Using the Life Story approach with an iPad application

Initial evaluation of work undertaken within a Mild Cognitive Impairment (MCI) setting

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1. Introduction

Studies have shown that reminiscence therapy and life story work are valuable approaches which can improve the mood, cognitive ability and well-being of those with Mild Cognitive Impairment (MCI).

There is also evidence to support the view that life story work can improve the relationship, whether family or professional, between the person with MCI and their carer(s).

This report shares our experience in using an iPad app to collect life stories from participants in a social, group setting. We hope the learning points will be helpful to those organisations considering how to approach the use of tablet technology within Mild Cognitive Impairment settings.

The Life Album project was a community-based pilot initiative financially supported by a Big Lottery Awards for All grant, and delivered in 2014 and 2015 by Newham New Deal Partnership (Newham NDP) with the support and participation of researchers at University College London Institute for Global Health, staff at the Memory Clinic at Newham, and the team at *stories etc* (HJ Holdings LLC).

We would like to thank all the project participants for their feedback, and especially story tellers and their volunteer prompter partners.

Fiona Baird
CEO
Newham New Deal Partnership
September 2015

2. About the Life Album project

The Life Album project was conceived as an extension of the work of Rodney Reynolds and Lucy Irvine, researchers at the UCL Institute for Global Health. They had undertaken a pilot study in reminiscence with elders in the local East London community, within Newham New Deal Partnership's existing Good Neighbours services for elders and people with dementia and their carers.

Aims and objectives

A key aim of the project was to allow participant elder storytellers to capture areas of significance in their lives for use in remembering and re-orientating, and also to act as an aid to families and friends. Working one-to-one with volunteers and in a social group setting would also provide participant elder storytellers with social opportunities and support in learning new ways of doing things.

Project design

Participating elder storytellers with mild cognitive impairment (MCI) were identified by Newham Memory Clinic. Volunteer prompters were recruited for the project, and trained by a specialist paid Coordinator, with additional training in oral history interviewing techniques. Group sessions were held in a high profile local venue, the Theatre Royal Stratford East, which kindly waived its booking fees.

The Coordinator devised and facilitated a structured thematic programme that over a number of weeks would produce online Life Albums:

week 1	week 2	week 3	week 4	Week 5	Week 6
Introduction/ handling session	Childhood/ growing up	Hobbies & past-times	Work	Family	Reflections

Feedback sessions and structured opportunities to share learning were factored in to the programme's thematic progression from one session to the next both for story tellers and for volunteer prompters. Observation was undertaken by the Coordinator and researchers during the sessions.

3. Toward identifying a digital application

The emergence of software applications for use with mobile technologies to support reminiscence work has been a trend in the past few years. Such software provides new opportunities for capturing and communicating individual's life stories. In doing so, participants gain the opportunity to become mobile digital technology users and both elder storytellers and the volunteers who prompt their reminiscences learn new digital skills.

Another output for the project, therefore, was the development, use, and evaluation of a software application.

Developing a bespoke app

Our original goal was to work with our partners and developers to create a bespoke app that would work on the charity's iPad tablet devices. We wanted an app that would allow a storyteller and a volunteer prompter to collaborate to produce life stories. The app would then store life stories in multi-media formats thus enabling ease of use and retrieval. The idea of something we had made together as a team and that would best meet the needs of participants was important - the process as well as the end product would serve as an enlightening experience.

We initially worked therefore to design a bespoke iPad app that would be easy to use for elder participants and their volunteer prompters. Based on an agreed criteria, a prototype journal app with clean design principles – *Lifestory* – was created. The minimal colour scheme was intended to provide maximum contrast so that choices of what one can do are prompted through touch exploration - reinforcing immediate reward since there is very little to get wrong and few options to create confusion. The prototype was free from category prompts for reminiscence work, allowing each recording to be unique in terms of a person's life. The app was designed to capture stories as a photos, written text or audio recording.
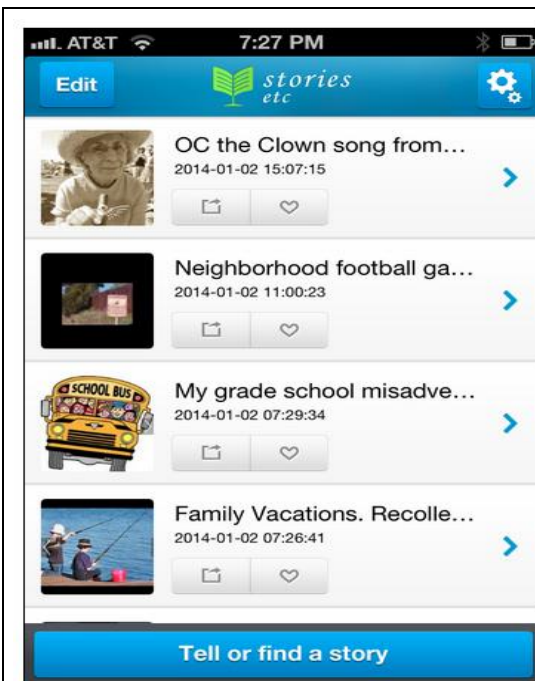
A review of the *Lifestory* prototype app identified some navigation and design issues in relation to use, particularly for the volunteer prompter, who would not be a skilled reminiscence facilitator or researcher, and the expectations of the story teller and their family and friends about access to material generated.

The project timescale determined that there would be insufficient time to modify the app before the reminiscence sessions were started. Our favoured way forward, therefore, was to select another app already in development, *stories etc.*

stories etc

stories etc, is an iPad app developed in the United States that had the majority of features we were looking for. Importantly, since it was still being developed, we could contribute feedback to future versions. The app was launched in 2013 and has since been used in a variety of personal ways as well as community learning settings within the gerontology community and the technology has been presented at the American Society on Aging (ASA) annual conference. The app was available at no charge from the Apple App Store.

Stories etc technical data

	• Developer: HJ Holdings LLC • Updated: Oct 08, 2014 • Version: 2.1.1 • Size: 16.0 MB • Languages: English, French, German, Italian, Russian, Simplified Chinese, Ukrainian • Requires iOS 6.0 or later Compatible with iPhone, iPad, and iPod touch. • Optimized for iPhone 5

Functionality

The app's various functions for capturing storyteller's memories and experiences, include audio, video, text, photos, ad hoc and storage. A range of prompts to create stories has been provided. These prompts are presented in both audio, for the visually impaired, and text, for the hearing impaired. Users create an account using a username and password and can then see the stories in a linear format. These can be grouped under pre-existing categories such as family/childhood/work but new categories can also be created.

A new function known as Bookshelf allows an individual's stories to be accessed on a PC through a web browser, using their account log in details. Once a story is created, it

can be 'shared' as an email link, Tweet or via Facebook which directs to the *stories etc* interface.
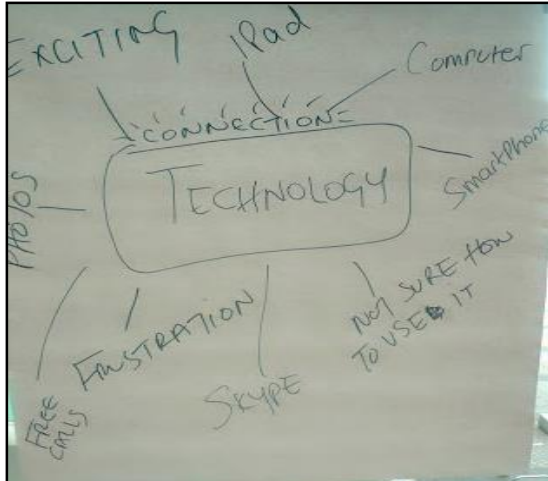
The app provided a tool which could structure the Life Story approach for those untrained in this area. A key benefit is that it could house life stories in a place that provides future access and some sharing capabilities. The design interface was attractive and we felt it would be appropriate to a range of people.

4.   The role of digital technology in the project

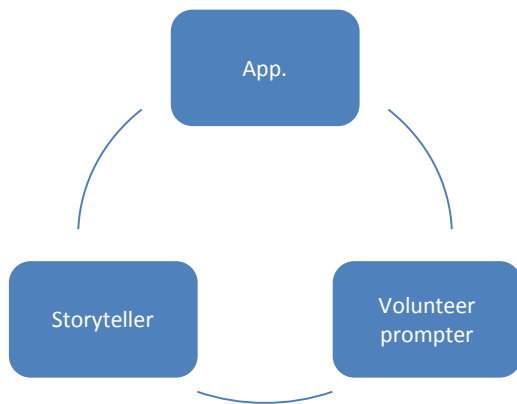**Confidence with digital technology**
It was clear from an initial brainstorm session with participants that everyone came with specific views about digital technology, particularly the over 50s:

Participant interaction with the app

Interacting with the app was carried out by the project coordinator and partners in order to understand functionality prior to its implementation into the project.

However, the primary users of the app were the storyteller and the volunteer prompter, who met on a weekly basis. Storytellers did not access their stories in between sessions due having limited or no access to devices and/or not having app know how to access the storage.

The introduction of a tablet application into the reminiscence process provided a handy tool to capture stories in a variety of ways, and to add interest for both storytellers and volunteer prompters. However, it also added additional complexity to the story teller/volunteer prompter relationship in creating a three-way dynamic which had to be managed. For example, maintaining dialogue and eye contact whilst utilising the recording functions was something that took a little time to adjust to.

Developing memory recall

The use of the app enabled participants to draw on experiences that they had not thought about for a long time. The app often informed the session content and vice versa. Physical triggers such as photographs and objects were a good lead in to a particular subject matter and group discussion prior to one-on-one interaction assisted as tools to encourage reminiscence. Photos taken from family albums (literally using the tablet to capture a photo of an older photo in an album) as well as google image search and capture of iconic images which may have personal relevance to the storyteller are two different and beneficial approaches to visual prompting.

Safe places and challenging exclusion

Overall, we felt that the benefits storytellers experienced from using the *stories etc* app for this project were maximised due to structured training and sessions and use of the device taking place in a supported, social environment.
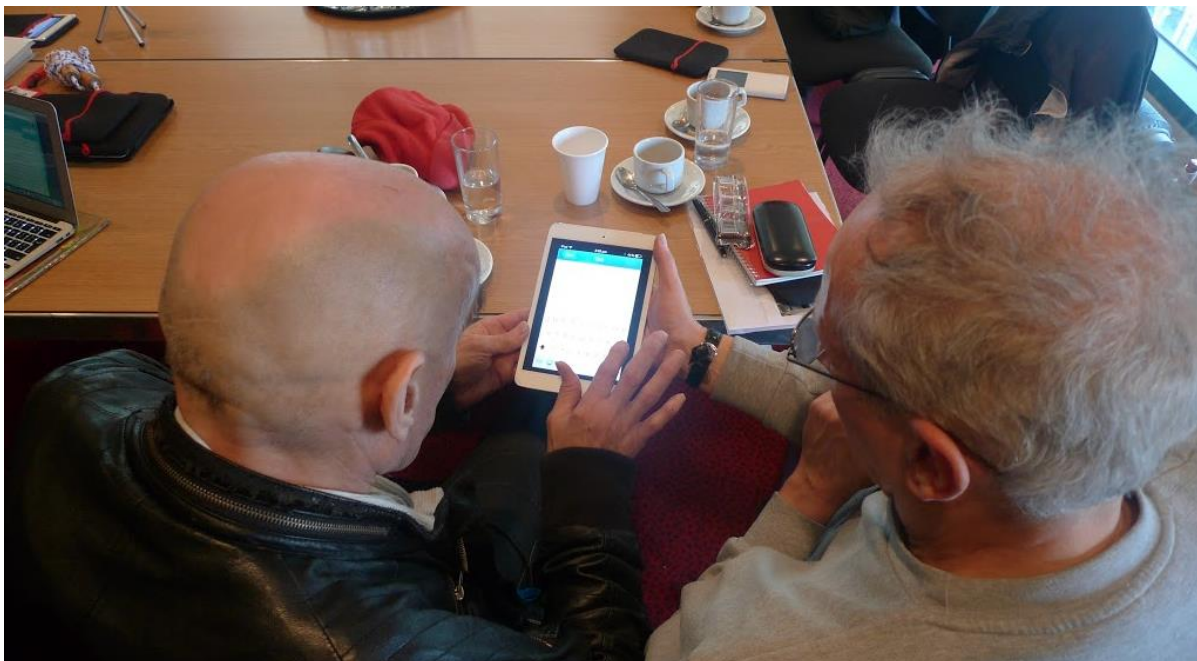
Case Study: A storyteller experience

*'Charles' was a storyteller with advanced MCI and one of the 80% of our participants who were not feeling **digitally confident**. He had never used the internet and was excited by the training in this area. His feedback showed that the training was still challenging and key elements were hard to grasp. This meant he became absorbed and weighed down in the early sessions with his technical ability rather than his aim to record his own stories.*

*He enjoyed the 'story exchange' with his volunteer prompter. He felt it was important this was a conversation rather than an interview in order to allow for a comfortable setting for memory recall. A **good bond** developed between both with trust and safety at its core. There was an occasion when Charles's volunteer prompter was unavailable and so he worked with another person and also in a group setting. This was a positive experience in the later sessions when self-confidence and group safety had been established. 'Charles' went on to share his Life Album with a friend and was able to guide them through the app and act as 'volunteer prompter'.*

5. Use of the app functions in the project

The use of the app functions during the project

The following assessment is based on participant feedback and Coordinator observation:

Function	Comments
Audio	The most popular function as it was least intrusive and provided genuine engagement between storyteller and volunteer prompter
Video	Great for recording a variety of emotions visually – however, video files sometimes took a long time to upload
Text	Typed stories, often no more than a paragraph, due to no 'save/edit' function on the app version we tested. We had to be conscious of having a surface nearby to type on, and some people found the keyboard on iPad difficult to use
Photo	Rather than a stand-alone format, photos were chosen in addition to the above functions and added to the stories serving as an identifiable 'icon' for each story
Music	No facility to upload favourite music, tunes or external videos
Back up/storage	This was essential for our project
Prompts	These could be switched off, and were for this project, see below

We sampled the app on a one on one basis 90% of the time. When we explored group interviewing, this would go no further than four in a group, with good interaction between all storytellers, as our project was an opportunity for storytellers to have a positive social experience.

A major feature of *stories etc* is that it includes a set of 'question prompts' for various categories that are spoken to users. These exist so that they can be used as a guide in a self-use setting as well as in larger groups. For the Life Album project, which relied largely on developing trust in one to one relationship between storyteller and volunteer prompter, it was decided not to utilise the app's question prompts as it was felt important for these questions to be devised by the volunteer prompters as part of the dialogue process. They were however, well designed by using 'real people' voices.

Case Study: A volunteer prompter experience

'Gaby' considered herself 'technically naïve' and so the app experience was a big learning curve as she had volunteered for the project to focus on the interviewing element. She found the app fairly simple to use, but would have been more comfortable using a basic glossary to help explain the processes with her storyteller. She felt she had become more of a technical evaluator of the app. She enthusiastically contributed to the question prompts generated as a group by all volunteer prompters. This route was decided upon as the stories etc question prompts were found complex by some. It seemed that coming out of the account and then back into the question prompts area was difficult to navigate and sometimes led to being signed out by accident without having saved the stories – these were then sometimes lost.

'Gaby' was the first of the group's participants to notice that the maximum length of audio to be recorded was capped at ten minutes. This information is not noted on the site and but is important for the dynamic in the story capturing setting. As a result, we then generated a 'How To' handout which included key info to be accessed quickly; question prompts/log in details/ technical considerations.

'Gaby''s experience demonstrated the multi-faceted nature of the 'volunteer prompter' within a supported environment and the training needs of volunteers in this role.

Functionality: Log in details
Many iPad reminiscence apps, including *stories etc*, require log in details to access personal accounts. However, password information was hard to remember for many of the storytellers on the Life Album project. As a result, we would recommend facilitated use of the app in its current incarnation for projects in settings such as ours.

Functionality: Post project access to the Life Album
Many storytellers we engaged with did not have their own tablet devices or computers, so could not see/hear their stories outside of the project setting, unless they utilised the device of a family member or friend.

The future availability of the app on Android would widen access to users, especially those not in an institutional setting, who might find the premium pricing of Apple tablet products prohibitive (although, as stated, the app was free on the Apple i-store).

We created a 'How to Access your Stories' sheet for users. This step by step guide helped users through the process of getting back into their accounts after the project ended. Whilst this worked for digitally confident storytellers, it was less of an option for others, who needed the support of a family member, friend, or carers to log in. However, these large laminated copies were hard to misplace

The future

As noted, the app version we tested was in development, and some features are being developed to become more stable. In terms of functionality, the participants of our particular project would have found the following helpful: more space to type in text story mode and developing editing functionality.

6. Project learning

Overview

As an initial evaluation, we felt that the *stories etc* app was a tool that was easy to navigate and therefore successful with the core users of this project: storytellers and volunteer prompts. Our analysis does not cover the impact of using an iPad application with other stakeholders such as carers, friends, family. This will be crucial when users state their aim as creating stories for others.

Despite some minor technical limitations, we were lucky to work with a very new app that was being tweaked as our project was running. This gave us enormous insight into not only the technical needs of our project users but also developed the technological

knowledge of our organisation. We would recommend considering the *stories etc* iPad app in an MCI setting, especially when the product has been developed further.

Getting clarity on project design
The Life Album project was a pilot project, and Newham New Deal Partnership made some changes in project design to achieve the objectives, based on largely practical considerations on delivery. Before selecting an appropriate app the project deliverer needs to clarify some key questions. These need to include:

- Will users prefer an apple versus android product?
- How important is clean design?
- Is the app to be used in a group or one on one setting?
- Is third party access to the material required?
- Are category and question prompts required?
- Is access needed via email or a desktop?
- Will users want material generated on other formats?
- What functionality will be required?

Learning points for other organisations
The key learning points for organisations considering utilising an app approach are:

- Assess whether outcomes are focused on technical, medical progress or social progress/learning
- Identify users, including facilitators and the wider circle of family, friends and carers
- Be open to the different requirements and use of app functions according to settings: as self-use, one on one or in group settings
- Consider participants' technological abilities and tailor activity accordingly
- Think about support material to prompt questions; photos, videos, music
- Clarify the role of interviewer/prompter in assisting the storyteller
- Establish later access and use of material created

7. About the Partner organisations

Newham Memory Clinic is a joint clinic by East London NHS Foundation Trust and Newham University Hospital provided by a multi-disciplinary team in geriatric medicine, neuropsychology, and psychiatry. Its goal is initial assessment and diagnosis of dementia and cognitive impairment in people of all ages.

Newham New Deal Partnership is a local charity working in East London. Our vision is of proactive and creative communities without barriers where everyone is able to fulfil their potential and live in dignity. The Good Neighbours service aims to reduce isolation and increase social contact, self-confidence and choice for elderly residents with dementia in the Newham community and beyond. In addition, the service offers carers respite and on-going befriending support through regular home visits. See http://www.newhamndp.org.uk.

The Institute for Global Health, University College London, is a world-leading centre of research and teaching excellence in global health. Its vision is to collaborate across disciplines to find solutions to global health problems. A cross-disciplinary approach is at the heart of its research and teaching, and we draw on the expertise of over 200 staff from across UCL.   See www.ucl.ac.uk/igh.

stories etc
The founder and developer, Patrick Talley, had personal experience of older relatives who were beginning to retell their life stories and who were suffering from dementia. He felt that along with himself, many others would be keen to capture these key life moments and would benefit from using a structured framework to be able to do this. See http://storiesetc.com/

8. Glossary

App: An application, or application program, is a software program that runs on your computer. Web browsers, e-mail programs, word processors, games, and utilities are all applications.

Android: Android is a mobile operating system developed by Google. It is used by several smartphones, such as the Motorola Droid, the Samsung Galaxy, and Google's own Nexus One.

Icon: An icon on your computer screen represents an object or a program on your hard drive. For example, the folders you see on your desktop or in open windows are icons. The files that you see in those folders are also icons.

iPad: The iPad is a tablet computer developed by Apple. It is smaller than a typical laptop, but significantly larger than the average smartphone. The iPad does not include a keyboard or a trackpad, but instead has a touchscreen interface, which is used to control the device.

Operating system: An operating system, or "OS," is software that communicates with the hardware and allows other programs to run. It comprises the system software, or the fundamental files your computer needs to function. Every desktop computer, tablet, and smartphone includes an operating system that provides basic functionality for the device.

Mac OS 8: An operating system that was released by Apple Computer on July 26, 1997. It represented the largest overhaul of the Mac OS since the release of System 7, some six years previously. It puts more emphasis on colour than previous operating systems.

MCI: Mild cognitive impairment (MCI) is a term used to describe a condition involving problems with cognitive function (mental abilities such as thinking, knowing and remembering). People with MCI often have difficulties with day-to-day memory. MCI describes a set of symptoms rather than a specific medical condition or disease.

Tablet: A tablet, or tablet PC, is a portable computer that uses a touchscreen as its primary input device. Most tablets are slightly smaller and weigh less than the average laptop. While some tablets include fold out keyboards, others, such as the Apple iPad and Motorola Xoom, only offer touchscreen input.

Touchscreen: A touchscreen is a screen display. Some touchscreens require a pen to make contact though most modern touchscreens detect human touch. This makes touchscreens ideal for computer kiosks, as well as portable devices, such as tablets and smartphones. While a touchscreen may look like an ordinary display, the screen includes several extra layers that detect input (human touch).