COVID-19 Inquiry Listening Project: 'Let's Be Heard'

Insight into COVID-19's disproportionate impact on individuals with dementia and unpaid carers: A Comprehensive Report

December 2023

Introduction

About Dementia is Age Scotland's Forum for Policy and Practice for individuals living with dementia and unpaid carers, funded by the Life Changes Trust. We aim to bring together those affected by dementia with public sector and community based professionals to influence policy and practice changes in Scotland. Our focus is on creating an environment where people with lived experience lead discussions and set the agenda for change.

In recent years, our core activity has centred on two lived experience Human Rights groups. These groups provide a safe space for people living with dementia and unpaid carers to share their views and influence policy. During the Scottish COVID inquiry, we collaborated with these groups, using one-on-one interviews and immersive workshops to identify central recurring themes.

To uphold the significance of these real life experiences within our report, we have dedicated separate sections to explore the impacts and experiences of individuals living with dementia, unpaid carers, and community based professionals. Each section highlights impacts and experiences followed by illustrative case studies drawn from our extensive engagement. It is important to note that these case studies are amalgamations of real experiences collected over our engagement period, enhancing their impact while maintaining the authenticity of each account.

While we express immense gratitude to those with lived experience who contributed to our engagement, we must acknowledge that some sessions experienced low attendance. This can be attributed to several factors. We recognised that discussions on this subject were 'triggering' and emotional for many participants. Instances of upset occurred during both working group meetings and individual interviews, underscoring the raw emotional nature of the subject for those with lived experience of dementia. Some participants expressed the need for space and time to process emotions, highlighting the ongoing emotional toll of the COVID-19 pandemic. As a result, we believe some people did not yet feel ready to share the impact that COVID-19 had on them or their loved ones.

Additionally, we recognise that low attendance may be influenced by fading memories, particularly for those living with dementia. The challenges of recalling specific experiences or reflecting on the impact retrospectively are evident. About Dementia's recent in person engagement tour for the new National Dementia Strategy revealed that discussions about the COVID-19 pandemic were infrequent, and those who did discuss it struggled to provide specific details.

Consequently, we decided not to conduct in person engagement for the Scottish COVID-19 Inquiry solely with people living with dementia but turned to our regular activists with early onset dementia and unpaid carers, who had already expressed some interest in the inquiry. It's essential to acknowledge a gap in obtaining direct experiences from individuals at more advanced stages of dementia, a gap that may be similarly felt throughout the broader Scottish COVID-19 Inquiry.

Another consideration is the challenge of reaching individuals who interacted with services during the height of the COVID-19 pandemic. Many of these individuals have either moved on or sadly passed away, leading to a change in the composition of current clientele within these services. Anecdotal evidence from a Day Centre within our network indicates a significant turnover of people living with dementia, with no clients from their March 2020 occupancy records remaining by March 2023.

Despite these challenges, we extend our gratitude to those who generously shared their time to discuss their experiences during the COVID-19 pandemic. While the engagement was more intimate than a typical working group meeting, this format allowed for in depth interviews, resulting in a comprehensive and insightful discussion. The following report details the interview stimuli and methodology used, along with key themes that emerged from these conversations.

We hope that the voices of lived experience captured in this analysis give an indicative account of the true impact of COVID-19 on individuals living with dementia and unpaid carers in Scotland. We would like to see recognition for the third sector staff and volunteers who went above and beyond during a time of crisis to ensure members of their community were not abandoned, and that the sacrifice and loss felt by this community are fully understood and recognised.

Living with Dementia

Care Partner

Community Based Supports
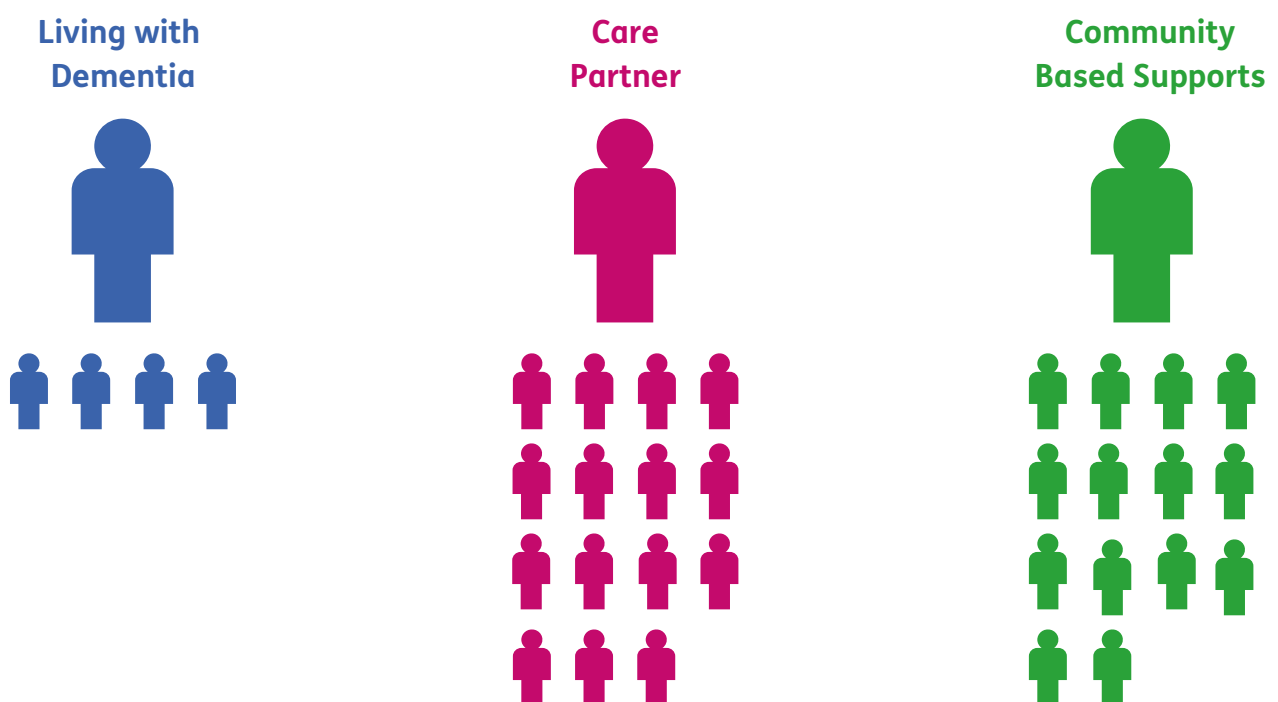
Key Findings

- The ongoing discussions around COVID-19 remain emotionally charged. The trauma felt is significant and not yet fully recognised.

- Limited access to and confidence in technology served as a significant barrier to accessing services. Those who did access technology, however, found it to be a great avenue of support.

- Individuals accessing peer support online and in person viewed it as a crucial and powerful tool to improve mental health.

- Carers and people living with dementia highlighted impacts such as isolation, loneliness and progression of dementia.

- Carers continue to carry a significant amount of guilt regarding what they could have done better during this period.

- Carers feel burdened by the unfair and unrealistic caring responsibilities that were placed on them overnight, with no support.

- Third-sector and community based professionals had to go above and beyond to serve and support community members when local authority services closed.

- People living with dementia, carers and community professionals feel frustration about the loss of direct support and the delays in reinstating it.

- People living with dementia received no direct guidance on shielding, leaving individuals and carers to self impose restrictions.

- Carers and community based professionals had to strike a balance between supporting people living with dementia and safeguarding or protecting their health and families.

- Community based professionals experienced a significant mental health impact, with many facing burnout.

- Community based professionals and carers noted distress in watching people living with dementia rapidly decline due to isolation and under stimulation.

The key findings in our engagement directly support findings within About Dementias September 2020 'Locked Down but not Forgotten' report.
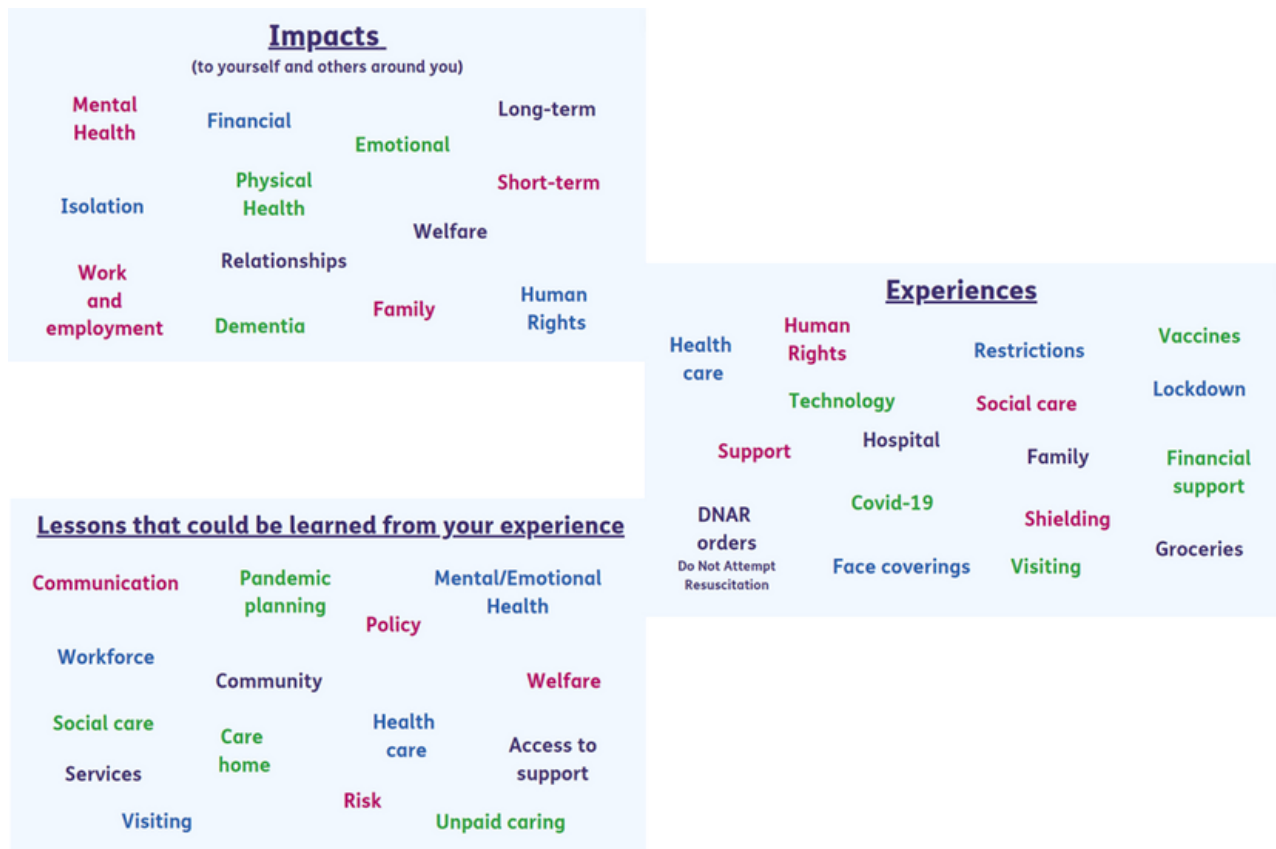
Methodology

Considering the broad range of experiences that people had during COVID-19, we felt it important to hear as many different views as possible from a variety of people and places. There were significantly differing experiences of access to services and support depending on the rural or urban nature of where people lived, and as we moved into regional lockdowns, there were further divides in experience depending on local authority areas.

To capture the impact and experience that COVID-19 had on people living with dementia, unpaid carers and community based professionals, About Dementia carried out several online one-to-one and in person sessions. Overall, we spoke with four people living with dementia, fifteen unpaid carers and fourteen community based supports. In March 2023, About Dementia held 3 online sessions, one for people living with dementia to directly share their views, one for carers to share their views and a wider meeting for anyone with a vested interest in sharing their views. The engagement was also held with carers at Townbreak Stirling. Conscious of capturing the experience of community based professionals and volunteers, About Dementia's largest engagement event was the COVID-19 Stakeholder Summit in April 2023. All contributors were exposed to the same stimuli, to identify cooccurring themes and allow for better read across during data analysis.

With consideration to fading memory, and the realisation that this was a delicate and emotionally charged topic for many, we provided a brief timeline of potentially relevant key dates during the period from January 2020 to December 2022 (the timeline proposed as the scope of the Scottish COVID-19 Inquiry).
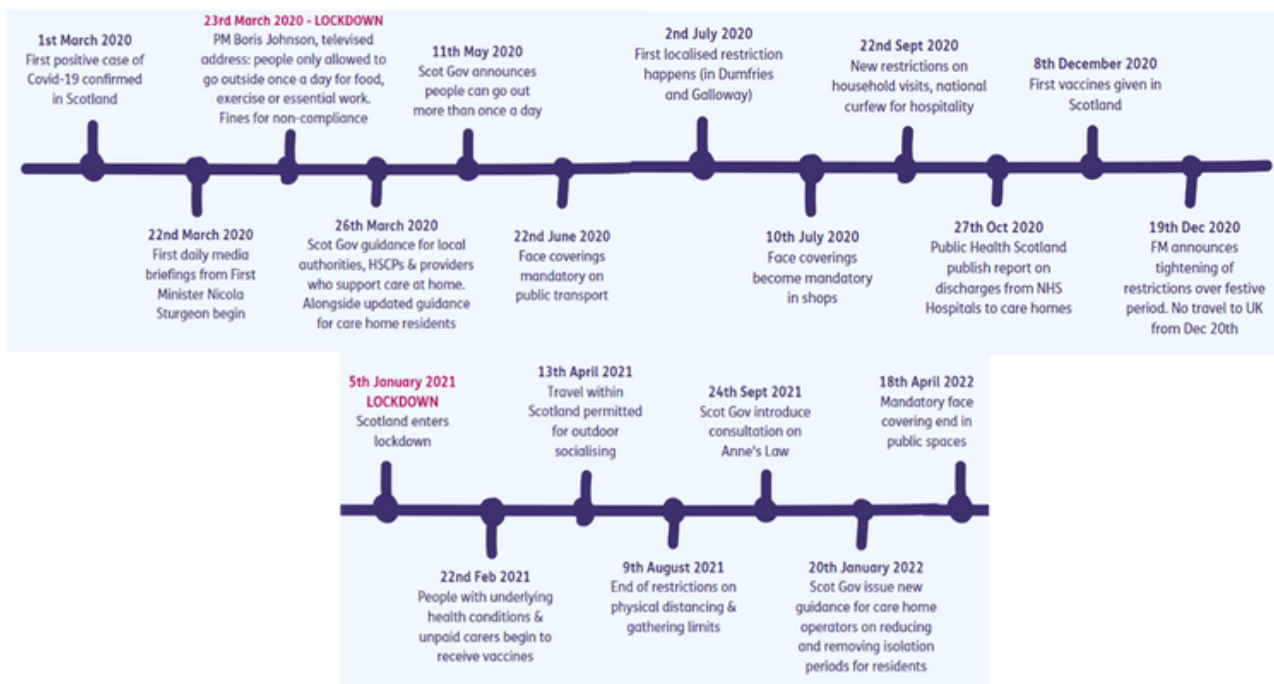
Following on from this scene setting, and to gain qualitative data that would be useful to the inquiry, About Dementia created prompt words for contributors to discuss the impacts and experiences that stood out most to them. Whilst we appreciated the broad scope that the questions allowed, we thought it would be helpful to present keywords to the interview participant to aid recollection. The interview participant also received the presentation and stimuli in advance, to aid preparation. The keywords presented were by no means exhaustive and participants were encouraged to talk about anything they felt was important for the inquiry to hear.

Impacts
(to yourself and others around you)

Mental Health Financial Long-term Emotional Physical Health Short-term Isolation Welfare Work and employment Relationships Dementia Family Human Rights

Experiences

Health care Human Rights Restrictions Vaccines Technology Social care Lockdown Support Hospital Family Financial support DNAR orders Covid-19 Shielding Do Not Attempt Resuscitation Face coverings Visiting Groceries

Lessons that could be learned from your experience

Communication Pandemic planning Mental/Emotional Health Policy Workforce Community Welfare Social care Care home Health care Access to support Services Risk Visiting Unpaid caring

The feedback on this methodology confirmed that it was a helpful approach to ensure and enable rich discussions around the topic of COVID-19.

"Thank you for including us."

"As a person living with dementia, it makes me feel worthwhile & able to meaningfully contribute."

"I liked the way the facilitators led the conference, the stories we heard from people with lived experience & those in the room and how interactive the day was. Fantastic, inspiring & insightful day."

People Living with Dementia

The decisions made by the Scottish government from March 2020 to April 2022 had a disproportionately severe impact on individuals living with dementia. Our engagement revealed that this disproportionate impact resulted, in part, from a lack of clear guidance on which rules applied to people living with dementia and whether they should 'shield'. Mixed guidance around shielding and self isolation forced individuals to weigh the risks of in person interaction against the mental health impact of remaining at home. Additionally, the loss of official support, extending beyond the pandemic's end, further exacerbated the challenges of a dementia diagnosis. While technology bridged the gap between social contact and isolation, online interaction was less effective and sometimes unfeasible for people living with dementia compared to in person socialising.

The COVID-19 death rates in Scotland indicated that people living with dementia were among the highest affected, with people living with dementia accounting for 28% of COVID-19 mortalities in 2020. The prevalence of dementia in care homes, where COVID-19 hit hardest, contributed significantly to the higher death rates, with approximately 62% of Scotland's care home community living with dementia.

The substantial impact that we would like to highlight within the inquiry lies with the frustrations of those living with dementia and unpaid carers regarding the failure to recognise dementia as an 'at risk' category on the shielding register. Unlike those with other life limiting diseases, individuals with dementia, who often experience additional health challenges due to their diagnosis, did not receive specific guidance on shielding and exemptions. In our 2020 survey on the impacts of COVID-19, 21% of respondents (18 individuals) considered themselves in an 'at risk' category due to both age and dementia diagnosis. Only 4 of these individuals received official advice to 'shield', revealing a substantial oversight by the Scottish Government.

This exclusion meant many were left without support, a stark contrast to other identified at risk groups. Had people living with dementia been included in the official

> "Mental health was the key issue for me, and that's back to peer support. My Alzheimer's isn't stereotypical, it's taken me time to understand it. It took a lot of me finding out stuff online because I didn't have anybody to talk to about that. I was diagnosed at the start of the pandemic so no support centres were open.
>
> There was a group I discovered who were technically breaking the law, or sailing very close to it. Meeting in-person because they thought that the social isolation was causing more harm to people in early-stage dementia than it was solving.
>
> If I hadn't of met them... I mean I'm so blessed I did. I don't where life would have panned out. It was very, very, very important to me".

shielding register, they and their carers would have been entitled to vital support, including food parcels and priority access to online grocery shopping.

A lack of direct support from the government was highlighted as a key impact of COVID-19 on people living with dementia. Especially for those who were living alone. A lack of guidance and a loss of support meant that people living with dementia began to either impose their own restrictions or consider breaking them to access vital support. Risk versus restriction was considered by every individual we spoke to during our engagement period.

From the perspective of those living with dementia, we heard of the mental health impacts that came with isolation and staying home. For those with access to technology, becoming adaptable to Zoom and Teams calls provided a much needed relief and a source of support.

"We have a peer support group in Fife, which had stopped completely. All our support from NHS stopped completely. Our support from everywhere actually stopped completely. And for a while, we were all left sitting in the house. Looking at four walls.

We then took on the technology, which was great, and that meant that some of us could meet online on a weekly basis to chat. But not all of our group could do that. Some didn't want to and some just didn't have the capability to get online. The impact on those people when all the restrictions were lifted was really noticed.

We could see that the dementia of people who hadn't been in contact advanced quite considerably compared to those in the group who had regular contact, and maybe had snuck out for a visit in somebody's garden or going to the park."

There is no doubt that many services adapted quickly to use technology as an arm of support. In addition to video calling, there was a vast increase in the number of telephone services available. Of those we spoke to living with dementia, streamlined technology was seen as a positive outcome of COVID-19. However, for others living with dementia, technology was the next step further into isolation.

According to a 2021 Age UK survey, approximately 2.7 million individuals aged 65 and above in the UK had refrained from using the internet in the past three months. The majority of this group states that they have never utilised the internet. Notably, digital exclusion is more pronounced among the elderly, with around 34% of those aged 75 and above and 10% of those aged 65-74 reporting non-use of the internet. In contrast, nearly all individuals under the age of 55 are internet users. Even among those who use the internet, their activities may be limited to specific tasks such as emailing or searching for information.

The quick move to an online world means mass exclusion of support for older people across Scotland. Given that a dementia diagnosis is more likely as we age, and that a significant proportion of those living with dementia are aged over 70 we can speculate that isolation from digital exclusion was yet another unfortunate and disproportionate impact of COVID-19 on people living with dementia.

Person Living with Dementia, Spring 2020:

"I sit here at home
Alone in my chair
No one to talk to
No one to care
It has to get better
It just has to be
Or I'll lose the person
I used to be"

Anecdotally we heard from a Dementia Day Centre Support Worker that people living with dementia who had their day services stopped were experiencing suicidal tendencies. The Support Worker raised concerns to social care about the suicidal comments from the Day Centre member, remarking that the person in question was especially isolated as their hearing became too impaired to manage befriending phone calls. The person living with dementia used poetry as an outlet for their frustration and isolation. It is a powerful reminder that people living with dementia, often left behind by serves prior to the COVID-19 pandemic, were thrown deeper into isolation. Especially those with additional impairments.

The repercussions of the pandemic have been multifaceted, affecting individuals both in terms of physical and mental well-being. Our engagement underscores the profound and lasting impact of the Scottish government's decisions on individuals living with dementia. From the high mortality rates to the exclusion from support systems, the repercussions of these decisions were felt acutely by a vulnerable population already grappling with the challenges of dementia. People living with dementia have emphasised the need for clearer guidance, recognition of dementia as an 'at risk' category, and tailored support to address the unique challenges faced by those living with dementia in times of crisis.

A poignant observation from service users has been the concept of 'a space on the table.' Even as individuals who have survived the pandemic return to their usual services or social circles, there is a palpable awareness that some friends are no longer present. This realisation has been emotionally challenging for both the individuals and the services involved, highlighting the lasting impact of the pandemic on social dynamics and community connections. The metaphorical "space on the table" serves as a stark reminder of the losses endured and the enduring pain experienced by those who have come through the pandemic.

Case Studies

Alan is 64 years old. He lives in a well-connected and established town. Alan would describe himself as a creative and confident person, who thrives on human interaction.

In 2020, during the COVID-19 Pandemic and lockdown, Alan was diagnosed with dementia. At a time when most services were closed, or seriously restricted, Alan struggled to find professional services to support him with his new diagnosis. The challenges of COVID-19 made it difficult to access to specialised support for dementia, as many relevant organisations only resumed full operations months or even years later, and some never reopened.

To combat growing loneliness and isolation, as well as a drive to understand his diagnosis more, Alan found himself drawn to a peer support group that operated on the fringe of COVID guidelines. The group initially attempted to adapt to the circumstances of the pandemic by transitioning their activities to online platforms. However, not all members possessed the necessary technological skills to participate in virtual meetings. As a result, those who were unable to navigate online spaces found themselves increasingly isolated and frustrated.

The group believed that the strict restrictions on social interaction were causing more harm than good, especially to individuals in the early stages of dementia. They began small and secret in-person meetings in public spaces after months of lockdown and isolation. Faced with the predicament of social isolation negatively impacting his own well-being, Alan chose to attend these gatherings despite the legal risks. He saw the potential benefits of these interactions in terms of providing him access to support, and potentially boosting his mental and emotional well-being. Alan believed that the risk was justified by the reward of peer support.

While Alan was coming to terms with his diagnosis, he still faced many challenges and setbacks. Despite being technology literate, the sudden move to digital contact by GP surgeries and doctors was frustrating to Alan.

When reflecting on the events of the pandemic, Alan is both sceptical of some of the rules and restrictions put in place but also understands that this was something nobody had ever faced before. It was an event that Alan had never lived through before, and nor had anyone else. Alan hopes that we learn from our experiences of COVID-19 and adapt the practice to make sure that marginalised groups such as himself are not so disproportionately disadvantaged and forgotten.

Irene's sentiments about the pandemic were complex, swaying between acknowledging its hardships and appreciating the newfound technological ways of working it brought about. Irene viewed increased online meetings as a pandemic positive. Her participation in virtual projects reignited her creativity and continued to influence her engagement.

For Irene, technology bridged geographical gaps, keeping her connected to family abroad through video calls. She recognised, however, that not everyone had this privilege. Irene acknowledged the digital divide, emphasising the necessity of accessible technology. She observed resistance to tech adoption, especially among unpaid carers and those with dementia.

Irene saw technology as a positive ally in dementia care, uniting individuals and mitigating pre-existing barriers, fostering a sense of community. Irene noticed a power shift as individuals with dementia organised independent online meetings, highlighting technology's role in fostering innovation and self empowerment.

Irene's journey underscores technology's dual role during the pandemic, illuminating its potential for connectivity, empowerment, and innovation, while also underscoring the imperative of inclusivity and digital accessibility.

Margaret is 82 and lives in Inverness. She was diagnosed with dementia in 2018. The onset of the COVID-19 pandemic introduced new challenges to her routine.

Before the pandemic, Margaret lived at home on her own and participated in community activities that provided a sense of support, and purpose. However, lockdowns and social distancing measures disrupted her routine, leading to increased isolation. Margaret used her iPad to virtually connect with family and healthcare providers, it became an essential lifeline but couldn't fully compensate for the loss of in person interactions.

A year into the pandemic, concerns about infection risk prompted Margaret's family to consider a care home. The transition brought its own set of challenges. Restricted visitation and adapting to a new environment proved difficult for Margaret. Care home staff faced the delicate task of balancing safety protocols with residents' emotional well-being.

While she was still able to use her iPad for virtual visits, offering a connection to loved ones, often care home staff would forget to set up the call for her or charge the iPad. This became distressing for Margaret and she became more isolated. To comfort her, care home staff tried introducing personalised activities, to enhance her quality of life within the constraints of pandemic related restrictions.

Unpaid Carers

There is no doubt, that unpaid carers across Scotland were instrumental in ensuring the social care system stayed on its feet during COVID-19. Carers UK research showed that an estimated 392,000 people in Scotland became unpaid carers as a result of the COVID-19 pandemic. Not forgetting the 729,000 unpaid carers who were caring pre-pandemic or the many thousands of unpaid carers who have yet to identify themselves (Carers Trust UK). Overnight, and without consultation, unpaid carers became 24/7 frontline 'staff' who held up health and social care in Scotland. The impacts we heard, from carers of people living with dementia, continue to be felt and we ask for better recognition of the substantial effort that unpaid carers contributed during this time.

During our engagement, we identified many different caring circumstances. The three we found to be most common were; unpaid carers living with someone with dementia, unpaid carers visiting someone in care homes, and unpaid carers who were providing care for someone virtually e.g. a carer living in Scotland, caring for a person with dementia in England.

"The pandemic was hard. My mum lost all her external social care support. To make sure she was safe I brought her to live with me and my husband, just before lockdown was announced. I am a social worker, and at first managed to work and care for her, but eventually, I had to resign as my mum's health declined.

I am grateful for the time I spent with her during the pandemic, but it was hard. I struggled for 18 months to secure social care for my mum, and I didn't want to complain because of my line of work.

I'm still grieving what happened in the pandemic, and still struggling with guilt and uncertainty of whether I am doing the best for my mum. But I am grateful that external support for both me and my mum is open, and that we can visit support groups together."

Cross cutting themes we encountered from the various forms of caring were:
- The incalculable amount of guilt and worry unpaid carers felt
- The substantial impact that caring had on people's mental health
- The forgotten level of isolation that affected unpaid carers
- The pressure and unfair burden to undertake a 24/7 caring role without support or guidance.

While we concede that many people felt these impacts of the pandemic, unpaid carers of people living with dementia felt them substantially harder, at times, than a majority of people.

Pre-pandemic, people living with dementia articulated to us that they felt that they fell off social care radars even with entitlement to a year's post diagnostic support. As a person living with dementia who was diagnosed during the pandemic aptly put, the system is 'a bit guilty of diagnosing people and forgetting them'. Post diagnostic support rates were at an all time

low before entering the pandemic, so while it is not a shock to see that carers felt even further detached from support during the pandemic, this has been a critically under-recognised social care crisis long before COVID-19 showed up. That being said, it does not take away from the impacts unpaid carers felt during COVID-19.

Unclear guidance on shielding and restrictions for individuals with dementia posed a significant challenge for unpaid carers. Throughout our interactions with unpaid carers, we learned about the taxing experience of navigating the delicate balance between the risk of transmission and the absence of clear restrictions. This internal conflict often stemmed from a desire to safeguard the well-being of the person they cared for. A dilemma of either adhering to restrictions and risking a decline in mental health or breaking restrictions to enhance socialisation and mental well-being, albeit with the potential for a decline in physical health.

"I effectively imposed a lockdown on myself and my mum. I stopped my mum from going to day care. We didn't go anywhere, or meet anybody... for over a year.

My mum loved the social side of day care, and that was difficult for her... to accept it was just her and me. I felt I had no other option, I knew I might withstand COVID, but I didn't think my mum would.

In May 2021, Mum went back to day care, but then a couple of weeks in she caught COVID. It was inevitable, I understood it would probably happen but I knew she needed that social outlet. If I'd kept her at home she would have been safe, but she would have died of boredom. She wouldn't have had a life worth living if she had stayed at home."

While there was inadequate guidance and support for unpaid carers, it's crucial to note that a caregiver did express appreciation for the Scottish Government's one-time payment of £460.20 at the beginning of lockdown.

Our 2020 'Locked down but not forgotten' report emphasised the heightened challenges faced by those in care homes and unpaid carers. The report underscored the emotional distress, worry, and guilt experienced by unpaid carers unable to visit their loved ones due to prolonged restrictions in care homes. The lack of consistent

"The extra care payment supplement was very welcome. There is a lot of focus on what we didn't get, but I appreciated the payment because some people in other parts of the UK didn't get anything."

guidance across care homes added to the frustration and confusion among unpaid carers and family members. When considering pandemic planning for the future, we would urge the Scottish Government to create a plan that is built on human dignity. For those living with dementia in care homes during the pandemic, dignity was often a commodity, not a priority.

> "Should we have another lockdown, there needs to be legislation in place to ensure people have at least one visitor in care homes, Anne's law needs to be fully implemented to give this legislation strength. As well as a carer, I am a nurse. Medical ethics during the pandemic were extremely questionable. I have never known nurses to be able to stop people from seeing their families. I just cannot get my head around the fact we were preventing people from going to see vulnerable people and make sure that they're okay, that's wrong."

> "There was no consistency between care homes. As well as looking after my husband with dementia, I had two aunts in care homes. Because of the visiting restrictions, I never saw one of those aunts for over 18 months. She was like a mother to me. The pandemic was horrendous from that point of view, it was very wrong. Even now [September 2023], the care home shuts down if there is a positive case of COVID-19. While I have friends in another care home who have a completely different set of rules."

A significant portion of this section has primarily delved into the impacts on people living with dementia, from the view of an unpaid carer. Little attention has been directed towards the unpaid carers themselves. This intentional omission serves to underscore a poignant revelation that emerged during our engagements - unpaid carers were often so immersed in ensuring the safety and well-being of the person living with dementia that they unintentionally neglected their own needs. This is because carers became the linchpin in the life of the person they support. If something were to happen to them, there would be no one there for the person living with dementia, people were very aware of this. And yet, there was no plan B, no emergency support in place to fall back to.

Numerous unpaid carers shared with us that, particularly during the peak of the COVID-19 crisis, when they did manage to connect with family, friends, or healthcare professionals, the conversations rarely revolved around their own well-being. Consequently, being overshadowed by the needs of their loved ones left unpaid carers feeling increasingly isolated, contributing to a surge in mental health issues. One unpaid carer poignantly described the pandemic as a 'desperate situation,' highlighting the profound sense of invisibility they experienced.

These individuals played a pivotal role in upholding the social care service, often at the expense of their own well-being. It is imperative that their contributions are not only acknowledged but that measures are taken to address the challenges they face, ensuring their mental and physical health is prioritised alongside the care they provide.

> "It is actually quite emotional thinking about all this again, the responsibility and the worry because I've kind of blanked it out, pressed a delete button in my hard drive. I look back and think 'God, how did I do all that'."

Case Studies

Sally is an older adult unpaid carer. She cares for and lives with her mum, who is living with dementia. Despite believing that her mum was vulnerable, due to factors of age and ill health, Sally and her mum received no official guidance to shield during the pandemic.

From the pandemic's early days, Sally took the initiative to enforce stringent measures, pre-emptively halting her mum's Day Care attendance and confining them to their home. Sally's commitment to her mum's well-being extended to drastic measures, including limited external interactions, avoiding medical visits and enforcing a year of home confinement. These restrictions also extended to Sally's personal life and support systems. Distancing herself from her partner in March 2020. This initial separation was planned for 6 weeks, however, due to the persistence of COVID-19, Sally did not see her partner again until Christmas 2020. This exacerbated Sally's feelings of loneliness and isolation.

Sally's motivation sprang from her recognition that, while she might withstand the virus, her mum's health was fragile and she may not survive COVID-19. There was a lot of guilt, anxiety, and pressure on Sally to do the right thing and to prevent potential transmission.

The absence of official 'vulnerable' classification and guidance left her perplexed. Her mum, who had several ailments including dementia, didn't meet the criteria. As the primary caregiver, Sally grappled with the burden of monumental safety decisions in the absence of clear guidance.

Muriel cared for her husband Ray. He was a cockney, a very social man, always immaculately dressed.

When the pandemic started, Ray just couldn't understand why people stopped coming into the house. His sons couldn't visit, as the garden visits distressed him, and when Muriel took him out for car trips, he'd ask why they didn't stop for coffee anymore. He thought he was being punished.

During the pandemic, he moved to a care home and his clothes went into quarantine for 3 days. But the care home lost all of them, every single piece. Muriel was able to visit him for an hour per week during the pandemic, each time she turned up he'd be wearing someone else's holey jogging bottoms.

Sadly, Ray passed away during the pandemic. The week he passed, the care home called Muriel to say they'd found his clothes. When Muriel arrived to collect them, she was handed two black bin bags to take home.

Jane reached out to About Dementia after spotting a call for COVID-19 impacts. Her connection with the organisation unfolded against the backdrop of a complex caregiving scenario, where she found herself juggling the needs of her mum, who had dementia, and her children, all living with autism and complex needs.

As the pandemic unfolded, Jane's household - her husband, mum and four children - coexisted under one roof. Unfortunately, due to the challenges that her mum was facing during her dementia journey, an intense strain on relationships grew. Jane's mum experienced significant behaviour changes during lockdown that came out mostly in physical and verbal abuse, especially towards the children. Due to no external support, or respite, Jane decided to separate the family. From the second lockdown onwards, half the family moved six miles away. This decision alleviated tension and while practical, it forced Jane into a constant struggle to adhere to restrictions. Jane grappled with an overwhelming sense of guilt. Balancing the needs of her family members, especially prioritising her mum's care, left her feeling torn.

Navigating the social care system also proved difficult for Jane. Social workers failed to comprehend the complexities of her family's situation, leaving her caught between conflicting demands. The guidance provided seemed disconnected from the practical challenges she faced, there was no information available to her on what she might to if she is caring for several people. This turmoil and worry led Jane to feel isolated in her struggles. Social workers tried to make her prioritise one person's care needs over the other, putting her in an impossible situation.

Before COVID-19, social care had made extending Jane's mum's care package a priority, as they could recognise the impact it was having on the family unit. There was a plan for her to attend a Day Care three days a week, on top of additional home support. This plan disappeared when COVID-19 began. In late 2020, when asking social workers for specific care support for her mum, Jane was told that the only option was to have her mum placed into a care home, and for Jane not to expect her to survive more than four weeks. Jane felt torn, cheated, and alone. Throughout COVID-19 she was given blunt and emotionless statements that isolated her and her family more and more.

In Jane's eyes, the guidance and planning for COVID-19 was based upon 'perfect conditions' i.e. having spare rooms, only one person to care for and the carer being in good health. Jane felt her situation was a 'perfect storm', without proper guidance and support.

"The disabled community, people living with dementia - they just didn't seem to be part of that [disaster planning]."

Community Based Support

In accordance with Scottish Government Guidance, community based supports closed their services overnight on 23rd March 2020, many of which did not reopen until far into 2022. Some never reopened.

In our contribution towards the COVID-19 Inquiry, we would like to highlight the life saving support that community groups, third sector individuals and volunteers contributed during the pandemic. Despite being met with challenges such as burnout and negative mental health, or the distress caused by seeing members of the community deteriorate, these individuals continued to work in creative ways to provide friendship, food and connection for people affected by dementia.

"While providing phone befriending (during the 1 year of our centre closure) I witnessed many folks mental health deteriorate due to extreme isolation. To the point of some wishing to no longer live.

So many groups closed during COVID. My wee charity is the last one standing!

These are your low level, first social contact groups. But they always look out for people as well. It's the first port of call for people who don't have family, who don't have that safety net of being involved with services. That's all been eroded away."

During engagement, we heard of third sector, voluntary lead groups delivering 'grow your own strawberry patch', or 'grow your own potatoes' kits directly to people. While other groups delivered 'afternoon tea' in the shape of a scone, butter and jam. Third-sector organisations were able to use their creativity to reduce the isolation that people felt during the pandemic and were the leading point of contact and support for their service users. One unpaid carer noted that it wasn't the GP, or social care who checked in on her and her mum during the pandemic, it was actually her mums day centre, Glasgow's Golden Generation, which is a community lead third sector organisation for people living with dementia.

Though once viewed as a dispensable limb of support for people, the pandemic forced a significant change in the roles and responsibilities of third sector and community based professionals, shifting from supplementary services for those living with dementia to becoming the sole support available. Communication gaps between local authorities, government, and community based supports often left community support staff and volunteers to make decisions independently, lacking sufficient information or guidance support.

We heard of Senior Support Workers taking on responsibilities typically handled by Social Workers, including addressing safeguarding concerns and coordinating home care. Support Workers managed waiting lists and documented concerns about members' well-being. Volunteers, many of whom were already beyond retirement age

before the pandemic, were increasingly tasked with significant responsibilities, such as driving a minibus to collect members in rural areas, delivering well-being parcels and conducting befriending phone calls. The amount of time they were expected to give was, in some cases, akin to a full-time job. The core contributing factor towards this shift in responsibility was the lack of planning, and mass closure of services, without proper thought for the social isolation and physical and mental health impact it would have on those reliant on external support. These government services, vital for isolated individuals, were the first to vanish, many of which never reopened, leaving a void that will be felt for years. The loss of these groups is not only impactful in the short term but also affects the community's ability to provide crucial transition services.

The abrupt shift in responsibility overnight not only affected the individuals being cared for but also took a toll on community based professionals, leading to ill health and social isolation. Some became unfit to return to work, while others experienced a loss of confidence. Our 2020 lockdown report highlighted the significant challenges community based professionals faced as they held a delicate balance between work and personal life. The global nature of COVID-19 meant that the pandemic couldn't be left behind in the workplace. Community based professionals and healthcare workers had to contend with the presence of the virus in their homes, leading some to make the difficult choice of living apart from their families to avoid the risk of transmitting COVID-19. For those who were unpaid carers outside of work, there was an added layer of stress and isolation during this period to try and effectively juggle caregiving responsibilities, while helping service users.

The mental impact on staff, including burnout, was raised as a substantial issue during engagement with community based professionals. Sustaining patience, energy, and creativity in the face of uncertainty became challenging, with burnout manifesting in long-lasting physical effects and ongoing trauma processing. Many of the community groups that remained open exist solely on the back of two or three passionate individuals wanting and willing to make change. It was noted by some of these individuals that they are not yet able to feel the full impact of the pandemic because they haven't stopped to assess its impact.

It became apparent during our engagement just how essential these individuals are, and that more must be done when planning towards another pandemic to ensure support and protections are in place for those who are handling the pandemic on its front lines.

Despite the unsustainable nature of the situation, the expectation for heightened support and responsibility on these

"As a team we've spoken about the impact it had on our mental health.

We all work in jobs like this because we want to make a difference to people. And you feel as if instantly that was taken away from us. That had a horrible impact on ourselves.

You just felt so helpless. I'm helpless here to help the folks that are really, really struggling".

individuals has persisted post-pandemic, contributing to an ongoing challenge that has yet to be adequately addressed.

During the pandemic, third sector professionals were acutely aware of the challenges posed by digital exclusion and the profound impact of isolation on people living with dementia and their unpaid carers. Despite a growing push for individuals to embrace and adapt to new technologies, professionals recognised this approach was not always suitable.

They empathised with the struggles faced by those seeking support, acknowledging that many were already holding on to their support systems by a thread. In this context, the idea of introducing additional technological complexities, such as providing iPads and encouraging online engagement, was seen as potentially overwhelming and counterproductive.

"People were clinging on to support with their fingernails; the last thing they wanted was an iPad and to be told to get online."

This sentiment encapsulated the delicate balance professionals had to navigate between promoting technological solutions and respecting the immediate needs and comfort levels of those grappling with the challenges of dementia and isolation.

Amid the challenges of the pandemic, there was a noticeable shift in the focus of third sector professionals, particularly as activity coordinators were moved from providing creative outlets, to ensuring people's basic care needs we met. This, coupled with staff losses, compelled services to streamline their efforts toward meeting basic needs, primarily centred around personal care and meal support.

This realignment meant that the aspects of care involving creativity, social interaction, games, and the simple yet profound act of spending time holding someone's hand had to be scaled back or deprioritised. These elements, once integral to providing holistic and enriching care experiences, found themselves relegated as services grappled with the urgent and essential demands posed by the pandemic. The tension between addressing immediate needs in times of crisis and safeguarding the long term well-being and fulfilment of individuals became a poignant consideration among all professionals.

In the wake of the COVID-19 pandemic, the landscape of dementia care provision underwent a profound transformation. Third sector and community based professionals found themselves at the forefront of unprecedented challenges, navigating shifts in responsibilities, struggling with digital exclusion, and witnessing the impact of isolation on both care recipients and unpaid carers. The experiences shared by third sector and community based professionals underscored not only the immediate challenges but also the long term implications for the quality of life within Scottish social care.

Case Study

Olivia is an activity coordinator known for bringing joy to the lives of individuals with dementia through creative means. Olivia found herself navigating uncharted waters when the COVID-19 pandemic struck, no longer able to carry out group creative activities.

Olivia's familiar routine of planning engaging in person activities turned upside down as her role shifted from helping to create joyful moments through arts and music, to helping vulnerable community members access basic needs like personal care and meal support. Olivia missed the laughter that echoed through her once lively sessions. The vibrant arts and crafts, music, and shared stories were replaced by the urgency of essential care, leaving a void in the holistic approach she cherished.

The weight of the sudden shift took a toll on Olivia. The passion and joy she once held dimmed as burnout set in. She felt a sense of helplessness, unable to provide the comprehensive care she once did. Olivia reduced her hours a year into the pandemic, to prioritise her mental health. When the pandemic finally subsided, Olivia did not feel confident to go back into the line of work she once loved.

"I had older people saying to me they would rather take the risk than the isolation. Being cut off from people was hellish. They would much rather the risk of catching COVID, than having no contact with anybody.

It was instant, overnight.
Formal support networks, the formal networks, the support – everything was taken away."

"It was the third sector and community based support that adapted."

"When they did start again [public services], the NHS were telling us: 'There's no way it's [capacity] going to be anywhere near what it was before'. But you've got to feel for carers, who can almost see that glimmer of hope at the end of the tunnel."

Lasting Impacts and Lessons Learnt

The COVID-19 pandemic posed unprecedented challenges for people living with dementia and unpaid carers. The shared experiences underscore the enduring psychological impact of the pandemic on individuals, with lingering effects on confidence, especially in social situations and the return to services.

"It was a difficult time. Nobody knew what to do. Nobody knew what was coming. Until you've been through that, you don't have a clue what you're doing. I hope if it comes around again, the next time we'll know better."

One glaring issue during the pandemic was the crisis in staffing levels and quality of care across home care, care home and hospital settings. Due to staff shortages, staff in all of these care settings are being given increased responsibility, at times with inadequate support or training. Due to the raised expectation that these front-line staff are to become jacks of all trades, we were told by people living with dementia and unpaid carers that they often lacked awareness of how dementia might affect behaviour, and lacked understanding of the fundamentals of dementia and how to manage someone living with dementia or an unpaid carer. Often this would lead to distressing instances of confrontation or disagreement for both the person living with dementia and unpaid carers. It emphasises the need for enhanced training. Adequately dementia trained staff is crucial for ensuring the well-being of people living with dementia, emphasising the need for better workforce planning and training. A comprehensive understanding of dementia is essential, especially during periods when family visits are restricted, to ensure quality care.

There remains ongoing frustration around the misconception that the crisis is over. The lasting impact of the pandemic can be seen in several ways, reduction in services available, extended waiting times for services, reduced availability of government community funding, and digitally focused medical appointments or assessments.

"I do think technology has a huge part to play in the life of people with dementia and their carers. But I also feel that healthcare is relying on technology too much. The emphasis now is not on face-to-face consultations with a GP, but phone calls and, and zoom calls. I just can't see how they can properly diagnose how you are over a telephone call or a Zoom call. They need to find a happy medium there."

Individuals expressed frustration at the continued blame on COVID-19 for existing challenges. There have been many lasting impacts of COVID-19 however, the consensus is that not all challenges are directly attributable to COVID-19. Those who engaged with us called for a move away from the mindset of attributing everything to the pandemic and to recognise the broader issues affecting service accessibility. Accountability for the root problem within services e.g. staffing or funding, would significantly reduce this frustration.

While the pandemic highlighted the importance of digital infrastructure, particularly in rural communities, and efforts were made to provide internet and education, misallocating resources, such as spending money on tablets or iPads, exacerbated the digital exclusion felt by older people, and those living with dementia. While technology streamlined a significant number of services, telephone and video appointments continue to dominate the public health space. Lessons must be learned to address digital inequities and ensure resources are directed toward areas of genuine need. Additionally, where possible, incorporating some level of in-person and face-to-face service, to cater to those who are not digitally inclined. Additionally, understanding the vital role of community groups in supporting those living with dementia or carers is necessary. Adequate funding is essential for sustaining critical services and addressing the evolving needs of individuals living with dementia and their carers.

"On relationships with doctors, even after this time if I have health trouble GPs are the last people I think of. Now, the Berlin Wall is in doctor surgeries, in the shape of receptions. They really grill you before you are maybe allowed a phone call with the doctor. I've had two face-to-face visits with a doctor in the last four years, both times I was hospitalised."

Restrictions limited the involvement that carers had concerning care planning for loved ones, especially in care home settings. The absence of carers due to restrictions raised concerns about potential oversights in care plan details. Efforts should be made to facilitate the involvement of carers in the care process, recognising their invaluable contributions and minimising the risk of crucial information falling through the cracks. The lasting impact on mental health was a recurring concern, with increased anxiety levels and a lack of available support services to manage this increase. The mental health repercussions of the pandemic have led to a surge in referrals for support services, highlighting the strain on organisations expected to do more with limited resources.

The pandemic underscored the significance of community support and collaborative partnerships. Strengthening connections between community based organisations and encouraging joined up thinking can enhance the overall support system for individuals living with dementia.

As we reflect on the challenges faced during the COVID-19 pandemic, it is imperative to learn from these experiences and implement changes that will better support individuals living with dementia and their carers. By addressing staffing issues, improving digital infrastructure, fostering effective communication, and prioritising community support, we can build a more resilient and compassionate system for the future. It is our responsibility to listen to those with lived experience, adapt to evolving needs, and ensure that the lessons learned contribute to lasting improvements in dementia care.

Conclusion

The insights drawn from the voices of lived experiences during our engagement have provided a rich tapestry of perspectives on the challenges posed by the COVID-19 pandemic, particularly in relation to dementia. About Dementia's consideration of these narratives has culminated in a series of recommendations that stand as a testament to the valuable contributions of those who passionately engaged towards this report.

The significance of these recommendations extends beyond the immediate context of the pandemic, transcending into the realm of future pandemic planning. It is crucial to recognise that understanding the long term effects of such global events is an evolving process, requiring continual reflection and adaptation. We have illuminated not only the vulnerabilities exposed by the pandemic but also the potential for growth and improvement in our collective response. Through a commitment to learning, adaptation, and the implementation of thoughtful recommendations, we can aspire to create a more robust framework that safeguards the wellbeing of individuals and communities in the face of future crises.

1. Shift from Blame to Solution Oriented Approach
- Encourage a shift from attributing all challenges to the pandemic towards a solution oriented mindset.
- Acknowledge that not every issue is a direct result of COVID-19, and address underlying systemic challenges.

2. Investment in Mental Health Services
- Prioritise mental health services in crisis response planning.
- Allocate increased funding for mental health support to meet the rising demand.

3. Sustainable Funding for Community Based Organisations
- Recognise the vital and increasing role of third sector and community based organisations in providing support.
- Ensure sustainable funding that matches increased service demands.

4. Flexibility and Innovation in Service Delivery
- Encourage flexibility and innovation in service delivery to adapt to changing circumstances.
- Explore new models that maximise impact without overburdening organisations.

5. Enhanced Communication and Information Sharing
- Establish better channels for communication between community based supports and decision makers.
- Ensure information reaches those who need it, avoiding delays and gaps in service provision.

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