

Self-managing Long Term Conditions Smartly



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Final Report July 2018

Incorporating all 3 reports to the Health and Social
Care ALLIANCE Scotland

Six Month Interim Report to ALLIANCE - March 2017

Background

Talking Mats is a social enterprise whose vision is to improve the lives of people with communication difficulties by increasing their capacity to communicate effectively about things that matter to them.

A previous project funded by the Alliance Impact Fund, focused on the original, physical Talking Mats. When the Digital Talking Mats (DTM) was described several participants requested the digital version to use at home to help them to self-manage their condition

Other people with various long term conditions, including dementia, learning disability, stroke and cerebral palsy have also requested support to use the DTM. One member of a self-advocacy group for people with learning disability said:

'It would be great to do a Talking Mat on the iPad before you go to see the doctor as it would help you to think about what you want to say.' Advocating Together Dundee

A key driver for this project came from these early adopters of the DTM who have shown us that there is potential for the DTM to be used more widely and become a mainstream tool for self-management. There are several features of the Digital Talking Mats that are different from the original version and which are particularly attractive to the people with long term conditions that we have talked to.

In addition, self-management for people with long term conditions (LTC) is now a key Scottish government strategy (Gaun Yersel, 2008) to encourage people to take responsibility for their own health, behaviour and well-being. It aims to put people in the *'driving seat ... to live their lives better and on their terms'*. We also know from the report, Realising the Benefits of Digital Technology (ALLIANCE and Scottish Enterprise, 2015), that there is a need to 'ensure that people, living with long term conditions and disadvantaged by inequalities in health, are participants and beneficiaries of digitally-enabled health and care'.

Currently the DTM is used predominantly by professionals but its intuitive design means that there is great untapped potential for it to be used by individuals with long term conditions as a self-management tool both in their own homes and in health and social care settings.

What we expected to do

The overall aim of the project is to empower people with a range of long term conditions (LTC), with and without additional communication difficulties, to manage their own health and well-being by using Digital Talking Mats (DTM).

Outcomes

We plan to use the DTM to support people to achieve the following:

- Become more aware of how the different facets of their lives interact with their health and well-being
- Have an increased understanding of the component parts of their health and social care needs
- Have improved reflection on their own situation *e.g. how they are managing mobility*
- Develop solution focused actions to improve their situation *e.g. getting a handrail for their stair*
- Increase their ability to discuss and express views with family members and carers
- Focus more on what matters most to them
- Provide information to professionals that is truly person centred rather than relying on families' or carers' views
- Increase self-motivation by helping them to take more control of their LTC
- Have more effective interactions with health and social care professionals by helping the person with the LTC to prepare what they think and need before they meet
- Contribute to the upgrade and development of the next phase of the DTM

Main activities

We planned to work with three partnerships to identify 30 people with different long term conditions

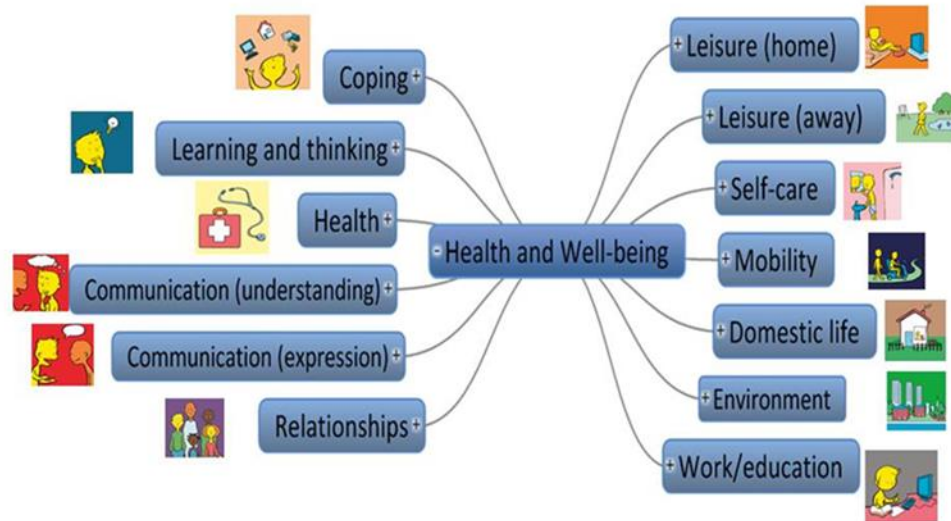
- | | |
|--------------------------------|--|
| 1. Alzheimer Scotland | 10 people with dementia |
| 2. Advocating Together Dundee | 10 people with learning disability |
| 3. Stroke Association Scotland | 10 people with neurological conditions |

We will use the **digital version of Talking Mats** to help people understand, reflect and express their thoughts on the component parts of managing their health and well-being. We will ensure that tablet devices are available for all participants and will lend devices to any participants who do not have access themselves or through their organisations.

We planned to visit each person in their own home on three occasions.

Visit 1

- Show them how to use the DTM and explain the different health and well-being symbol sets (see below)



- Ask them to use the DTM with whichever symbol sets they want, to add in comments and actions on the report page of the DTM and then email their completed DTM to us weekly.

Visit 2

Visit again in approximately six weeks to review how they are managing, to discuss their emailed reports and to collect quantitative and qualitative information on the following:

1. How easy it was to use DTM
2. How helpful it was to reflect on their self-management
3. How many mats they have done
4. The topics which they used
5. The issues which have been raised by using the DTM
6. How easy and useful it has been to record and share their views
7. Who they have shared their mats with
8. Self-management solutions that have been generated and implemented

Visit 3

Visit again in no less than six months to monitor the ongoing use of the DTM with each individual repeating the evaluation point from visit 2 and also evaluating the long term impact of their self-management and pay particular attention to sustainability.

We will be in touch with each participant throughout the project and between visits to provide off site support by email and phone. Ongoing feedback about the use of the DTM will be sought and recommendations that will influence future upgrades will be gathered. It may be that some people will also require extra support and a further visit.

Final event

Organise a final event for all participants to meet and share their experience and learning through the project (what worked well, what supported self-management and what was more challenging). This information will be included in the final report.

What we actually did

As at end of March 2017 we have completed the following:

Materials

We have prepared

- 1. Accessible information sheets for participants and organisations**
- 2. Accessible instructions on how to use the DTM**
- 3. Baseline tool as a low-tech Talking Mats with score sheet**
- 4. 6 week evaluation sheet for visits 2 and 3**

Participants

We contacted relevant organisations and recruited 8 participants with dementia, 10 participants with learning disability and 5 participants with stroke.

Visits

We have completed visit 1 with 22 participants and visit 2 with 6 participants

Talking Mats

We have received 84 completed Talking Mats via email from participants

Support

We have provided off site support by email and phone to those participants and carers/support staff who required it and additional visits to 2 participants to provide extra support.

Involving people in ongoing design of DTM

We have collected feedback from all participants who have commented on the technical aspects of the DTM and will collate these for discussion with the DTM developer.

What difference we actually made

How people are better able to self-manage

Throughout the project we are reflecting on what self-management means and one participant with dementia made an important point

‘None of us are really independent in life’

We feel it is important to bear this in mind and realise the value of people asking for support from others.

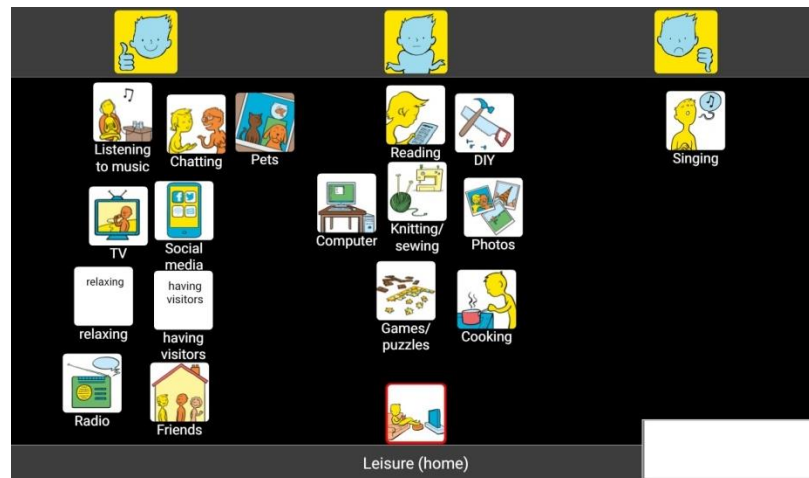
The participants with learning disability have all required support from staff (in varying degrees) to use the DTM. This does not mean however that they are not ‘self - managing’. The DTM has allowed staff to open up conversations about issues that sometimes people don’t want to discuss and helping the person to come up with their own ideas about what would help. This ownership of the way forward is helping the person choose better lifestyle choices.

The following examples show how the DTM (so far) is fulfilling the original outcomes outlined in the aims of the project including helping people to understand component parts of their health and social care needs, to reflect on their own situation, develop solution focused actions, increase their ability to discuss and express views, focus more on what matters most to them and increase self-motivation

Participants with learning disability

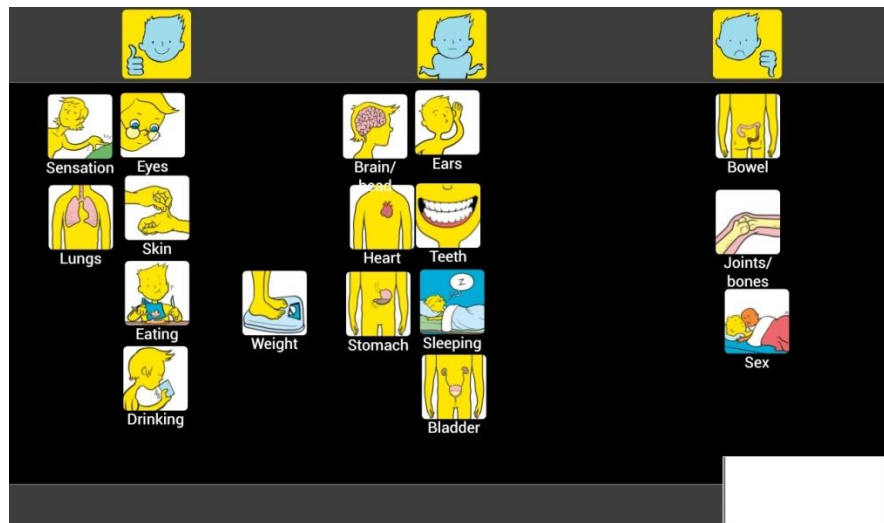
- One participant with learning disability has diabetes. Through using the DTM she has stopped buying takeaways every night and is now buying M&S ‘Balanced for You’ meals. This is a huge step forward for her as she refused to discuss healthier eating before.
- Another participant using the DTM said *‘I can use this for my review!’*

- A woman with learning disability is going to complete the DTM before she goes to her next GP appointment so she can use the completed mat to show the GP how she feels she is coping since she has been on her anti-depressant medication. She wants the GP to speak to her rather than her support staff who go with her.
- A man with autism completed a mat with his support worker looking at the topic **Leisure Home** and the things he liked and did not like to do. This triggered a conversation about how lonely he felt, the fact he did not feel listened to by services and how at times he felt suicidal. He had not shared this with staff before and an appointment was made for his GP. The topics he has chosen for subsequent mats have included Communication and Coping. He is sharing these with staff with are giving them a much better understanding of how best to support him.



Participants with Dementia

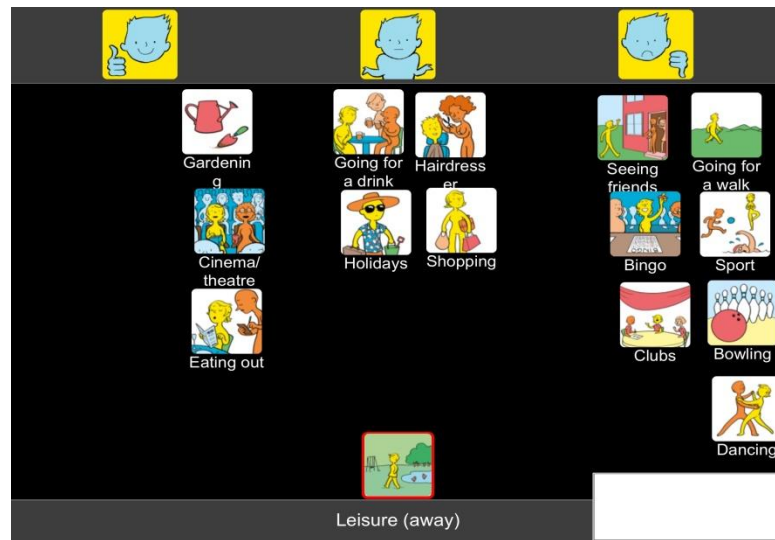
- One man with early onset dementia has identified that he used to enjoy singing and has decided for the first time in his life to join a choir. This is not something that had come up in conversation before. Despite the diagnosis of dementia he has realised that he is still keen to try new things
- A 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*'



- On another mat she said '*It (**Environment Mat**) prompted us to get alterations done to the bathroom*
- A family carer said '*He is coping well with the sessions and is trusting his own answers rather than asking me if I think the answer is right*

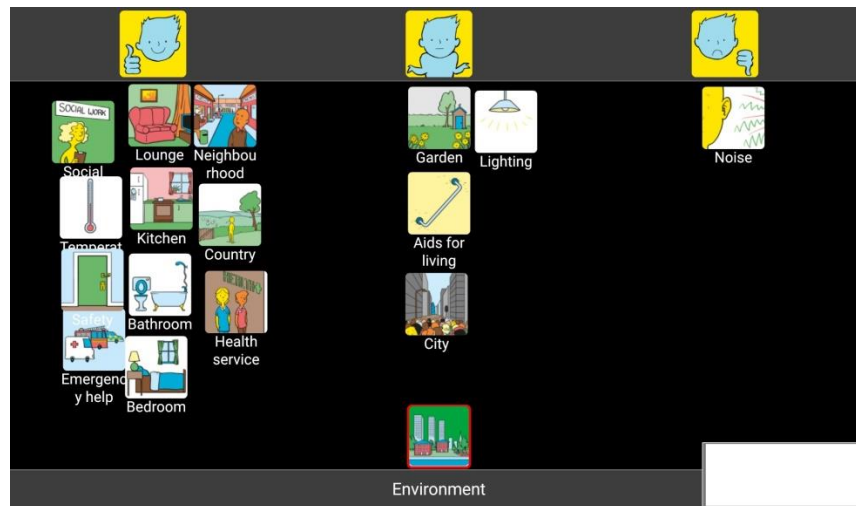
Participants with stroke

- A man with severe receptive and expressive aphasia indicated that he wants to try to use Facebook to keep in touch with friends/ family
- The wife of a man with stroke said '*This (**Leisure away**) has highlighted how few things he can do away from home. We discussed this but can't see how we can change the situation.*' However at the second visit he used the same mat and indicated that he had been thinking about his mobility and was about to start swimming and a fitness class.



The following comments show how people were reflecting on their own situations

- *'Looking at the mats made me realise things – I didn't know. I didn't know I felt like that.'*
- *'The mats gave me the opportunity to say more and gave me room for clarification'*
- *'I wouldn't have bothered to have such deep thoughts if it hadn't been for Talking Mats'*
- *'It made me think not just about dire thoughts – it prompted me to think about the good things.'*
- *It made me think of things I would like to do*
- *Doing Talking Mats doesn't tire me – it seems to stimulate me and give me energy*
- *'This mat (**Environment**) showed me how happy I am in my own home and my neighbourhood'*



Differences between how the Original and the Digital Talking Mats work

Several participants had previously used the original low-tech version and, although we did not specifically ask them to compare, we observed several features which make the digital version more attractive.

These include:

- Participants liked the way that the topics are structured in thematic groups in the DTM and cannot be lost or mixed up.
- Most participants found it easy to go through the process of creating their own mats as the DTM is designed to automatically lead people from one page to the next. Several participants did not even need the instruction handout.
- Participants liked being able to reflect and evaluate their own progress both by comparing mats on the internal DTM filing system and checking what mats they have done and when.
- They valued being able to add their own comments and actions on the report page. The addition of the microphone feature will greatly assist with this
- After a few early hiccups, they have found it easy to email their completed mats and have commented on the potential of sending them to others including family and professionals.
- The DTM is less cumbersome, does not require a table and several participants have used it on their laps.

We have not yet shown people how to import relevant photos or images from camera role to personalise or to create submats. This will be introduced at the second or third visit depending on the ability of the participant.

We will add a question about the differences between the Original and the Digital versions in the evaluation sheet at the second and third visits if the person has previously used Talking Mats.

Challenges and changes

Participants

We have not yet recruited all 30 participants but are confident that we will as we are only 6 months into the project. We initially obtained consent from 12 people with stroke after visiting a local stroke club but currently have only 5 actively involved. There have been several reasons for this including illness, holidays and lack of suitable tablet device. We have names of a further 5 people with stroke to contact.

Some people said that they wanted to be involved but did not have a suitable tablet device. We are investigating purchasing devices to be able to loan out to participants who do not have access to one.

We have noticed that initially some people appear hesitant to reflect on their lives but as they get more confident using Talking Mats they seem to find this easier. We will continue to monitor this.

As we begin to do the second visits we are aware that it may be better to be more proactive in offering additional support for those who have not used Talking Mats previously. However we are keen not to be seen to be 'bothering' people.

Technical

Some people could not manage the technical task without assistance. Some found it hard to remember to tap the symbol before swiping it to where they wanted to place it. However carers have commented that this has improved as more mats are done. We are monitoring this.

Many of the participants were unable to type comments on the report page of the DTM and their carer/support worker did it instead. We have now learned that they can dictate their comments by using the microphone icon on their keypad so we will explain and demonstrate this to all participants from now on.

Few people used the **Actions** box. Perhaps we did not explain this clearly enough and again, now that people can dictate straight into the **Actions** box, this may make it easier.

Some people commented that the symbols are small. We need to emphasise that they can enlarge them with a pincer movement.

Some people have been confused by the top scale. They are unsure whether they are indicating that they **like** something or are **able to do it**. We need to explain the feature which allows them to choose the top scale more fully.

Noone so far has indicated that they have shared their mat with anyone other than us or their carer/support worker. However several people have indicated that they see the value in sharing mats with their GP or Social worker. We will follow this up later in the project.

Evaluation

We have realised that it is too soon to redo the baseline measurement at 6 weeks as people have not been using the DTM for long enough to know if it is making a difference to their lives. We will use it at the third visit instead.

Learning for the future

We have an increased awareness of the meaning of self-management as we observe how participants are using the DTM. Self-management does not mean being totally independent and all but 1 of the participants (so far) is doing the DTM with a carer/support worker.

We are observing how participants are using the DTM to think about their situation, state their own views and share them with carers/support workers. We are also noticing that there is a shift in some relationships as the carers/support workers realise that the person with the LTC can make decisions and express their own views rather than having decisions made for them.

The baseline tool we developed (a low-tech Talking Mats with specific questions) is too abstract for some participants. We realise that we could have made some of the outcomes tighter in order to facilitate a simpler and more accessible baseline tool. We have also realised that it is too soon to redo this baseline measurement at 6 weeks as people have not been using the DTM for long enough to know if it is making a difference to their lives. We will use it at the third visit instead.

One volunteer from the local stroke group offered to buddy a woman with stroke and is visiting her weekly to complete a mat. This is an unexpected model which may be helpful for others.

We will be more explicit about some of the technical aspects of using the DTM but need to take care not to overload participants with information.

We are gathering the comments on the technical aspects of the DTM and will share these with the DTM developer who is keen to adapt the DTM wherever possible.

We are keen to examine how the use of the DTM can become sustainable and are including a discussion on this with participants at the second and third visits.

Twelve Month Interim Report September 2017

Background

We are now twelve months into this project the overall aim of which is to empower people with a range of long term conditions (LTC), with and without additional communication difficulties, to manage their own health and well-being by using Digital Talking Mats (DTM).

What we expected to do since last report

Visit 1

Complete first visits to show participants how to use the DTM and explain the different health and well-being symbol sets - completed

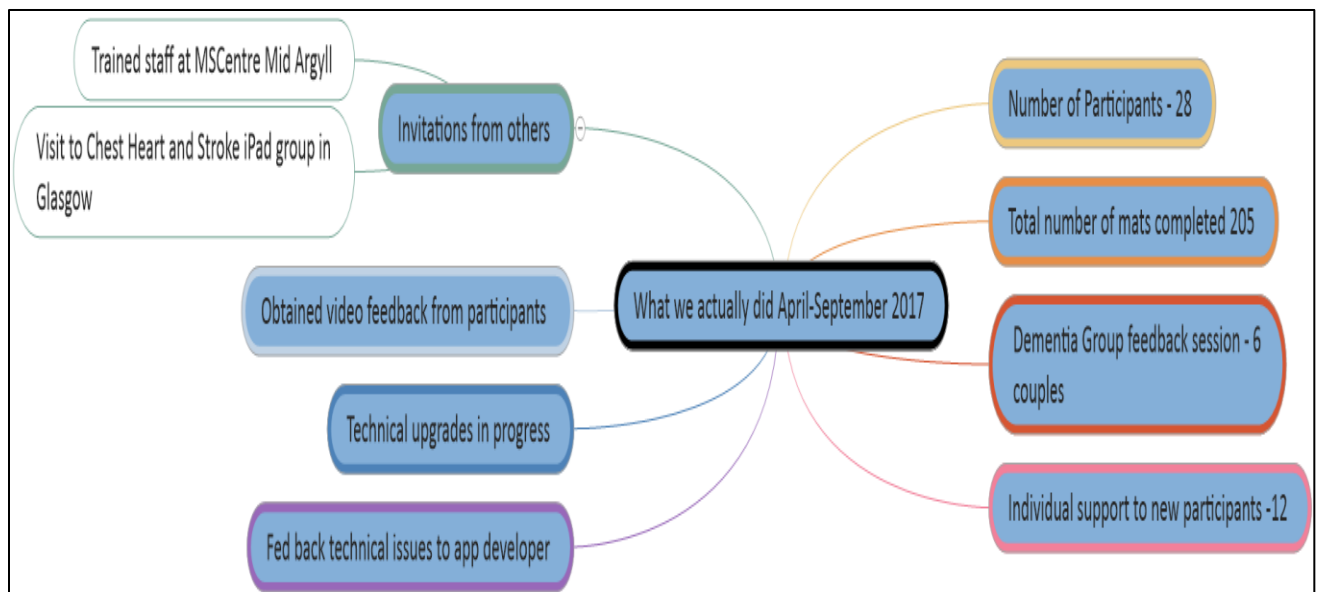
Visit 2

Complete second visits to review how they are managing, to discuss their emailed reports and to collect quantitative and qualitative information on the following - completed

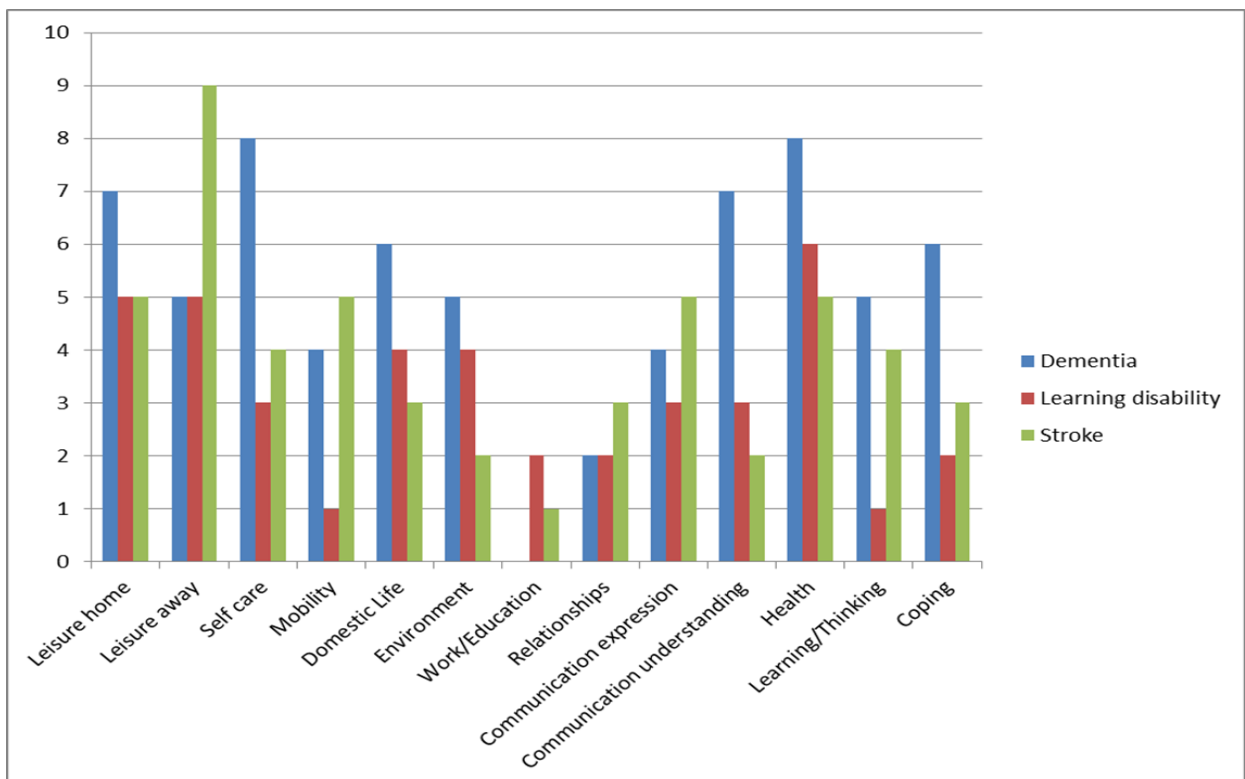
Visit 3

Arrange to visit everyone for a third time. – see Challenges and Changes

What we actually did



Mats completed



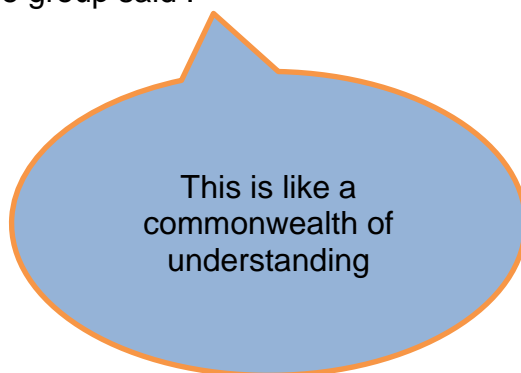
From the information presented in the mats and additional comments from participants we have noted some common themes emerging. These are slightly different for each group. Participants are highlighting issues through the use of the DTM and identifying ways of addressing some of these. There is understandably some reluctance about exploring all of these issues in more depth.

People with dementia	People with LD	People with stroke
Communication Other health issues Mobility Sex Changing relationships	Communication Other health issues Chance to have views heard Support needed	Communication Other health issues Mobility Younger participants identified different goals

Dementia Group Feedback session

This was one of the most successful experiences in the project so far as it turned into a focus group with lots of sharing of ideas, connections and suggestions for future use of the DTM. The group asked to have another session early in 2017 to meet each other again and to help with the write up of the final report.

One man in the group said :



We plan to facilitate similar groups for the participants with learning disabilities and stroke.

Technical issues

- iPad needs to be switched on by someone else
- Cannot remember password
- Sometimes prompting is needed
- Tap and drag is difficult
- Have text under top scale on mat
- In Comments box it would help if the first letter was capitalised
- Action box not always understood

What difference we actually made




The following comments and accompanying video highlight the positive impact that using DTM is having on the lives of the participants in this project.



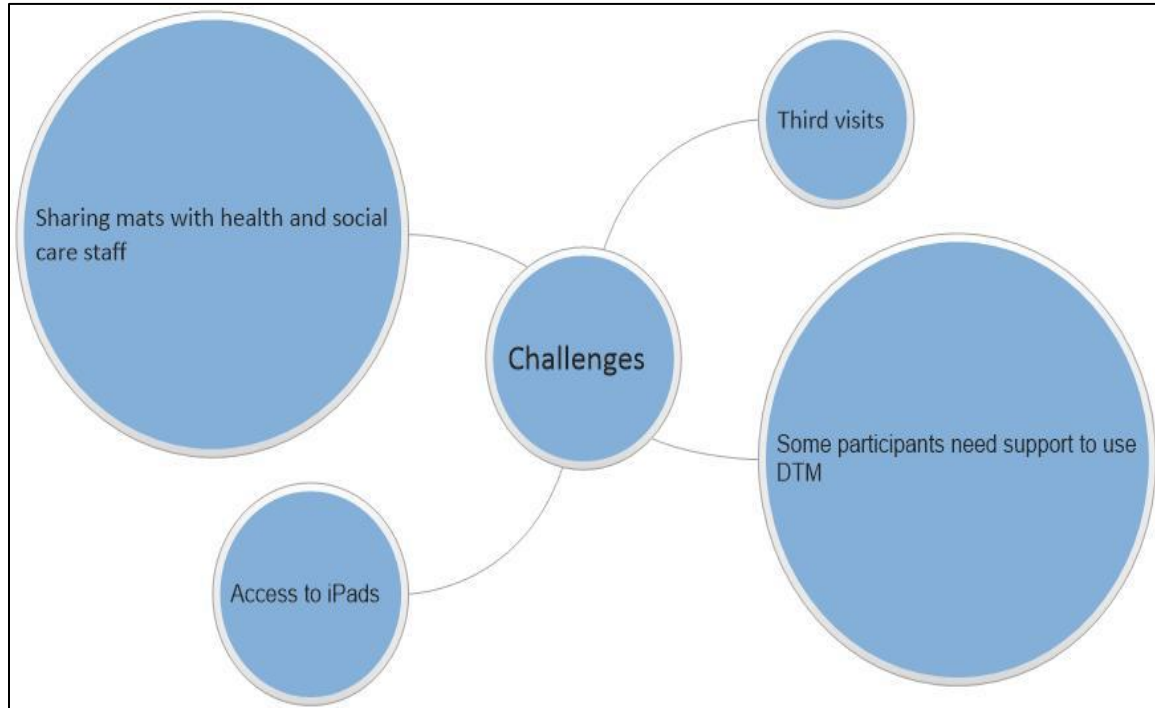
- *I find where I used to be able to speak and finish my sentences I am now hesitant as I forget which words to use*
- *It helps me sort out my thoughts – very useful*
- *I get so much out of the process*
- *I come up with insights which might help me in the future*
- *I can now talk to (my wife) in 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*

Here are 3 examples of self-management solutions:

<p>A young man who has had a stroke has expressed his desire to go back to work as a chef</p>	
<p>A woman with dementia has got an accessible bathroom</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>	

Challenges and changes



Third Visits

We expected to visit everyone for a third time but instead, responding to a suggestion from one couple living with dementia, we decided to bring people together to evaluate:

- their use of the DTM
- the information obtained
- plans for individual future use
- extending the use of DTM for others

Support to use DTM

This was positive for many people as partners were able to listen to the views of the person with the long term condition which was often a struggle without the Talking Mats. In addition partners may be the people who need to make changes happen. Some other participants however are dependent on paid support to help them use the DTM which means they are not always using it as often as they would like.

Access to Ipad

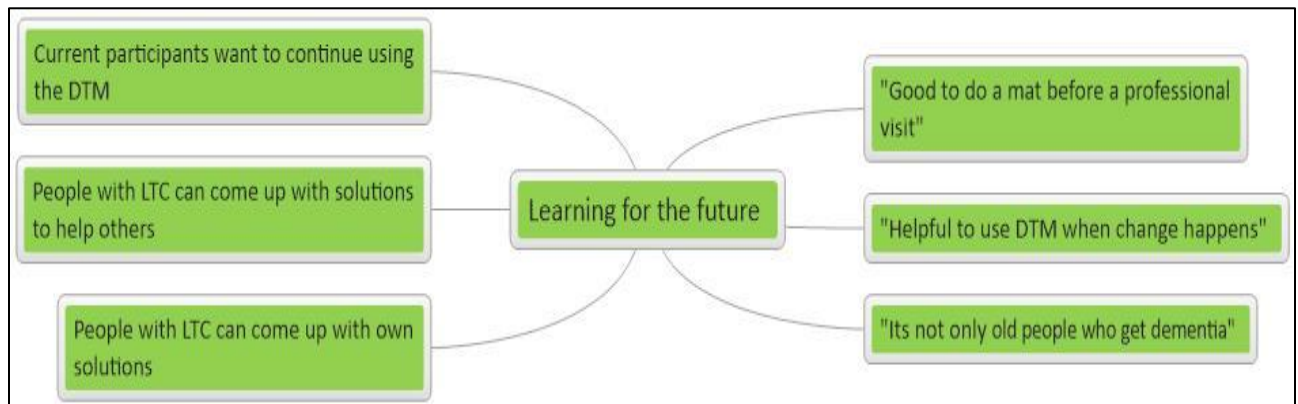
Two participants only have access to the iPad at the Centre so it's sporadic and they may not be able to get logged in. Also the Wi-Fi at the Centre is poor which means syncing takes a long time and this was putting them off a bit. They are working with staff at the Centre to get funding for their own iPads.

Sharing Mats with professionals

Several participants want to share their mats with health and social care staff but are not sure how this will be received. We are exploring ways of increasing awareness starting by speaking to Speech and Language Therapy Departments, and presenting at conferences,

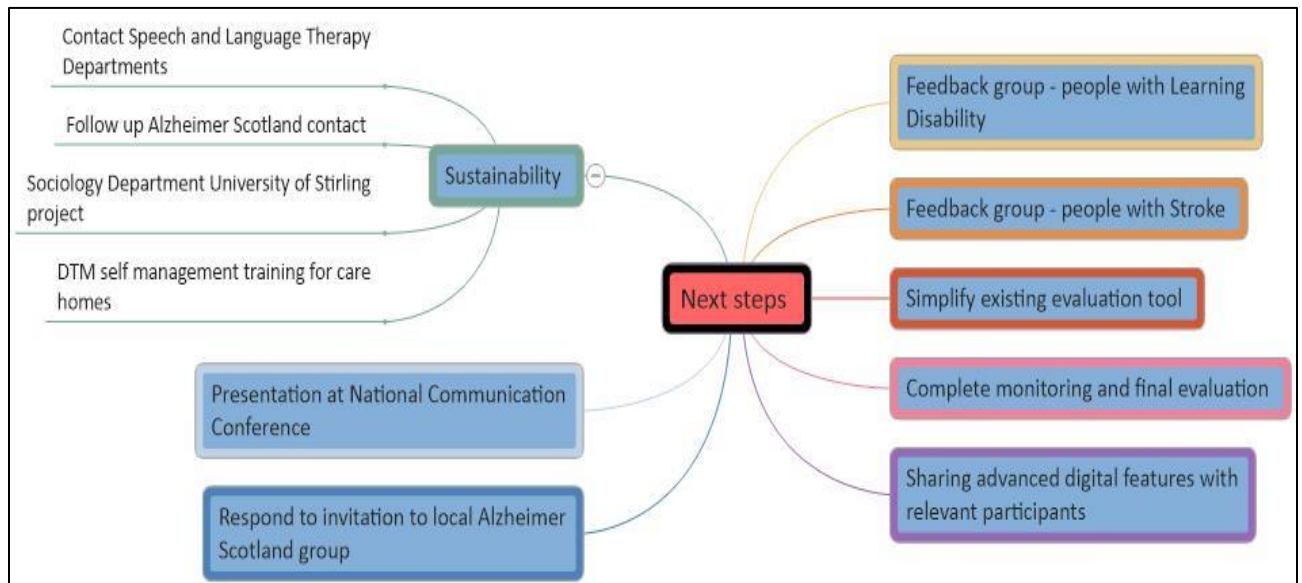
Learning for the future

The following points came from discussions with participants



- Doing a DTM before a meeting with a professional can be an easier way to think things through and get points across.
- Several people thought it's important to do a DTM at a time of change such as moving house, going into hospital etc.
- The people in the dementia group really bonded and felt strongly that too often dementia is portrayed as an old people's problem and they felt their issues are different.
- We were struck by how well participants came up with self-management solutions both for themselves and for each other.

Next steps



Additional suggestions from the dementia group

- Partners doing mats as well. This idea came from one couple who explained to the group how they both used the DTM separately on the same topic which is helping them manage their relationship.
- Do mats at different times of day to see if that made any difference to the engagement and information gained. 4 participants are piloting this
- Making a portfolio of printed mats to show to hospital staff
- Use completed mats as a visual “This is me” record

Final Report to ALLIANCE

April 2018

Background

The overall aim of our project was to empower people with a range of long term conditions with and without additional communication difficulties, 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.

What we expected to do since last report

Our plan for the final phase of the project was to:

- Support continuing participants to use the mats for self - management and share advanced features of the Digital Talking Mats App with them
- Liaise with other professionals within Health and Social care about the feasibility of participants sharing mats digitally with them
- Obtain feedback from participants with learning disabilities and staff who supported them
- Obtain feedback from participants with a stroke
- Speak to local Alzheimer groups
- Present the project at a national communication conference
- Look at ways to make the use of the digital app sustainable within Health and Social care
- Complete the final evaluation

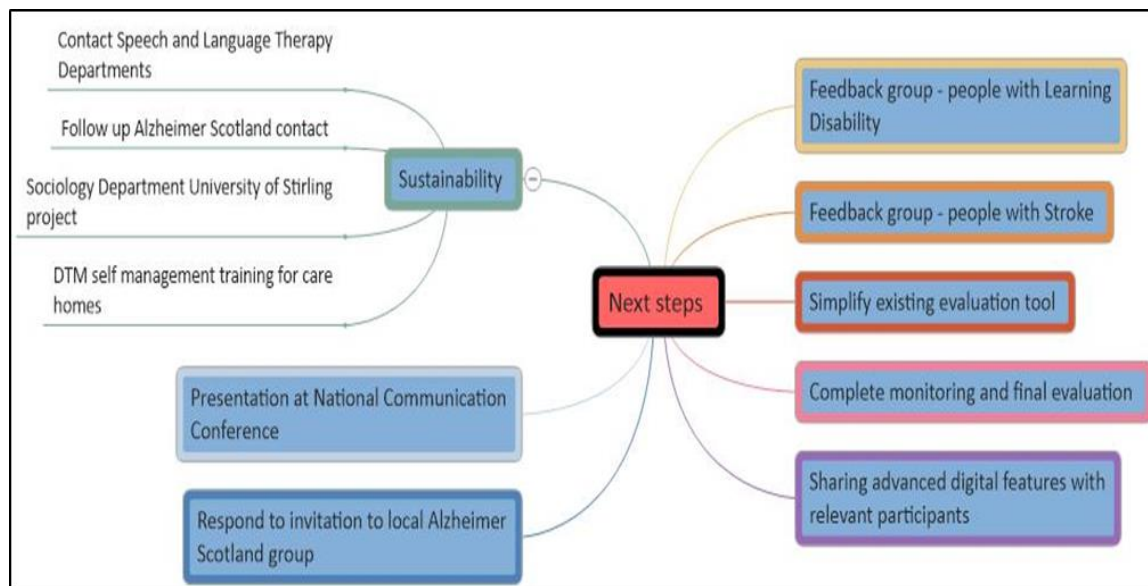


Figure 1 Next steps from previous report

Additional suggestions for the final stage of the project came from the dementia participants. These included:

- Individuals producing a portfolio of printed mats
- Creating a Talking Mats version of 'This is me'
- Comparing mats done at different times of day
- Couples doing mats on the same topic

What we actually did

Supporting participants

We supported those who continued with the project and updated them on the advanced features of the App such as importing photos. We also advised them on the new top scales that had been added following feedback.

Sharing about the project

We met with professionals in Health and Social Care to look at barriers within their systems to using the Digital App.

We met with several groups within the third sector to tell them about the DTM and the project.

Participants shared their experience of the mats with others in their networks including local dementia support groups, a learning disability self -advocacy group and a stroke peer group.

We presented the 12 month project findings at the Communication Matters National Conference in Leeds.

Feedback and evaluation

We obtained feedback from participants, families and support staff as part of the final project evaluation.

Evaluation

Participants

There were a total of 28 participants in this project. All but one individual completed at least one mat. The remaining 27 participants were living with one of three different long term health conditions. There were 8 participants who had a stroke, 11 participants with dementia and 9 participants with a learning disability. Participants were coded using with S, D or L respectively followed by their participant number within each category.

Participants were asked to complete a minimum of 6 mats.

Of the 27 participants, 15 completed all 6 mats requested.

Of these 15, 12 participants across all categories continued to complete mats over the 18 month period of the project.

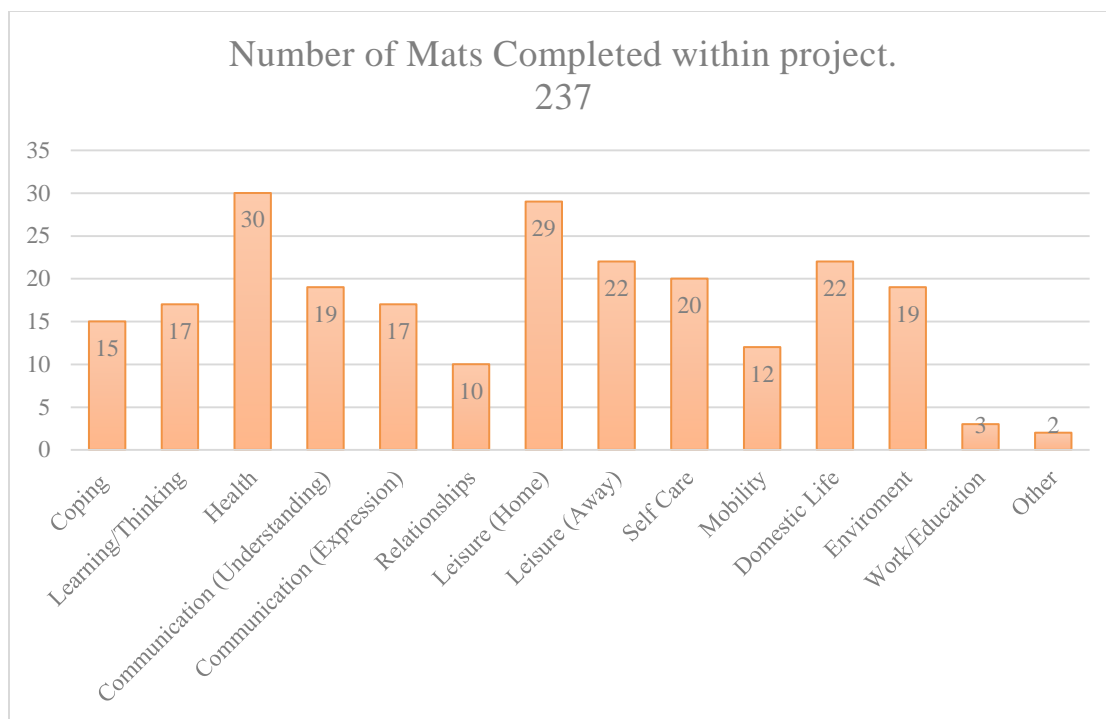


Figure 2 Mats completed over the course of the project

Participants completed 235 mats across all 13 topic areas in the Talking Mats Health and Wellbeing resource. Two participants created their own topics which were not in this resource: a 'football' mat and a 'meals' mat. This took the total number of mats completed to 237.

The top three topics completed across all participant groups were:

- Health
- Communication (understanding and expression)
- Leisure (home and away)

For each individual participant, and depending on the chosen mat topic, the top scales could differ from mat to mat.

To help us analyse the data from all the mats we used the top scale 'Going Well, Sometimes going well, not going well' which was the best fit for evaluating any changes to health and well-being.

Dementia Findings

Dementia is a progressive condition which results in gradual deterioration over a period of time. One of the interesting findings was that over the course of 18 months, health needs may have fluctuated but none of the participants showed a significant decline as might have been expected.

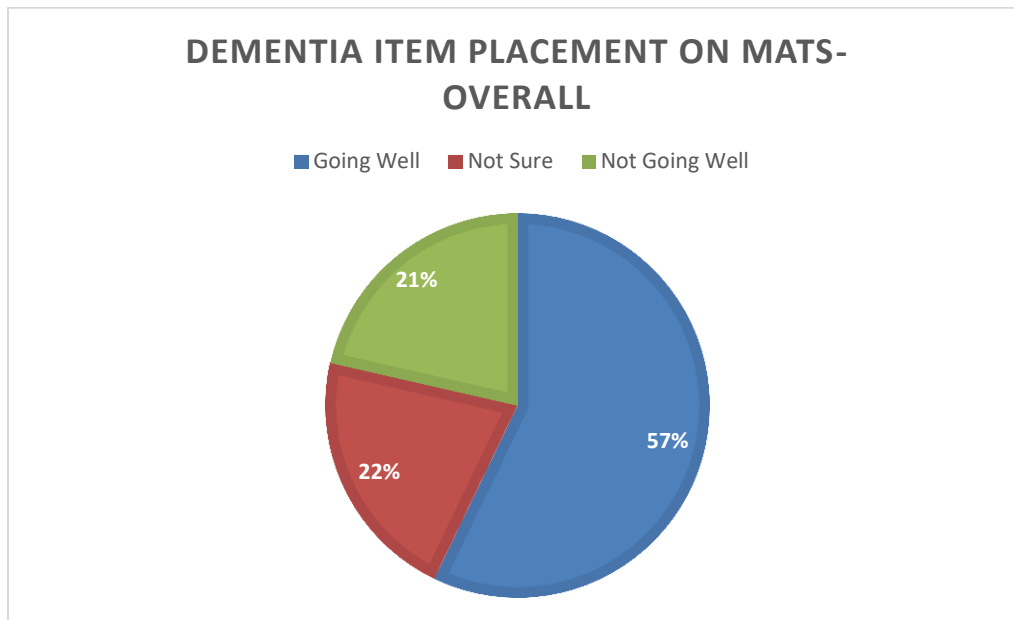


Figure 3 Overall views on Mats by participants with dementia

Ninety seven mats were completed by people with dementia.. The above chart shows that generally there were more areas of their life that individuals with dementia felt were going well compared to areas that were not going so well.

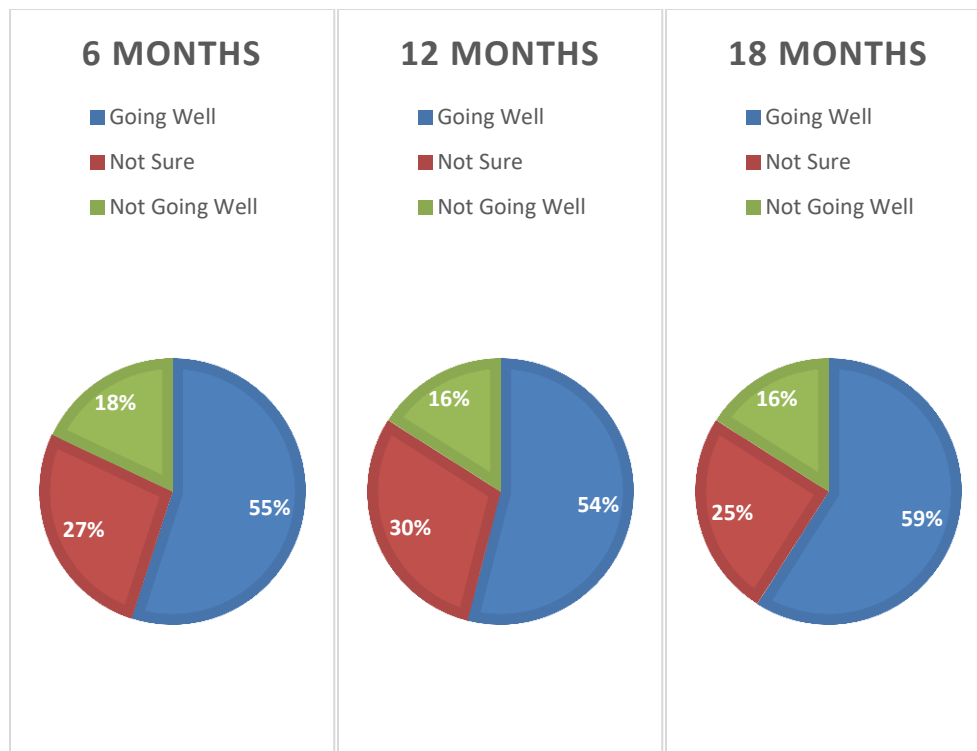


Figure 4 Mats completed by dementia participants at the 6 month, 12 month and 18 month final report stage

The first finding is that at 18 months the participants living with dementia actually felt their well-being had improved.

Stroke findings

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

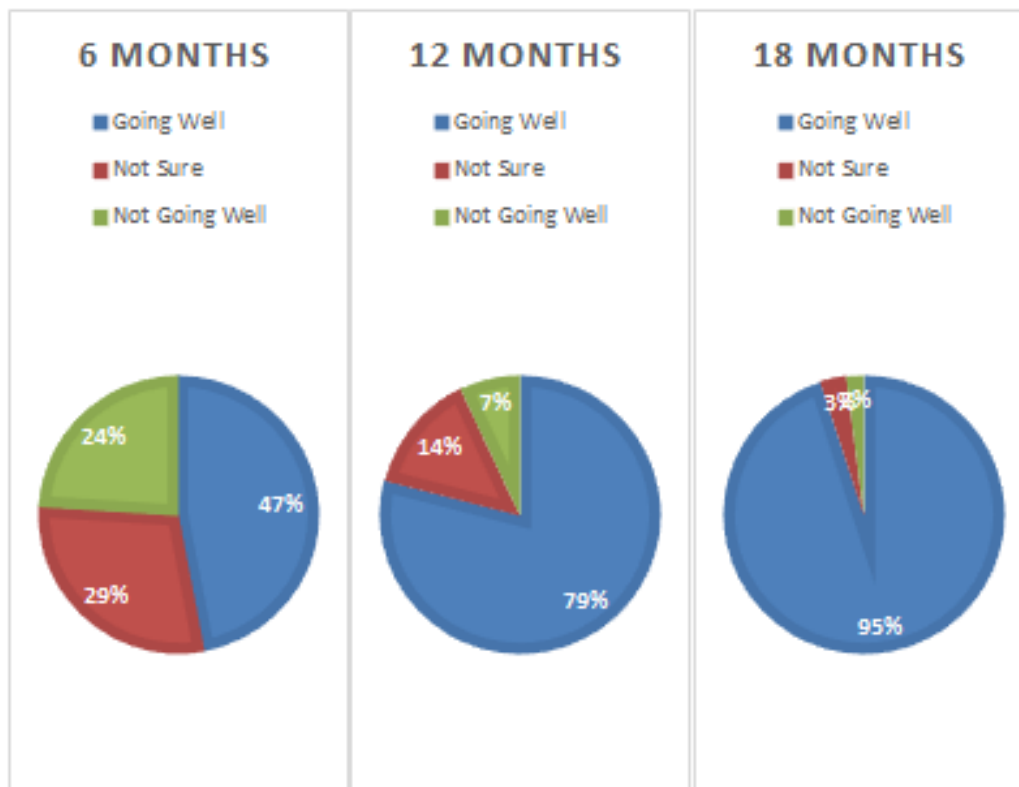


Figure 5 Mats completed by participants with stroke at the 6 month, 12 month and 18 month final report stage

Learning disability findings

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.

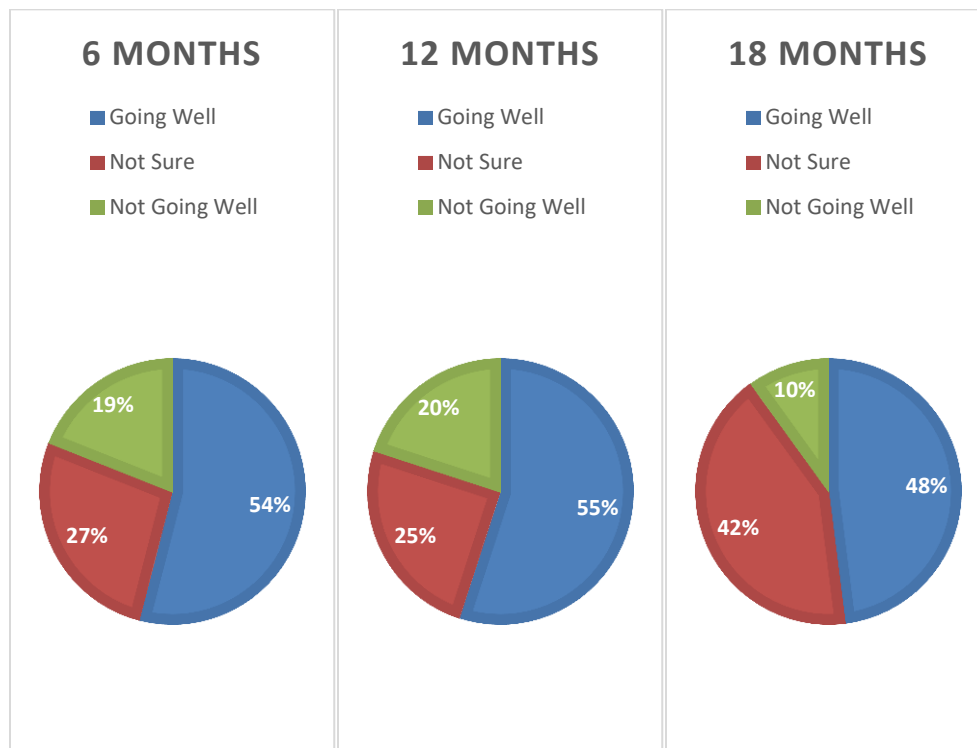
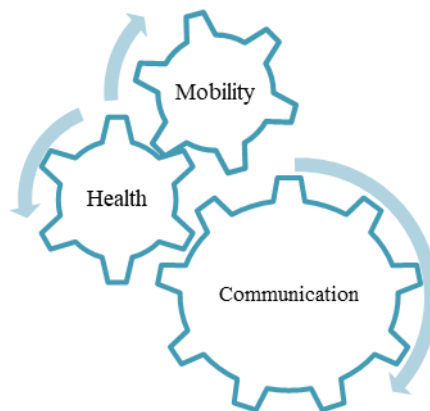


Figure 6 Mats completed by participants with learning disability at the 6 month, 12 month and 18 month final report stage

Themes

The three most common themes that emerged and were common across all of the different groups were with Health, Mobility and Communication. Several participants across the three groups reported changes in their health whilst simultaneously, noticing a change in their mobility.

Although the mobility topic was chosen only 12 times, these completed mats highlighted a link with the person's health and their ability, desire and enjoyment of leisure activities, in particular 'leisure away'.



It is important to note that while all participants are living with either dementia, stroke or learning disability they also have additional health concerns and often these were more of an issue than their main diagnosis.

What difference we actually made

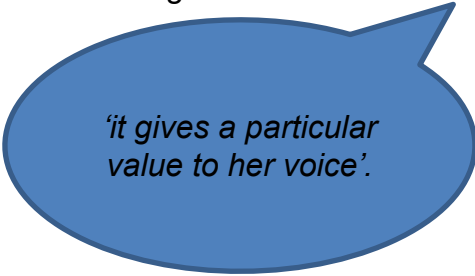
The following comments and accompanying video highlight the positive impact that using DTM had on the lives of the participants

Quality of Life

If individuals are gaining the ability to communicate their thoughts and feelings about the things that matter to them (the basic principle of Talking Mats), then this will enable them to have more control within their lives.

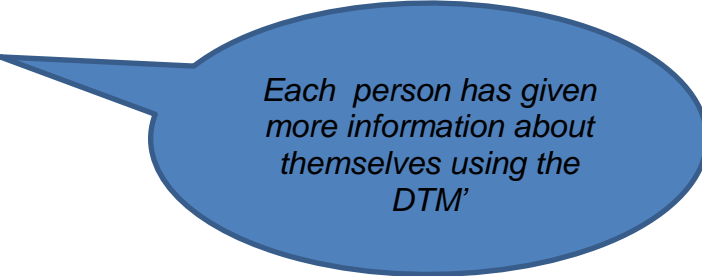
Throughout the duration of the project we obtained feedback about the usefulness of the DTM as a self-management tool. We met with individuals, held three groups for participants with dementia and a group for participants with learning disabilities. We also obtained feedback from families and support staff.

When speaking of one of the participants with learning disabilities a support manager said of the DTM



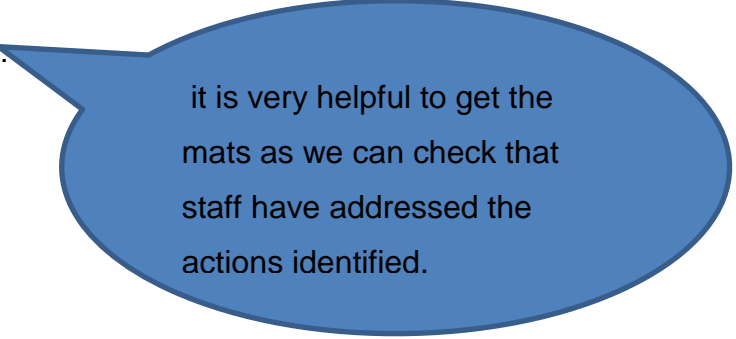
'it gives a particular value to her voice'.

This manager also said.....



Each person has given more information about themselves using the DTM'

....and also noted that as a manager....



it is very helpful to get the mats as we can check that staff have addressed the actions identified.

A member of staff from another organisation commented

'It would be brilliant if we could use it all the time, mats help focus a conversation'

One of the dementia participants 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

The following 3 stories highlight how using the DTM being has helped to improve the participants overall quality of life.

1. One participant with a stroke and very little expressive speech had ongoing difficulties with his lungs. Three mats were completed on this topic and show the progress from 'not going well' to 'going well' after they had seen the GP. The DTM helped him to effectively communicate how he was feeling to the individuals around him and as a result address his health issues.

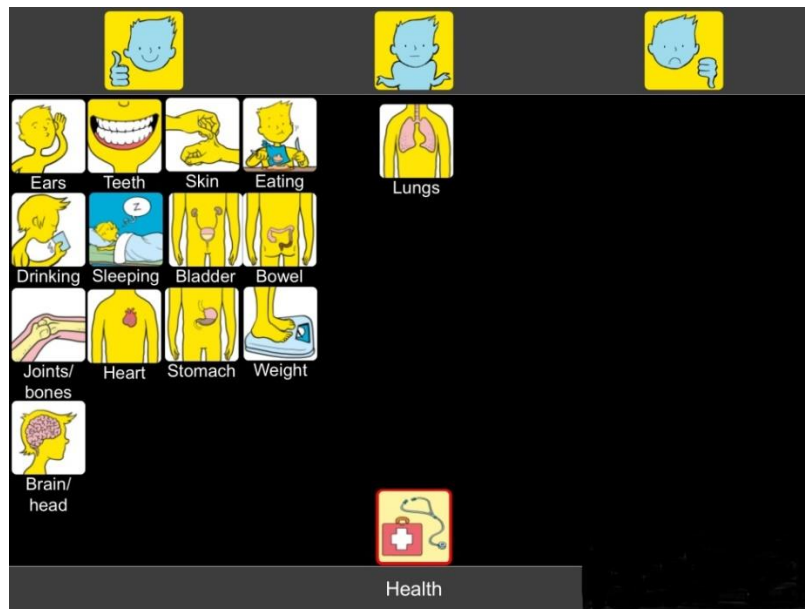


Figure 7 Stroke participant's first mat on Health

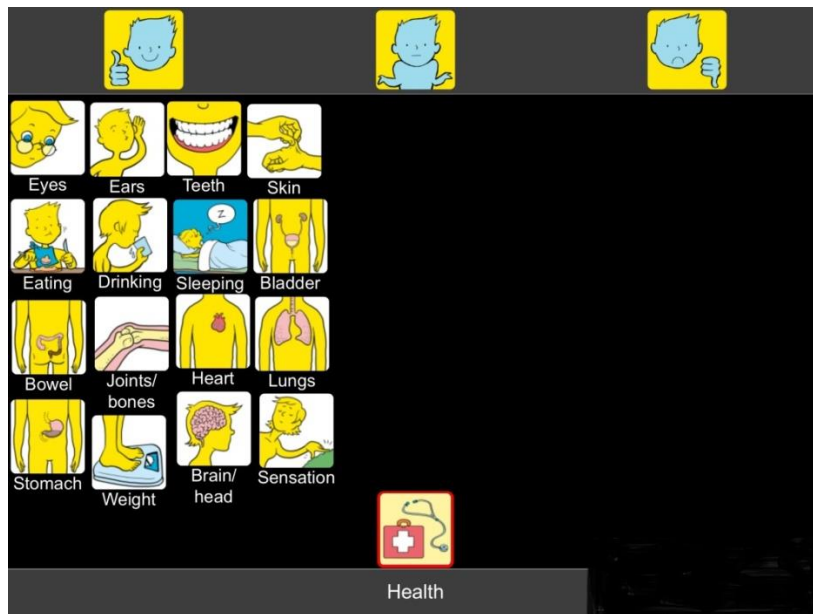


Figure 8 Stroke participant's final mat on Health

2. After doing a mat on self care and seeing what was not going well, another 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 galvanised him into action and allowed him to set goals for himself which he has achieved



Figure 9 Stroke participant's mat on Self Care

3. 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.

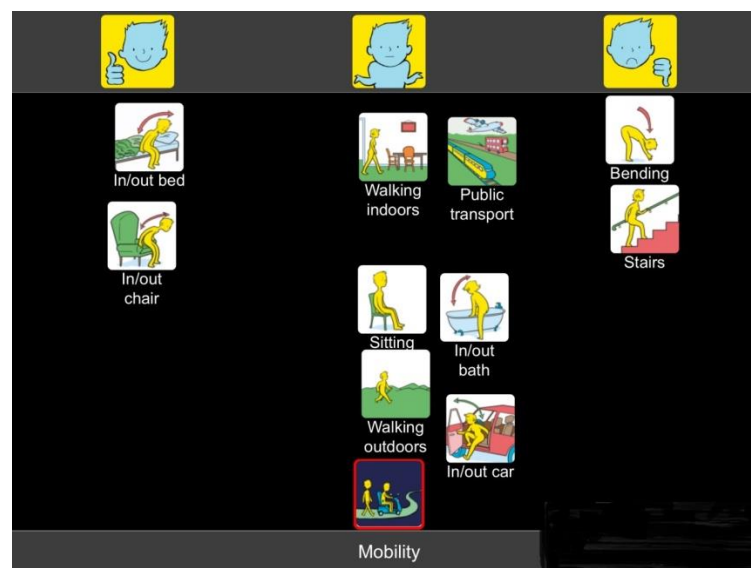





Figure 10 Learning disability participant's mat on Mobility

Here are 3 further examples of self-management solutions:

<p>A woman with severe expressive aphasia used the App to highlight problems with her eyesight and now has glasses which has made a huge difference to the quality of her life</p>	
<p>A man with dementia gained insight into problems with his mobility and using the App reminded him to move every half an hour and to take his time</p>	
<p>A woman with a learning disability identified she wanted to keep fit and is now attending Zumba classes</p>	

Challenges and changes

Since the interim report there have been the following challenges and changes:

Attrition

In any project involving people with long term conditions there is always the challenge of drop out. There were a total of 28 participants in this project and all but one individual, who had other serious mental health difficulties, completed at least one mat. Participants were asked to complete a minimum of 6 mats and 15 completed all 6. For those who did not complete all 6 mats there were several

reasons including 2 people with stroke who felt they had improved so much that they did not need to use the mats and others who had additional health issues which meant they were unable to continue.

Technical

Technical issues previously identified

- iPad needs to be switched on by someone else
- Cannot remember password
- Sometimes prompting is needed
- Tap and drag is difficult
- Have text under top scale on mat
- In Comments box it would help if the first letter was capitalised
- 'Action box' not always understood

How these technical issues were addressed

All the people in the project who needed assistance to switch on, remember their passwords or needed prompting had support to do this.

The tap and drag function was discussed with the app developer but it was not possible to alter this in the scope of the project

In November the app developer released an updated version of the Digital Talking Mats with changes including adding obvious clothes on those symbols where the character appeared to be naked, additional relevant symbols, a more comprehensive list of wording for the top scale and a toggle feature to switch the wording for the top scale on and off. To read the full extent of changes read the attached blog <https://www.talkingmats.com/listening-to-our-customers/>

All the participants had access to this updated version.


The initial problems with logons have been resolved and only one couple reported a technical problem which we were able to fix with help from our app developer.

Action and comments boxes – less people than we had hoped have added comments to these, despite our demonstrating how to use them. We have concluded that for many participants, they may have difficulties with writing and once they have completed the mat they feel that it's done and just want to email it over to us.


With the upgrade to the app this has allowed participants to use a wider range of top scales. Adding the text under the top scale symbols was a great help to participants in remembering the top scale that had been chosen.

Top scale
One of the key skills in using Talking Mats is getting the top scale to reflect the question that you are asking and to be consistent.


Here is a range of top scales to choose from:



Going well



Sometimes going well



Not going well

Going well	Sometimes going well	Not going well
Managing	Need some help	Not managing
Can do it myself	Need a little help	Can't do it myself
Very important	Quite important	Not important
Really good at	Quite good at	Not good at
Want to do	Sometimes want to do	Don't want to do
Happy	Not sure	Not happy
Like	Not sure	Don't like

Figure 11 Upgrade to top scale choices

Sharing with professionals

In the interim report we commented that not many participants were sharing their mats with professionals. Although all participants thought it was a good idea to

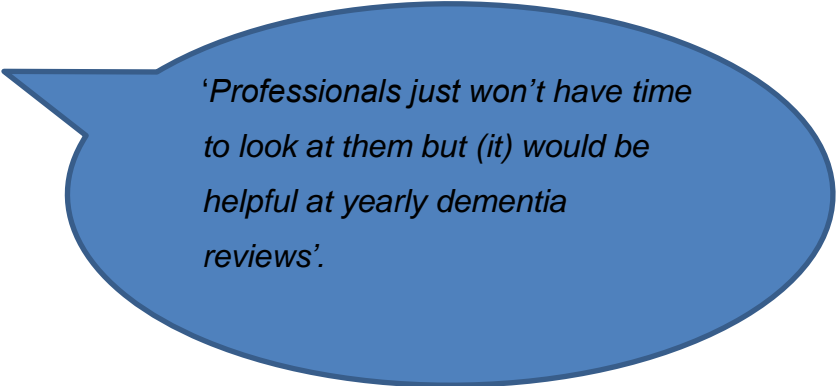
share some of their mats with Health and Social Care professionals such as medical and nursing staff, this only happened rarely. One person shared their mobility mat with someone from their local Social Work team (they were not clear who exactly this was) and another person shared his health mat with his GP. This reluctance to share could be because people have been unsure how this alternative way of presenting their well-being information would be received. In addition, people rarely have an ongoing relationship with professionals such as GPs and social workers where they have built up enough trust and confidence to share their views. Where participants did share their mats regularly it was with frontline support staff with whom they already had an ongoing relationship. If mats were shared with other professionals then often it was the support staff that facilitated this at the participant's request.

The two learning disability support organisations that supported participants to take part in the project have purchased the DTM to extend the use of DTM to other people with learning disabilities.

At the beginning of the project, participants were keen to share their mats with family members and this has included spouses, children and grandchildren. The spouse of one participant with a stroke even used the DTM with her sister who had also had a stroke. One participant with dementia demonstrated the DTM to visitors from Japan who were in Scotland visiting dementia experts, including those with lived experience.

Another participant with dementia showed her portfolio of mats she had collected to the GP and she also takes it with her to hospital appointments and her dementia groups.

One person commented that ...

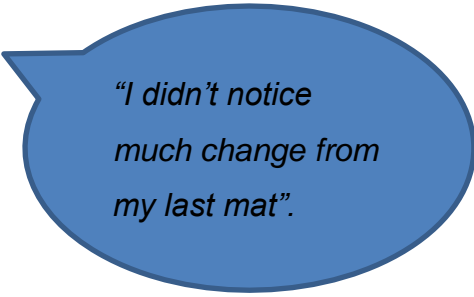


'Professionals just won't have time to look at them but (it) would be helpful at yearly dementia reviews'.

Learning for the future

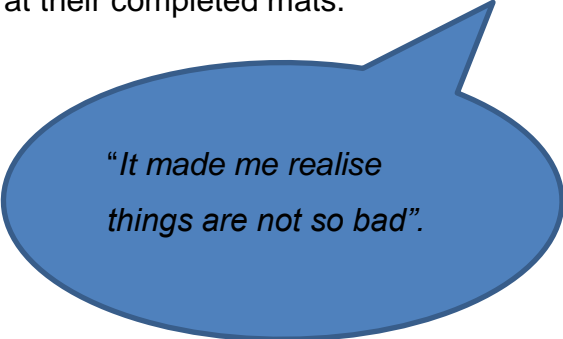
Lack of deterioration shown in mats over time

Dementia is a deteriorating illness and the findings that, for many people living with dementia there was little change in their mats over the 18 month course of the project was an unexpected learning not to assume.



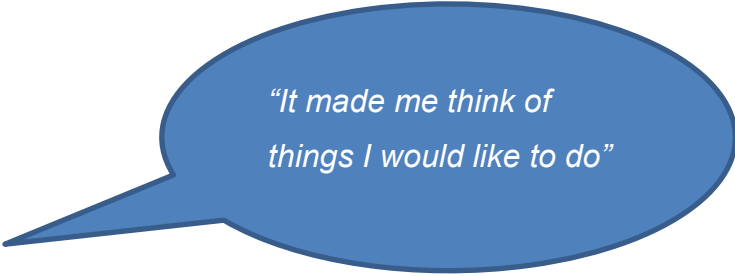
"I didn't notice much change from my last mat".

In addition 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".

Many of the participants 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"

Group meetings

The group meetings, where participants met each other and shared their views, were very valuable and we would have liked to have included more of these during the project but they proved to be logistically difficult to organise because of timing, travel, weather and illness.

This is me adaptation

Although we liked this suggestion made by one of the participants this was not feasible within our time scale.

Comparing mats at different times

A Talking Mat is only a snapshot of how an individual is feeling at that time, on that day. Some of the dementia participants pointed out that over the course of a day an individual may have different thoughts and feelings toward the same issue. Two of them offered to do the same mat in the morning and also in the evening for comparison. We encouraged them to do this but only one person did this for a few days and we did not receive enough data for analysis.

At the last group meeting for participants we had 3 people with dementia and 1 person with a stroke and their families. We asked for comments on the content of the final report and had some discussion about comparing mats. The feedback was that the mornings tend to be better as people get more tired as the day goes on. However one person said they did manage in the evenings.

We believe there is the potential for a future longitudinal study of the use of Talking Mats.

Couples mats

Some partners of people with dementia voluntarily completed the same topic mat which allowed us to compare views between couples. Although many of their

views were the same, not surprisingly, there were differences. In particular one spouse indicated that communication (fluency and articulation in particular) were not as going as well as her husband with dementia thought. The most striking difference was in the topic of **Coping** where 'confidence' was at totally opposite sides of the mat for another couple.

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. We would like to explore this further.

At the final group meeting, the wife of one of the stroke participants heard for the first time that other couples were doing mats on the same topic to compare views. She thought it was a great idea and will start doing it.

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. We think this is a great idea and are encouraging other participants to consider this.

Others thought they would just look at their mats on the iPad to compare

'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

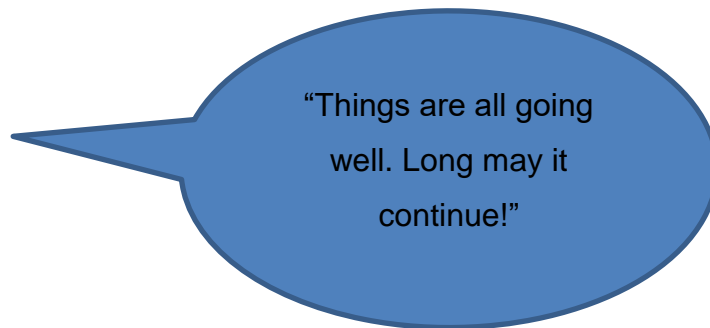
Extending the use of DTM into other areas

We have been approached by two Universities who are working with a housing organisation to extend the use of the DTM into housing. This resulted in us

preparing a joint proposal which has been accepted to collaborate to develop a new resource.

Positive feelings

As well as helping participants self -manage their long term conditions, an unexpected and highly significant 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.



Dissemination

In an endeavor to raise awareness of Talking Mats as a self-management tool we have contacted other organisations and have presented this project and discussed how Talking Mats could be better embedded in Health and Social Care systems:

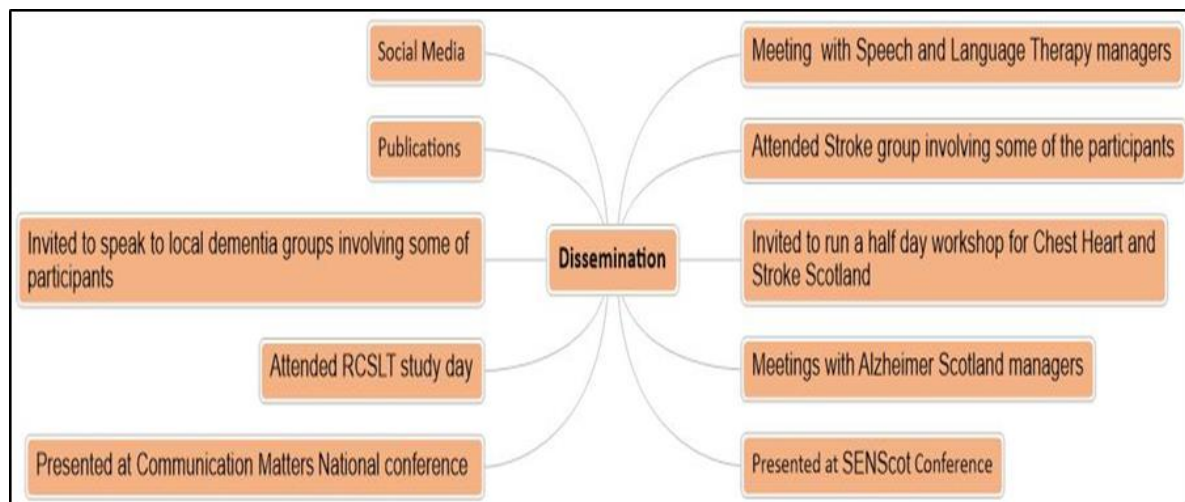


Figure 12 Dissemination plan

All of these have resulted in an increased interest in the use of the DTM for self-management.

We will also disseminate the final report as widely as possible, write a paper for publication and attend future relevant conferences.

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.

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