

Digital life story books and dementia

Supplementary Table 1: Usability, Usage and feedback of Digital LSB

Participant	Ability to use TV/DVD player with assistance ⁺	Need to remind to play ⁺⁺	Reminder notes ⁺⁺⁺	System in Ready Mode [*]	Average usage per week	Feedback about LSB project ^{**}	Wanted to make changes in movie ^{***}	Preference (book vs. Movie) ^{****}
John	Can use	yes	no	yes	3-4 times	Good Idea	no	The movie, more then everything.
Sam	Sometimes	yes	no	yes	3-4 times	Brilliant Idea	no	The movie, because it involve all other parts that I like, music, songs etc.
Nia	Can't	yes	no	yes	3-4 times	It is good	no	I like the book, I always can open & read. The movie, I like too but no one wants to show me.
Betty	Can use	yes	no	yes	3-4 times	Yes I liked	no	The movie, because I can see it & remind me more. Very relax compare to book.
Mary	Can use	yes	no	yes	4-5 times	Wonderful	no	The movie, because of the music and my voice.
Ann	Can use	yes	yes	yes	7-9 times	Good Idea	no	Both are the same! I like both. Sometimes I want to read & sometimes I want to watch.

⁺Participant ability to operate their own TV and DVD player with assistance from relatives and staff.

⁺⁺Whether someone needs (e.g. relatives, care home staffs) to remind participant to watch their own movie.

⁺⁺⁺Do participant provided reminder (e.g. notes next to TV) to play their movie which is in their DVD player.

^{*}Whether the TV and DVD player with participants movie in standby mode to be played easily by participant.

^{**}Very brief feedback from participant about what they about 'This is Your Life Story Movie' project.

^{***}Do participant wanted to make changes in their movie after the movie completed and gifted to them.

^{****}Which one, either the life story book or life story movie preferred by participant if both available.

Digital life story books and dementia

Supplementary Table 2: Highlights of Feedback on usefulness and benefits of Digital Life Story Book

	John	Sam	Nia	Betty	Mary	Ann
Participant's feedback	Yes! It bring back my memories... I remembered that I love to play golf. I can see all them again! I can see my wife ...nice to see her again & again...make me to feel nice. I like all the songs. The songs that I & my wife used to dance. Nice...very nice!	Yes! The movie brings back my memories. I remember all that in my mind. The movie brings back all that memories. The movie tells my wonderful life, the childhood was very great...church! Lots of enjoyment...It brought back the time again! The right type of music, that I liked...I enjoyed...My own voice is good. (Feel like 'sit in the moon', can't believe)	It is good...I like it! I feel like I'm famous. I don't know but; I like to watch again & again...I don't know! I feel happy to watch it. I can see them all again! Just by sitting! Nice memories ...I feel happy...very happy.	It reminds me many things, bring back my memories. Make me feel good. The movie makes me feel happy... Very triggering. Stimulating my memories. It makes me to look back my life 'I had good life'...I'm happy about my life. I'm happy about my life. Make me very happy, all my family can understand my life & see them over-over again	Wonderful! Best thing that ever happen to me after meeting my husband. I enjoyed. I have tears. Good memories. Stimulating & trigger memories (very good one). The movie bring back happy memories	I think it is good idea. I can see back my live stage by stage...Wonderful. I can see my life again...I remember many things that I never able to remember. The movie tells about me...songs and ballet make me happy.
Relative's feedback as proxy	Its bring back memories to him & encourage him to think. Its seem he is happy. Bring back memories & stimulating. Make him feel happy	Every time Sam will sit until the movie finish & he will thumb up. That seconds (when he watching the movie) it happy with smiles, trigger lots of discussion & stimulating memories (bring back memories). Make him feel good without doubt & he enjoyed very much.	She liked because all about herself and her family. Bring back her memories, stimulating with good expression from her. Happy, good mood & she feel famous.	Surprised she's been chosen. Yes, helped her to recall people and events from the past. Happy and reminiscent	Wonderful & very good. Yes 'memory comeback'. The movies bring back her memory & good to see 'them' back. Make her feel good.	She thinks it most interesting, dramatic music at beginning but likes it very much. I'm sure it stimulated her. She responded to the music & The ballet section. She really enjoyed. Stimulated, happy, nostalgic at times

Digital life story books and dementia

	John	Sam	Nia	Betty	Mary	Ann
Staff's feedback as proxy	Encouraged John to ask questions about people he may not have recognized and asking about their whereabouts now. Happy – He enjoyed the photographs and was able to remember some members of his family	Will enjoy it while it's on, but does soon forget about it. Good while he is watching it.	It probably helps her remember things.	It seemed to put something back into her life. Very happy	Give them something to be proud of / discuss. Very happy	Encouraged and motivated Ann to remember parts of her history. Ann enjoys talking about her family
Relative's feedback	Help me to spend good ½ hour with John... very productive & not like before. Make me feel better because John happy by watching the movie	Feel good & happy. At least for ½ hour Sam happy. I was really great! Honestly I feel, I'm doing good for Sam. What else I want. Wonderful idea...Really, really good because it make Sam happy while watch it.	Fantastic idea! The movie makes my relative happy & I'm glad to see her (Nia) face full of happiness. Help me to go back to understand Nia's life better. The movie help me to match her story that she use to tell me. He make more sense to me now. I glad that I helped Nia to left her legacy & I did something very good for her. (Nia would ask different questions every time she watch together with me)	It was quite enjoyable. It made me feel good. It made me think about the past. It helped me to remember things... Reminiscent	Old pictures & songs bring back good memories. Trigger many-many memories. Very precious moment. The movie bring backs everything. The movie brings memories/ we feel good. Sometimes make us feel sad (e.g. mother & father pictures). Make sad but also make you happy about life... We miss our childhood life.	I felt excited and pleased on mum's behalf and the family and myself. Mum would really enjoy seeing it. Pleasure in seeing photos of mum's life; obviously it covers some of my life too. Enjoyment in showing my daughters and watching their reactions and particular pleasure seeing the ballet & listening to some of the music. Nostalgic, happy, moved by the ballet section & some of the music. Emotional at times.

Digital life story books and dementia

	John	Sam	Nia	Betty	Mary	Ann
Care staff's feedback	<p>I felt it was a good idea. When residents come into a care home, we know very little about their history. Yes, I feel I know John much more than I did before. I gained more information about John. What music he liked etc. I know about his interests and his family.</p>	<p>They are very good. Help us know a lot more things about the person, also nice to see a background of the person pictures etc. Enjoy chatting about the past and it seems more real</p>	<p>I got to know more about Nia and her family even though I have cared for her ten years and know some family members, still learnt a lot from the movie. I will be able to relate more with Nia when she talks about her family.</p>	<p>Yes I was able to discuss it & I learned from it. I learned even more about the client</p>	<p>Yes I was able to discuss it & I learned from it. I learned even more about the client</p>	<p>This movie is very good, with a very high content of information. Yes, it helped me understand Ann more. Their past history makes them who they really are, and without information like this, we really don't know them. I found out things that I never knew about Ann and her life. People who suffer with dementia may go back to a certain point in their life, and knowing more about Ann's past life / history will benefit staff in assisting to Ann's needs.</p>

Digital life story books and dementia

Supplementary Appendix 1

Questions for Participants, Relatives and Staff

- a. How did you feel about taking part in 'This is Your Movie' project?
- b. What do you think about your movie?
- c. Do you think this movie helped you in any way?
- d. In your opinion, what 'benefit' did you gain from your movie?
- e. How did the movie make you feel?
- f. Anything that you would change about your movie?
- g. Do you think that you will watch it again?
- h. Would you like others to see it?
- i. Which one do you prefer, the book or the movie?

Questions for Relatives and Staff as a proxy

- a. How did you feel about your relative (name)/ client taking part in the 'This is Your Movie' project?
- b. What does your relative / client think about the movie?
- c. Do you think this movie helped your relative/client in anyway?
- d. In your opinion, what 'benefit' did your relative/client gain from this movie?
- e. How did the movie make your relative/client feel?
- f. Anything that you would change about your relative's / client's movie?
- g. Do you think that your relative / client will watch it again?
- h. Would your relative /client like others to see it?
- i. Which one does your relative /client prefer - the book or the movie?

Digital life story books and dementia

Supplementary case vignettes

Supplementary vignette 1: Sam

Sam was a 74 year old man who joined the study initially at his brother's suggestion. He was divorced and living alone, and had entered residential care after memory difficulties had developed.

The researcher worked closely with Sam's brother to develop Sam's life story book, which was presented to him as a gift. Sam was very happy and excited with his life story book and was especially proud of his army life. Both were happy to join the digital life story book project 5 months after the completion of the life story book project. The first draft of the movie was presented to Sam and he agreed to record his voice for narration. Together with his brother, some of Sam's favorite songs were selected. Sam was also interested in his favorite football team's song and a relevant video clip. Sam was excited when the movie was screened for a second time together with his voice and background music and songs, and after some minor corrections were made to the narration, he approved the drafted movie. Sam watched his movie 3 to 4 times a week.

Sam's feedback about his life story movie included:

"The movie brings back my memories very much. I remembered all that in my mind. The movie brings back all that memories. The movie tells my wonderful life, the childhood was very great...my church!"

Although Sam prefers to have his life story book and his movie, his first choice would be the movie;

"The movie, because it involve all other parts that I like, music, songs etc."

Sam's brother also thinks Sam enjoyed the movie more;

"Wonderful idea...really, really good because it makes Sam happy while he watches it...at least for ½ hour Sam is happy... Every time Sam will sit until the movie finishes

Digital life story books and dementia

& he will give a thumbs up... Those seconds (when he is watching the movie) he is happy with smiles, triggers lots of discussion & stimulating memories ...The movie helps him be calm, sit down & enjoy” (Sam’s brother)

Sam’s brother also thinks the movie is better than the book;

Both are very good. Without doubt the movie much better, movie contains background music, Sam’s voice...many things... (Sam’s brother)

Feedback from the care home staff indicated that they are also pleased with Sam’s movie;

Helps us know a lot more things about the person, also nice to see a background of the person, pictures etc. Enjoy chatting about the past (with Sam) and it seems more real with the movie now (Staff)

Sam’s quality of life scores having had the movie for 4 weeks had improved beyond the initial baseline level and his depression score was also at the lowest recorded during the project (see Table 3). Autobiographical memory was also better than at the initial baseline, with the knowledge based memory at its highest level. With the exception of memory for specific events, which is slightly less than after he had received the conventional book as a gift, Sam appears to have shown most positive changes during this final phase of the project.

Supplementary vignette 2: Mary

Mary was a 73 year old widow diagnosed with mild Vascular Dementia, who had been resident in the care home for three years. Mary’s main interests apart from talking to people were writing poetry, creative work and watching television. Mary was randomly allocated to produce a life story book through the life review process. She was very active in life review sessions, providing very rich information about her life story. All Mary’s outcome measures improved during the life review process (see Table 3), with a particular improvement in her recall for specific events and incidents during her life. Her scores then fell during the period

Digital life story books and dementia

when she had the conventional book, perhaps because she prefers to be interactive with someone about her life story.

Mary agreed to take part in the digital life story book project with her sisters, and they discussed a list of background music, songs and video clips to include in the movie. After a few weeks, the drafted movie was screened to Mary, who was visibly excited to watch it, singing along with the songs in the movie.

I stopped listening to music & songs for a very long time. All of these songs are full of memories and have a story behind it...nice! Very nice!

Although Mary had some difficulties with speech she decided to record her own voice in her movie, and achieved this, recording small segments at a time. She was clearly proud and highly excited when the movie was completed and her sisters also were very pleased with the outcome. When asked how she felt about the movie, Mary replied:

I enjoyed it. I have tears. This is my life in a movie & not everybody gets this. Wonderful! Best thing that ever happened to me, after meeting my husband

As observed from Mary's reaction, she was more excited with her movie compared with her life story book

The movie, because of the music! Good memories. Stimulates & triggers memories! Very good one!

When the sisters and staff were asked 'Do you think this movie helped Mary in anyway?'

They answered;

Digital life story books and dementia

“Yes ‘her memory comes back’. The movies bring back her memory - good to see ‘them’ back” (Sister)

Gives her (Mary) something to be proud of & to engage in discussion (Staff)

Her sisters who had shared the same childhood and teenage life with Mary also felt their memories were triggered by the movie. Every time the movie was played to them, Mary and her sister were observed to engage in active conversation full of laughter and excitement. Each of them would recount stories responding to movie clips or the pictures in the movie.

Old pictures & songs bring back good memories. Trigger many-many memories, all very precious moments. The movie bring backs everything. The movie brings memories and we feel good. Sometimes it makes us feel sad (eg mother & father pictures). Makes us sad but also makes you happy about life...We miss our childhood life (Sisters)

Staff reported improved knowledge about Mary after watching the movie. Staff thought the movie would help in communicating with Mary.

I learned even more about my client...Yes I was able to discuss it & yes I learned from it (Staff)

Comparing scores on the outcome measures before and after receiving the movie (see Table 3), Mary improved on all measures, and all were improved compared with the initial baseline. However, whilst autobiographical memory for factual knowledge was at its highest at the final assessment, memory for specific events was lower than had been the case immediately following the life review process. Quality of life scores were identical following the life review and following the availability of the movie.