

TECHNOLOGY ENABLED CARE

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**'Ask Us About Dementia'
Pilot Support Service
Independent Evaluation**

May 2021

Owners, Authors & Referencing the Data

Owners: This data is the ownership of Technology Enabled Care (TEC) Cymru and their funders the Welsh Government on behalf of the 'Ask Us About Dementia' pilot support service. As independent researchers, the data was recruited, collected, analysed & written up independently for the 'Ask Us About Dementia' pilot by the TEC Cymru in-house Research & Evaluation Team, forming an independent research perspective.

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Referencing: When using the data as a source please reference the authors of the data accordingly.

Introduction

Dementia is an illness that effects not only the individual with the condition but also that individual's wider social support systems. These systems of support and care are often made up of family members as long-term, unpaid carers¹. Being an unpaid carer for a family member with dementia can often be a stressful and upsetting experience, with many carers feeling isolated and often experiencing their own levels of inadequate support².

While there is support out there for unpaid carers, such as respite care options and support groups, access often varies due to a number of factors. Access can be dependent on location; whereby extremely rural areas may struggle to have full access to support³. Care support at certain times can also be expensive or reliant on small waiting lists to ensure timely access⁴⁻⁵. These factors can create possible barriers in accessibility to support for individuals with dementia and their carers.

While these services are available for carers to access, it has been reported that services struggle to meet the demand of supporting everyone that needs it⁶. While this has been a known issue within care sectors for a long period, it has only become more challenging and problematic with the impact of the COVID-19 pandemic^{7,8}. Its impact has meant that services offering support, particularly face to face services such as support groups, have been unable to offer the same levels of support to individuals with dementia and their family carers. This dramatic reduction in care services face to face means that family carers are taking on more of this burden without the same levels of support, in an already extremely difficult and emotional time^{9,10}. The reduction in support and care availability due to the pandemic has left individuals with dementia and their families with worsening mental health levels, and increased difficulties in connecting with support services¹¹⁻¹³.

Many family carers look to care services to provide help to their family member with dementia, with these services often providing respite and much needed recuperation for the unpaid carers. Health and social care staff, often known as paid carers, however, have also been stretched to breaking point in most recent months with the COVID-19 pandemic¹⁴. This has taken its toll on care areas such as care homes which have seen an increase in staff sickness, and also logistics becoming increasingly difficult in how to provide care and support in the community to those individuals with dementia and their families who are still at home¹⁵.

While assistive technology, helplines and video services have become more readily available in recent years for carers to access¹⁶⁻¹⁸, due to the pandemic there has been a rapid need and a shift towards easily accessible methods of support for carers, particularly unpaid carers in this format^{19,20}.

Research suggests that the use of helplines and video consultations relieve stress of unpaid carers and dramatically reduce the pressure they feel as they have been able to gain guidance and support²¹.

With the pandemic effecting care services across the whole of the UK, in Wales there was recognition of how it was impacting family carers and that this needed to be rectified and ensure support was available for carers to have access to now, but also in the future. Due to this, Health and Social Care Wales implemented the 'Ask Us About Dementia' pilot, a national dementia service, offering support to family and paid carers. This pilot was partnered with an informatics video consultation programme 'Attend Anywhere (AA)' brought alive in Wales by TEC Cymru.

The pilot dementia service worked by ensuring that both unpaid carers and health and social staff could book video consultations with dementia practitioners from various specialities, such as dietetics and speech and language therapy. The practitioners were able to provide knowledgeable advice, skills and signposting to further local services available to the carer.

The 'Ask Us About Dementia' pilot was linked closely to pilot sites. The pilot sites were able to book virtual consultations for health and social staff and the unpaid carers by triaging appointments to the relevant dementia practitioners. This ensured that carers' video consultations were matched to best fit the practitioners who had specific knowledge in the areas where support was needed. Practitioners in the video consultations were always paired to ensure that a range of skills could be provided and increase levels of peer learning amongst practitioners too.

Aims

The aim of this pilot service evaluation is to present the findings into how video consultations worked within the 'Ask Us About Dementia' pilot project for its users and pilot sites, completed with the use of a mixed-method research approach. The evaluation focuses on the use and value of video consultations within a pilot service, along with any benefits and potential challenges of using video consults as the primary method of consulting within dementia services.

Method and Summary of the Data

To evaluate the 'Ask Us About Dementia' pilot service, mixed methodologies were used in the form of a focus group, surveys and interviews. Dementia practitioners who were part of the service delivering the video consultations were invited to participate in a focus group (N = 5), and a specific practitioner survey was created for those who were unable to attend the focus group (N = 7).

Family carers and health and social staff at the time of accessing the dementia service were asked if they consented to participate in telephone interviews (N = 6) and a survey (N = 11) at a later stage in the pilot service. This was a separate survey to the practitioners. A retrospective survey (N = 6) was designed and distributed to the pilot sites involved in the service, focussing on their role in the set-up of the pilot.

The focus group, along with all surveys and interviews, were centred on the use and value of video consultations as the mode of delivery for the service sessions. The practitioner focus group and the telephone interviews with family carers and health and social care staff were thematically analysed. All survey data was analysed in terms of response distribution.

These mixed methods were used as a scoping exercise to investigate what the most suitable methodology would be in reaching practitioners and service users for a larger pilot evaluation, where appropriate research and evaluation funding is available. This larger evaluation would further aid the end-goal of informing future decisions in the long-term roll out of the service on a national level.

Results

Dementia Practitioner Findings

100% of dementia practitioners from the survey (N = 7) reported that they felt the pilot service achieved its aim of providing timely access to expert advice and signposting on dementia care through the use of video consulting, as well as supporting peer learning between health and social care practitioners. 85.71% of practitioners felt as though the pilot service increased awareness of allied health professionals, and improved access to their expertise through video consulting. 100% of practitioners also reported that they had positive experiences of using 'Attend Anywhere' as the mode of delivery for the pilot service sessions.

Thematic Analysis- Practitioners

As seen from the quantitative results, dementia practitioners were happy with using video consultation as part of the pilot. This is also reflected in the findings from the focus group and qualitative comments of the survey, whereby practitioners' narrative surrounding video consulting support its use for dementia services.

"I've just found AA to be superb really...the platform is excellent"
(Hospice palliative care family support).

"It would be impractical doing it FTF- financially, timewise, all sort of unviable" (Hospice palliative care family support).

Themes highlighted from this analysis include video consulting allowing for collaborative working, being easy to use and providing a further route for users to access support. Quotes are provided below.

As suggested, practitioners were pleased with being able to use video consultations to experience and improve on their peer learning and collaboration.

"It has been interesting linking up with other colleagues across Wales, it has been a good real link up across skills" (Occupational Therapist, BCUHB).

"It has been good to meet other professionals, especially those I haven't worked with before" (Dementia Lead Speech and Language Therapist, HDUHB).

"Working alongside other health care professionals and learning from their knowledge" (Clinical lead dietician, HDUHB).

"It was an excellent opportunity to work as a multidisciplinary team"
(Advanced Audiology Practitioner, CAVUHB).

Video consulting was also seen as *"lovely just to kind of pitch up and do your stuff"* (Hospice palliative care family support) and easy to use by the practitioners.

"I use it as part of my day job and find it a great platform to use"
(Pharmacist, HDUHB).

"I have found it relatively easy to use and the sessions haven't had any IT issues during the actual consultation" (Clinical lead dietician, HDUHB).

Video consulting also allowed for an added access line for carers to seek and gain support.

“A couple of our calls were people coming in as former carers, so being able to phone and speak to us in a non-judgemental way asking- “am I doing the right thing is this right from what I learnt all those years ago” they didn’t have to say in front of their peers if they weren’t feeling confident. It was lovely that we could provide that level of reassurance” (MH Physiotherapist, CAVUHB).

“It is really useful people have another platform because we were having people who were often turned away from other services like GPs when they were wanting to bring up those conversations. It was nice that they had another option to come through to us and get that done and that’s so important especially in dementia, as soon as we can” (Palliative care social worker, ABUHB).

While video consulting did yield many benefits for the dementia practitioners, there were some concerns surrounding confidence levels of using a new video consulting platform and the time taken to become fully conversant.

“I’m not in the NHS so AA is a really alien concept to me. For me it’s about the confidence, and there’s sometimes a gap between the last time you did it a month ago and now and that’s a bit strange and you’ve forgotten” (Social Care Workforce Development Partnership Co-ordinator).

“I think you need to have a bit of time to develop your confidence if you’re going to do it, and plan that into your diary” (Social Care Workforce Development Partnership Co-ordinator).

While confidence levels were an issue for a small number of practitioners, this was counterbalanced by others who suggested that they had a wealth of support providing to them in using video consults and had access to a plethora of readily available resources. It is evident that practitioners need the confidence to use video consulting platforms which can be achieved with regular use.

“We were offered training at the beginning and regularly throughout if we needed a top up session” (Palliative care social worker, ABUHB).

“I did some of the TEC Cymru training with the videos and that has been really useful as well because I’ve done some group work, so it was useful to reinforce knowledge so that has been handy” (Hospice palliative care family support).

“The more you use the more comfortable you get really” (Hospice palliative care family support).

“Opportunity to increase confidence with using telehealth” (Speech and Language Therapist, BCUHB).

“Following the training it was straight forward to use. However, if I had accessed it more frequently, I would have become more proficient at using the system” (Dementia Lead, PTHB).

Although certain practitioners were concerned about digital exclusion for some of the dementia pilot users,

“Aware of patients being able to access it digitally. And I know there’s lots out there from digital wales lots of different initiatives, but it is restricted if you don’t know how-to use the platform” (MH Physiotherapist, CAVUHB).

“I’m wondering moving forward whether it could be both, if people aren’t comfortable digitally, we can still offer it on a telephone” (MH Physiotherapist CAVUHB).

When speaking with family carers they were extremely satisfied with their video consultations and experienced no difficulty in access or use. This is highlighted in quotes with family carers from the telephone interviews.

“Clear instructions were provided and communication prior to meeting was very good” (Family carer).

“If I had to set up the appointment I would struggle, but it was just click on a link, isn’t it? I didn’t have to ask my daughter or anything” (Family carer).

Family Carers and Health and Social Care Staff Findings

Quantitative results from the survey data with family carers and staff that accessed the pilot service (N = 11) highlight that **81%** of respondents rated VC as **'excellent'**, **'very good'** or **'good'** (see Figure 1). This suggests that respondents were satisfied with their use of video consulting.

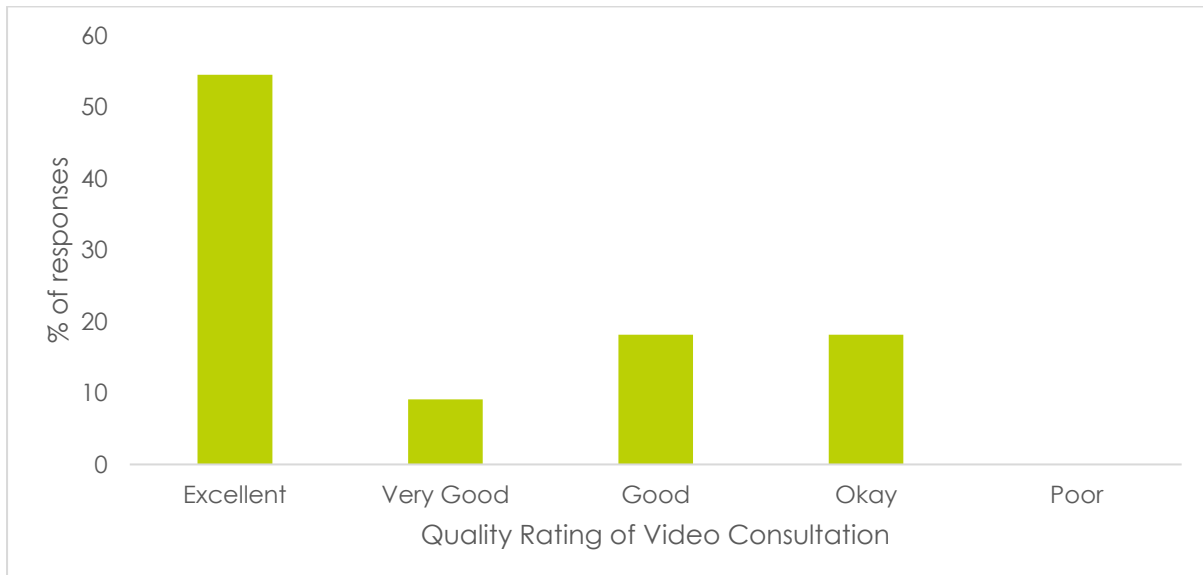


Figure 1. Family carer and health staff VC quality ratings.

Findings from the survey also indicate that the average confidence level for using VC was **71%**, with **100%** of respondents stating that they would use VC again to access the dementia service.

Along with this, **90%** of those would recommend VC as an option for other individuals to use, and **81%** felt as though the video consulting appointment had prevented the need for a face-to-face session.

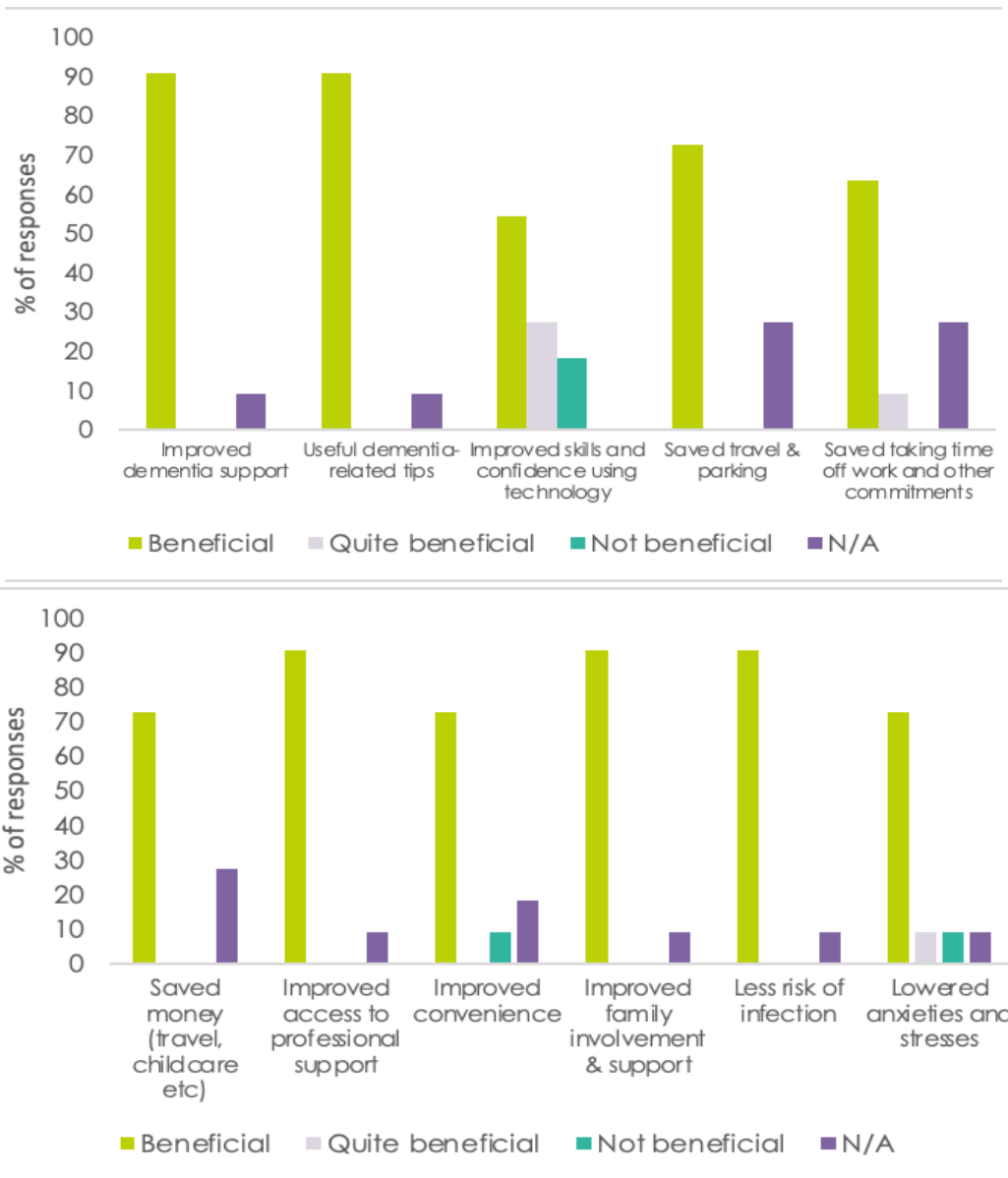
Benefits and Challenges to VC

Respondents also rated whether there were any benefits (see Figures 2 and 3) or challenges (see Figure 4) to using video consulting for their sessions. Respondents rated these questions using Likert scales.

Due to the low numbers of the survey, responses have been combined into 'Beneficial' = very beneficial and beneficial, 'quite beneficial' and 'Not Beneficial' = not at all beneficial and not beneficial. The same combination has also been applied to challenges with 'Challenging' = very challenging and challenging, 'quite challenging' and 'Not Challenging' = not at all challenging and not challenging.

The highest rated benefits reported were 'Improved dementia support' (90.9%), 'Useful dementia tips and suggestions' (90.9%), 'Improved access to dementia support' (90.9%), 'Improved family involvement' (90.9%) and 'Less risk of infection' (90.9%).

While 'Saved taking time off work and other commitments' (63.64%) and 'Improved skills and confidence using technology' (54.54%) were rated less beneficially, it had no impact on the previously reported positive confidence ratings of using video consulting.



Figures 2 and 3. Percentages of VC family carer and health staff benefits.

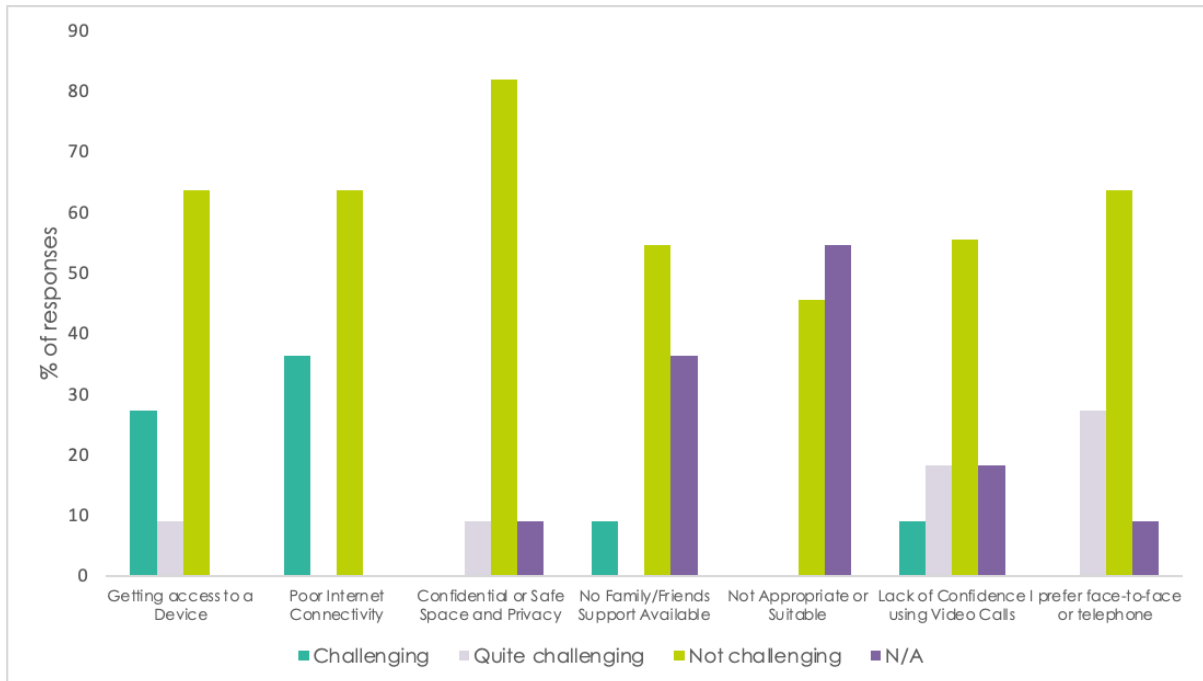


Figure 4. Percentages of VC family carer and health staff challenges.

The highest rated challenge was 'Poor internet connectivity' (36.36%) and 'Getting access to a device' (27.27%). While these were the highest rated challenges, 100% had previously said they would use video consulting again. The lowest rated challenges were 'Confidential space and privacy' (0%) and 'Preference to face-to-face and telephone' (0%).

Thematic Analysis- Family carers and health and social care staff

Similarly to the results highlighted with practitioners, family carers and staff that accessed the dementia pilot service were incredibly satisfied with their session and happy with the platform in accessing support. The thematic analysis includes survey and interview data.

"Sometimes you don't have a chance to speak to somebody like that, doing it over VC was good" (Family carer).

"I feel it worked extremely well. I am thrilled to have a service on hand like this for my service users to attend. It will be a huge shame for it to go - I love it!" (Dementia support worker).

"They were great. They gave me loads of information in which I could understand" (Family carer).

“They told me who to contact and some information that I followed up on. And at the end of the conversation with them, I felt far more positive” (Family carer).

“I can see this service becoming invaluable for unpaid Carers. It saves us time which we never have enough of and answers difficult questions in a relaxed way!” (Family carer).

“Actually, it was really helpful. Because I'm sure you're aware that it desperately, desperately under supported in the community. And it's been, you know, our nine-year battle with this disease? Very much a battle of getting the right help. And the right support. So yes, it was really, really good” (Family carer).

“That was a good way to access that type of advice that I wouldn't have been able to, so it was good” (Family carer).

“Very pleased with consultation all my questions were answered” (Family carer).

“In this kind of service having online access is time saving and efficient” (Family carer).

“This is an excellent Service and incredibly beneficial. I really hope it can continue” (Health adviser).

What was noted as important to family carers was the opportunity to be able to fit appointments around existing dementia care, so there was no need to leave the house for appointments.

“Because carers come in with me in the day. So it would be best for me to stick to the day time. You know, if somebody was with my husband, and I could speak to somebody more freely on the computer than” (Family carer).

“I could do it in the house as well, you know, can work around me then. Sometimes you got to go to hospital or go to somewhere and then you got, you know, yeah, so it was good. It was done in the house where you can relax” (Family carer).

“I don't have evenings. It's that little space after [name removed] goes to bed when I fall down and I'm exhausted. Yeah, no, it was good timing” (Family carer).

While there were some issues with connectivity as reported within the challenges above, these were easily overcome within the sessions and did not greatly impact the service appointments.

"I am very familiar with video calls and therefore confident, I also have a safe and private space to use while on the call. We were suddenly 'thrown out' of the call at one point - both speech therapists and myself - we did not know why this happened, but were quickly reconnected after a few minutes" (Family carer).

"Connection caused issues with delays, but otherwise lovely and helpful people" (Family carer).

"I was not familiar with this calling service, maybe an extra clear large writing explanation saying click here or even a button or highlight on the email, I am 27 and tech savvy, but older people may have difficulty knowing where to click" (Family carer).

As the quantitative findings suggested, many carers would also use the service again via video consulting.

"It has been helpful. I'm sure I would use them again" (Health and care worker).

"Great accessibility and project, I hope to use it again to keep navigating dementia together" (Family carer).

"Very pleased with the service and would use again - good to have such expertise with no waiting time. I can also act on the advice given immediately to improve my dad's care" (Family carer).

From the thematic analysis, the opportunity to speak with more than one practitioner was extremely helpful via video consulting for the carers. This is evidenced in the quotes below.

"It was nice to because I spoke to two people. Yeah, they were very helpful. Give me some, you know, some ideas to go forward with" (Family carer).

"[Name removed] and [Name removed] were so informative- not just for the service user but has also provided me with knowledge in my role" (Dementia support worker).

“The dementia stuff has been very helpful, the people have been superb but the follow up with the other organisations that are supposedly there to help you, I think are run by robots” (Family carer).

“Great to have two specialists helping discuss the issues I face with my Gran, it is really assuring to talk things through, and they provided useful information without having to go through several people and steps to obtain it” (Family carer).

“Having a tailored call saves time as you can get right to the point and having two people sharing the conversation means that different areas of expertise are covered, which is a thorough approach” (Family carer).

“It was also helpful to have other professionals sign posted and I will follow this up today. I can highly recommend this project” (Family carer).

Pilot Sites Findings

From the pilot site survey (N = 6), 83.33% of respondents rated the ease of the booking system as 'excellent' and 'very good', with 100% reporting that they were kept well informed about upcoming appointments.

83.33% of the pilot sites also reported that they felt the pilot service had achieved its aims of increasing awareness of allied health professionals, and also that the service has been able to provide timely access to support through the use of video consulting.

Narrative comments left by respondents on a whole suggested that they were extremely pleased with their involvement in the service, and hoped that there would be scope to be able to expand into further areas across specialities.

“It is an amazing service and I hope it continues” (Creative Director).

“Knowing that I can signpost people to the service or support then in accessing it is great. Under normal circumstances it can be really difficult to get a referral to the staff groups represented through the service so being able to potentially arrange an appointment to chat with an OT, physio, CPN or other specialist within a week or a few weeks is incredibly valuable! I think it is an absolutely wonderful service!” (Dementia advisor).

“This type of service should be extended to other areas like occupational health” (Researcher, Swansea Cancer Centre).

"I found the system very easy to use but it could be more difficult for someone with dementia, which is why it's great that you can arrange the appointment for them!" (Dementia Advisor).

Pilot Sites Suggestions

There were a number of suggestions raised by pilot sites within the analysis, with one pilot site highlighting that the service should *"advertise the service more so that more people are aware of the service and what it has to offer."* Another suggestion included a greater availability of appointments on offer as this particular site had struggled with the limited slots. These will be added as a recommendation at the end of the report.

Discussion

Overall, it is evident that video consulting has worked extremely well within this pilot 'Ask Us About Dementia' service. Practitioners, family carers and health staff and the pilot sites involved so far have had positive experiences as highlighted within the results. Having the ability to use video consulting as a means to conduct appointments has been invaluable. While there were some challenges noted at times, these were overcome easily and should not take attention away from the wealth of positives that have been reported when using video consulting.

For practitioners, video consulting allowed for peer support and learning to be made readily available across Wales, ensuring that the best advice and support was available to those accessing the service.

Family carers and health and social care staff really valued the opportunity to be able to speak with more than one practitioner, by speaking with two they felt they were given more specific advice. This was easily achievable using video consulting for the pilot and would be increasingly more difficult using a different method of consulting, such as telephone or face-to-face due to the logistics behind it. Video consulting provided an easy platform to achieve this and would all continue to use the service if available in the future.

Pilot sites were also in agreement that the platform was easy to use and felt they were kept well informed of upcoming appointments. Thematic results also suggest that the pilot sites valued having the opportunity of the service and hoped for it to be extended across various specialities.

A limitation of the independent evaluation is that unfortunately, participant numbers across all surveys, interviews and focus groups were lower than expected. While numbers were low, this is an initial pilot evaluation, and the

responses did yield rich results. This is an area for improvement as seen in the recommendations below.

Recommendations

While the initial independent TEC Cymru evaluation of the pilot service 'Ask Us About Dementia' has highlighted that video consulting works well as part of the service, and would recommend continuing this pilot study into a national scale-up. There are however recommendation points to consider when moving forward:

- More dedicated research time that is properly commissioned and funded, ensuring that a full evaluation service benefits from greater participant uptake and outputs.
- Ensure greater availability of appointments are available for pilot sites.
- Raise further awareness of the 'Ask Us About Dementia' service to relevant services, organisations and individuals that may benefit from its use.

References

1. Górska S, Forsyth K, Irvine L, Maciver D, Prior S, Whitehead J, et al. Service-related needs of older people with dementia: perspectives of service users and their unpaid carers. *International psychogeriatrics*. 2013 Jul 1; 25(7):1107.
2. Jennings LA, Reuben DB, Evertson LC, Serrano KS, Ercoli L, Grill J, et al. Unmet needs of caregivers of individuals referred to a dementia care program. *Journal of the American Geriatrics Society*. 2015 Feb; 63(2):282-9.
3. Giebel C. "Current dementia care: what are the difficulties and how can we advance care globally?" *BMC Health Services Research*. 2020; 20(1).
4. Donnelly NA, Humphries N, Hickey A, Doyle F. "We don't have the infrastructure to support them at home": How health system inadequacies impact on long-term care admissions of people with dementia. *Health Policy*. 2017 Dec 1; 121(12):1280-7.
5. Meiland FJ, Danse JA, Wendte JF, Klazinga NS, Gunning-Schepers LJ. Caring for relatives with dementia—caregiver experiences of relatives of patients on the waiting list for admission to a psychogeriatric nursing home in The Netherlands. *Scandinavian Journal of Public Health*. 2001 Apr; 29(2):113-21.
6. Tropea J, LoGiudice D, Liew D, Roberts C, Brand C. Caring for people with dementia in hospital: findings from a survey to identify barriers and facilitators to implementing best practice dementia care. *International Psychogeriatrics*. 2017 Mar 1; 29(3):467.
7. Michalowsky B, Hoffmann W, Bohlken J, Kostev K. Effect of the COVID-19 Lockdown on Disease Recognition and Utilization of Healthcare Services in the Older Population in German: A Cross-sectional Study. *Age and ageing*. 2020 Nov 17.
8. Giebel C, Lord K, Cooper C, Shenton J, Cannon J, Pulford D, et al. A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *International journal of geriatric psychiatry*. 2021 Mar; 36(3):393-402.
9. Bleijlevens MH, Stolt M, Stephan A, Zabalegui A, Saks K, Sutcliffe C, et al. RightTimePlaceCare Consortium. Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia:

evidence from the European RightTimePlaceCare prospective cohort study. *Journal of advanced nursing*. 2015 Jun; 71(6):1378-91.

10. Giebel C, Cannon J, Hanna K, Butchard S, Eley R, Gaughan A, et al. Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Aging & Mental Health*. 2020 Sep 18:1-8.

11. Gonzalez AS, Harding E, Zimmerman N, Hoare Z, Brotherhood E, Crutch SJ. The impact of the first UK Covid-19 lockdown on carers and people living with low prevalence dementia: results from the Rare Dementia Support survey. *medRxiv*. 2020 Jan 1.

12. Hanna K, Giebel C, Tetlow H, Ward K, Shenton J, Cannon J, et al. Emotional and mental wellbeing following COVID-19 public health measures on people living with dementia and carers. *Journal of Geriatric Psychiatry and Neurology*. 2021 Jan 26:0891988721996816.

13. Giebel C, Lord K, Cooper C, Shenton J, Cannon J, Pulford D, et al. A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers. *International journal of geriatric psychiatry*. 2021 Mar; 36(3):393-402.

14. Keng A, Brown EE, Rostas A, Rajji TK, Pollock BG, Mulsant BH, et al. Effectively Caring for Individuals With Behavioral and Psychological Symptoms of Dementia During the COVID-19 Pandemic. *Frontiers in Psychiatry*. 2020; 11.

15. White EM, Wetle TF, Reddy A, Baier RR. Front-line nursing home staff experiences during the COVID-19 pandemic. *Journal of the American Medical Directors Association*. 2021 Jan 1; 22(1):199-203.

16. Sriram V, Jenkinson C, Peters M. Carers' experience of using assistive technology for dementia care at home: a qualitative study. *BMJ open*. 2020 Mar 1; 10(3):e034460.

17. Tuijt R, Rait G, Frost R, Wilcock J, Manthorpe J, Walters K. Remote primary care consultations for people living with dementia during the COVID-19 pandemic: experiences of people living with dementia and their carers. *British Journal of General Practice*. 2021 Feb 23.

18. Dang S, Gomez-Orozco CA, van Zuilen MH, Levis S. Providing dementia consultations to veterans using clinical video telehealth: results from a clinical demonstration project. *Telemedicine and e-Health*. 2018 Mar 1; 24(3):203-9.

19. Cuffaro L, Di Lorenzo F, Bonavita S, Todeschini G, Leocani L, Lavgogna L. Dementia care and COVID-19 pandemic: a necessary digital revolution. *Neurological Sciences*. 2020 Aug; 41(8):1977-9.
20. Brown P, Oliver E, Harrison Dening K. Increasing need for telehealth services for families affected by dementia as a result of Covid-19. *Journal of Community Nursing*. 2020 Oct 1; 34(5).
21. Shaw CA, Williams KN, Lee RH, Coleman CK. Cost-effectiveness of a telehealth intervention for in-home dementia care support: Findings from the FamTechCare clinical trial. *Research in nursing & health*. 2021 Feb; 44(1):60-70.