

Self-managing Long Term Conditions Smartly



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Final Short Report to ALLIANCE

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Background

Self-management for people with long term conditions (LTC) is now a key government strategy to encourage people to take responsibility for their own health, behaviour and well-being. Talking Mats received funding from The Health and Social Care Alliance Scotland to look at how using the Digital Talking Mats (DTM) can help people with LTCs to manage their health and wellbeing and to recognise their own strengths and abilities.

Aim

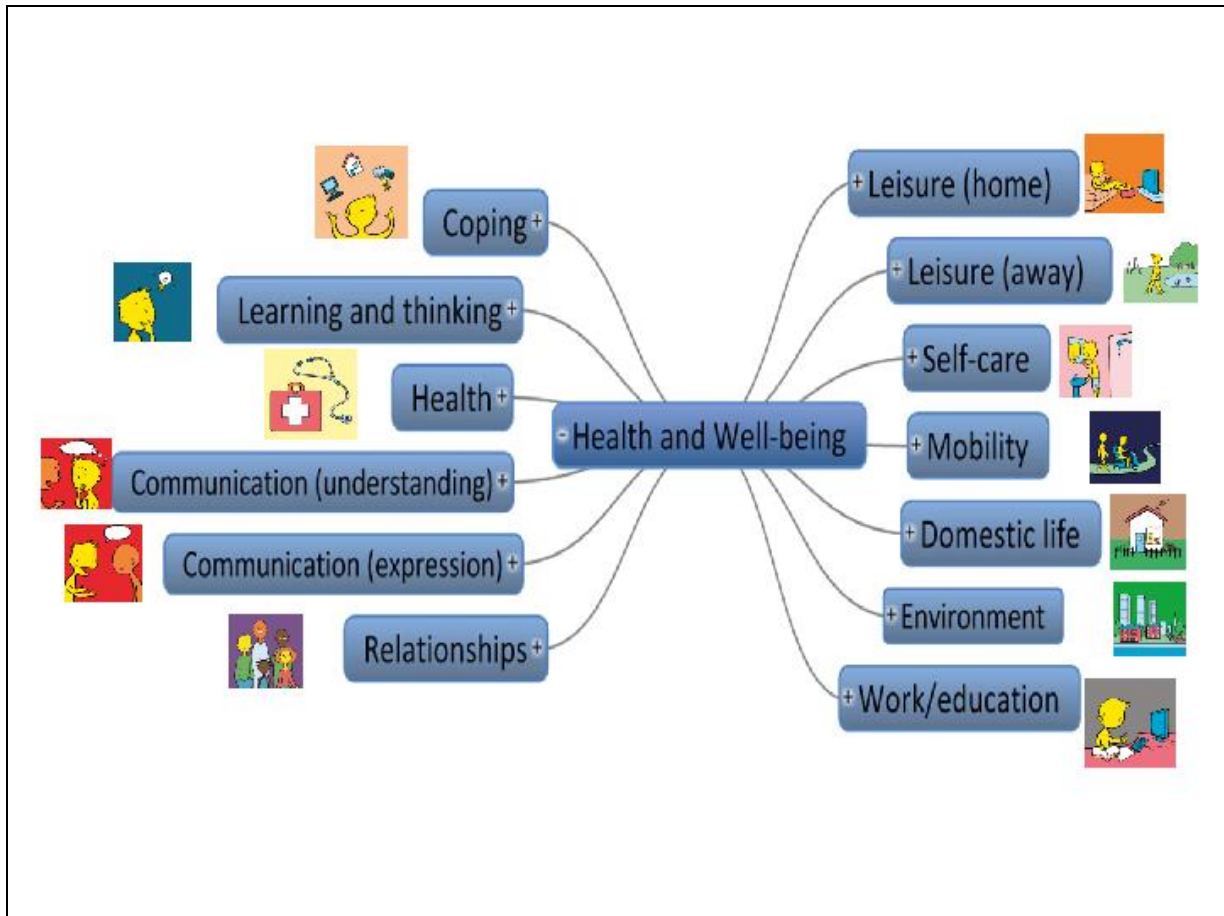
The overall aim of our project was to empower people with different long term conditions, to manage their own health and well-being. Through using Digital Talking Mats (DTM) we hoped that participants would be able to have more control over their lives and have improved communication with families and professionals.

Methods

There were a total of 28 participants in this project living with one of three different long term health conditions - 8 participants who had a stroke, 11 participants living with dementia and 9 participants with a learning disability. Each participant had access to a tablet device and was given a personal digital Talking Mats licence which gave them access to 13 topics in the Talking Mats Health and Well-being resource. We visited each participant at home and taught them how to use it and asked them to complete at least 1 digital Talking Mat per week for 6 weeks on any topic they wished. The design of the digital Talking Mat allowed them to email their mats directly to the researchers.

We visited each participant a second time to discuss on how easy it was to use the digital Talking Mats and their views on their completed mats. We asked those

who wished to, to continue sending us completed mats beyond the initial 6 weeks. We visited them again in 6 months to discuss how they were managing.



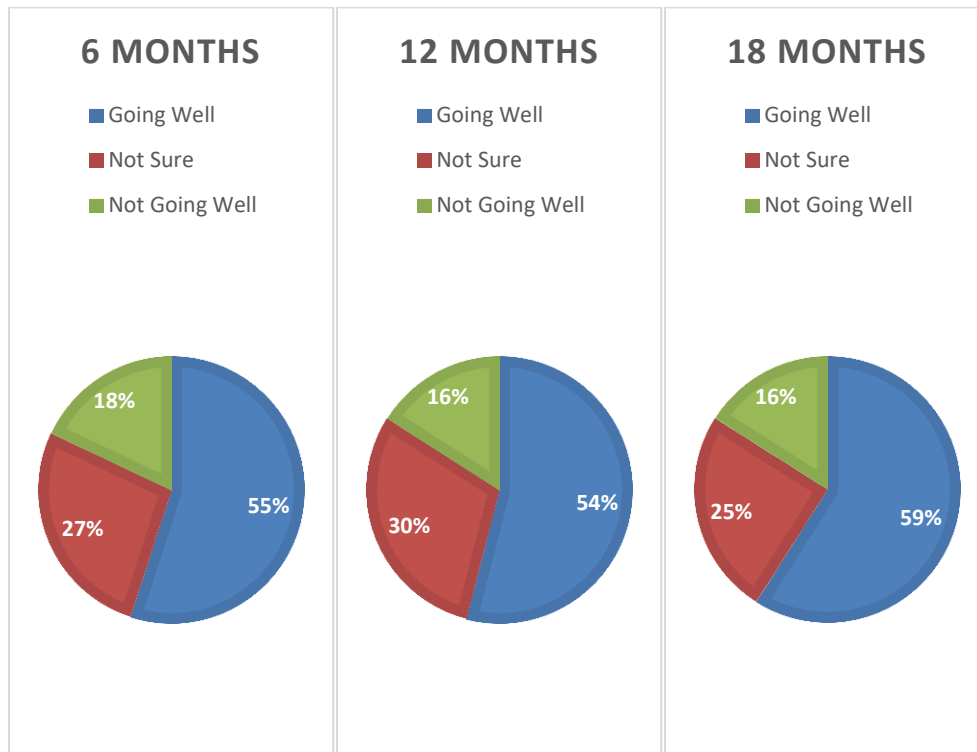
Topics on Digital Talking Mats to choose from

Results

Twenty seven out of the 28 participants (one individual had additional health problems and did not continue), completed at least one mat. Fifteen (15) participants completed all 6 mats and 12 participants continued to complete mats over the length of the project. Participants completed 235 digital mats across all 13 topics and 2 participants created their own topics ‘football’ and ‘meals’.

People living with dementia

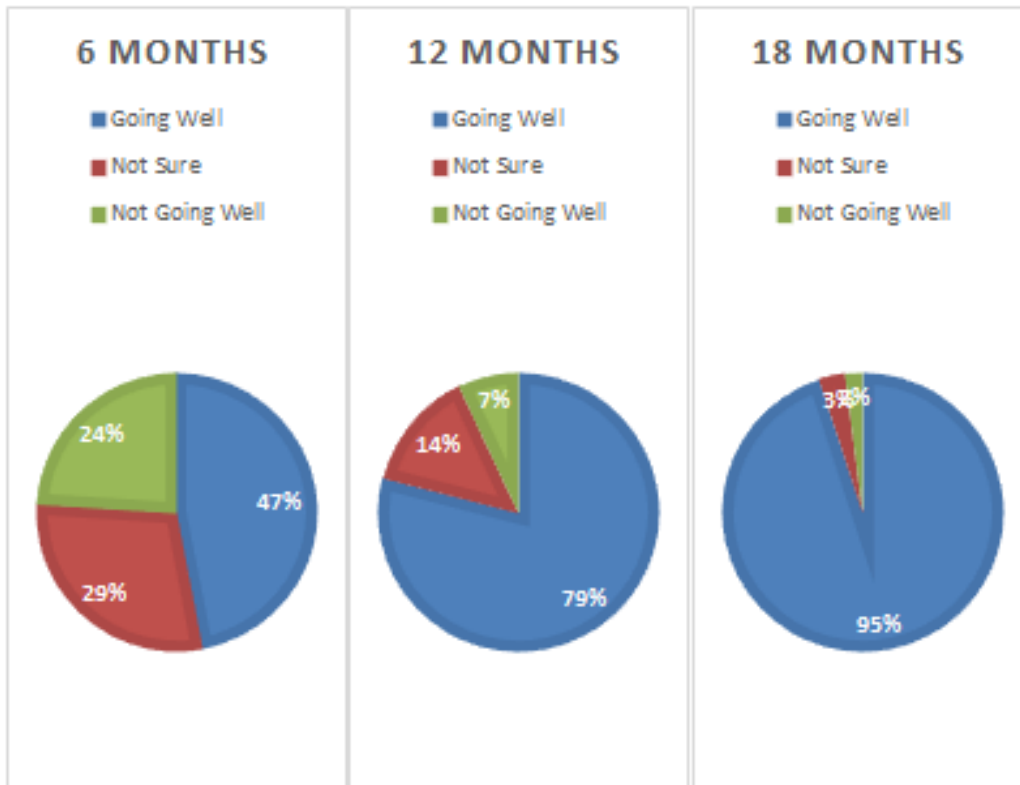
The first finding was that at 18 months the participants living with dementia actually felt their well-being had improved, despite dementia being a progressive illness.



Mats completed by people living with dementia at 6 months, 12 months and 18 months of the project

Participants living with stroke

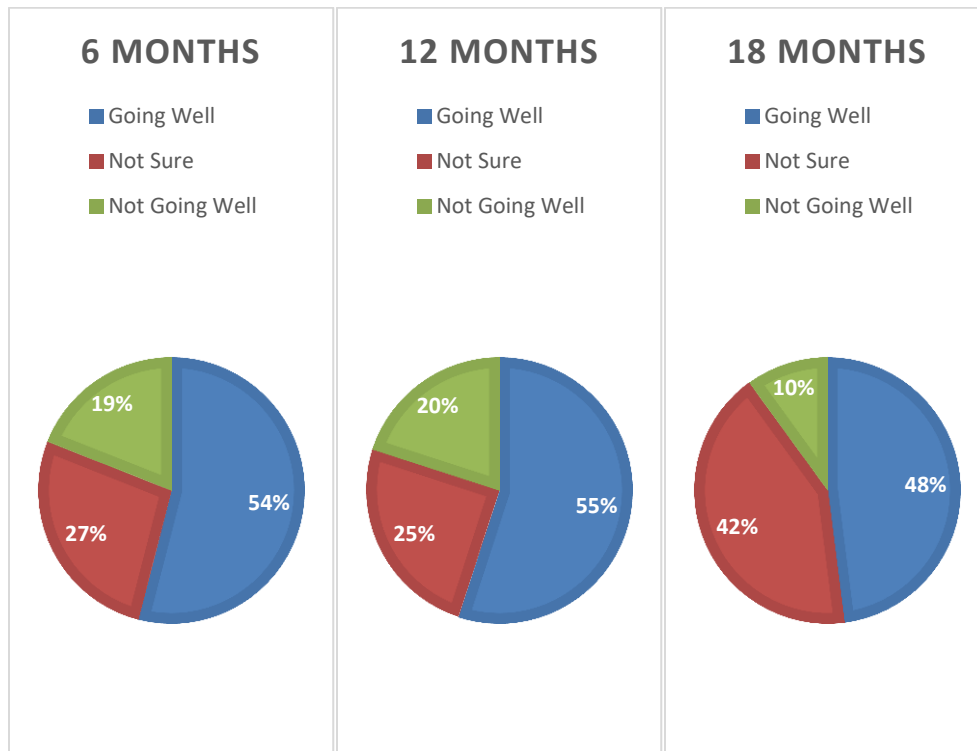
For the participants living with stroke 95% felt things were going well at the end of the project in comparison with 47% at the beginning



Mats completed by participants with stroke at 6 months, 12 months and 18 months of the project

People living with learning disability




At the end of the project the percentage of people who felt things were not going well had reduced from 19% to 10%. Furthermore the percentage of people indicating that they were not sure about their views had increased from 27% to 42%. There can be a tendency for people with learning disability when using Talking Mats, to express their views at either end of the mat and to rarely use the mid- point. However being able to use the unsure mid- point is noteworthy as it indicates that the participants in the project realised that they could express their views not only as black or white but could indicate that they were unsure. This awareness opens up the potential for people to express views more thoughtfully with opportunities for further exploration.



Mats completed by participants with learning disability at 6 months, 12 months and 18 months of the project

Examples of self-management solutions

We received numerous examples of how using the Digital Talking Mat supported people to self-manage situations in their lives. Here are three:

<p>A young man who had a stroke expressed his desire to go back to work as a chef</p>	
<p>A woman with dementia indicated on her mats that she was not happy with her bathroom. She now has had an accessible bathroom put in.</p>	
<p>A young woman with a stroke set her goal to tie her hair back by herself –even if its messy I'll have done it...it will be a huge achievement.</p>	

Comments

Throughout the project we gathered participants' comments

- *It helps me sort out my thoughts – very useful*
- *I get so much out of the process*
- *I come up with insights which might help me in the future*
- *I can now talk to (my wife) in a way I couldn't before*
- *I'm more relaxed now*
- *I come up with niggly health things that my partner didn't know*

- *It helped me to pinpoint my goals – made it clearer. I know goals in my head butmurky.....this made it clear. It helped me to see what I could and couldn't do*
- *None of us are really independent in life'*
- *I'm more relaxed now*

Many participants were encouraged by the things that they could still do and were often surprised about how positive their lives were when they looked at their completed mats. *'It made me realise things are not so bad'*.

Others reported that the use of the DTM during this project gave them a better understanding of their own individual health and social care needs. *'It made me think of things I would like to do'*.

When speaking of one of the participants with learning disabilities a support manager said of the DTM ... *'It gives a particular value to her voice'*.

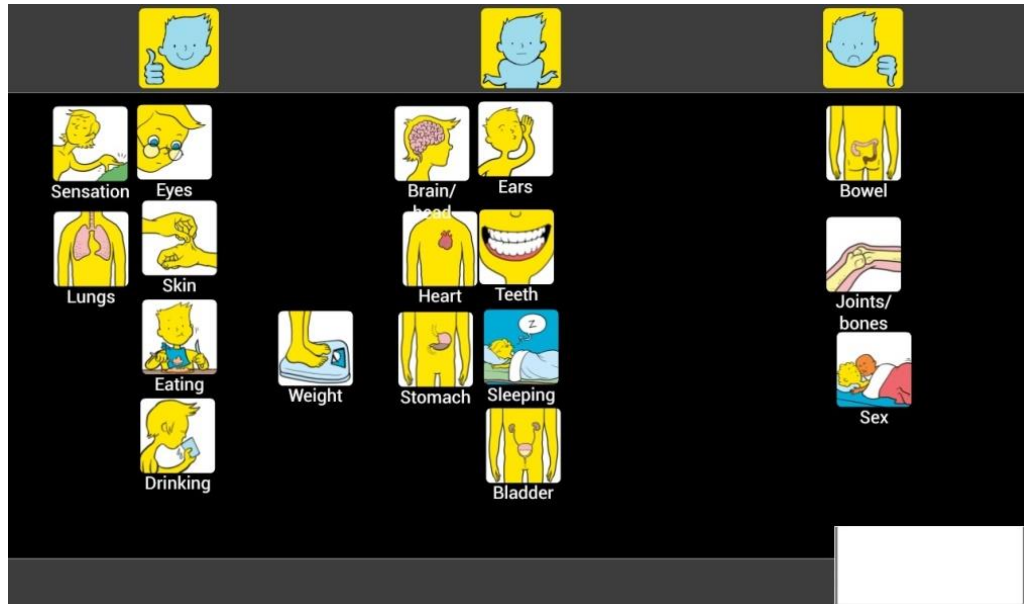
This manager also said... *'Each person has given more information about themselves using the DTM'*.

One of the participants living with dementia said... *'It helps with the nuances of life'*.

And the partner of a stroke participant said ... *'Talking Mats has made you look at what is not going well then identify actions to make it better'*.

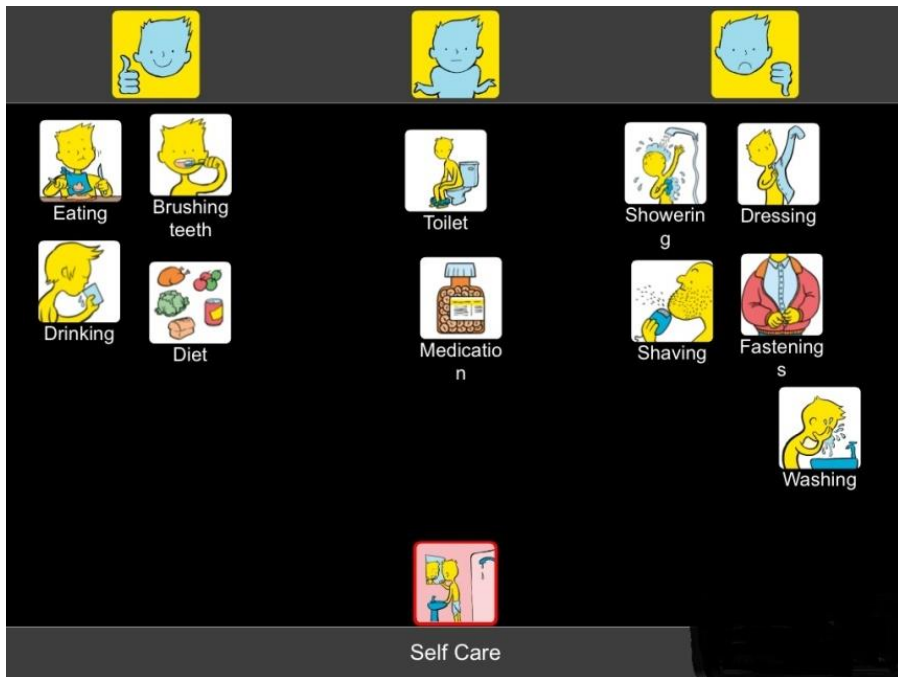
Stories

1. A woman with dementia said 'It (Health mat below) made me realise things are not so bad and made me think I will continue with my exercise classes, carry on walking, socialising and eating well'



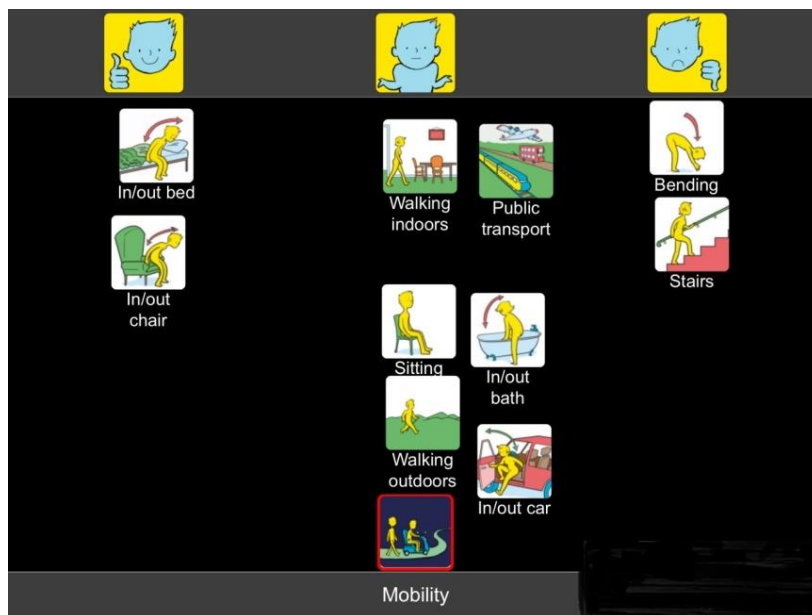
Mat on Health by woman living with dementia

2. After doing a mat on self care and seeing what was not going well, a man with a stroke realised he could do more for himself and 15 years post stroke, although still needing support from his wife with lots of areas of his self care, he is now getting undressed and into bed himself. Doing the mats prompted him to take action and allowed him to set goals for himself which he has achieved



Self Care mat from man with a stroke

- Using the DTM highlighted how one woman with learning disabilities was becoming reluctant to go out of the house following a fall and was low in mood. She improved her leisure outcomes and emotional wellbeing by getting a mobilator following a physio assessement. This enabled her to get outside more.



Mat on Mobility from woman with learning disability

Couples mats

Several couples told us that it was very useful for them to share their views with each other about the same topic as it helped them listen to each other better. They all wanted to continue to do mats together.

Developing a book of printed mats

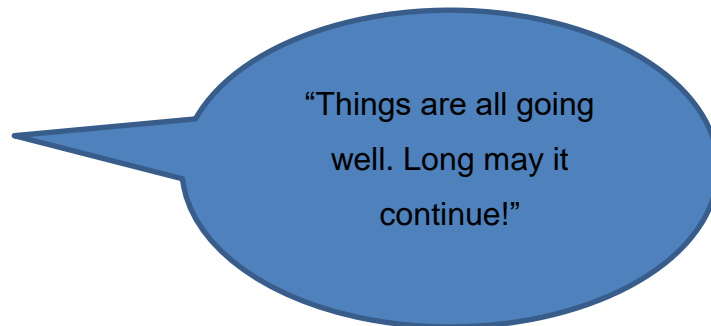
One husband of a woman with dementia printed out all his wife’s completed mats and saved them in a display folder which he showed to family members, others living with dementia and to professionals.

'Keeping my brain active'

The same couple thought that using the DTM was helping to keep the participant's brain active and they used it for this purpose as well as to help them self-manage their lives

Conclusion

As well as helping participants self-manage their long term conditions, an unexpected outcome of this project is that many people found that using the DTM helped them see the positive things in their life and not just the negative. It also highlighted that despite having a long term condition and, for many also a deteriorating one, that things were not getting worse.



Acknowledgements

Thanks to all the participants and those who support them who volunteered to take part in this project. We are very privileged to have worked with them and to have heard their stories. We have learned huge amounts from them and are encouraged that for many, Talking Mats has helped them manage their lives better.

Many thanks also to Sarah Parker, final year Psychology Student at Stirling University, for her invaluable help in analysing the project data.

Finally we are very grateful to the Health and Social Care Alliance Scotland ALLIANCE who funded this project and provided support.

Full report incorporating all 3 reports at 6, 12 and 18 months are available on our website : <https://www.talkingmats.com/wp-content/uploads/2018/07/20180713-Alliance-full-report.pdf>

Link to a video from one of participants: <https://www.alliance-scotland.org.uk/digital/digital-health-and-care/what-is-digital-health/stories/improved-communication/>