DEVELOPING A DEMENTIA INFORMATION PORTAL FOR DEAF BRITISH SIGN LANGUAGE USERS: A PILOT STUDY

Manchester Interdisciplinary Collaboration for Research on Ageing: Seedcorn funding

Summary Report
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Research aims and objectives

There are 3 primary research aims:

- To develop and pilot a dementia information portal (ideally with a mobile app) that will share information about dementia in British Sign Language;
- To evaluate the usefulness of having such information in BSL;
- To provide the foundation for a larger scale study, including greater appreciation of the role of information in supporting Deaf people living with dementia and their families.

Background

One of the key findings from the Alzheimer's Society funded project 'Deaf with Dementia' (DwD) was that information should be made available online to Deaf people in their native language and needs to be visually concise and accessible for Deaf BSL users (Appendix One). Concerns were raised however that translation on its own from English to BSL did not guarantee cultural intelligibility or full access for Deaf people (Ferguson-Coleman et al, 2014). How information is presented, not just what is 'said' is important.

Following the initial meeting with the Collaborative Learning Group (some members of which were previously involved in the DwD project), it was agreed to pilot a comparative presentation of online material. Specifically to contrast a translation of pre-existing information material designed for hearing people with a bespoke version of that material (a transposition) that aimed to utilise Deaf preferred ways of knowing and presenting. This can be achieved by having someone produce in BSL some deaf-friendly scenarios and/or graphics incorporated on the screen, in keeping with the context of the video. A small pilot would then provide information and feedback with a view to identifying preferences and features to be developed further in subsequent stages of future projects. The introduction of cybernetics e.g. animated avatars was suggested but for this kind of study, it was dismissed as it is more culturally appropriate to have a real-life person presenting, not an avatar. Also avatar technologies are not yet sophisticated enough to replicate the degree of linguistic detail required.

The filming work was carried out by the research assistant in order to create two different clips. The first version was a BSL translation using the text provided from the 'Getting to know me' as a script, presented by a Deaf BSL translator. The latter version was a presentation of information, using the text provided as a guide, transposed by the same translator in a number of different real-life settings. Both videos were edited by the assistant using Windows Movie Maker, which was readily available in the office. However, the idea of using graphics was unable to be achieved within such a short period of time and budgetary constraints.

A webpage was created and consisted of a BSL clip explaining the purpose of the pilot study, together with two other clips known as Clip A and Clip B (Appendix Two). Inserted below that, was a short survey (Appendix Three) with 4 questions, 3 of them closed, for which we used Survey Monkey software.

The webpage created was up and running under the Deaf with Dementia site on the University of Manchester website for a period of two weeks for people to respond to on a voluntary basis. [http://www.nursing.manchester.ac.uk/deafwithdementia/pilotbslclips]. The link was distributed through Facebook and Twitter.

As shown by Google Analytics (Appendix Four), the webpage got 203 hits, most of which came from the United Kingdom, however some were from outside the UK, including America., Of hits that occurred, just over 50%, were direct and 34% were click-throughs from Facebook.

From the survey results (Appendix Five), we identified that we received 29 responses and all of the respondents chose to leave a comment. 22 out of those are deaf and one respondent skipped Q3. All except 2 of the respondents are BSL users; they are both deaf. 25 of respondents liked Clip B (BSL transposition) best against 4 who preferred Clip A. All of those who preferred Clip A are deaf BSL users.

To conclude, Clip B proves to be a popular choice as a resource for Deaf people who need information about dementia in BSL. From the comments, it is evident that transposition is the best way of getting across information on a topic such as dementia, rather than a straight forward translation. This is how the presenter felt when producing both versions in BSL as they felt Clip B was most culturally-appropriate and they were more at ease delivering such information in BSL. Key points mentioned in the feedback were;

- Clip B was found to be more relaxing and natural. Respondents felt the presenter was more engaging as she presented the information in a way which was more culturally appropriate and more 'deaf friendly'.
- Clip B was filmed in different settings/locations with a break in between different sections; this gave respondents chance to absorb the information.
- Subtitles were well-received; it is seen as a 'reinforcement' when a word being fingerspelt is not familiar.
- Movement in the background, known as 'visual interference', should be kept to a minimum as it can be too distracting when watching the presenter.
- More visual resources are needed for information on a topic such as dementia e.g. images or statistics.
- There is room for improvement with the lighting and the quality of the video.

It is therefore recommended that information be delivered in such a format and that funding be sought for assistance from media services for their expertise in video-filming in

order to achieve a better quality of picture/lighting and to include scenarios and graphics, thus expanding on this initiative further and making such information available to BSL users.

The limitations in this study were the small sample of participants, the limited time-scale, being unable to follow up with online participants to understand more about their preferences and what underpinned them.

References

Ferguson-Coleman, E., Keady, J., & Young, A. (2014). Dementia and the Deaf community: knowledge and service access. Aging and Mental Health, published online, 05 Feb 2014, doi: 10.1080/13607863.2014.880405

Appendix One

Deaf with Dementia project (DwD)

Our work with the Deaf community on the 'Deaf with Dementia' project has clearly shown that information in BSL is vital BUT the translation of information from English to BSL is not very effective.

Why?

- The structure of translated material follows hearing people's preferences. It is usually not the 'Deaf way'
- Deaf people are usually not involved from the beginning in making sure the information is structured in the best way possible. The information should not just be 'for' Deaf people, but 'by' Deaf people.
- Deaf people's visual strengths are not made the best use of if material is created in one language then translated into BSL. Starting from scratch in BSL means that it is possible to explain things in a way that is more visual.
- The use of role play, animation, visual pictures etc. are better ways to promote knowledge and understanding rather than the translation of written scripts between languages.

In this project we want to pilot the 'transposition' of information, rather than the 'translation' of information. This means:

(i) we use, with permission, information that we know is accurate and trustworthy e.g. from one of the Alzheimer's Society leaflets.

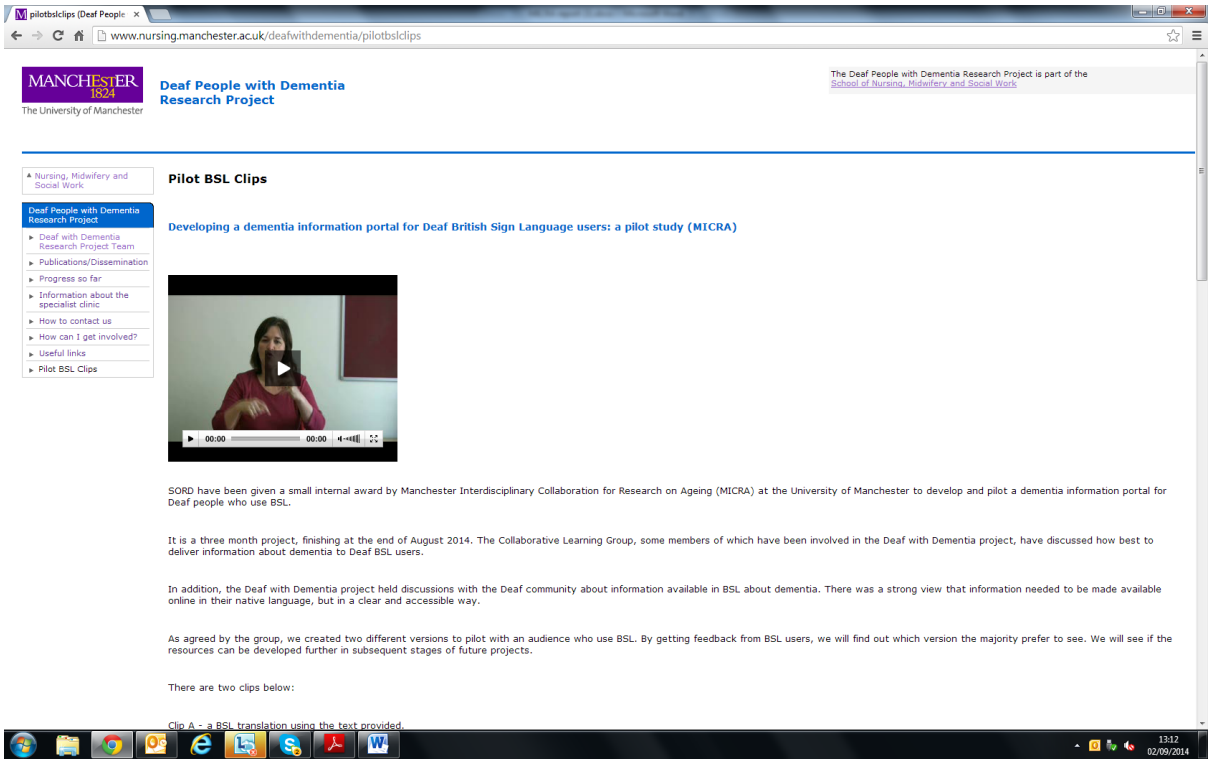
(ii) In a Deaf-led project we work with other Deaf people to think about the best ways to convey that information for Deaf people so everyone feels in touch with it and that it makes sense from a Deaf perspective.

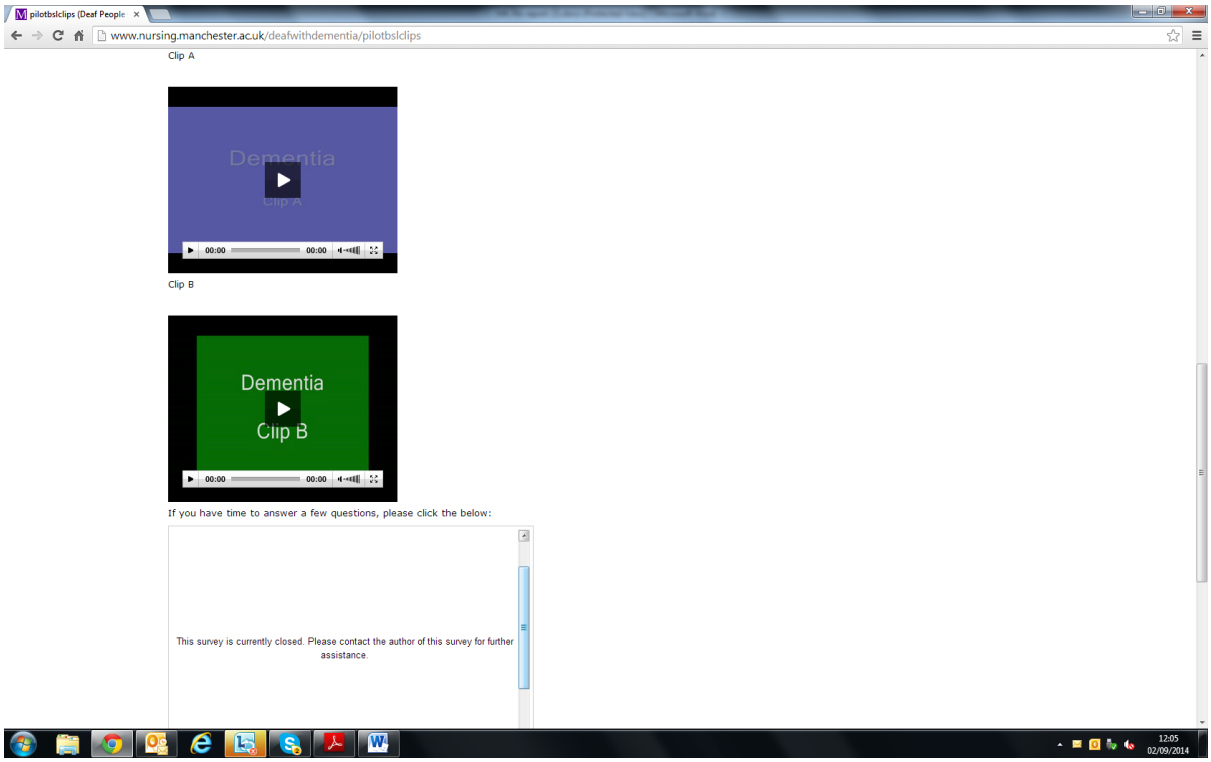
(iii) We then produce the information probably in the form of an acted out scenario.

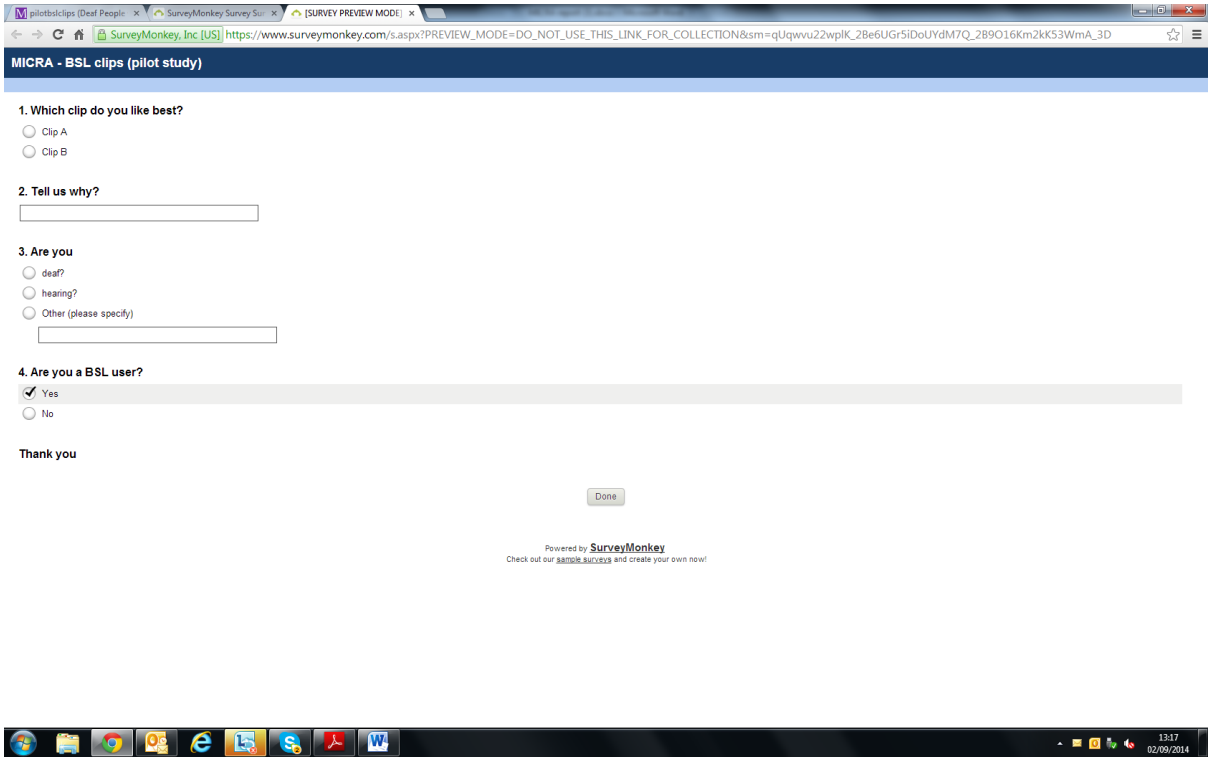
(iv) We post it on a test web site and invite feedback online and in person from other Deaf people.

(v) We report whether this approach to the creation of dementia friendly information by Deaf people for Deaf people works.

Appendix Two: A snapshot of the webpage






pilotbslclips (Deaf People
SurveyMonkey Survey Su
[SURVEY PREVIEW MODE]
SurveyMonkey, Inc [US]
https://www.surveymonkey.com/s.aspx?PREVIEW_MODE=DO_NOT_USE_THIS_LINK_FOR_COLLECTION&sm=qUqwvu22wplK_2Be6UGr5iDoUYdM7Q_2B9O16Km2kK53WmA_3D
MICRA - BSL clips (pilot study)
1. Which clip do you like best?
Clip A
Clip B
2. Tell us why?
3. Are you
deaf?
hearing?
Other (please specify)
4. Are you a BSL user?
Yes
No
Thank you
Done
Powered by SurveyMonkey
Check out our sample surveys and create your own now!
13:17
02/09/2014

Appendix Three: A preview of the survey

MICRA - BSL clips (pilot study)

1. Which clip do you like best?

- Clip A
- Clip B

2. Tell us why?

3. Are you

- deaf?
- hearing?
- Other (please specify)

4. Are you a BSL user?

- Yes
- No

Thank you

Appendix Four: Statistics from Google Analytics

	Landing Page	Acquisition		
		Sessions	% New Sessions	New Users
		203 % of Total: 86.38% (235)	73.89% Site Avg: 74.04% (-0.20%)	150 % of Total: 86.21% (174)
	1. /deafwithdementia/pilotbslclips	**203**(100.00%)	73.89%	150(100.00%)

Source	Acquisition		
	Sessions	% New Sessions	New Users
		203 % of Total: 86.38% (235)	73.89% Site Avg: 74.04% (-0.20%)
1.	(direct)	**102**(50.25%)	68.63%
2.	m.facebook.com	**45**(22.17%)	97.78%
3.	facebook.com	**12**(5.91%)	58.33%
4.	l.facebook.com	**12**(5.91%)	83.33%
5.	t.co	**11**(5.42%)	100.00%
6.	Google	**8**(3.94%)	0.00%
7.	twitter.com	**7**(3.45%)	71.43%
8.	lm.facebook.com	**2**(0.99%)	100.00%
9.	staffnet.manchester.ac.uk	**2**(0.99%)	0.00%
10.	mail.aol.com	**1**(0.49%)	100.00%

Appendix Five: Questions summaries from the use of Survey Monkey

Q1) Which clip do you like best?

- **Answered: 29**
- **Skipped: 0**

Answer Choices	Responses
Clip A	**13.79%** 4
Clip B	**86.21%** 25
Total	29

Q2) Are you

- **Answered: 28**
- **Skipped: 1**

Answer Choices	Responses
deaf?	**78.57%** 22
hearing?	**21.43%** 6
Responses **Other (please specify)**	**0.00%** 0
Total	28

Q3) Comments (see below)

Q4) Are you a BSL user?

- **Answered: 29**
- **Skipped: 0**

Answer Choices	Responses
Yes	**93.10%** 27
No	**6.90%** 2
Total	29

Q3) Comments

Comments from those who like Clip A best;

[deaf, BSL user]

R26: Green background and clear

R23: Clip B has too much background info that is distracting & lighting in wrong place. But clip A could be improved by using background information like statistics and visual information like including the spellings of different dementia. Also use pictures as well.

R17: In BSL explaining simple calm clear understand information ok

R2: In Clip B the Presenter too far back and some of the background are bit too distract but like the slide of each part and good colour of clothing stand out more for better visibility with signing

Comments from those who like Clip B best;

[deaf, BSL user]

R29: I like Clip B because that included subtitles and break into different location. Clip A is important and the dementia is serious issues but people views very negative about this. So Clip B reflects the fact and in the positive ways. Some of Clip B I couldn't see signer's face.

R28: Better with environment background

R25: Good range of background and smoother information in BSL

R24: More information and brief subtitles to help me to understand better.

R21: more clearer despite the distraction of people walking past and the leaves!

R19: It feels more relaxing to have a variety of backgrounds, although the signer is sometimes a bit too small (especially if you don't expand the video to full screen).

R15: Information with subtitle clear but not background

R14: more relaxed watching because of different backgrounds

R13: Break between for giving information. Change of background. Word to prompt me.

R12: More informal and easier to follow. However, it would be good if there is no movement at the background like buses going past or people walking by. Also softer backgrounds. Because it was difficult to see sometimes, for example in front of the cyclist shadow. More close up to the signer - a bit too far.

R9: More informal and relaxed

R8: nice background and different clips

R7: Clearer with better background

R6: Clear explain match my BSL concepts better

R5: Subtitle harder words, change scenery(not moving background)

R1: Feels warmer and more human and the words help if not able to read fingerspelling quick enough.

[deaf, not BSL user]

R20: Seem I understand little bit more Clip B, more then Clip A, I'm from America, need to understand more about dementia, my mother have it.

R11: More informative

[hearing, BSL user]

R27: It is good to have titles between clips - it makes it clearer. It gives the video a clear structure. The presenter gives more examples, which makes the information clearer and is more deaf friendly. NB. Lighting is poor in some of the clips.

R22: More interactive and interesting.

R18: Less boring. Makes visual connections between content and setting. felt more personal and engaging.

R16: Seems more natural, headlined sections, terminology displayed on screen

R10: It was easier to watch in short chunks. Some of the background lighting could be improved.

R4: More natural

[BSL user - this respondent skipped Q3]

R3: Looks more professional . Information clearer