



Forget-Me-Nots Dementia Enquirers Report



What impact has COVID-19 had on my connections with others, especially the Forget-Me-Nots?

October 2021



Key messages from Dementia Enquirers projects

1. People with dementia can lead their own research projects – both drawing on previous life skills and learning new ones to explore the questions that most interest them.
2. The research questions that people with dementia generate can be different from existing research questions. They are based on lived experience – on topics that will make a real difference in people's lives.
3. “Being in the driving seat of research” doesn't mean that you have to do everything yourself. Team work and support can really help. But controlling the research and leading the way gives people with dementia a huge boost in confidence.
4. Making the language and processes of research more accessible helps everyone!
5. Research *between* people with dementia makes communication and engagement more possible, because having something in common increases trust.

Date of publication October 2021

You can download this report here:

<https://dementiaenquirers.org.uk/individual-projects/forget-me-nots/>

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Contents

Acknowledgements.....	4
Abstract.....	5
Introduction	6
Methods	8
Results	15
Conclusion	24
Bibliography	26
Appendices	27

Acknowledgements

The Forget-Me-Nots Service User Group

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To the research team in the Kent and Medway NHS and Social Care Partnership Trust and the members of staff who helped us tailor our report to be properly presented...

To our fellow DEEP Groups, who work every day to make sure the voices of the people with dementia are heard...

Thank you - this project would not be possible without you!

Abstract

The COVID-19 pandemic disrupted many lives, causing many plans and lifestyles to change. Although a negative time for many, a group of individuals living with dementia saw this as an opportunity to investigate and share their experiences of COVID-19 with the world.

In November 2020, the Forget-Me-Nots, a Kent and Medway NHS Partnership Trust service user group in Canterbury, received a grant from the 'Dementia Enquirers' programme to conduct a research enquiry on,

“What Impact has COVID-19 Had on My Connections with Others, Especially the Forget-Me-Nots?”

This project took place between December 2020 and August 2021. It is led by a working party comprised of service users, students, and volunteers. Additional Forget-Me-Nots members were recruited as participants through volunteer sampling, creating a total sample of 11 participants. All participants contributed to creating interview questions by participating in a preliminary conversation with a student or volunteer. From there, a list of questions for structured interviews was generated to collect data for the study. Forget-Me-Nots members interviewed each other via video conferencing or telephone. Throughout the entire process, students and volunteers provided individualised support to each participant, ensuring everyone was able to participate fully.

We hope this enquiry helps to reduce feelings of loneliness and empower people with dementia. We also hope to inspire future research in this area, and provide direction for future work with older adults living with dementia.

Contact information: Clare Streeter (c.streeter@nhs.net)

Introduction

The Forget-Me-Nots (FMNs) is a service user group of older adults with dementia, currently consisting of around 20 members, with roughly equal amounts of men and women. The group's members, who will be referred



to as “DEEP Enquirers”, range in age from 60 to 88 years old. The FMNs was founded in November 2012.

The aim of our group is to help people with dementia and to communicate to healthcare staff to help reduce the stigma surrounding dementia. Since the COVID-19

pandemic, we have been forced to meet online for the first time in those 10 years. This, along with other factors, has been a struggle for many of our members. We wished to do this Enquiry to improve the lives of people with dementia and find out how best to assist them not just during the pandemic, but also in the future. Our group is supported by students, and volunteers, and they have been fantastic in helping us attend seminars, and organise other projects, including this Enquiry.

Part of our struggle as people with dementia, is communicating our feelings to professionals in a forum where we can be heard. This is something that the group has given us the opportunity to do. This Enquiry focused on one key question in particular: “What Impact has COVID-19 Had on My Connections with Others, Especially the Forget-Me-Nots?”. We investigated this by asking FMN DEEP Enquirers questions about different aspects of their struggles with the pandemic, such as technology, and physical/mental health issues, which have been ongoing throughout the pandemic and beyond. Questions can be found in Appendix A.

Background Information

Little things mean a lot to people and can make a big difference for someone with dementia. For example, social isolation can have numerous negative effects on people with dementia, such as sleeping issues (Goodman-Casanova et al., 2020), and mental health issues such as agitation (Manca, De Marco & Venneri, 2020). As such, even minor things, such as having a befriender to talk with once a week, can be helpful for the mental health of people with dementia. This support is made more easily accessible with technology. However, some reports warn that the shift to more technology in healthcare services may make it harder for people who need more support with technology, such as people with dementia (Ageing in coastal and rural communities, 2021). This is because they may feel stigmatised by not being able to access healthcare or digital communication. To support people with dementia, it is important to implement skilled care home staff, caregiver support, and proper healthcare support, as is outlined in Numbers' and Brodaty's (2021) report on COVID.

One goal of this Enquiry is to provide people with dementia with a voice for their concerns during the pandemic and how it has affected them. This is due to the fact that academic research has not properly incorporated the views of people with dementia in their studies (Vahia, 2020). As a result, we feel that this Enquiry will be very important in allowing professionals in both the healthcare and research and development industries to have a clear view on how this pandemic has affected people with dementia. Including our voices of people with dementia is important to our discussion, especially due to the fact that the isolation present during the pandemic disproportionately affects older people (Morrow-Howell, Galucia & Swinford, 2020).

Methods

1.Information on Participants (DEEP Enquirers)

The Working Party

It was agreed that a working party would be established to lead the Enquiry and represent the group. This was formed by 3 members of the Forget-Me-Nots who were committed to devoting time and energy to the Enquiry beyond that of a participant. Other members of the working party included placement psychology students and volunteers. They would help to chair the meetings and communicate with us to ensure access to the virtual platform which was to be used for the meetings. The working party meetings took place once a month at the same time.



Figure1. The working party.

The working party reported back to the Forget-Me-Nots group every month, and minutes of meetings were produced and sent to every member, including those who were unable to attend.

Recruitment of the DEEP Enquirers

After hearing that our application to Dementia Enquirers was successful, the FMN group discussed the proposed topic title and that information would be obtained via semi structured conversations with open-ended questions. We hoped to recruit 10 members and explained that the interviews would take place virtually. Forget-Me-Nots members were encouraged to take part as an interviewer, interviewee, or both.

Swiftly, 12 participants from the Forget-Me-Nots were recruited for the Enquiry and will now be referred to as **DEEP Enquirers**. Only one out of the 12 individuals withdrew and one DEEP Enquirer was supported to take part despite being hospitalised. All 11

DEEP Enquirers were paired with a volunteer or placement student, who supported them throughout the process. 4 of the DEEP Enquirers took part as both an interviewee and interviewer. 3 out of 4 interviewers living with dementia came from the working party but an additional member of the Forget-Me-Nots was happy to take on the role of an interviewer with support.



2. Materials

Interview Questions

The working party decided the questions to be asked in the interview. This group met monthly for 1.5 hours and worked to an agenda which was dementia friendly in length and layout.

During the first of the monthly working party meetings, much discussion took place led by the 3 DEEP Enquirers which resulted in agreement on the 6 themes for the questions to be based upon. The 6 themes were:



To develop questions for each theme, students and volunteers individually contacted each DEEP Enquirer to discover their thoughts and opinions. In the next working party meeting, there was a discussion regarding the questions to be asked based on the conversations. This

resulted in a draft set of questions, which was then trialled in a pilot interview between two DEEP Enquirers.

This was reported back to the working party and evaluated in a working party meeting. After this meeting, the questions to be asked during the interviews were re-drafted and then revised again at a later meeting after there was more thought given. The final set of questions used for the interviews consisted of 13 questions, which can be seen in Appendix A. Also, from realising how tiring the interview was going to be for both interviewer and interviewee, both of whom have dementia, we agreed that it should last no more than 1 hour.

Technology Questionnaire

In addition to the interview, it was agreed that a quantitative questionnaire consisting of closed questions and tick boxes would be posted to DEEP Enquirers in addition to taking part in an interview. This was used to create a scale of how much each person used technology before and after COVID-19. Our technology questionnaire can be seen in Appendix B.

3.Consent and Ethics

Consent Form

A consent form was created by the working party with advice from DEEP and Kent and Medway NHS Partnership Trust. This can be seen in Appendix C. We wanted to ensure this form would be clear and accessible for people with dementia to complete. During all stages of recruitment and interviews, DEEP Enquirers were reminded they can withdraw at any time without any consequences.



Confidentiality

There was some discussion before a consensus was reached that the data would be anonymised. To ensure this confidentiality, the



transcription of interviews included no names of DEEP Enquirers or individuals that were mentioned in their interview. To store the data, we used a password protected drive. No identifiable data was saved to personal devices. All of this was expressed to the full group to ensure everyone was comfortable with how their information would be stored.

4.Data Collection/Procedure

Firstly, an information sheet, consent form and tick box questionnaire were given to DEEP Enquirers who expressed interest in the project. Dependent on individual preference, this was conducted through email or post. This was followed up by students and volunteers who phone called each DEEP Enquirer to confirm they had received these forms and asked if they had any questions about the forms or project.

After these forms were returned, a time for the interviews which was mutually convenient for all involved was arranged by the students and volunteers.

A student or volunteer attended the interview to support each member in accessing the meeting. They played little or no role in the interview themselves. Thus, retaining the integrity of the role of the DEEP Enquirers. In some cases, a family member would join the DEEP Enquirer to support them in answering the questions. This was left to individuals to decide.



All interviews were conducted remotely either through Lifesize, which is a video platform similar to zoom, or by telephone, depending on each individual's preference.

The interviews ranged between 30 and 50 minutes long. There was time allocated before this to ease all parties into the interview. This part also included a brief outline of what the study was about, why it is being done and to ensure all parties were happy to take part. The interviews were recorded using BigHand, an approved recording application used by our NHS trust.

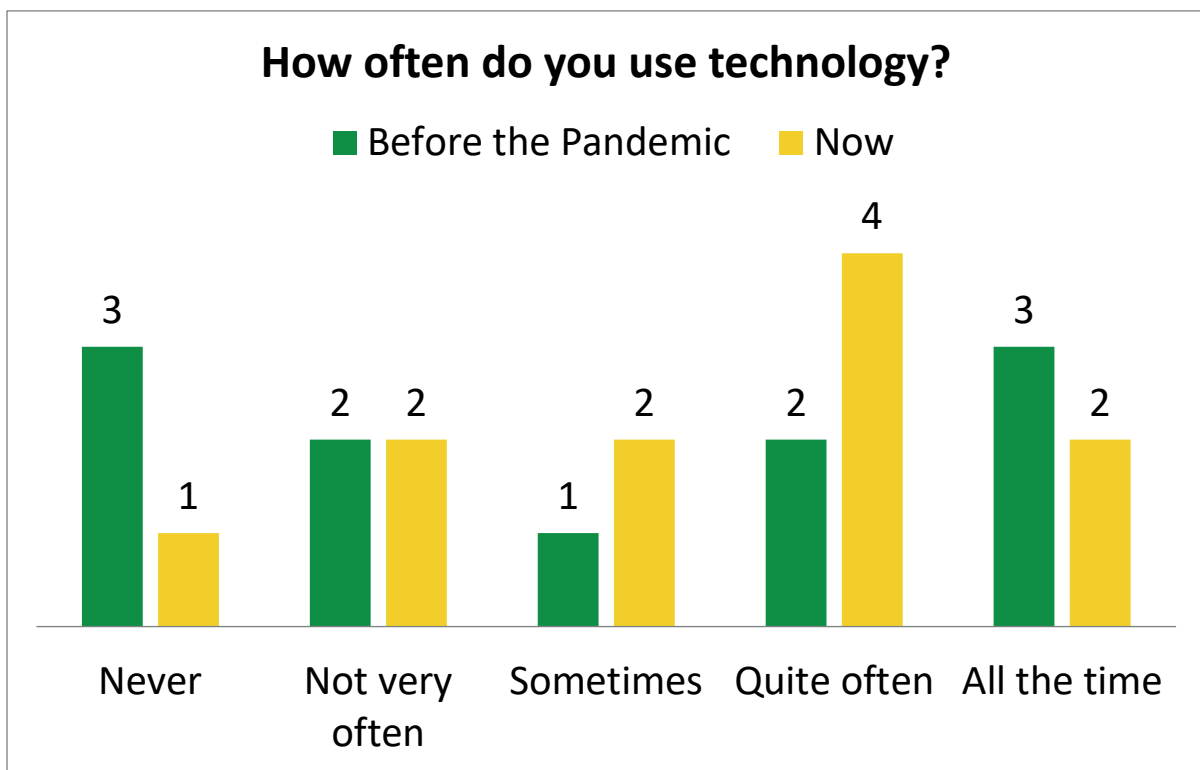
Once the interviews were complete, the students and volunteers conducted informal transcription and thematic analysis to establish key points.



Results

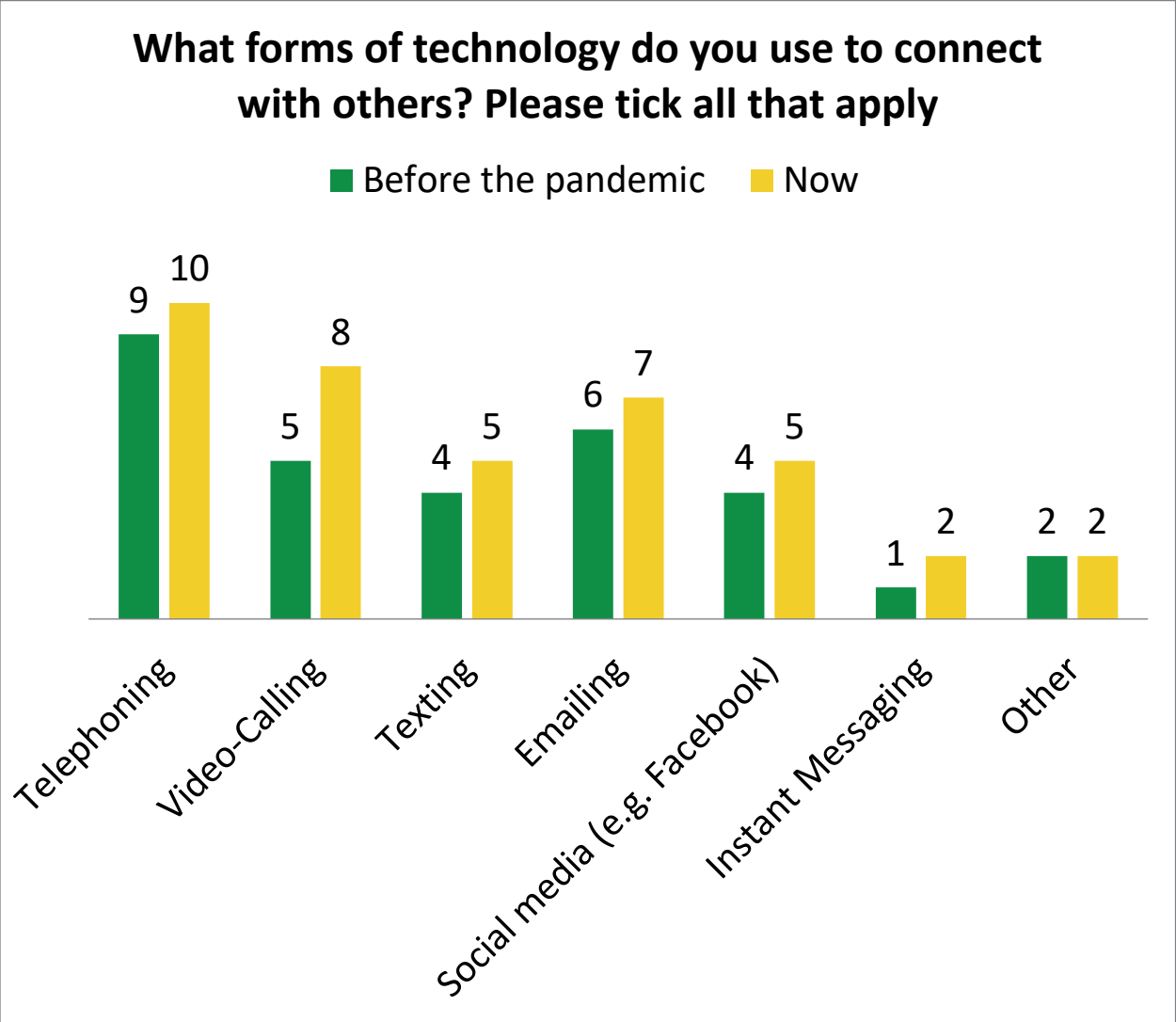
Use of Technology

DEEP Enquirers used very little technology before the pandemic. Since the pandemic began their use has increased (see Graph 1). Surprisingly, two people used technology “all the time” now versus three before the pandemic. We believe this may be because DEEP Enquirers have picked up different hobbies since the pandemic began, which will be explored later.



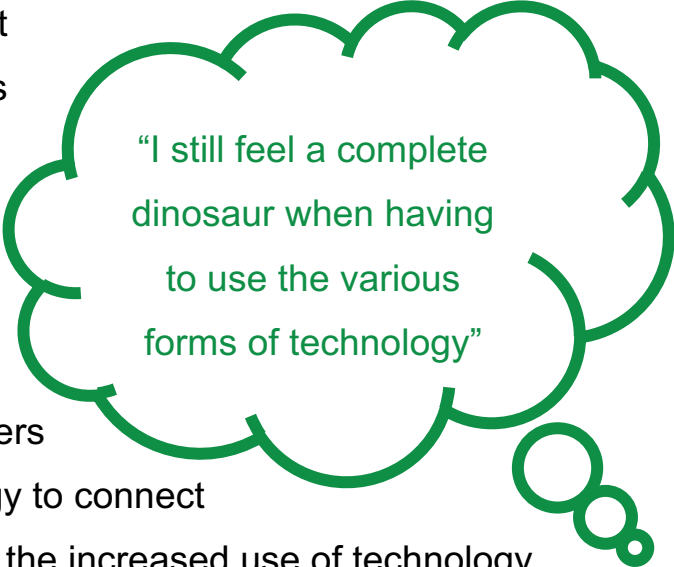
Graph 1.

As shown in Graph 2, telephoning was the most popular use of technology amongst the DEEP Enquirers before the pandemic. Since the pandemic began, DEEP Enquirers reported an increased use in all forms of technology. The use of video-calling showed the biggest increase since the pandemic began. This includes using Zoom, Lifesize, and Skype to connect with others.

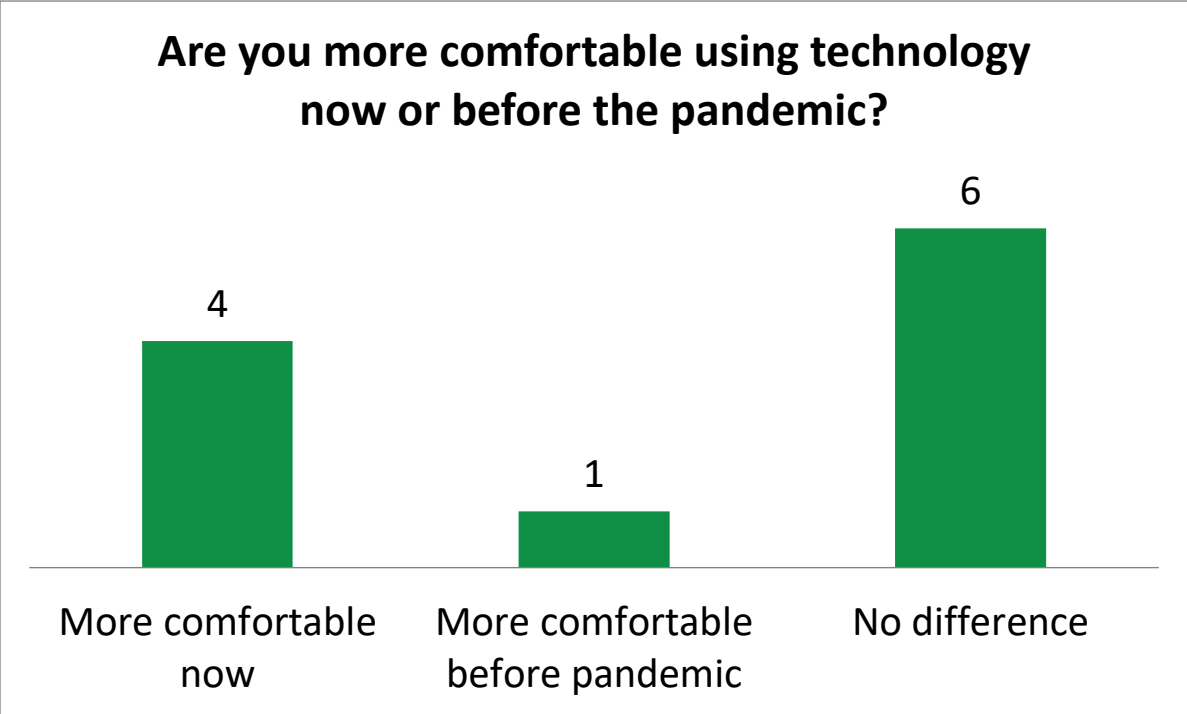


Graph 2.

When using such technology, most enjoyed and received technological support from partners, students, volunteers, or charities. Some need repeated and sustained support to further develop technological skills. Once developed, ongoing support may still be needed. This includes email reminders for meetings or sending the link on the morning of the meeting.



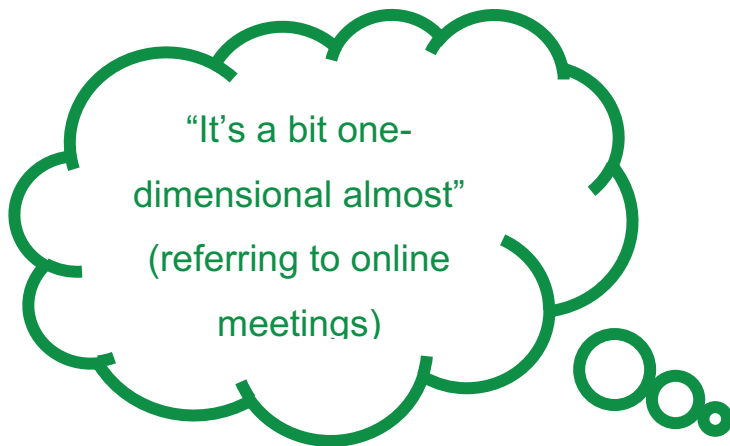
Despite the increased use of technology, 8 of 11 DEEP Enquirers required support to use technology to connect with others. Furthermore, despite the increased use of technology, 6 of 11 DEEP Enquirers reported they felt no difference in their comfort level with using technology (see Graph 3).



Graph 3.

Face to face activities

Interviews indicated that using technology to connect with others can be impersonal, and social events are greatly appreciated. Leaving the house to attend meetings can create a welcome change in scenery, and



greater connections arise from face-to-face meetings. Face-to-face meetings can also be a form of cognitive stimulation, which is reported to be therapeutic.

However, using technology meant more connections were made. Projects such as this DEEP enquiry were originally in-person, but went online due to COVID. Meetings happened online, and many who may not have met in-person were able to meet online.

Despite its benefits, we recorded users of technology being better off and more connected, whilst non-users were worse off. Support must be focused on those who cannot use technology.

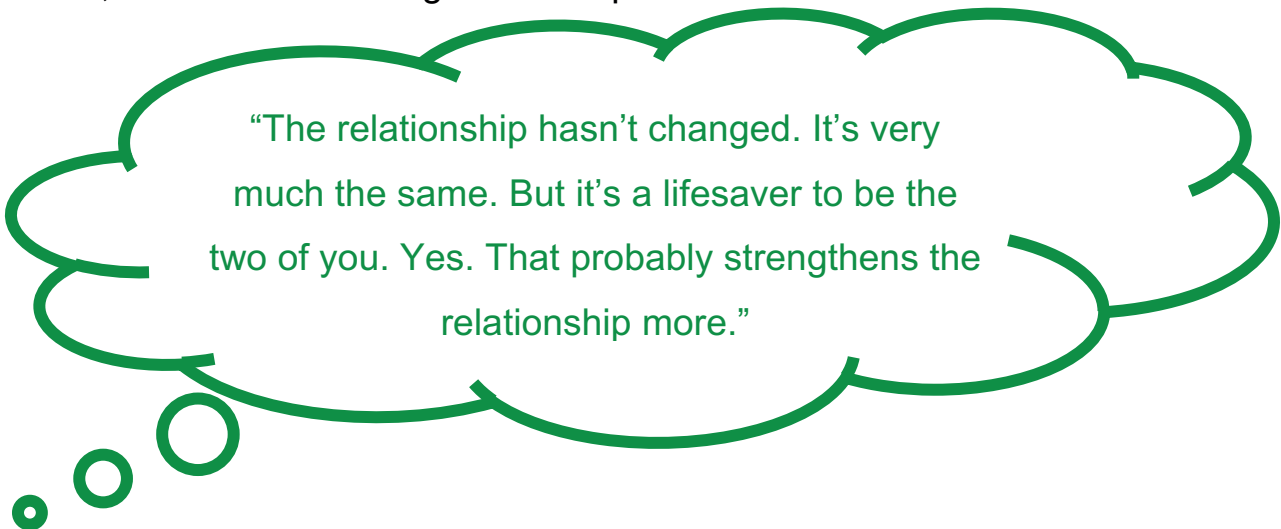
In concluding our survey of technology use in FMN, we have shown that people living with dementia can use technology, but they need support to do it, whether through a charity, students, volunteers or family. We now examine some of the wider issues that may increase technology uptake among those living with dementia in the time of COVID.

Relationships with Others

Enquirers felt that they had little support from and connection with healthcare providers such as their GPs. Whilst some have had support from mental healthcare professionals, other Enquirers reported little to no support. Some DEEP Enquirers were quite frustrated with the lack of contact.

However, Enquirers were able to maintain relationships with others. There was lots of use of Zoom and Skype to connect with families and friends online, as the Enquirers were unable to travel to see family and friends. Whilst Zoom was a good alternative, face-to-face meetings were preferred. People living close to the Enquirer were also able to connect face-to-face. One Enquirer even commented that they used this time to reconnect with family and friends.

Enquirers reported that other relationships have strengthened. For example, they have connected with those in their environment such as others in their neighbourhoods or partners they are living with. However, for those living alone remained very isolated. Only 4 Enquirers lived alone, but it did have a significant impact on them.

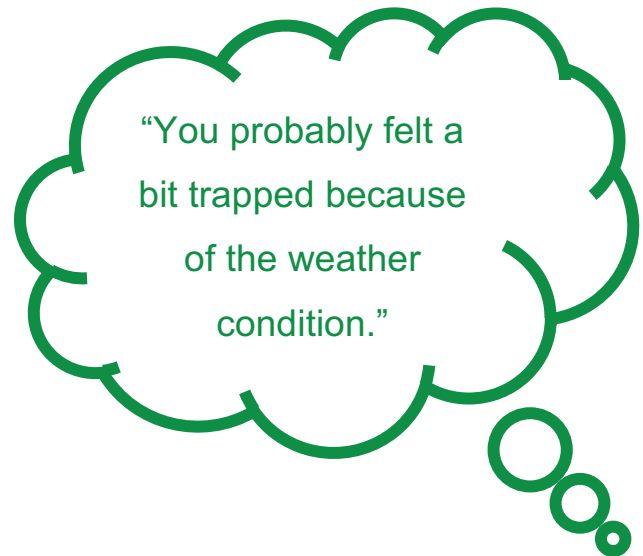


“The relationship hasn’t changed. It’s very much the same. But it’s a lifesaver to be the two of you. Yes. That probably strengthens the relationship more.”

Coping Strategies

A common coping strategy involved the outdoors. This included going on walks and doing gardening.

However, because of the nature of these coping strategies, many found it much harder to cope during the winter, and some changed their coping strategies depending on the season.

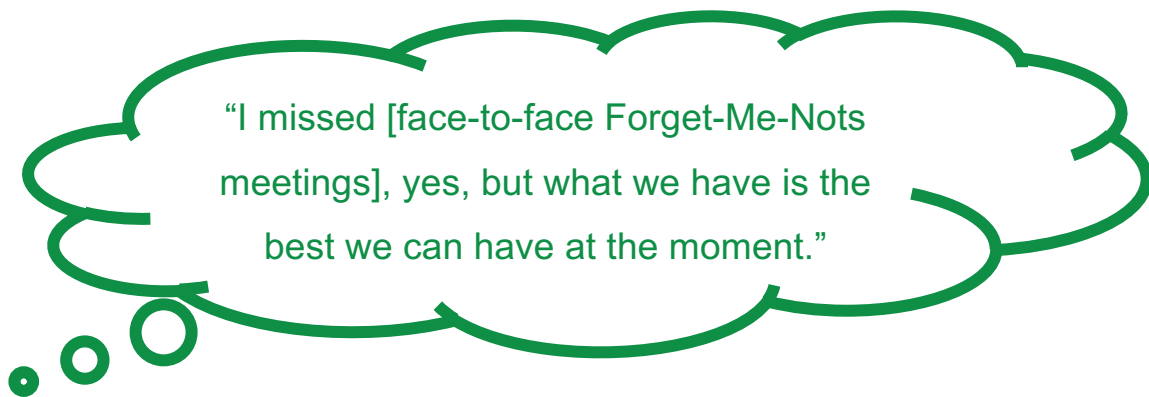


Enquirers also said that receiving support from partners and family members was helpful in staying positive during the pandemic. Two participants also began receiving help that may have previously been declined. This includes helping with shopping or arranging food collection, or helping with technology, as stated above.

Maintaining structure was important too. This was supplemented by keeping diaries and writing things down.

Challenges presented by lockdown

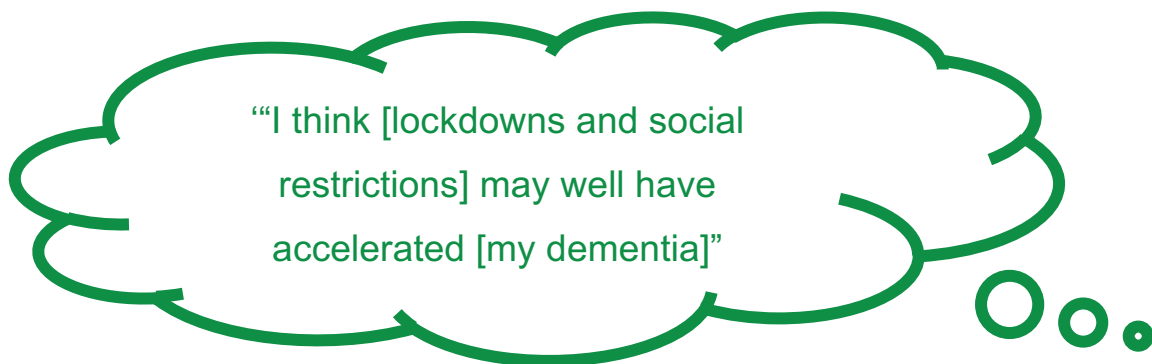
Lockdown has resulted in a complete shift in lifestyle for those with dementia. Many wanted to travel and attend social events in a face-to-face setting. Similarly, 9 participants commented that they missed the face-to-face Forget-Me-Nots meetings. As meetings have gone online, many felt confined to their house. They felt they were unable to see and relate to others in a similar position to themselves. If Forget-Me-Nots meetings were in person, they would be able to see and interact with people, and make a whole event of it. Despite this, some DEEP Enquirers remain resilient, though they did report significant difficulties due to social restrictions.



Impact on physical/mental health

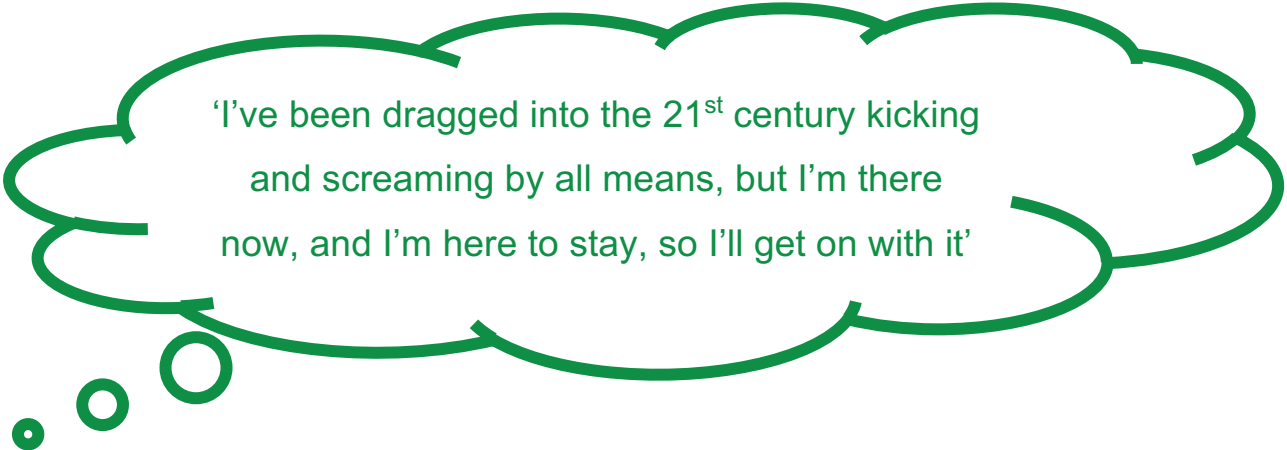
2 DEEP Enquirers are known to have taken a fall requiring hospital admissions. However, there were no reports of DEEP Enquirers having COVID. There were also some reports of improved physical health, which may be due to doing more walks and outdoor activities. Additionally, there were some instances of weight gain.

In terms of mental health, everyone reported noticeable decline in their dementia. However, they were unsure if it was due to natural progression or accelerated by lockdowns and social restrictions. There were also reports of lowered confidence and increased anxiety. One participant explained that they felt more anxious, especially about the pandemic, because they were already clinically vulnerable.



Any positives?

Despite the negatives of the pandemic, there were many positive outcomes too. DEEP Enquirers have begun to appreciate the smaller things in life, and relationships with partners, family members, and others who lived close by have become closer. The DEEP Enquirers' increased use in technology has also meant that they have allowed life to improve with the use of technology. Finally, the Enquirers commented that they fully value the support from students and volunteers throughout the pandemic.



'I've been dragged into the 21st century kicking and screaming by all means, but I'm there now, and I'm here to stay, so I'll get on with it'

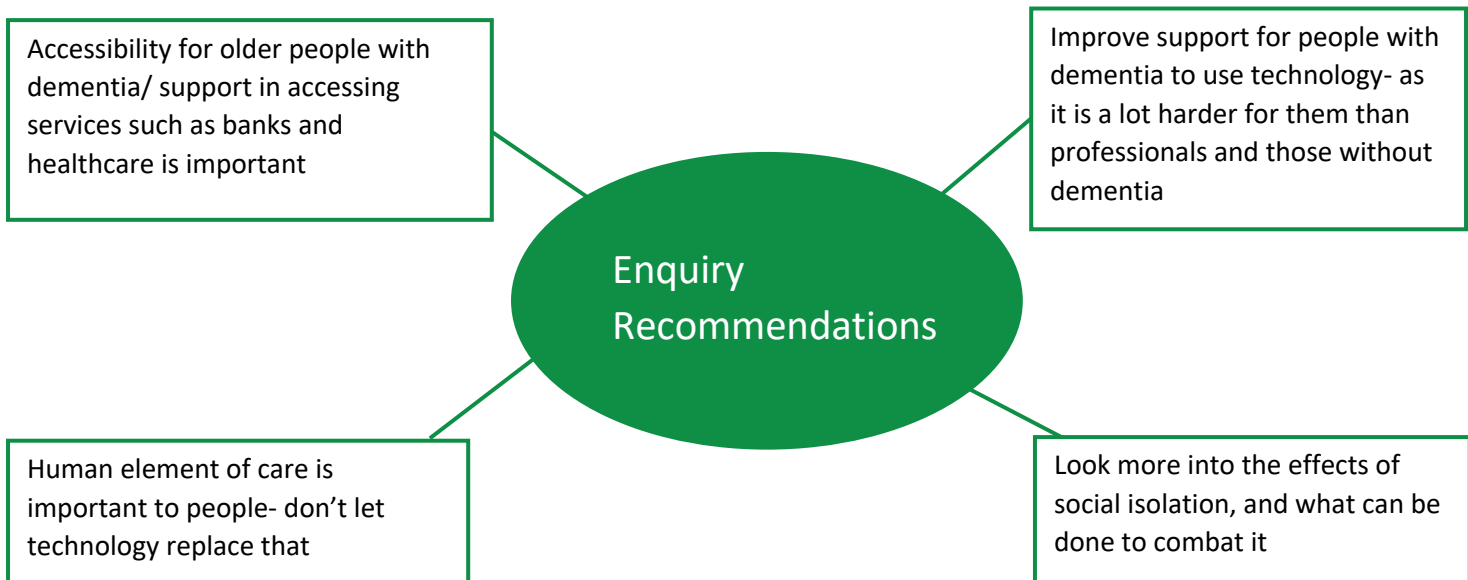
Conclusion

In conclusion, this Enquiry has taught us several important lessons about what people with dementia experienced during the pandemic, and how we can help them during the future. Firstly, most older people with dementia used technology more during the pandemic, however, they still required consistent support to feel properly supported. Many used technology, to maintain their connections with people online, allowing them to maintain their relationships with family and friends. However, many reported a poor relationship with healthcare providers, and have difficulty communicating their needs to them over technology. Many Enquirers turned to outdoor activities such as gardening to cope with the pandemic, but the darker, colder seasons meant that they needed to stay indoors, and therefore were a lot harder to deal with. This inability to go out was a key challenge presented via the lockdown, as Enquirers stated a strong sense of social isolation. This social isolation of the pandemic played a large part in the general decreased mental and physical health that Enquirers reported, with Enquirers citing issues such as weight gain, increased anxiety and reduced self-confidence.

Lessons learned during the Enquiry

In addition, we have learned some valuable lessons about Enquiry writing in general, that made our project both functional and unique. Firstly, communication played an important part in our project, with the working party and students/volunteers constantly contacting one another, allowing the project to run very smoothly. Part of this communication was our ability to disagree with each other, yet still come to constructive conclusions that allowed us to move forward with the Enquiry in a way that was helpful and productive. Also, the students that have helped us have seen considerable growth in their abilities and knowledge during this Enquiry, and the ability to foster said growth is one of the reasons Enquiries such as these are so important.

Finally, we have created some recommendations for care and research that we wish to present:



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Appendices

APPENDIX A: Interview questions we used to gather data from participants

What Impact has COVID had upon my connections with other people, including the Forget-me-Nots?

Throughout this interview, we refer to technology as using it to communicate and connect with others. This includes using the landline, phone, tablet, computer, and so on. This also includes functions such as emailing, texting, and Zoom.

1. What was your experience of using technology to connect with others before this COVID-19 pandemic (thereinafter referred to as “the pandemic”)?

PROMPTS (USE IF NEEDED):

Can you tell us what technology you have used?

Can you tell us how well you used it/can you describe your ability?

2. How has your use of Technology changed in the pandemic, in order to connect with others?

PROMPTS (USE IF NEEDED):

Can you tell us what technology you have used?

Can you tell us how well you used it?

Who have you connected with? Friends? Family? FMNs/other people with dementia?

3. 'What are the challenges (positive or negative) of technology you have experienced as someone with dementia?'

PROMPTS (USE IF NEEDED):

Have you been supported? If so by who?

4. 'How have you overcome them?'

5. 'How has the pandemic affected your relationships with others?'

PROMPTS (USE IF NEEDED):

Close friends/ family?

FMNs/others with dementia?

Local community/people near you?

6. 'Since March 2020, we have experienced 3 lockdowns in different times – summer, winter, now. How have you coped?'
7. 'Have you changed how you cope with the pandemic as it has progressed?'

PROMPTS (USE IF NEEDED):

How have your coping strategies changed with the season? (because the season affects how we coped)

8. 'Lockdown has ceased face-to-face meetings with the FMNs. Have you missed them, and if so what have you missed the most?'

PROMPTS (USE IF NEEDED):

Have you missed? :

F2F meetings?

The FMNs in general?

Students/volunteers?

The walk/journey to the meeting?

9. 'Do you think lockdowns and social restrictions have affected your dementia, and if so, how?'

10. 'How has your physical and/or mental health been looked after by professionals?'

PROMPTS (USE IF NEEDED):

How has technology been used in your care from professionals?'

'Has the frequency of encountering healthcare professionals been affected?'

11. 'In what ways, has the experience of the pandemic affected your physical health?'

12. 'In what ways, has the experience of the pandemic affected your dementia, and your general mental health?'

13. 'As someone living with dementia, have there been any positive experiences throughout the pandemic, and if so what were they?'

PROMPTS (USE IF NEEDED):

How has connecting with others helped you?

How has technology supported your connections?

Highlight the little successes – projects, going out on walks, talking to neighbour more, etc

Improving your skills with technology?

APPENDIX B: Questionnaire used to gauge participant's technology usage

DEEP Enquiry

Please complete this questionnaire and mail it back to us alongside your consent form. Details on how to send it back is on the back of the consent form.

Throughout this questionnaire, we refer to technology as using it to communicate and connect with others. This includes using the landline, phone, tablet, computer, and so on. This also includes functions such as emailing, texting, and video-calling such as Zoom or Skype.

Please complete all questions, and tick the options that describe you the most. Tick only one answer per question unless specified.

Name:

Date:

1.How often would you use technology before the pandemic?

- Never
- Not Very Often
- Sometimes
- Quite Often
- All the Time

2.How often do you use technology now?

- Never
- Not Very Often
- Sometimes
- Quite Often
- All The Time

3. What forms of technology did you use to connect with others before the pandemic? Please tick all that apply.

Telephoning

Video-Calling

Texting

Emailing

Social Media (e.g. Facebook)

Instant Messaging

Other (please note down the form(s) of technology):

4. What forms of technology do you now use to connect with others? Please tick all that apply.

- Telephoning
- Video-Calling
- Texting
- Emailing
- Social Media (e.g. Facebook)
- Instant Messaging
- Other (please note down the form(s) of technology):

5. Are you more comfortable using technology now or before the pandemic?

- More comfortable now
- More comfortable before the pandemic
- No difference

.....

APPENDIX C: Consent form given to participants



Forget-Me-Nots' 2021 DEEP Enquiry Consent Form

You have agreed to take part in the following enquiry – **What Impact has COVID had upon my connections with other people, including the Forget-Me-Nots?**

- You have the right to be anonymised.
- All interviews will be recorded and stored on KMPT devices.
- All recordings will be transcribed by students/volunteers.
- Your interview will not be published in full. However, certain details and themes may be mentioned in the final product. These may be published in local and national media, in publications, or other promotional material for which it may be suitable.

If you give consent, it allows us to use details from your interview. You have the right to withdraw at any point without consequences up until the report has been finalised.

If you have any questions, please contact **Theo Chan** at theo.chan@nhs.net before signing this form.

Please putting "X" in the following boxes that you give consent to:

- I agree for my interview to be recorded and stored by the KMPT.
- I agree that my interview will be used in the DEEP Enquiry.
- I understand and agree that I have the right to withdraw my participation without consequences at any point until the report is finalised. Once it is finalised, it is not possible to make any amendments.
- I agree that the DEEP Enquiry report can be shared publically, and that anyone can read the report.

Name:

Signature:

Date:

