

Data Saves Lives Project Lessons Learnt Report



October - December 2016



1. Context

- 1.1 Data Saves Lives was a three month research project working with Manchester University. The project builds on the work being carried out through the Community Asset work stream of Salford Integrated Care Programme for Older People and supports Salford's overarching commitment to becoming an age-friendly city, supporting older people to stay healthy and well.

“Using the knowledge and life experiences of older people to make life better by listening to and valuing their views: making sure this influences services to be better in future by building on community strengths. This will keep older people in Salford healthy, happy and independent for longer.”

***Vision agreed with older people through the community asset working group**

- 1.2 Two complimentary programmes are currently running across Salford to support older people stay healthy and well, *Salford Together integrated care programme for older people* and the *Ambition for Aging Big Lottery project*. Both have objectives relating to achieving greater independence and improved wellbeing for older people in Salford within communities. For individuals ways of achieving this include taking part in wellbeing conversations and completing their own wellbeing plans, learning digital skills and becoming more involved and active through social or exercise activity. Inspiring Communities Together along with other partners have a role in supporting older people to achieve these objectives.

2. Background to the project

- 2.1 Data Saves Lives <http://www.herc.ac.uk/get-involved/data-saves-lives> is a public engagement campaign designed to highlight the positive impact of health informatics research on public health. This approach has already demonstrated positive outcomes in the younger age population but has yet, however to be fully utilised in older age research. This short term project working with the University of Manchester set out to see if health data collected by older people themselves, using traditional health equipment at home (such as blood pressure or glucose meters), or more advanced technologies, such as smartphones and wearable activity trackers e.g. smart watches could have a positive impact of health and wellbeing alongside improving and maintaining mobility, and independence. This project using a community reporter model of collection individual stories sought to better understand how people aged 55 years and over can collect and use health data to keep themselves active, mobile and healthy. The project was funding through a grant secured by Health e-Research Centre (HeRC; University of Manchester) who project managed and facilitated a project team in both Manchester and Salford - Inspiring Communities Together (Salford) Macc (the voluntary, community and social enterprise sector support organisation for the city of Manchester and a community reporter licensee). and Crossacres Resource Centre run by Age Uk (Manchester). Both Salford and Manchester delivered a community reporter model approach to deliver the project.

3. Aims and objectives

- Involve older people, carers, and service providers in shaping research on the use of health data and health technologies to improve health and well-being in later life:
- Understand if and how people collect data to look after their own health. For example, by measuring blood pressure, testing blood sugar, or by keeping a food diary.
- Encourage older people to generate health data by testing health equipment such as a health wearables, that keeps track of how active a person has been, or how well they have slept.
- Develop a strong, sustainable community network of people interested in engaging with health data and technology in older age research.

3.1 *This lessons learnt report focuses on the Salford aspect of the project delivered by Inspiring Communities Together (ICT). A report of the full project will be produced by Manchester University and a short film bringing together the story from both Manchester and Salford will be produced by Macc*

4. Project methodology: Part one - Community reporters

4.1 In order to encourage older people to generate and collect health data ICT used the Community Reporter model which supports providing communities with a voice and a platform on which their voice can be shared with others. ICT recruited 12 older people from existing networks and engagement channels to take part in a five-week community reporter programme: Community Reporters learnt how to tell their own stories, collect stories, how to upload the content onto the community reporter website (all content is tagged – **#datasaveslives**), and spent time collecting stories from friends and family to provide a data capture of the role of health data in an older person's life.

4.2 The training followed the tried and tested community reporter model with a focus on the use of data in a health context including:

- Developing a shared view of what is health data
- How older people might already collect health data without thinking about it (blood pressure testing, diabetes checks, keeping track of medication prescriptions)
- Different ways in which health data can be collected for example mobile phones, fit bits, traditional health equipment (HeRC will provide Withings Smart watches for community reporters to test in week three.)
- How older people use the data they already collect. For example to manage their own health, share with their carers or health professionals, make personal judgements about when they may need further support.
- How older people might use data in the future to manage their own and/or loved ones health and wellbeing, and what is required to enable this future use of data, or make it more attractive.

Table 1 - Break down of community reporter engagement

No.	Age	Gender	Neighbourhood	Number of volunteer hours contributed
4	65+	Female	Little Hulton	48
1	65+	Male	Little Hulton	12
3	65+	Female	East Salford	36
2	65+	Male	East Salford	24
2	65+	Female	Ordsall and Langworthy	12
Total volunteer hours				124

Table 2 – programme of activity

Week 1: What is Community Reporting?	
Activity	Learning outcomes
<p>Sabine van der Veer (researcher from the University of Manchester) attended the first session which took place at St Sebastian's community Centre, East Salford to provide the participants with some understanding of the project and its aims. After the session, the development workers spoke with all the participants and it was agreed that the subsequent sessions would be held at Old Lane Community Resource Centre in Little Hulton to try and engage with more people. After the change in venue five more people joined the course</p>	<ul style="list-style-type: none"> An introduction to Community Reporting, going through community reporter websites and the basics of how to tell a story. Exploring how photography can tell a story and each participant took a photo on the theme of 'Health' and what that term meant to them. At the end of the session, the participants had learned how the term 'health' has many different meanings to different people and that through doing something as simple as a photograph, they can tell a story. Not everyone is able or ready to move from their own environment to engage in projects – moving to a venue which some people felt more comfortable in enabled more people to engage in the project and built relationships across neighbourhoods
Week 2: What is Health Data?	
Activity	Learning outcomes
<p>In this session, each participant was given a tablet with lots of different health apps on. Individually and in pairs the group looked at the apps that interested them most and then discussed which were their favourites and why in the large group. The health apps ranged from pedometers, calorie counters, meditation and relaxation apps to apps about exercise routines.</p>	<ul style="list-style-type: none"> People learnt about the wide variety of free health apps available, all of which record health data in some way. Two female reporters really enjoyed using the apps, at the end of the session, one downloaded the food calorie counter app onto her phone and the other downloaded the eyesight app so that they could continue to use them at home. All the other reporters took the information sheets with the app details home.
Week 3: Telling your story with film	
Activity	Learning outcomes
<p>In this session participants explored how to tell their story using film. This involved learners using tablets to plan and record their own stories. During this session, learners were also given Smart Watches and taught how to set up accounts with them.</p>	<ul style="list-style-type: none"> Creating email addresses when needed Using a tablet to synchronize their watches. Two of the reporters set their Withings watch to 4,000 steps a day target, while the remainder took the given average of 10,000 as their target. One reporter (male) installed the Watch App on his phone and within minutes of setting it up was inputting data about himself and also checked his resting heart rate to see if it was within a healthy range.
Week 4: How to interview people	
Activity	Learning outcomes
<p>This week, the learners practiced how to conduct an interview and prepared to interview a neighbour or friend about how they manage their own health data.</p>	<ul style="list-style-type: none"> The big learning point for the group today was that when answering questions, they needed to give long, full sentenced answers. They learnt that doing this helped tell a clearer story when being filmed. One male reporter was very nervous about speaking on camera, often only saying the odd word, but having prepared to be interviewed, was able to speak much more confidently and in fluid sentences.

Week 5: Recording your story

Activity	Learning outcomes
<p>During session three participants were given a Withings Smart Watch to try out and use to manage their own health data. This included recording how many steps they took, their sleep pattern and even their heart rate. In this final session, the group recorded their stories about what changes they had made, if any, to their health and wellbeing, based on this data. Sabine van der Veer (HeRC, University of Manchester) also conducted a focus group with the participants.</p>	<ul style="list-style-type: none"> As well as capturing stories from the reporters on the course, we spoke to our regular community reporters who attend our Drop Ins. In October, we discussed the project and set them the task of finding someone to interview and capture their story. Two pieces of content were made, including one interview conducted by Reporter Steve who interviewed his neighbour about a recent heart monitor he'd had fitted on his body.



This photo taken by one of the reporters (65, male) was taken because he wanted to show how the amount of information and services that are available to people can be a little overwhelming.



shows the barriers a lot of older people have to accessing health care. These included getting an appointment, fear of going and not knowing where to start

5. Methodology: part two - Testing use of technology as part of ongoing exercise class

5.1 Working with Salford Community Leisure, Inspiring Communities Together engaged with an Older Person exercise maintenance class (Step Up) based at the Salford Sports Village over 3 weeks and recruited 8 older people to test the use of Withings smart watches.

5.2 The aim of the first session was to raise awareness of the project and recruit people to take part in the use of the Withings smart watches. This session corresponded to week four of the community reporter training.

5.3 At the second session, HeRC staff loaned each participant a Withings smart watch and provided everyone with instructions on how to use them. Each person set up their own target, only three participants kept to the standard target of 10,000. The remaining five had targets ranging from 4,000 – 8,000 steps.

5.4 At the final session, one week later, HeRC facilitated a focus group:

- to review the data collection and get feedback from the group on if and how they used technology,
- to seek their general views on benefits and disadvantages of using the technology,
- to see whether it affected their motivation to exercise at home
- to find out if anyone felt they could now better assess the overall impact on their own health and wellbeing based on the feedback of the data collected



Table 3 - Project outcomes

Project Objective	Commentary
	<p>In total, the community reporters created 27 pieces of content (five photo stories and 22 video stories). To view the stories, visit www.communityreporter.net and type in <i>datasaveslives</i> into the search bar.</p>
<p>Involve older people, carers, and service providers in shaping research on the use of health data and health technologies to improve health and well-being in later life:</p>	<p><i>"I was pleasantly surprised about the enthusiasm for the watches."</i> <i>"This seems to have been a very positive experience for a number of older people."</i> Sabine van der Veer from The University of Manchester</p> <p><i>"It was nice being part of something new. I felt like I got something out of it."</i> Community reporter</p>
<p>Understand if and how people collect data to look after their own health. For example, by measuring blood pressure, testing blood sugar, or by keeping a food diary.</p>	<p>At the start of the project there was very little awareness of health data and how it could help the participants manage and/or improve their own health and wellbeing.</p> <p><i>"I've never used it [health data] before"</i> (Male reporter, 65+)</p> <p><i>"I always go to the doctor when I need a test or something"</i> (Female reporter, 65+)</p>
<p>Encourage older people to generate health data by testing health equipment such as a smart watches, that keeps track of how active a person has been, or how well they have slept.</p>	<p><i>A male reporter was very surprised to see how little he slept each night. It wasn't until he looked at the data on the App, that he realised how often he was waking up and how late it was before he fell asleep. He made a commitment to adjust his sleep routine.</i></p> <p><i>"Good to see a visual of my heart rate, blood pressure and weight"</i> (Male reporter, 65+)</p> <p><i>"The watch was comfortable to wear and I could monitor my daily steps which was essential to my wellbeing plan"</i> (Female reporter, 65+)</p> <p><i>One of the female community reporters (10,000 steps) really enjoyed using her watch, so much so that when she knew she had not met her pedometer target for the day, she would go for an extra walk along Littleton Road to meet her target.</i></p> <p><i>One of the female reporters who had limited mobility (target of 2,000 steps) had very low expectations of the usefulness of the Smart Watch and her own activity levels "I can't walk very far anyway". However, after the first week, she was pleasantly surprised at how far she actually did walk, purely inside her own house.</i></p> <p><i>One person from the Step Up class said that having the watch made her 'motivated' to walk more. She had started to use her Stepper at home again to achieve her target after not using it for years.</i></p> <p><i>"Convenient to wear even in the bath or shower, in fact all the time when doing any activities or sleep!"</i></p>
<p>Develop a strong, sustainable community network of people interested in engaging with health data and technology in older age research.</p>	<p>Members of both the community reporter group and Step Up class engaged well with the project and expressed an interest in being involved in more research.</p> <p>Community reporters: <i>"It's been quite exciting to take part and use the tech. I didn't want to give it back!"</i></p> <p>Step Up class members: <i>"I would like to do more things like this."</i> <i>"I'd like to know what the result of this project is."</i></p> <p><i>"I think the project showed that there's appetite and potential in Salford to do more around health tech."</i> Sabine van der Veer from The University of Manchester</p>

6. Salford context – working towards meeting the objectives

- 6.1 As stated at the beginning of the report, the Data Saves Lives project feeds into Salford Together and Ambition for Aging priorities:
- Salford Together Objective two: The commitment by mature people to support their own health and wellbeing
 - Ambition for Aging vision two: Older people are able to access information and services to keep them healthy and engaged in activity
- 6.2 We can see how this project has energised this group of older people to look more carefully at their own health and wellbeing and how they now feel more confident in general in accessing their own self-generated health data. One person specifically mentioned how she used the Smart Watch to help her monitor her progress with her wellbeing plan. *“The watch was comfortable to wear and I could monitor my daily steps which was essential to my wellbeing plan” (Female reporter, 65+)*
- 6.3 Many of the older people have moved on to engage in other community and health related activity once the project ended.
- One participant (with limited mobility) who lives close to the Peel Resource Centre in Little Hulton has start to volunteering there.
 - The Little Hulton residents have joined the Ambition for Aging project, creating a new network where they are using their newly learnt Community Reporter skills to explore how to make Little Hulton more age friendly.
 - One East Salford resident has joined the existing Ambition for Aging group in Broughton.
 - The community reporter group have been invited to join Inspiring Communities Together monthly community reporter meet ups to enable them to continue to create stories and further develop their community reporting skills.
- 6.4 The project also had a social impact, the comment below is typical of the feedback to the team: *“It’s been nice to go out and meet new people. I’ve never been to Little Hulton before.”*

7. Lessons learnt

- The high level of commitment and enthusiasm of the older people who took part was key in the success of this project.
- Several older people made positive changes in their behaviour as a result of reviewing their own health data (i.e. sleep routine, activity level)
- Some participants struggled at the beginning to understand what was meant by “health data,” but during the project built skills and knowledge.
- The plan to bring the two groups together (Community reporters and Step Up class) wasn’t realised as there wasn’t enough time to arrange and deliver. However a smaller engagement exercise did take place. Increasing the project duration from five weeks to a longer period may have mitigated these issues.
- One lady found it difficult to see due to her eyesight issues. She couldn’t really see the pedometer scale on the watch and had found using the app on the tablet very difficult.
- The cost of the tracker type devices was identified as a possible issue in encouraging more older people to use health equipment to generate health data



“The watch is really good and worth having, however the cost is very expensive and out of my price range. If cheaper, I would consider buying one.” “For the cost of the watch, I would expect it to do more”

- One Step up class member made the point: ***“During the summer, I’m out gardening all the time, so I do a lot more movement. But in the winter, I’m inside a lot more. I’m not going out walking when it’s freezing cold.”***

8. Next steps

- 8.1 As part of the project outcomes there is an allocation of £1,000 to support Inspiring Communities Together to continue to work with older people. Working with Manchester University this funding will be used to purchase some smart watches which can be used with the community reporters and at Step Up classes to carry out a longer term data saves lives project.

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