 and the role of a line manager for staff who have been redeployed. A paper on the thematic analysis of the experience of redeployment can be accessed at https://10000morevoices.hscni.net (https://tinyurl.com/yy458zvy). The findings in this paper incorporates all staff who completed the survey "You and your experience of working during Covid-19 Pandemic" and includes reflections of staff redeployed into Care Homes* during the first wave (*other areas of redeployment include acute clinical areas such as ICU and COVID-19 wards).

6.8 Personal Response

Figure 37 explores how staff responded personally to the stressors experienced during the first wave of the pandemic. The three signifiers asked staff to reflect upon extreme responses such as drinking more alcohol, eating more or exercising more. The dominant signifier, indicated by 68% (n= 95) of respondents was eating more than usual. There is also a secondary pattern of 31% of responses indicating they drank alcohol more than usual.

Figure 37. Triad 7 (n=95) At this time I find I am...

Although in the narrative staff did not reflect upon the signifiers, the respondents did share the deep and personal impact of the pandemic.

"...Working during this Pandemic has been a privilege but also incredibly overwhelming and I have never experienced a time like this in my career before where both on and off duty it consumed my thoughts..."

"... I held several dying hands, I cried many tears and then I went home and cried some more. That's how distraught I was (and somehow still am)..."

This is important insight into the potential long term effects of the pandemic on the workforce in Care Homes. It demonstrates a potential need to support staff in regulating drinking and eating as the pandemic progresses and an awareness of the need for emotional support throughout the pandemic. This is further explored in section 6.9 which considers the source of support.

6.9 Source of support

Figure 38 illustrates where people sought help when trying to cope with the pressures of the COVID-19 pandemic. The signifiers included accessing help though Health & Wellbeing opportunities through the organisation (or Care Home), professional support or through engaging with personal coping techniques. Evident in the strong pattern formation 89% (n=76) of respondents indicated they engaged with personal coping techniques.

Figure 38. Triad 8 (n=85) To help me cope with the pressures of COVID-19 pandemic I have...

These findings reflect the need to support staff to develop such self-care mechanisms and inner resilience to engage with coping techniques. In relation to this it is important to highlight only one respondent highlighted they sought support from Health & Wellbeing opportunities through the organisation – this presents a challenge to the various agencies who work with Care Homes and employers of staff in Care Homes in the provision of Health and Wellbeing support during the pandemic. It may even reflect a gap in the provision of such opportunities during the first wave by the employers in Care Homes and the supporting agencies. This is an important area for further development to ensure staff in Care Homes can access support to develop inner resilience and coping strategies and opportunities to enhance health & wellbeing are available to the staff through their employer or supporting agencies.

In the narrative of the small number of respondents who sought professional help the staff reflect upon the intense anxiety they experienced, particularly at the start of the pandemic. Again these quotes reflect the need to strong compassionate leadership during the pandemic and gives insight into the long term impact the pandemic may have on some staff (in particular for staff who experienced a large numbers of residents passing away at the start of the pandemic). This includes reflection on the difficult scenarios Care Home managers had to face in the early days of the pandemic and the experience of isolation in trying to protect their residents.

"...I had just started in a new job as a care assistant in a nursing home when COVID-19 started being reported on the news... within weeks we had residents ill with COVID-19 symptoms but not tested unless postmortem... those tested were positive and once care home residents did get tested as routine there were lots of positive tests..."

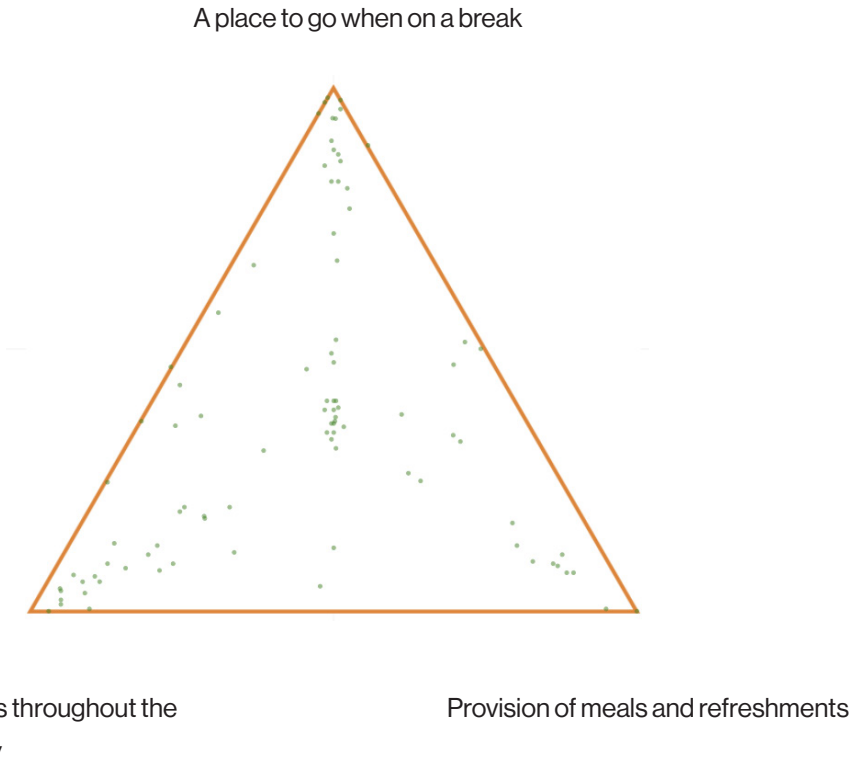
"...I will never forget the trauma preparing for this pandemic, I will never forget it as it has changed me forever. I am now an anxious, fearful and angry person, unrecognisable to my colleagues and family... The trauma of hearing the Department and ministers beg those with underlying health conditions and those of a certain age to shield safely at home...whilst making plans to introduce the most vulnerable in our society to the virus face to face. I will never forget the trauma of completing health and safety risk assessments to include having potentially no staff as they will not get a test if they required to self-isolate, having space to store my deceased residents in the case the funeral directors would not collect the bodies as in New York, France and Italy. I will never forget the trauma and anger of learning that the PPE I ordered in February had been re-directed to the NHS..."

This reinforces the importance of providing opportunities to support the Health and Wellbeing of staff from staff on the frontline to Care Home managers providing leadership for the Care Home.

6.10 Support during shifts

Figure 39 reflects upon simple factors which can offer support to the staff during a shift in the Care Home. The signifiers included a place to go when on a break, the need for more breaks and the provision of meals and refreshment during a shift. There is an even spread towards two signifiers – more breaks throughout a shift (51%/n=46) and a place to go when on break (49%/n=45).

Figure 39. Triad 9 (n=91) At this time, to reduce my anxiety during my shift I need...



It is evident in the narrative the provision of a safe area to take a break and the capacity to offer extra breaks has been a challenge in the Care Homes due to the competing challenge of staffing levels and the lack of physical room in the Care Home building.

"...Although we were a COVID-19 amber area we were not able to have a safe area to eat and in fact had no choice but to eat outside or in areas which had no cooking facilities; staff are still waiting on the arrival of a safe place to eat and some where to go and chill out during working hours..."

"...As Home Manager in a Care Home, the responsibility carried was immense. Advising and guiding staff and maintaining a COVID free Home throughout it all has been incredibly stressful and exhausting. Not getting a break or time to rest, reflect and recoup. I feel mentally and physically exhausted...."

"...I will never forget looking at my roster and thinking 'who is going to care for all these people' as my staff numbers declined... if it had not been for the help of the Trust I do not know what would have happened to my residents..."

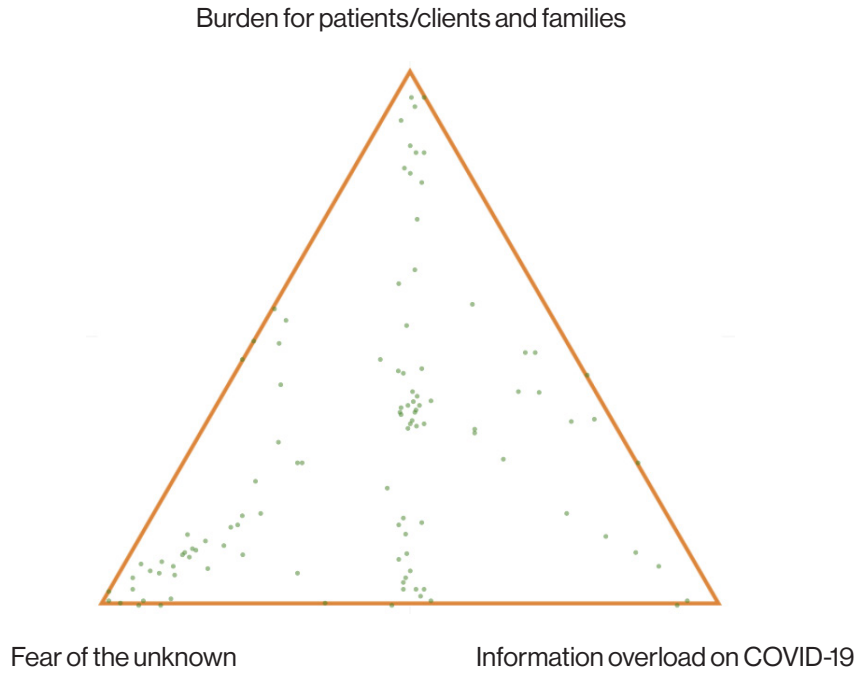
"...Staff level were badly hit at the start of the pandemic with 49% of all the either self-isolating or bank members of staff refusing to come into the Home during March and April 2020. Care Assistants refusing to come in through fear and resigning. Staff refusing to come into the Home were acting through the fear and uncertainty of what was to come..."

Reinforcing the importance of supporting the Health and Wellbeing of staff in Care Homes two important factors are the need for a break area where staff can take timeout and also the importance of more breaks. These are important factors highlighted in the project "You and your experience of wearing PPE" undertaken by the 10,000 More Voices initiative, highlighting the need for breaks to hydrate and a place to safely remove PPE. (Report can be accessed through www.10000morevoices.hscni.net)

6.11 Burden

The final statement on the personal impact of the pandemic explored what factors contributed to the staff anxieties or concerns. Illustrated in Figure 40 the signifiers included a burden for clients (or residents) and their families, fear of the unknown and information overload.

Figure 40. Triad 10 (n=109) When I have felt anxious about COVID-19 the factors which contribute are...



The majority of respondents (67%/n=73) indicated the main source of anxiety was the unknown. This is particularly true in the narrative where staff reflected upon the early days of the pandemic – with a sense of being forgotten as the system responded to the first wave.

"....There was a lacking in communication and we felt we were on our own. We were forgotten about..."

"...The pandemic was an exceptionally trying time for everyone in the Home. Partly it was fear of the unknown, what to expect and to what extent would the Home be affected by COVID-19. How many residents & staff would be affected? Implementation of contingencies?..."

"...We lost a number of Staff who resigned and just walked again through fear of the unknown..."

Fear of the unknown was also compounded by the lack of or contradicting information in the early days of the pandemic.

"...What didn't go well was the amount of contradictory communications coming from different many departments which lead in many cases to uncertainty and a level of individual interpretation of guidance; this was also not helped by lack of guidance from regulatory bodies. It was latterly in June that support was offered from local Health Trust but I am sure this was the same for many managers in the independent sector..."

"...The lack of guidance at the beginning was shocking. No one really knew what to do and what procedures were correct. The government provided guidance about PPE but it wasn't available. It was a scary time..."

"...Thankfully we planned, prepared for worst case scenario, fortunately this was not needed. The fear of what was coming was far worse than actually dealing with the work..."

"...As a manager it was a terrible emotional and heart breaking experience, I was making decisions for my whole home and lacking support and guidance. My major issues were the lack of PPE and ensuring my residents and staff were properly protected. It wasn't until the beginning of May when I had full PPE for a week. At the start, and somewhat still, being bombarded with emails and unclear advice, staff wanting me to answer all questions when I was very much scared too..."

This highlights the importance of clear, concise and consistent messaging from governing bodies to the Care Homes. As the pandemic progresses there is an important balance to be achieved in the provision of the information in a timely manner to reduce anxieties in relation to the "unknown".

Another source of anxiety and concern was a burden for the residents and their families, as indicated in 45% (n=49) of responses. Staff at all levels shared their intense concerns for the resident's wellbeing in the absence of family visits and also the difficult decisions they had to make in relation to care (for example transfers to the hospital or end of life care) during the first wave.

"...The most memorable moment was escorting a client into an Ambulance. She asked us if she was going to be okay. This client never returned to the Nursing Home she died a week later in Hospital. That had the greatest impact on me..."

"...It is difficult for residents in the care home who do not see their relative. Some residents feel abandoned. One in particular stands out. Her daughter would facetime her on the mobile, but when she saw her daughter, the memories seemed to flood back and she would begin to sob - is that my .... (Daughters Name), because she seemed upset by seeing her daughter, her daughter felt it best not to facetime and upset her. She died during the pandemic, I and some of my colleagues, felt she died of a broken heart, thinking her family had forgotten about her. She was reminded of 'The Virus' but couldn't remember the reason she wasn't seeing her family..."

The narrative of the responses highlights the deep and lasting impact the first wave of pandemic had on the Care Home staff. In the early days of the pandemic many carried the burden of protecting and caring for residents in the absence of clear guidance and support. It is therefore crucial to acknowledge and learn from the key messages to support and maintain the health and wellbeing of staff, families and residents as the pandemic progresses in Northern Ireland.

7.0 SUMMARY OF KEY MESSAGES

The following section summarises the key messages highlighted in sections 4-6 under 5 key themes. It is important to highlight this information influenced and informed the actions detailed in "the Rapid Learning Initiative into the Transmission of COVID-19 in Care Homes" and is echoed in this summary. The full RLI report and interactive version of RLI can be accessed at www.health-ni.gov.uk/publications/rli-final-report (DOH, 2020).

7.1 Technology

- Residents and relatives identified the importance of staying connected throughout the pandemic. For many residents this has meant embracing and learning new technology. The timely provision of technology for residents to remain connected is crucial for the health and wellbeing of residents and relatives. This includes the availability of WiFi and resources such as access to iPads and relevant software to facilitate virtual visiting.

- For many relatives it was clear virtual visiting was difficult and did not meet the needs for all residents and relatives. On such occasions the technology can become a barrier and alternative methods to connect are essential – for example for a resident with dementia may struggle with the concept of a virtual visit and would desire contact with their relative or for someone who communicates through Sign Language, it is important they can communicate effectively using their own language.

- Staff are conscious of the need to keep residents and relatives connected however this also requires additional time and support at time of great pressure. For virtual visiting to be effective staff need dedicated time with the resident and relatives for this purpose and also to have an understanding of how to safely use the technology.

- Residents living a Care Home remain part of a wider community. The use of technology is recognised to support residents to remain connected with their communities for example local church groups, prayer meetings, reading groups etc.

7.2 Communication, Information & Guidance

- Staff within Care Home, in particular Care Home managers, need information in a timely manner to support them in communicating with families and to plan for changes in guidance. Communication and flow of information at all levels needs to be consistent, efficient and robust - from strategic bodies to the Care Homes and to residents and relatives it impacts. Care Home managers need one point of access for information to flow through to the Care Homes to support changes in policy and guidance.

- Relatives of residents need to be able to speak to those providing and care and to be involved in and assured of the delivery of care. It is important Care Homes have a communication process to support meaningful engagement between the Care Home and the relatives of residents. This is crucial for relatives at a time when they are unable to visit freely.

- During the pandemic there have been increasing demands on Care Homes to provide information to multiple agencies. It is important to Care Home managers there is a single point whereby they feedback data to give a strategic overview of the Care Home sector. This process needs to be simple

and slick, acknowledging the competing demands on the Care Home managers. Such an approach will help balance the volume of information shared electronically against the daily challenges of leading in a Care Home during the pandemic.

- Residents, relatives and staff have great insight into what would support the residents and the wider Care Home community during the pandemic. In the development of guidance and resources it is crucial staff and leaders of Care Homes, residents and relatives are empowered to influence and shape the work at all levels and ultimately ensure it can be effectively embedded into practice.

7.3 Health & Wellbeing

- Relatives of residents play a vital role in supporting the health & wellbeing of the residents. As key partners, relatives should be part of the decision making processes to support and advocate for their relatives. To effectively support relatives and residents there needs to be a relationship between the Care Home and relatives which is built on trust, openness and transparency.

- Residents recognised and valued the efforts to staff to entertain them and provide both physical and mental stimulation during the pandemic. Creative engagement by all staff, from kitchen support to dedicated activity nurses is highlighted in the positive experiences of residents and reassuring to relatives. This also includes creative methods to stay engaged (outside of technology) for example letters, postcards, celebrations.

- Residents and relatives both highlight the need for continued care through ongoing provision of services into the Care Homes –this includes input from primary care and allied health professionals for residents with acute illness, management of long term conditions and rehabilitation. Residents and relatives recognised on occasions this may need to be facilitated through video conferencing and telephone consultation; however regardless of how the service is delivered residents and relatives highlight the importance of services being available and also continuing to support their health and wellbeing.

- Staff have openly expressed the difficult impact of the pandemic on their own mental health and well being. With few staff accessing help there is a need to develop health and wellbeing strategies to support staff in light of the ongoing and long term nature of the pandemic. Staff need support in selfcare, resilience and other personal coping mechanisms. Also staff highlighted simple practical measures to support them to include additional time to rehydrate during a shift and areas where staff can remove PPE for a short time to rest.

7.4 Safe and Effective Care

- Staff highlighted the importance of compassionate leadership and teamwork as key elements during the peak of the first wave. These are also identified by staff to respond safely and effectively to the pandemic – particularly faced with challenges such as staff shortages or lack of practical resources; Where the Care Home manager or management team demonstrated strong and visible leadership the staff have felt supported during difficult days.

- The pandemic highlighted the need and opportunity for staff to train in additional areas relating to working within the Care Home. The provision of training has been a positive response to the management fo COVID-19 and supported staff to develop. It is important such opportunities continue and even extend to support staff to embed new skills and knowledge into their daily work.

7.5 Working in Partnership

- In the initial stages of the pandemic both staff, residents and relatives felt forgotten in decisions regarding resources and guidelines. Reflective throughout all the key messages is the importance of the developing relationship between the strategic government bodies (PHA, DOH, RQIA) with the Care Home sector, relatives and the residents themselves.

- Underpinning many of the key messages from relatives is the importance of a relationship based approach to support them to be identified as partners in the care of the resident. Relatives and residents should be central to decisions regarding care and therefore need an open channel of communication and a process to ensure everyone is informed of the needs and care delivered to the resident.

Overall this project has demonstrated the value and importance of learning from the experience of residents and relative; however to support ongoing engagement there will need to be a continued shift in the culture and more opportunities available to ensure the voices of residents and relatives can be echoed loudly in work to support Care Homes, even beyond the pandemic.

8.0 NEXT STEPS

The next steps required is to ensure the key messages outlined continue to be heard and actions taken to enhance and improve the experience of residents, relatives and staff in Care Homes. There is no doubt the journey so far has been a difficult one and it is not over yet. This report reflects the distance travelled and many of the challenges ahead to manage the risks of the pandemic and keep residents, relatives & staff of Care Homes safe.

Many of the key messages included in this report have been woven into the recommendations of the RLI into Transmission of COVID-19 into Care Homes (DOH, 2020). This work is led by the DOH and supports multi agency response informing the actions for future waves of the pandemic. It is recognised the importance of maintaining an ongoing channel of feedback to continue to learn from the experiences of residents and relatives of Care Homes. The work will be taken forward through the Regional Surge Plan for the NI Care Home Sector Operational Group, which is representative of DOH, PHA, HSCB and RQIA.

Copies of this report can be downloaded at http://0000morevoices.hscni.net. It is the ambition of the 10,000 More Voices team that this project supports ongoing conversation and challenge about how we can continue to make positive changes to support the health & wellbeing of the residents during the pandemic. If you have any queries or wish to discuss this work you can contact the team by email at 10000morevoices@hscni.net.

8.0 APPENDICIES

APPENDIX 1.

MEMBERS OF RAPID LEARNING INITIATIVE IN TRANSMISSION OF COVID-19 IN CARE HOMES: SUB-GROUP 1

Chair: Linda Craig, PHA

Aine Morrison, DOH

Briege Donaghy, NHSCT

Dannielle Mallen, DOH

Elaine Connolly: RQIA

Fionnuala Gallagher, SEHSCT

Gwyneth Woods, NHSCT

Johny Turnbull, PCC

Roisin Doyle, HSCB

Ruth Burrows, Four Seasons

Ruth Johnston, RCN Independent Sector Nurse Manager Network

Sharon Balmer, DOH

Suzanne Pullins, NHSCT

APPENDIX 2.

Promotion Infographic

10,000 TEN THOUSAND MORE VOICES

CARE HOMES AND COVID-19 PANDEMIC
We Want to Hear From You...

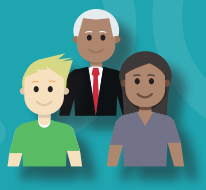
As someone connected to a Care Home in Northern Ireland we want to hear about your experience so we can identify good practice and understand what actions are required to improve your experience. The purpose of this project is to explore the experience of residents living in Care Homes and relatives & staff engaging with Care Homes.

How Do I Tell My Story?

I am a resident

As a resident of a Care Home you can tell your story using a printed copy. Every Care Home will receive surveys with stamped addressed envelopes which can be completed by you. You can be supported by a relative, your activity coordinator or any healthcare professional to complete the survey. The 10,000 More Voices team is also available during office hours and can complete the survey with you through a telephone call or video conference.

I am a relative



As a relative of someone living a in a Care Home you can tell your story through www.10000morevoices.hscni.net. On the website click on the link "Care Homes & COVID-19 Pandemic – The Relatives Perspective". You can also request an easy read printed copy and stamped addressed envelope by contacting the 10,000 More Voices Office.

I work in a Care Home

As someone working within the Care Home sector (as an employee or through an in-reach service for example District Nursing, Speech & Language Therapy, Podiatry etc..)you can tell your story through the online link found at www.10000morevoices.hscni.net. Click on the link "You and your experience of working during COVID-19 Pandemic".

You can contact us on 028 9536 2868 (Monday-Friday 9am-5pm). We would be happy to hear from you – sharing your story will help to shape the response for Care Homes during the COVID-19 Pandemic. Surveys should be submitted before 13th July 2020.

WE ALL MUST DO IT TO GET THROUGH IT

This project is part of the Rapid Learning in Care Homes initiative managed through the Department of Health. More detail is available at www.health-ni.gov.uk/rapid-learning-initiative

06/20

10,000 More Voices Initiative is managed by-
Regional Lead for Patient Client Experience (PCE): Mrs Linda Craig: linda.craig3@hscni.net
Assistant Director for AHP, PPI and PCE: Mrs Michelle Tennyson: michelle.tennyson@hscni.net

http://10000morevoices.hscni.net