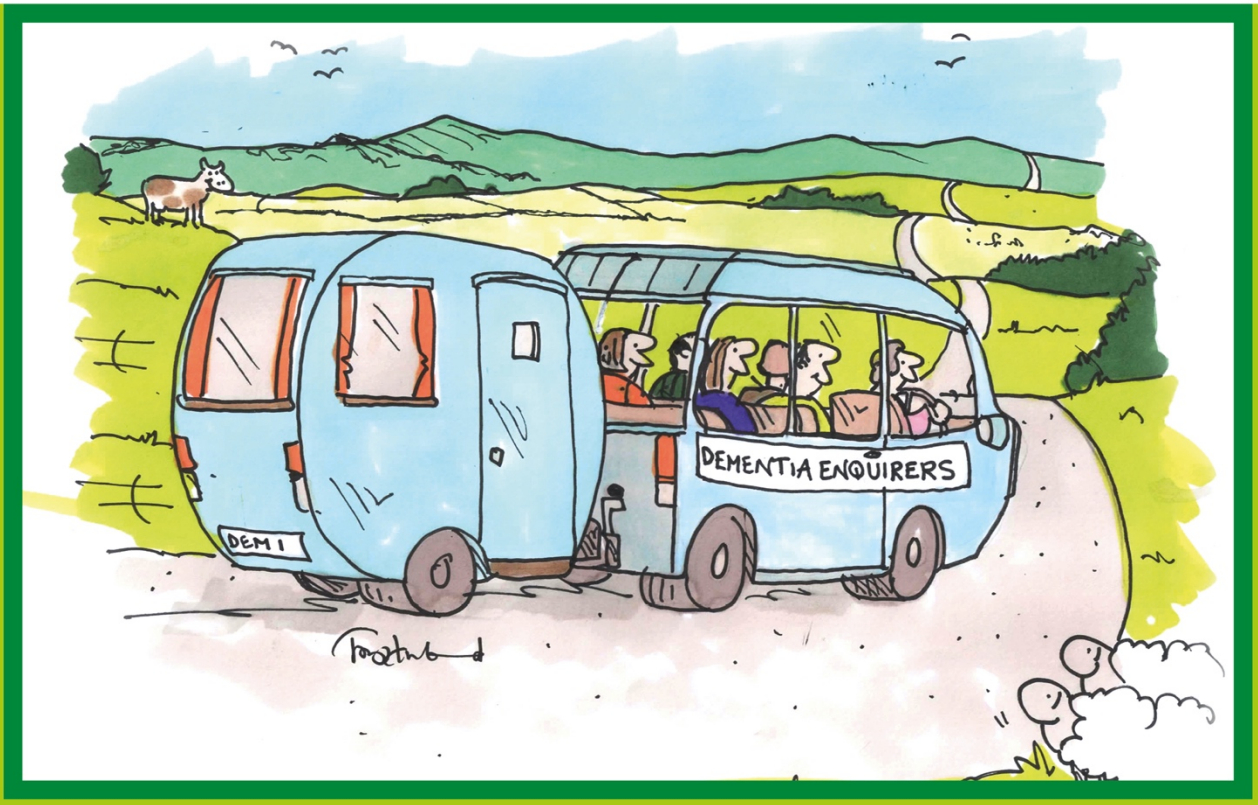
DEEPNESS
DEMENTIA MEDIA

DEEPNess on the Isle of Lewis
Dementia Enquirers Report



The necessary components of a dementia responsive teaching video

July 2020

Dementia Enquirers

COMMUNITY FUND

iD Innovations in Dementia

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 May 2021

You can download this report here:
https://dementiaenquirers.org.uk/individual-projects/deepness-on-the-isle-of-lewis

You can read other Dementia Enquirers reports here:
https://dementiaenquirers.org.uk/individual-projects/

To find out more about Dementia Enquirers visit:
https://dementiaenquirers.org.uk

Contents

Acknowledgements 3

Accessible Summary 4

Introduction 5

Methods 5

Findings 8

Conclusions 9

What Next? 11

DEEPness Dementia Enquirers Project Questionnaire 12

Acknowledgements

DEEPness would like to acknowledge and thank the following for their support in making this project work:

The members of the Expert Group, who gave us both their time and their knowledge, without whom this project could not be done.

The National Lottery Community Fund, Innovations in Dementia and the Dementia Enquirers Pioneers for agreeing to fund the project.

And finally Philly Hare, from Innovations in Dementia, who supported us through the process.

Accessible Summary

DEEPness has carried out some work to find out what type of video content works best for people with dementia. We were mainly interested in finding content to help people with dementia use technology.

We had 14 people taking part. They also acted as our Expert Advice Group. Our Expert Group were asked to watch 3 videos we had made and then tell us which was best for them. The videos were of a young woman, an older woman and a middle-aged man.

The results told us that the content had to be clear, told slowly, and said more than once. They also told us the person on the video was not that important.

Introduction

DEEPness is part of the DEEP network, based on the Isle of Lewis in the Outer Hebrides. In 2019 we were awarded a Dementia Enquirers award of £5,000 to carry out a piece of research to answer the following question:

> What are the elements required to create educational video content that will enable those with dementia to follow it in a way that responds to their needs? And therefore keep them in charge of the process, both of using and choosing technology?

Methods

After creating the first draft text for the manual “Alexa & Me: a dementia responsive guide to Alexa”, it was sent to a number of people for comment. The main comment we received was that many of the instructional videos already available for Alexa were chaotic and wild - typical of the YouTube genre for tech, and therefore not dementia responsive. It was this that drove the need not only to ask the question, but also to answer the question.

People with dementia have led throughout this project - from the idea to where we are currently. As per our proposal, the Expert Group have both advised and been part of the decision-making process on every aspect of the project. The Expert Group was recruited from contacts in the Cross-Party Group on Dementia Scotland (6 people in total), islanders through dementia groups (4 people in total), and various contacts with people on mainland (5 people in total from Inverness, Ullapool and Dingwall). Meetings with the Expert Group were held by Zoom, as described in the methodology below.

On reflection, although this was useful in a focus group way, there was, in our opinion, too much in agreement with everything that

was said or suggested. We suggest that one-to-one interviews may have given us a much wider range of responses and helped improve our data set (which we were rather disappointed with).

The project adopted an action research methodology that is based on a participatory and narrative approach. This involved:

1. Setting up the Expert Group
2. Writing of initial questionnaire by DEEPness (Appendix 1)
3. Approval of questionnaire by Expert Group
4. Questionnaire out to volunteers with lived experience
5. Analysis of questionnaire
6. Information to Expert Group for approval
7. Making of 3 Videos based on questionnaire results
8. Dissemination of videos to volunteers for comment
9. Analysis of volunteer responses

The project was, and still is, clearly led and controlled in an ongoing way by those who have a lived experience. It is 'for us, by us and with us' in its design, governance and implementation. We are supported as needed by family members, our DEEP mentor and other supports on Lewis.

As an action research project, we wanted to go beyond finding the answer to our question by creating dementia-responsive video material. This will open up the possibility of technology in general, and Alexa in particular, to our own members, other group members and indeed anyone who wishes to use this technology.

Our second desired outcome was that the successful implementation of dementia-responsive video materials will create conditions in which people with dementia and their families can take power over available technology through using technology to meet our self-defined needs. Indeed our main aim is for us to retain autonomy, whilst maintaining interdependent relationships with people who are important in our lives.

We had hoped to work with the University of Highland and Islands, but after an initial conversation they never got back to us, and we

did not feel the need to pursue them further. This however should be something that other projects should be aware of, as we did not feel we were being taken seriously by the department.

Since this was in effect a pilot piece of work, we recruited 15 volunteers, of whom 10 had a cognitive impairment and 5 were unpaid primary care providers. We decided not to use the DEEP network of groups, as there was another 9 pieces of research that would be competing for group members' time.

We sent our volunteers links to the 3 videos we had created, and a copy of the questionnaire. We asked them to watch all three and then tell us:

1. What was good about video 1 2 3?
2. What was not so good about video 1 2 3?
3. How did the male presenter come across? Excellent, Good, Not So Good
4. How did the female presenter come across? Excellent, Good, Not So Good
5. How did the teenage presenter come across? Excellent, Good, Not So Good
6. Which, if any, of the presenters worked the best for you and please tell us why?

Findings

As stated earlier, we initially recruited N=15 volunteer testers. One volunteer failed to return the form. We therefore had a cohort of N=14.

All three videos were thought to be excellent or good by all 14 respondents.

The respondents also liked the pace of the videos, the clarity of language, and the length of the videos.

4 respondents thought the male was the most confident, whilst 3 thought the teenager was more knowledgeable. The unpaid care respondents found they could relate to the woman presenter. Here's a lesson for the future: we need to recruit both a better gender and age mix in this group, as this study leaves too many unanswered questions. (All of the care providers were women in their 50s).

When answering 'what was not so good', it was mainly environmental things. For example, 3 respondents said there was too much stuff in the background for people to focus. 2 respondents thought the video needed to be brighter, whilst 2 others thought it should be dimmer.

The greatest amount of feedback we received was about the importance of repeating information. 8 respondents (over half) stated that this would be the most helpful thing that could be done.

Because of this we have adopted a three-hit checklist (often used by religious leaders and politicians):

1. Tell people what you are going to tell them
2. Tell them
3. Tell them that you have told them

We are currently using this in developing films for the recovery college course "Alexa & Me: A Dementia Responsive Guide To

Alexa", that will go live on Deepness Dementia Recovery College at the end of June 2020 on **www.deepnessdementiamedia.com**

Perhaps the most interesting question was the last one. The responses told us one main thing, and that was that different respondents thought that different presenters were best. Before the study, we thought that one presenter would be seen as the way forward because of training, personality or some X factor. This was not the case, and each presenter was preferred by a small group of respondents. In response to this we are reflecting this in our own video materials. We are doing this by making three videos for each Alexa topic. So that when a person finds the right presenter for them, they can then follow their preferred presenter throughout the course.

Conclusions

Did we learn anything new through this exercise? Probably not. But importantly, we were given a clear reminder that people are indeed different - and when we are seeking the answer to a question, we should not be surprised when we get many answers. We are looking in the main to create answers that allow us to put in place solutions for the many. This is for us one of the great weaknesses of research as it is done today. It is too often a misguided position for us to take.

Taking a person-centered approach, the real way forward is to view each person not as a single case study, but as a valid research project. For us, this effectively means that models do not work, and 100 clients again means 100 plans or models - as what each person needs will be different. So we need to make different style videos for the few, rather than try to make them for the many.

In summary, here are some of the things we have learnt from this project:

- To keep consistency, it's better to film the video and then voice-over the instructions

- One-to-one interviews might have been more productive than focus groups
- Recruit both a more balanced gender and age mix in respondents
- It is important to get the right pace, clarity of language, and length in the videos
- Have a simple background
- Repeat information. Tell people what you are going to tell them, tell them, and then tell them that you have told them

What did not work?

Over the course of the project there were a few things that we did not succeed in doing. These were:

- We did not offer a cartoon version using Toonley though we did try it. The software did not lend itself to the type of film we wanted, and was really clunky to use beyond the most simple of cartoon projects. We expect that this will change in the next three years as more products become available.
- The plan to film Agnes setting up Amazon Show was also not followed up because of the Covid19 situation. This is something that DEEPness will follow up in the future.
- We did not use analysis software, due to both the number of participants and the similarity of the answers. This meant we could complete the analysis quickly, without setting up and running the software.
- We wanted to work with Stockport Educate but we are still waiting on Stockport getting in touch. Our best guess is that their confidentiality policies are hindering any cooperation.

What Next?

It is clear that what works differs from person to person. We have therefore concluded that, going forward, we will make each video three times, using all three presenters, with people having the option to use any of them. We intend to make all 14 videos over the next three months when our studio is finished. Until then we have used the best of YouTube.

The Alexa guide will be freely available on DEEPness Dementia Online Recovery College as soon as possible, with all the new videos (42 in total) being added as and when finished.

We will also record a Dementia Diary in the near future. We are hoping to involve some of the Expert Group in this recording.

DEEPness Dementia Enquirers Project Questionnaire

Thank You for agreeing to take part in our Dementia Enquirers project, the purpose of the research project is to discover whether there are components within video content that make it easier for people with dementia to understand. Watch each video answering the first two questions at the end of each video

Video One Click on the Link Below to watch Video 1

https://vimeo.com/385318183

What was good about video 1?

What was not so good about video 1?

Now watch video 2 Click on Link Below

https://vimeo.com/392028128

What was good about video 2?

What was not so good about video 2?

Now Watch Video 3 Click on link below

https://vimeo.com/392032242

What was good about video 3?

What was not so good about video 3?

How did the Male presenter come across? Circle one answer

Excellent, Good, Not So Good

How did the Female presenter come across? Circle one answer

Excellent, Good, Not So Good

How did the Teenage presenter come across? Circle one Answer

Excellent, Good, Not So Good

Which if any of the presenters worked the best for you and please tell us why?

Thank you for your help once completed please return to

ron@deepnessdementiaradio.com