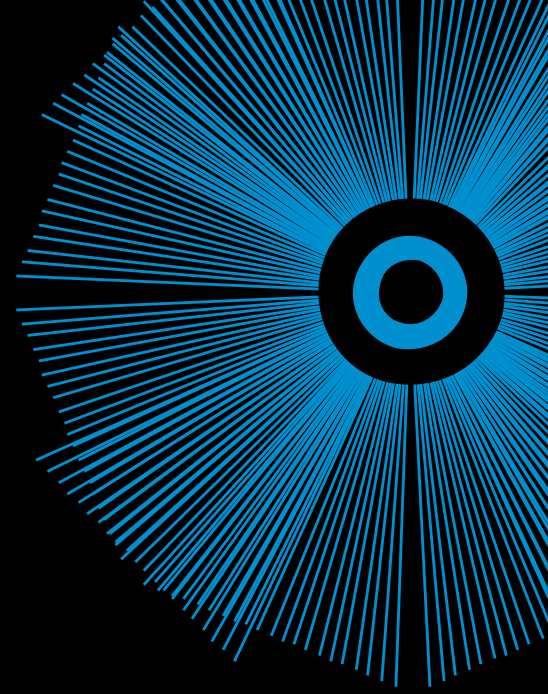# Shine 2014 final report

A Study of the Use of Self-Management Techniques in Patients with Mild Cognitive Impairment

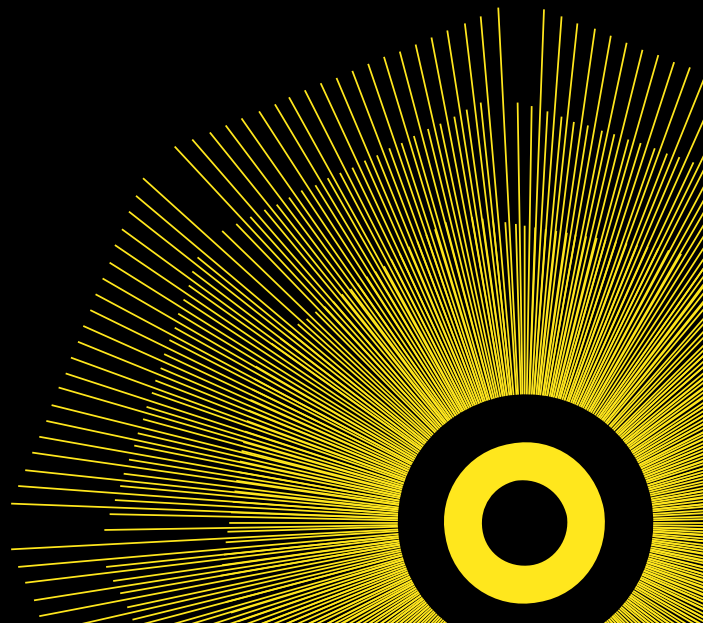Devon Partnership Trust

September 2015

Part 1: Abstract

Project title: A Study of the Use of Self-Management techniques in patients with Mild Cognitive Impairment (MCI)

Lead organisation: Devon Partnership Trust

Lead Clinician: Dr David Pearce

So what began with me wondering how the course could help ended with both of us feeling a whole lot better not only about our present memories, but also how to preserve what we have to face the future with greater confidence.

Abstract

Mild Cognitive Impairment (MCI) accounts for around 20% of diagnoses currently made in our Memory Clinic and these patients have an approximately 1 in 7 risk of converting to a dementia. A literature review has shown no well-validated treatment currently available and one of the main drivers for this project was the absence expressed at the G8 Dementia Summit by Alistair Burns (national DH clinical adviser on dementia) of any systematic delivery in the NHS of a service to older people with MCI.

Our Shine proposal was to develop an innovative and evidence based self-management programme for MCI patients that showed that teaching self-management skills helps them with their day-to-day lives and reduces the risk factors for conversion to dementia.

The THYMe groups (Think Health for Your Memory), were facilitated by two mental health Occupational Therapists, supported by the Lifestyles team. They were run over five weekly sessions (with the exception of one group which we trialled over 6 weeks) with a one off reunion session after 3 months.

Each session followed a similar format but focused on a different risk factor for developing dementia (regular exercise, a healthy diet, mental stimulation, stress management, an active social life and quality sleep). Self-management skills taught included weekly goal setting and problem solving. The patient and their friend/relative were encouraged to set goals which were checked for SMART criteria, their importance to the patient and the patient's confidence in achieving the goal. Goal feedback was then given the following week. Each week also involved a memory problem solving session.

Over the course of the project we:
- Ran 9 groups with 49 patients and their friends/relatives successfully completing the programme
- Showed statistically significant improvements in the Patient Activation measure, our primary outcome measure and other measures
- Found evidence of increased knowledge of, and positive changes to, dementia risk factors
- Had uniformly positive feedback from group attendees
- Developed a well-received train-the-trainers course
- Trained staff at a local Healthy Living centre to deliver the course
- Manualised the THYMe programme to enable adoption elsewhere
- Presented the results at local and national conferences
- Worked with Age UK and Exeter University towards continuation of the THYMe groups via a multicentre trial

Main Challenges:

1. During the course patients were successful at completing their goals and their knowledge of the risk factors and confidence to self-manage their illness improved. This, however was not sustained over the longer period.
2. In spite of enthusiastic support from local managers, the current financial strictures in the NHS has made the adoption of a new treatment plan unlikely.

Learning points:

1. We have produced a successful self-management programme that improves the confidence of MCI patients to manage their own health and healthcare provision, raises their awareness of the risk factors for conversion to dementia and provides them with skills and information to make healthy changes to their lifestyles.
2. In order to maintain improvements and be cost-effective, these groups are best delivered by the third sector as part of an integrated service.

Part 2: Quality impact: outcomes

Our initial Shine proposal was to develop an innovative and evidence based self-management programme for patients diagnosed with MCI. Our original plan was for 70 patients to complete the programme over the course of the project and to show that teaching of self-management skills helps patients with their day-to-day lives and reduces the risk factors for conversion to a dementia.

Our THYMe groups (Think Health for Your Memory), were facilitated by two Occupational Therapists from the community mental health team, both of whom are experienced in teaching self-management skills.

> ..... the help, advice and encouragement given by [facilitators] was invaluable in putting my [memory] problems into perspective and overcoming them

The groups were also supported by Torbay and Teignbridge Healthy Lifestyles teams who helped advise on group content and also attended the last week of each group to provide information on what support their teams could offer. We took referrals from the memory clinic based at Torbay Hospital as well as community older people's mental health teams across the Torbay, South and West Devon area and later in the project also opened the groups up to DPT's Exeter memory clinic. Groups were run over five weekly sessions (with the exception of one group which we trialled over 6 weeks) with a one off reunion session after 3 months.

Each group session followed a similar format but focused on a different risk factor for developing dementia. We called these the '6 Pillars for a Healthy Lifestyle for the Brain' (regular exercise, eating a healthy diet, mental stimulation, stress management, an active social life and quality sleep).

> We have learnt the importance of drinking water and associating with other people. We are going to do more of both, the latter by joining a walking group

> The most positive thing I have taken from the course is not to get stressed about forgetting, to take a step back, think and use some of the leaflets and print out to help

Self-management skills are the cornerstone of the groups and each week goal setting and problem solving were practiced.

> I have been encouraged to try and help myself

The patient and their friend/relative were encouraged to set goals which were checked for SMART criteria, their importance to the patient and the patient's confidence in achieving the goal. Goal feedback was then given the following week. Each week also involved a memory problem solving session.

Setting and achieving goals helps to make me feel more positive

The big thing that came out of it was goal setting, which actually gave me something to look forward to, a lot better than just drifting

Since the start of the project we have made significant alterations to the metrics used in order to improve the credibility of the results we achieve. At the start of the project we decided to change the main outcome measure from a scale of our own devising to the Patient Activation Measure (PAM). Our thinking on this was influenced just prior to the start of the project when a paper was launched by the King's Fund on the importance of Patient Activation. At the launch it was proposed that the PAM should become the standard measure in the NHS of a patient's knowledge and ability to self-manage. This would be via the purchase of a national license. Whilst this has had to be bought we felt that using a well-validated scale that has also been shown to predict future service usage would enhance the credibility of the results and enable us to tap into the zeitgeist.

We also received feedback from the psychologists that assessing cognitive status via the ACE-111 at the beginning of the course and then three months after as initially planned could make assessing patients in future difficult, due to the practice effect. We therefore decided to look for different secondary measures of change. As we found that the knowledge of lifestyle risk factors for developing dementia was low in group participants (and the general population) we have been testing these at the start and end of each group. We have also been assessing how successful group participants are at achieving their goals by the use of Goal Attainment Scaling which is also a well-recognised tool in this area. Here we have been employing it using the method advocated by Prof. Turner-Stokes[ii]

We have also been using the Dementia Quality of Life (DEMQOL) tool to assess improvements to quality of life. There is no specific quality of life measure available for MCI so we used the DEMQOL which has been validated in patients with dementia.

In the early stages, we experienced some difficulties with the completion of the PAM and DEMQOL questionnaires. Patients and their friend/relatives often missed questions, in some cases invalidating their scores. We improved the readability of the questionnaires which ameliorated the problem to some extent but unfortunately we have still not been able to include all data collected within our results below.

All quantitative outcome measures were completed at the beginning and end of each course and again at a 3 month follow up.

Summary of Quantitative Results

PAM Results:
The average PAM scores increased significantly when compared at the start and end of the groups.
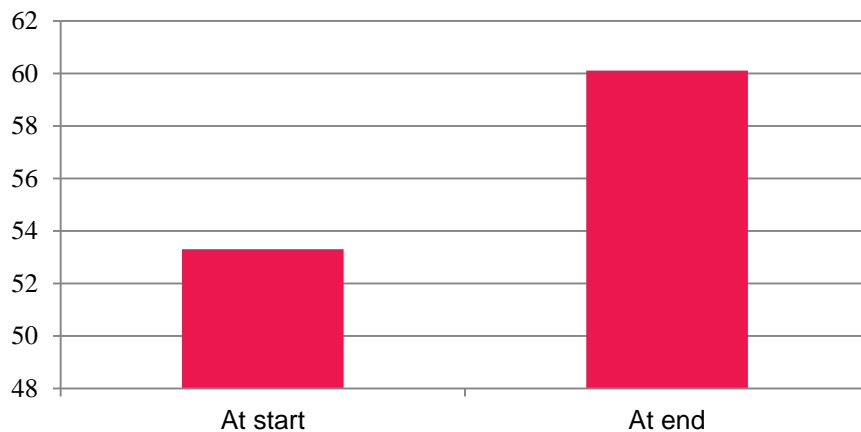

Fig 1. Bar chart of average PAM scores at beginning and end of 5 or 6 week THYMe group (n=43 p< 0.0001, the mean of PAM at group start minus PAM at group end equals -6.867, 95% confidence interval -9.899 to -3.836).

Modified Proxy-DEMQOL:
Whereas patient's scores of their quality of life as measured by the DEMQOL did not improve, their relatives/friend perceptions of the patient's quality of life measured by a modified proxy-DEMQOL did.
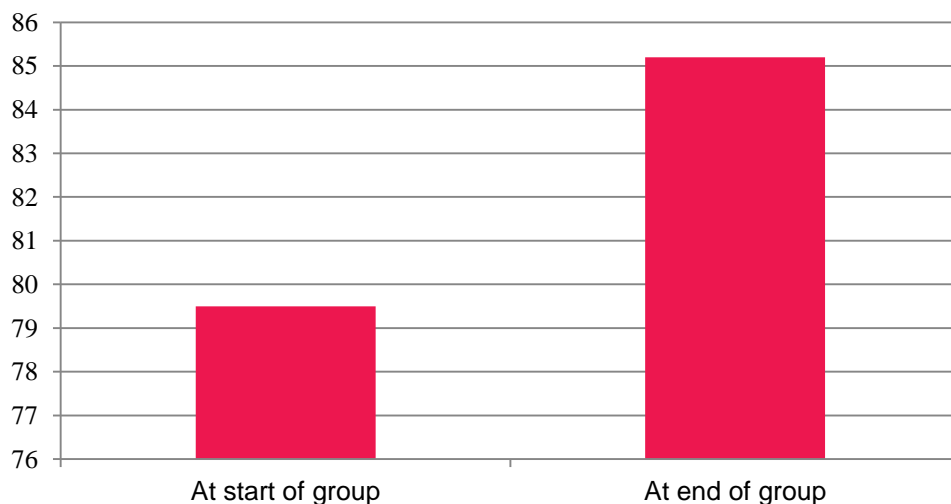

Fig 2. Bar chart of average modifed DEMQOL-proxy score at beginning and end of 5 or 6 week THYMe group (n = 17, p< 0.05.   The mean of the modified DEMQOL-proxy score at start minus score at end equals -5.6552941176, 95% confidence interval -10.6265464235 to -0.6840418118).

GAS Scores:

Patients were successful at achieving their goals and their knowledge of the risk factors for progression to a dementia increased.
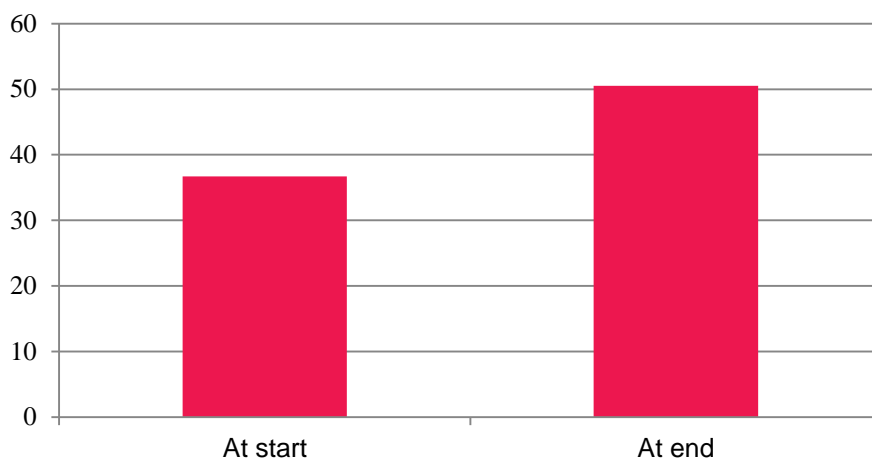

Fig 3. Bar chart of average GAS scores at beginning and end of 5 or 6 week THYMe group (The mean of GAS scores at start minus GAS scores at end equals -13.8210375669.   95% confidence interval -15.9127739333 to -11.7293012004. p<0.0001)

A full explanation of the quantitative results can be found in Appendix 3.

Qualitative Results

Although the quantitative outcome measures have been useful in putting a numerical value on the success of the intervention we believe its full value cannot be fully captured within these parameters. If we are successful in continuing to run the groups beyond the end of the project we will explore other options for measuring the success of the intervention. However, in order to gain a better picture of the impact of our intervention we collected a variety to qualitative data alongside the quantitative data. This is summarised below and comprised feedback surveys, focus groups and patient stories as well as taking measures of attendance. This has enabled us to demonstrate outcomes otherwise missed such as acceptance, improved self-esteem and formation of new friendships all of which had significant impact on the lives of our attendees.

The class all had similar problems and were not afraid to admit them. This gave me confidence not to hide my situation but join in – improvement is possible

[name] has now accepted that he has a problem so I'm now not a nag but a helper

[I am] learning to accept that I have a problem and accepting ways to deal with it. Being given some hope.

Satisfaction Surveys:
Attendees were asked to score a series of positively phrased statements on a Likhert scale of 1-5 where 1 represents strong disagreement with the statement and 5 represents strong agreement with the statement.

Average scores were consistently high throughout the groups (see questionnaire and break down of results in appendix 3). One question which consistently scored slightly lower than the others and particularly so in group 9, is around how much the information given prior to the groups helped people to know what to expect. Anecdotal evidence suggests this is a common complaint in groups related to memory difficulties however it is worth noting this again and considering what other measures could be taken to improve this before any scaling up measures are taken.

Our satisfaction surveys also asked attendees to comment on what they would change about the groups, what was the most valuable thing they learnt and what changes they have made as a result of the groups. Responses were used to guide development of the groups.

What would you change?

No, the size of the group was right, a larger group would have been intimidating

A little too long

What is the most valuable thing you learnt from the groups?

Many of my problems are because I don't pay full attention

To set weekly goals

To not get stressed out

What changes have you made as a result of attendance at the groups?

To keep up word puzzles, keeping my brain active and having more exercise

Plan ahead and be a bit more organised

To support my mother to be more independent

Our Training for Trainers course, delivered by the project lead also received positive feedback, particularly in regards to the facilitation of the workshop with **92%** saying they would definitely recommend it to others.

Focus Groups:
Due to the demands on staff time we obtained feedback and qualitative data from focus groups as opposed to semi-structured interviews on an individual basis, as originally planned. Focus groups have proved to be much more efficient and have also promoted further contact between group members. We ran two focus groups over the course of the project period. Attendees from our first group were invited to the first of these in October 2014 and attendees from groups 3 and 4 were invited to the second in January 2015. Focus groups were found to be an excellent arena for exploring people's feelings about the groups in detail and provided a plethora of learning that we were able to use in future group development.

Attendance:
Attendance has been relatively high and group attendees were consistently motivated to attend the groups wherever possible.

I have learnt a lot with this group, it was great

Over the nine groups we ran **81.7%** of attendees (49 people) attended **80% or more** of the programme (≥4 out of 5 weeks of the programme or ≥5 out of 6 weeks). We consider these excellent attendance rates to be reflective of the value placed on the groups by the attendees. To put this in context the Co-Creating Health phase one evaluation of depression self-management groups gave a successful completion rate of 66% (where successful completion was taken as attendance at a minimum of 5 out of 7 weeks)[1].

Reunion Results Summary

Quantitative results from reunion sessions (one off session held approximately 3 months after the last week of the course) have been disappointing with an apparent drop in activation levels, although they do remain above baseline. See appendix 3 for a full explanation.

Again we feel these results do not adequately reflect our observations of the group. Although there are lessons to be learnt around maintenance (discussed later), facilitators have described reunion sessions where attendees appear not to have recognised the achievements they have made when left to their own devices. Despite initially stating that they have not been able to maintain the progress they

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[1] Co-creating Health: Evaluation of first phase, An independent Evaluation of the Health Foundation's Co-creating Health improvement programme (2012)

achieved in the groups when prompted by facilitators they have gone on to give examples such as self-referring to the Lifestyles team, continuing social groups started during THYMe, eating more fruit, paying attention to food labels, being more active and some have been able to continue to set weekly goals.

Part 3: Cost impact

Given that this is a new service where previously none existed, and any potential cost-savings will only be delivered several years later, we are unable to study these in detail. However, we can look at alternative therapies and compare THYMe to these.

Since the start of the THYMe project, a large-scale proof of concept trial, the FINGER trial[2], has shown that multi-domain interventions, based on lifestyle factors similar to the THYMe groups, can reduce the rate of cognitive decline in at-risk individuals. This study took place over two years and was relatively rigid, intensive and costly, for example involving 10 group/individual sessions with nutritionists, 10 group sessions with psychologists, an individual aerobic training programme with a physiotherapist, etc. The cost of implementing this would limit its widespread introduction and it is not known whether patients continued to follow the regime when the study period ended.

The THYMe programme may answer these problems. Firstly, as well as being only five sessions long, we have manualised the intervention so that it can be delivered nationally. Furthermore, the THYMe programme is designed to be delivered by suitably trained Band 3 workers or Age UK volunteers etc. as opposed to NHS staff. It is therefore envisaged that it will be considerably more affordable and able to be implemented at scale.

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[2] Ngandu, T. et al. (2015) A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly people (FINGER): a randomised controlled trial. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60461-5/abstract

Part 4: Learning from your project

We can identify a number of key factors leading to the success of the groups and the wider project:

- Groups run by knowledgeable and experienced staff create a relaxed and supportive group environment. This encourages excellent group dynamics where people felt able to share their stories and talk freely. We also encouraged attendees to share contact details so that peer support could continue after the groups ended.
- The presence of a friend/relative contributes greatly to successful outcomes and we frequently observed positive collaborations between patient and friend/relative. Feedback from friends and relatives has shown that they have often found the groups as helpful as those with the memory problems.
- Excellent team work and communication. A team that were willing to be flexible to suit the requirements of the project and were committed to making it a success.
- Working on the understanding that the project is a learning curve; to this end, we ensured we had ample opportunities to feed into the PDSA cycle through professional discussion, reflection and patient experience detailed below.

  - **Focus Groups and feedback surveys:** supported patient driven improvements, for example following our first focus group changes were made to our healthy eating session to make it more relevant to memory and feedback given on the surveys led to a reduction in group length.
  - **Post group debriefs:** followed each group session where facilitators recorded what had gone well and what they wanted to change. This led to improvements such as the introduction of the 6 pillars of a healthy lifestyle for the brain, following the suggestion that a more robust course structure would improve clarity.
  - **Steering Group Meetings:** were held approximately monthly where progress was reviewed and learning points and next steps discussed. These meetings drew together feedback gleaned from other sources and were an excellent forum for the team to practice the problem solving skills they were modelling in the groups.

Challenges

Inevitably, we have also come up against a number of challenges over the project period:

- Difficulties in time management, both within and outside of the groups, has been a constant underlying theme. Team members have needed to wrestle the demands of the project with competing job roles and pressures. Our initial target of 70 people successfully completing the programme was unrealistic

and we adjusted our expectations accordingly. In spite of this the PAM, our primary outcome measure, still showed statistically significant improvements.

- Patients in the older age groups can have significant problems with isolation and physical conditions that hamper maintenance of self-management. Although we have anecdotal evidence that attendees were able to maintain some of the progress made in the groups, there is a need for integration with community services to maintain improvements.

- Feedback from group attendees has been that one reunion session after 3 months of 'going it alone' isn't enough. Referrals onward to the Lifestyles team have also not been as high as expected. Should the groups continue with Age UK workers, group attendees would be automatically linked into their services, providing continuity and consistency in support after the course had ended.

- The current financial climate in the NHS is a significant challenge. We kept senior management and commissioners involved in every step of our project and had some very positive feedback, however further funding has not been forthcoming. This has provided the opportunity to collaborate with third sector colleagues where this intervention better sits anyway.

- We encountered difficulties with our initial choice of proxy outcome measure, the carer's PAM. The label of 'carer' was not felt appropriate by friends and relatives of MCI patients, who did not consider the questions applicable to their circumstances. Hence we trialled a different questionnaire based on the proxy DEMQOL, a quality of life measure. This was much better received and also showed a statistically significant improvement.

- We encouraged peer support in the groups and set up a private Facebook group, closely managed by the project team, where group attendees could keep in touch, swap experiences, ask each other questions and access resources. However few attendees joined, largely due to the small percentage familiar with social media.

- We began work on our communications strategy early on in the hope that spreading the message of our success would engage potential future backers. We provided regular updates to stakeholders and have presented at conferences, including delivering a poster and verbal presentation at the Health Services Research Network symposium. Group attendees have also acted as advocates including one gentleman presenting about THYMe to the board of Governors.

Learning for the Future

- Mild Cognitive Impairment is no barrier to effective self-management
- Whilst self-management groups are effective in improving patients' confidence to manage their own condition, this needs to be integrated into a pathway that allows for further opportunities to reinforce the gains made.

- The true potential of group work is found in opportunities to share experiences and come together with a common purpose; people feel empowered when they learn they are not alone. We will need to ensure the ethos of the groups is carried forward if successful in our bid to collaborate with Age UK.
- Continuous feedback from all involved in the project was the key driving force for improvement via PSDA cycles.
- The value of dedicated project time cannot be underestimated, including time to get together as a team.

Lessons learnt for Implementing and Sustaining Innovation in the NHS

- The financial climate in the NHS is one of cost saving, reorganisation and decommissioning. However, demonstrating early and significant cost benefits is difficult in a long-term condition. Evidence of such benefits needs to be robust and outcome measures well designed from the outset. Alternatives such as the use of the third sector should be explored early on wherever possible.
- Good PR is imperative and every opportunity should be taken to spread the message about the intervention and its achievements. Opportunities can come from anywhere and the more people who know about an intervention the greater the chance of success.

Part 5: Plans for sustainability and spread

The major challenge to sustainability has been the present financial position of the NHS. The bulk of the Devon Partnership Trust catchment area is under the auspices of the NEW Devon CCG. In 2013/14, the CCG's financial position was in deficit by £14.5 million which led to the Devon health community being identified as one of 11 "financially challenged health economies". One response to this has been the CCG publishing a list of services which were being considered for disinvestment. Given this there was really little chance of a new service such as the THYMe groups being funded, however worthy it was. Having said that, one of the main learning points from the project was that the intervention is best delivered where there can be a seamless transition to a maintaining service. Therefore we have been working with Age UK and, to a lesser extent, Westbank (a community Healthy Living Centre) to continue the work from here.

There are, however, national drivers for the continuation of a service for MCI groups, one of these being the absence expressed at the G8 Dementia Summit by Alistair Burns (national DH clinical adviser on dementia) of any systematic delivery in the NHS of a service to older people with MCI. Age UK are very keen to work with us to implement the THYMe groups and we have had many meetings with local and national staff. They consider that data collected to date provides an appropriate foundation for further work, having demonstrated that the group approach is acceptable to participants and family members and that it can be delivered by health care professionals within an NHS service setting.

In future we intend to focus on the service being delivered by volunteers identified through Age UK branches. As the THYMe groups so far have only been delivered by NHS staff, it has been decided that further feasibility testing is indicated for this. We therefore wish to train and use the local Age UK sites as 'demonstrator sites' whereby local Age UK staff are trained in the THYMe approach and begin to deliver the groups under supervision. We have already trained staff at Westbank, a local Healthy Living centre via a 'train-the-trainers' course and this approach could be used for Age UK volunteers.

Once this has been completed locally, we then hope to be able to move to a larger, multi-centre trial of Age UK volunteers delivering the THYMe groups in association with Age UK and Exeter University. For this we will be looking for sources of research funding, e.g. making an application to the National Institute for Health Research's Research for Patient Benefit programme of funding, the next deadline being May 2016.

We have also recently begun initial discussions with Public Health England South West about the groups and they are keen to be involved.

Conferences addressed
Health Services Research Network (HSRN) Symposium 2015, 1-2 July 2015
Devon Dementia Partnership Conference. Date: 14th May 2015

6th National Memory Services Forum, Tuesday 29th September 2015 (Upcoming)

Posters displayed
Health Services Research Network (HSRN) Symposium2015, 1-2 July 2015

Nominations
Nominated for Devon Partnership Trust's Celebrating Achievement award

Appendix 2: Resources from the project

1. Selection of THYMe Group Resources

(a) THYMe Resource Book for group attendees:

Client Resource Book.pdf

(b) THYMe group facilitator manual, sample pages:

THYMe
Think Health for Your Memory

Facilitator Manual Week One

Debbie Burnell and Simon Ridley, Occupational Therapists

Devon Partnership NHS Trust   Healthy Lifestyles "Small steps... right direction"   The Health Foundation Inspiring Improvement | Shine

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this one down. Ask participants to try one or several…remind about protective factors of habits, routines etc...

Maintaining a healthy Lifestyle for your memory (twenty five minutes)

Quiz: Risk factors for Dementia over which we have some control
Put up blank sheet first then results from week one (after you have done the quiz!).

'We would now like to get an idea of what things you think may contribute towards our memories deteriorating more quickly and us possibly developing a dementia. For each of the following items can we have a show of hands for those that think these things could lead to a dementia, those that don't think they can and those who don't know or aren't sure.'

Read out each one, count the hands and note down on the flip chart. As in week one, make sure people do not personalise this quiz. We are referring to a general risk rather than their individual lifestyle.

Put up results from week one and say how well everyone has done and how much they have learnt. Though please note, if they answered "No" or "Don't Know" in any numbers to any of the risk factors then you will need to reinforce the message, giving the evidence and benefits of that area. Talk about how positive this is as these are things that we have control of in our lives and that we can all try to change to lower our risk of our memories deteriorating

Link the results from this to why we have been making changes over the past four weeks to try to slow down/stop us developing a dementia. This is a strong motivator to continue with the changes we have already made and to identify others. This then links to maintaining changes section below

Introduction to Maintenance

'This group was set up for people with a Mild Cognitive Impairment (MCI) because evidence suggests that if you make changes in the areas of the six pillars of a healthy lifestyle you will reduce your risk of your memory problems getting worse or getting worse more quickly and of developing a dementia. Making these changes will also help you manage your memory problems on a daily basis, as you will be more alert, and your brain will be able to work at its optimum level.'

'As you are aware, there is no medication that will directly improve your memory or prevent it from getting worse, some of you may be taking medication that will help reduce the risk factors e.g. medication for your heart, cholesterol, blood pressure etc…and it is

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		Yes	No	Don't Know
	Are These Risk Factors for Developing a Dementia?			
Being physically inactive				
Smoking				
High Blood Pressure				
High Cholesterol				
Obesity				
Too much fat in your diet				
Stress in your life				
Lack of an active social life				
Lack of mental stimulation				
Drinking too much alcohol				

Week 2 Session Plan

Time	Agenda	Flip Chart	Page
10mins	Recap	How Memory Works Types of memory Use the Senses Risk Factor Quiz 6 Pillars (x2) What is Self-Management?	3
30mins	Goal Follow Up	Questions to help you set a goal (hand written flips from last week) Our goal needs to be	3
35mins	Mentally Challenging your Brain Social Activity Group discussion Recap	What kind of things have you done in the past that have challenged your brain (handwritten) What can we do to begin to challenge our brains (handwritten)	4
15mins		Break	
30mins	Memory Problem Solving Process This Weeks Problem	Problem solving Cycle Memory Problems – Explore (handwritten) Memory Problems – Solutions (handwritten) Try it Out (handwritten)	7
30mins	Goal Setting Introduction Group Goal Setting Group Feedback	Our Goals Need to be Questions to help you set a goal (x2) Blank questions flip for facilitator goal (x2)	8
5mins	Next Week	Write on a white board and explain	10

- What about if you did not feel you achieved the goal?
- Did the questions we asked that help? How?
- Does talking your goal through with someone else help? How and why? How does this affect your motivation?
- Did planning and prioritising help you achieve the goals? Why?
- Did having a knowledge of what things you could change help you to set goals? In what way?
- What happens if you set a goal that is too difficult/big?
- Having goals you were confident you could achieve?

'Changes I Have Made' Chart:

'One way to help keep ourselves motivated is to acknowledge the things we have already achieved and not forget them (easily done with memory problems). Here is a sheet you can simply add things you do to keep as a reminder of your achievements. Spend a few minutes now writing down the things you have changed/achieved over the past five weeks. You will notice that this may also help you identify areas of the six pillars that you have not made any changes in….as they will have less written down.'

Summary of Maintenance

'We need to be able to continue to make and maintain changes. You've just identified a range of ways that you can do this. We will be typing these up and sending them out to you to help you maintain this. Goal setting has helped you make changes over the past five weeks and the six pillars have helped to make you fully aware of what helps. You can now carry on setting goals to make and maintain changes.
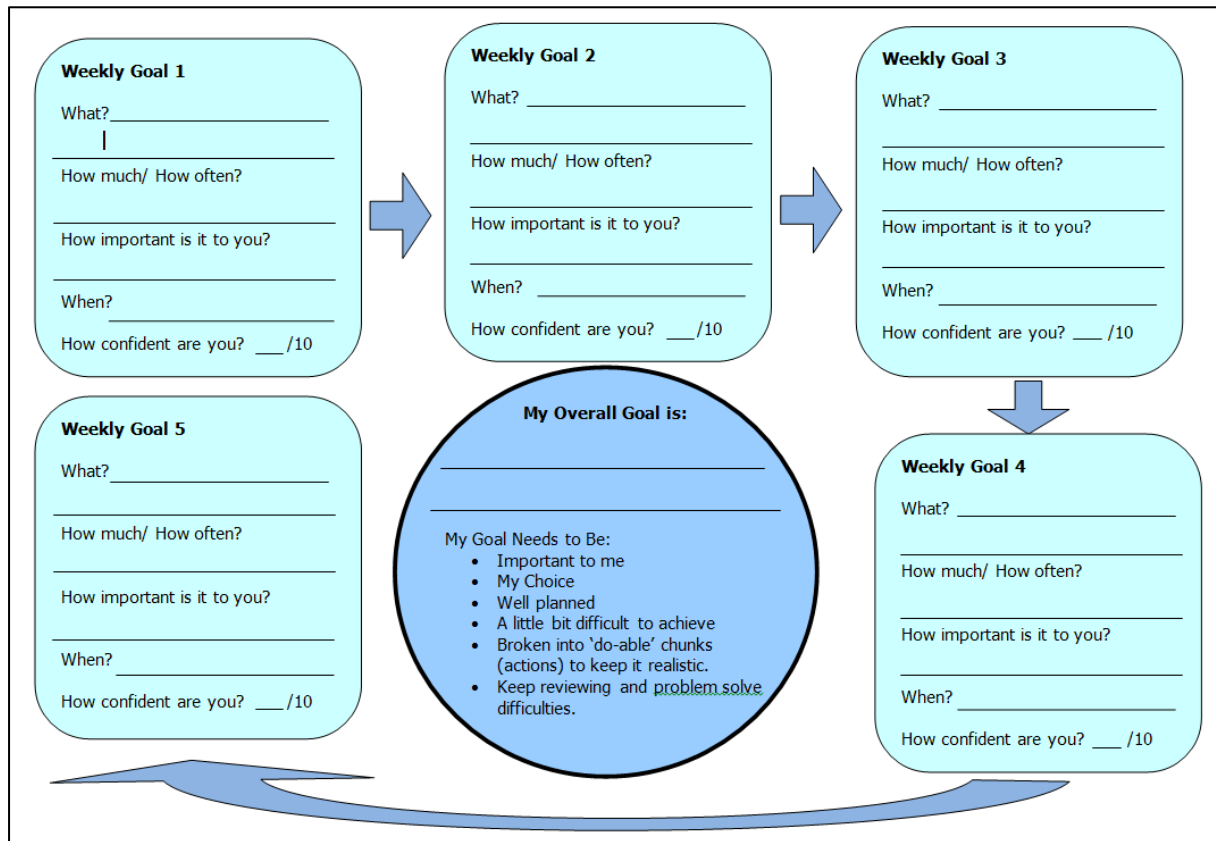
Evaluation (thirty minutes)

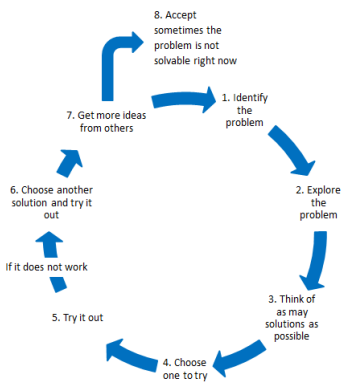*'It is important for us and for you to know if this group has been of benefit.'*

Hand out the evaluation sheets and give them time to complete them. Once complete collect them in and move onto explaining what they should do if they are worried about their memory getting worse in the future.

'If you are worried about your memory getting worse see your GP and ask for another referral to the Memory Clinic. Do this sooner rather than later as there may be medication and other treatment if it has moved on to a dementia.'

(c)   THYMe group goal setting sheet:

Weekly Goal 1

What?_____

_____

How much/ How often?

_____

How important is it to you?

_____

When? _____

How confident are you? ___ /10

Weekly Goal 2

What? _____

_____

How much/ How often?

_____

How important is it to you?

_____

When? _____

How confident are you? ___ /10

Weekly Goal 3

What? _____

_____

How much/ How often?

_____

How important is it to you?

_____

When? _____

How confident are you? ___ /10

My Overall Goal is:

_____

_____

My Goal Needs to Be:
- Important to me
- My Choice
- Well planned
- A little bit difficult to achieve
- Broken into 'do-able' chunks (actions) to keep it realistic.
- Keep reviewing and problem solve difficulties.

Weekly Goal 5

What?_____

_____

How much/ How often?

_____

How important is it to you?

_____

When? _____

How confident are you? ___ /10

Weekly Goal 4

What? _____

_____

How much/ How often?

_____

How important is it to you?

_____

When? _____

How confident are you? ___ /10

(d)   Flip chart pages sample

6 Pillars of a Healthy Lifestyle for the Brain

1. Regular Exercise

2. Eat a Healthy Diet

3. Mental Stimulation

4. Stress Management

5. An Active Social Life

6. Quality Sleep

Welcome

Today's Session

- Housekeeping
- Getting to know each other
- Finding out what you would like from the group
- What is self management?

    Break – Tea/Coffee and biscuits

- What is Mild Cognitive Impairment (MCI)?
- How memory works
- Tools to help
- Explanation of booklets/notebooks

Time for questions – during the group or individually at break or at the end

Problem Solving Process

8. Accept sometimes the problem is not solvable right now

7. Get more ideas from others

1. Identify the problem

2. Explore the problem

6. Choose another solution and try it out

If it does not work

3. Think of as may solutions as possible

5. Try it out

4. Choose one to try

2. Selection of Communications Resources

(a) Service Leaflet:

Useful information and websites

Useful information and websites

The Healthy Lifestyles Team (Torbay)
01803 208840
www.torbaycaretrust.nhs.uk/yourlife/
healthy_lifestyles

Health Promotion Devon (All areas of Devon excluding Plymouth and Torbay)
01884 836026
www.healthpromotiondevon.nhs.uk

Age UK
0800 169 6565
www.ageuk.org.uk

Devon Carers Service
08456 434 435
 www.devoncarers.org.uk

Torbay – signpost for carers
01803 666620

Torbay Carers Forum
www.torbaycarersforum.co.uk

Devon Community Directory
www.directory.devon.gov.uk
Search Memory Café

Devon Partnership NHS Trust
Patient Advice and Liaison Service (PALS)
0800 0730741
www.devonpartnership.nhs.uk

Tell us what you think
If you would like to know more about us, need information in a different language or format or have a concern, compliment or complaint, then please contact our PALS Team:

PALS Team
Devon Partnership NHS Trust
Wonford House Hospital
Dryden Road
Exeter EX2 5AF

Freephone: 0800 0730741
Email: dpn-tr.pals@nhs.net

You will also find useful information about our services and issues related to mental health and wellbeing on our website at
www.devonpartnership.nhs.uk

Reference: 407/09/14

Devon Partnership **NHS**
NHS Trust

**THYMe
Think Health for
your Memory**

A group to help you
manage your memory

The Health Foundation Inspiring Improvement | Shine

Introduction

A new group programme has been set up to help people with Mild Cognitive Impairment (MCI). The aim is to help you live better with MCI and to understand and, hopefully, reduce the risk factors for your condition progressing.

The MCI Self-Management project is part of the Health Foundation's Shine 2014 programme. The Health Foundation is an independent charity working to improve the quality of healthcare in the UK.

Why have I been referred to this group?

This group is specifically for people with MCI who will have been referred either through a Memory Clinic or the Community Mental Health Team. MCI is a condition where people have memory problems that, whilst more than would be expected for their age, are not of a serious nature.

Though many people with MCI do not get worse, over the years a proportion do. However, the latest research has shown that simple lifestyle changes may reduce this risk. These lifestyle changes include increasing mental and physical activity and changing your diet and are, in many ways, similar to those that help reduce the risk of heart attacks and stroke.

Is this a research trial?

No, but as this is a new programme, in order to evaluate how helpful it is, we will be asking you to complete some short questionnaires at the start and finish of the programme and again three months after you have completed the programme. We will also ask if some people can give us more detailed feedback on the usefulness of the groups. Whilst this will help us and hopefully yourself greatly, it is, of course, entirely voluntary.

What happens in the group programme?

There are five weekly group sessions in the programme, each lasting about three hours to include a coffee break. The main focus of the groups will be to help people become more mentally and physically active as these factors are believed to reduce the risk of memory problems worsening. We will also be giving advice on strategies to help coping day-to-day with memory problems.

There will be the opportunity in the final sessions to speak to a member of the Healthy Lifestyles team who can arrange individual and group support.

A typical group session might comprise:

*   Practising a memory strategy
*   Learning about one of the risk factors that might worsen memory problems
*   Setting goals to achieve based on the above.

Can I bring someone with me?

Yes, these groups are designed for you to attend with a family member or friend who will also benefit from the help and support provided.

What happens after the groups have ended?

We will be offering a follow-up session after three months to see whether the benefits of the programme have continued beyond the end of the groups. This might be in the form of a group reunion.

Where can I find out more?

(b) Poster presented at HSRN Symposium:

Think Health For Your Memory (THYMe): Self-management groups for people with Cognitive Impairment

Dr David Pearce, Amy Brayley, Alex Puchala and Caroline Nicholson

"From the very first session it made a difference"

david.

Background

A diagnosis of Mild Cognitive Impairment (MCI) is given when a patient has memory and/or other cognitive deficits that are greater than expected but are not of a severity for a diagnosis of a dementia. Such patients are at a high risk of conversion to a dementia but at present there is no well recognised intervention to help them. There is, however, growing evidence that taking part in a multi-domain activity programme may reduce the risk of dementia in high risk individuals.

Our intervention

THYMe is a 5 week, group programme designed specifically for people with MCI. Each group consists of 7-8 patients each of whom are encouraged to bring along a partner or friend. Self-management is the cornerstone of the groups and each week goal-setting and memory problem solving are practiced. Group participants are encouraged to set goals which are checked against SMART criteria. The course programme also contains an educational element based around the '6 Pillars of a Healthy Lifestyle for the Brain' (i.e. regular exercise, healthy diet, mental stimulation, stress management, active social life and quality sleep) to empower participants to take control of their own health.

References:
Downloaded:
Fachre, P et al. (2007). Conversion from subtypes of mild cognitive impairment to Alzheimer dementia. Neurology 68 (4) 288-291.
Knot K, et al. A complex multidomain intervention to reduce the risk of dementia in mild cognitive impairment-The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) Study design and progress. Alzheimers Research & Therapy, 7(1), 1-20.
Kivipelto, M, Mangialasche, F, Ngandu, T 2014 The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) Study design and progress. Alzheimers & Dementia. The Journal of The Alzheimers Association 9(6), 657-665.
Puchala, A. (2015, May 18). Service users during the reunion (Digital photograph). Property of Devon Partnership NHS Trust.

www.health.org.uk/areas-of-work/programmes/shine-2014/related-projects/devon-partnership-nhs-trust

Aims

THYMe aims to provide a cost-effective, evidence-based group intervention for people with MCI. Our goal is to increase people's confidence in managing their own health and improve their quality of life.

Outcomes

The THYMe project started in June 2014 and to date we have run eight groups with 79.6% of attendees successfully completing the programme* (43 patients, mean age 76.8, SD=12.7 years). Participants completed Patient Activation Measure (PAM) questionnaires before and after the intervention. We also used Goal Attainment Scores (GAS) to measure self-reported outcomes. Both PAM and GAS results showed significant improvements from the first to last group, see Figure 1 and 2 below.
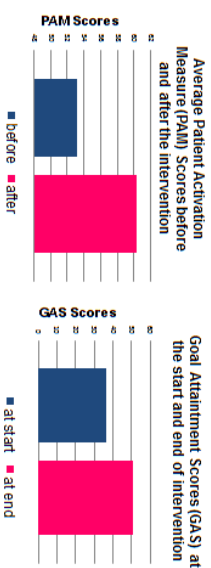
*successful completion taken as attendance at a minimum of 4 out of 5 sessions

PAM Scores

Average Patient Activation Measure (PAM) Scores before and after the intervention

■ before ■ after

Fig. 1 p< 0.0001, (mean of PAM at start minus PAM at end equals -7.115, 95% confidence interval -10.363 to -3.867)

GAS Scores

Goal Attainment Scores (GAS) at the start and end of intervention

■ at start ■ at end

Fig. 2 Mann-U, p< 0.01

In the future

The THYMe programme will be freely available. We are also plan randomised control trial compa treatment as usual i.e. providing out self-help resources.

Case study: Anne and Tom's St

Tom (patient): I first heard about the groups from clinic... It was all helpful and I think that everyone away from it.

Anne (wife): I could probably say that I learned m often said that my memory was worse than his, b were stress related, to the point that I would forg need to be more aware of controlling stress, I thi these days. During the groups we challenged ours cooking, we did more walking and drank more wa more word games and SUDOKU...

Tom: I have always found word games hard, howe started playing cards again, something that we bo

Anne: I used to always worry about Tom. I was fir things alone.' Now, even if he makes a mistake or it. THYMe groups helped both of us... and we con ourselves, we even got a white board where we v

The THYMe project was funded by th and delivered by Devon Partnership Tru

The Health Foundation
Inspiring Improvement

Devon Pa

(c) E-Newsletter

Appendix 3: Outcome Measure Details

1. Patient Survey Outcomes

(a) Patient survey:

(b) Average feedback survey score for all groups:
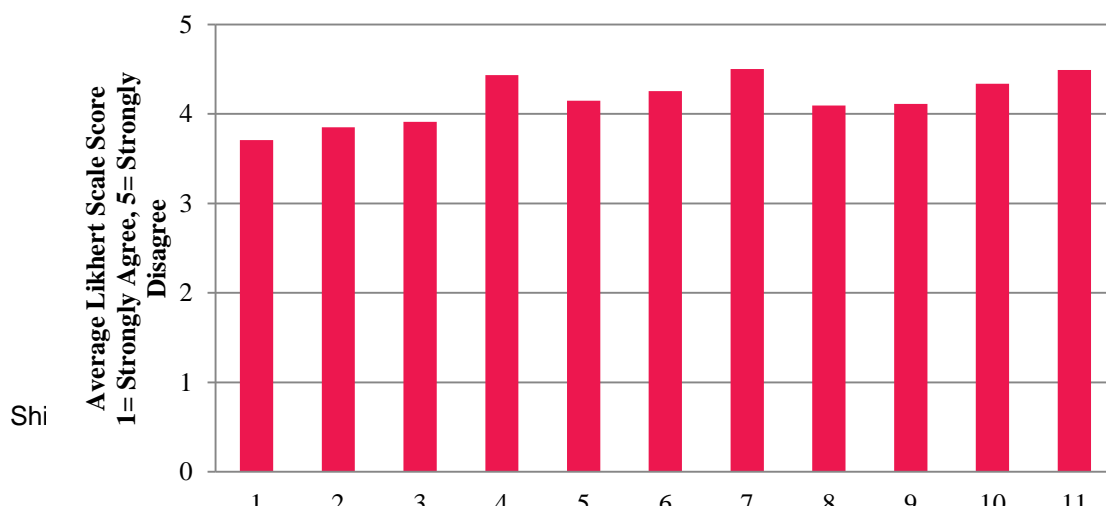
2. Full Breakdown of Quantitative Results

There are no specific quantitative measures for ability to self-manage or quality of life that have been validated for patients with Mild Cognitive Impairment and indeed this group of patients does present with some quite specific challenges for this. Firstly, in spite of being called "Mild Cognitive Impairment", often the level of disability and memory impairment is quite high, leading to the possibility of inaccurate recall in questionnaires. Secondly, whilst there are scales for use in dementia, these are designed for patients who are even more severely impaired and thus they contain items on, for example, washing and dressing, that are not appropriate to patients with MCI.

Overall 65 patients were referred to the groups, 39 men and 26 women. Patients were excluded from the quantitative study if they did not complete at least 4 out of the group 5 sessions. Also we did not get correctly completed questionnaires from all patients which left a study group of 43 patients, 26 men and 17 women, for our primary outcome measure. Their age range was 51-90 with an average age of 76.95. One patient with visual impairment underwent testing with the MOCA-Blind and scored 16/22, the other 42 being tested with the ACE-111 and having an average score of 83.6/100 (range 71-97).

The Patient Activation Measure (PAM)
This was our primary outcome measure for the evaluation of the self-management groups, which we purchased from Insignia Health via a research license. Patient Activation has been defined as "an individual's propensity to engage in adaptive health behaviour that may, in turn, lead to improved patient outcomes.'[3]. The PAM questionnaire gives a raw score that can then be converted into one of four levels of activation, with patients in Level 1 being the least activated and those in Level 4 showing the highest level of activation.

We chose this measure for the following reasons:
1. Patient Activation is a concept that is becoming increasingly recognised and we believe that the PAM has potential to become a standard tool in the NHS in the future. For example, this has recently been the subject of a paper by the King's Fund[4].
2. Sustainability was the main focus of the evaluation and thus we needed to show evidence of potential cost-savings, but the relatively short time-scale of the project meant that we could not look at either conversion rates to dementia or service usage. There is published evidence to show that lower levels of activation as assessed by the PAM are associated with greater healthcare costs. For example, Hibbard et al found that patients in the lowest

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[3] Skolasky, R.L. el at (2085 Patient Activation and Adherence to Physical Therapy in Persons Undergoing Spine Surgery. **Spine**, 2008;33(21):E784-E791..
[4] Hibbard J.. and Gilburt, H. **Supporting People to manage their health. An introduction to patient activation.** The King's Fund. ISBN 978 1 909029 30 9.

level of activation group had 8% higher healthcare costs than those in the highest group[5].

Average pre- and post group PAM scores
We received completed before and after PAM questionnaires from the 43 patients. These showed a statistically significant improvement in the attendees confidence to manage their own illness (n=43 p< 0.0001, the mean of PAM at group start minus PAM at group end equals -6.867, 95% confidence interval -9.899 to -3.836).
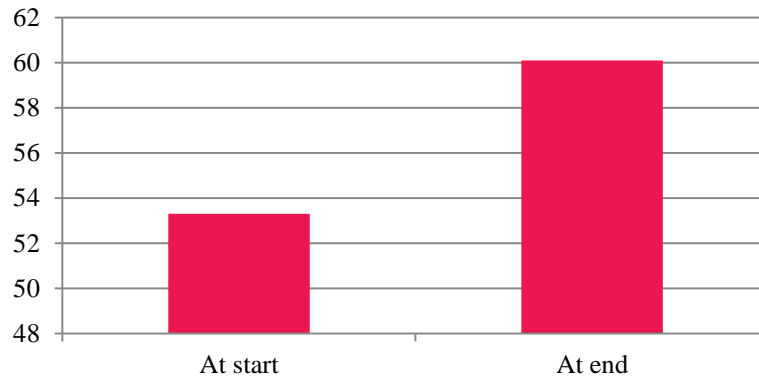

Fig 1. Bar chart of average PAM scores at beginning and end of 5 or 6 week THYMe group

PAM scores for those with low initial activation
The interesting finding from the Hibbard study[iii] is that the cost gains are only significant when improving the activation levels of those with the lowest initial level of activation. Hence, moving someone from Level 1 to level 2 brought about cost savings, whereas moving someone from Level 3 to Level 4 didn't.

Therefore in addition to evaluating the general change in levels of activation of the whole group, we have also evaluated the change in those with the lowest levels of activation. In order to show evidence for the potential of healthcare cost savings we would need to show that the average increase in PAM scores is not solely due to those with already high scores being activated more, but also that those who were initially in the lower levels were also benefitting, as it is change in these patients that will lead to cost savings. In short, we needed to show that we were not 'preaching to the converted'.

Here we took the 24 patients in activation levels 1 and 2 at the start and there was still a statistically significant increase in their average PAM scores as shown in the graph below (n=24 p= 0.0011, mean of PAM score at start minus PAM score at end equals -7.083, 95% confidence interval of this difference: From -11.023 to -3.144).

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[5] Hibbard, J. et al, (2013) Patients With Lower Activation Associated With Higher Costs; Delivery Systems Should Know Their Patients' 'Scores'. **Health Affairs** 32.2 (Feb 2013): 216-22.
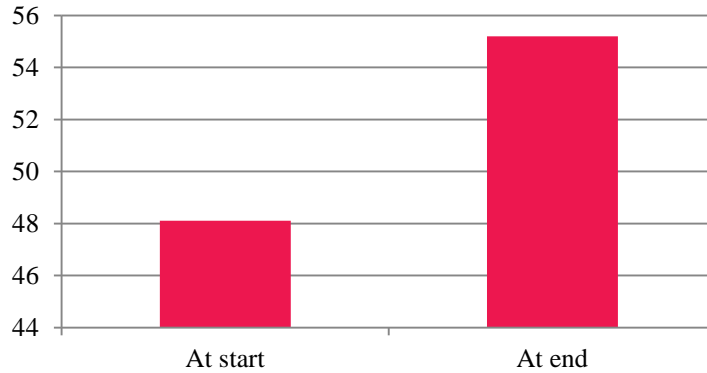
Fig 2. Bar chart of average PAM scores at beginning and end of THYMe groups for attendees with initially low activation levels only

PAM scores at the reunion meeting

We had the opportunity to evaluate 28 patients at the reunion meetings, approx. 2 -3 month after the group ended. This showed that there was an overall decrease in the average level of the PAM scores to almost baseline levels after the gap.

For this overall group the differences between the average PAM scores at the start and at the reunion were not statistically significant.
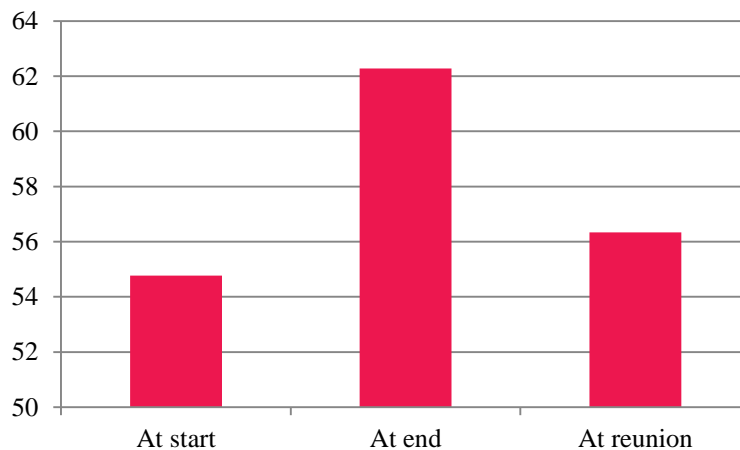
Fig 3. Bar chart of average PAM scores at beginning, end and at reunion session 2-3 months following THYMe groups

PAM scores for those with low initial activation at the reunion meeting

For those patients with low initial activation there was also a drop in PAM scores when compared at the reunion meeting. Interestingly the drop seemed to be smaller and nearly, but not quite, remained significantly higher than at the start (p=0.0697, the mean of PAM scores at start minus PAM scores at reunion equals -2.943 95% confidence interval of this difference: From -6.160 to 0.274).
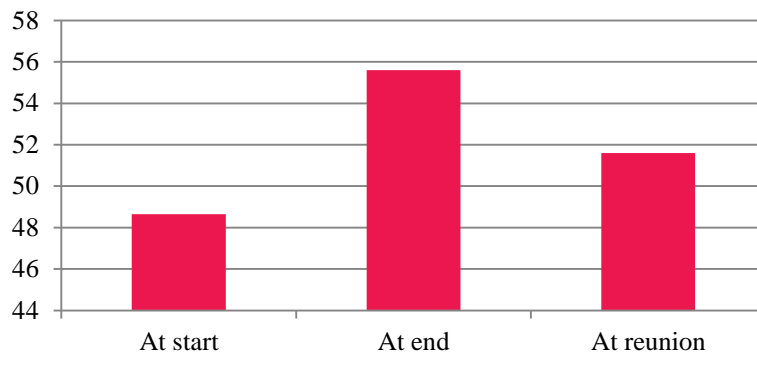
Fig 4. Bar chart of average PAM scores at beginning and end and 2-3 month reunion THYMe groups for attendees with initially low activation levels only

The Carers-PAM

As stated above, one difficulty with evaluation in this group is that, in common with the other measures, the PAM has not been validated in patients with Mild Cognitive Impairment. Here memory difficulties could lead to difficulties in completing the form accurately. Therefore at the start of the programme we asked the people accompanying the patients to the groups to complete the Carers-Patient Activation Measure (Carers-PAM). This is a measure of perceived confidence in the ability to care for someone.

However, due to the relatively mild level of disability of the patients, the people accompanying them did not feel that they were 'carers' and this test caused a level of disquiet amongst some participants and was therefore abandoned after the fourth group. We therefore only had completed before and after scores on 12 participants which, unsurprisingly given the low numbers and participants concerns over filling them in, showed no significant change (average Carers-PAM at start of groups was 58 and at end, 59.9).

Quality of life – The DEMQOL

We considered several measures to look for changes of quality of life (QOL) at the start and end of the group. There are no specific tools to measure for QOL in MCI and, after taking advice from researchers at the Exeter Medical School, we decided to use the DEMQOL. This has been validated to measure QOL in patients with dementia and the items in the DEMQOL were more likely to pick up the changes that we were looking for than other QOL measures such as the EQ-5D than concentrated more on physical than mental abilities.

Completed before and after DEMQOLs were obtained on the 43 patients but showed no statistically significant increase pre and post the groups. The average DEMQOL before was 89 and afterwards was 90.8.

Quality of Life – Modified DEMQOL-PROXY Measure

Following the decision to cease the use of the carers-PAM we then considered how best to capture information from the people accompanying the patients. These are a potentially very useful source of information, assuming they were more cognitively intact, they may be able to give a better insight into changes that the patient may have difficulty in recalling.

Again there is no validated measure for this. The DEMQOL-proxy measure has been validated as a proxy of QOL measure for patients with a mild/moderate dementia[6]. This is a 31-item scale which does include items that are related to patients with a considerably more severe disability than our patients, such as the ability to wash/bathe themselves. We therefore decided to modify this scale by removing these items, leaving a 27 item questionnaire which we implemented from Group 5 onwards. This was considerably more acceptable to the people accompanying the patients than the carer's-PAM.

Even though we had a reduced sample of 17 relatives/friends, this never-the-less showed a statistically significant increase in their perception of the patient's QOL from the first to last group (n = 17, p< 0.05. The mean of the modified DEMQOL-proxy score at start minus score at end equals -5.6552941176, 95% confidence interval -10.6265464235 to -0.6840418118).
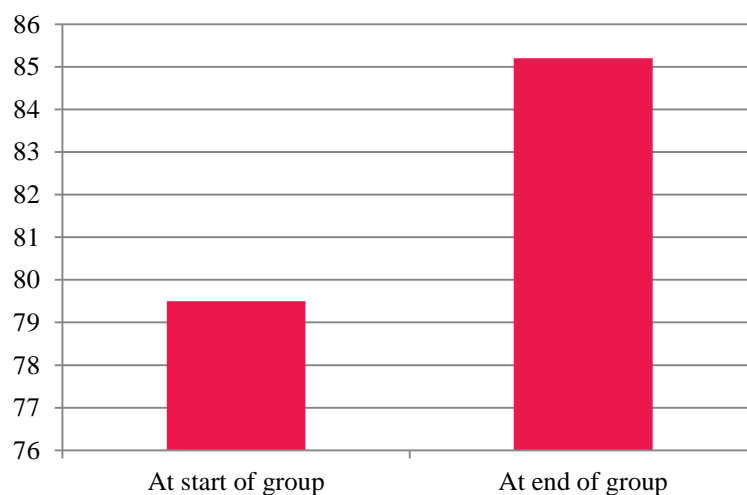

Fig 5. Bar chart of average DEMQOL-proxy score at beginning and end of THYMe groups

Due to the later start we only had 9 patients at the reunion who had all three DEMQOL-proxy scores filled in which was not sufficient for statistical analysis.

Goal Attainment Scaling

Goal-setting is a common theme of most self-management programmes. In their study of what patients with early dementia and their carers would like from a self-management programme, Toms et al found that the ability to set realistic goals was one of their priorities[7]. Given that the goals set should be specific, measureable and time-limited, being followed up at the next group meeting, assessing how successful group attendees are at achieving the goals set is a further way of evaluating the effectiveness of the groups.

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[6] Smith, S.C. el al., Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. Health Technol Assess. 2005 Mar;9(10):1-93, iii-iv

[7] Toms, G. R., Quinn, C., Anderson, D. E., & Clare, L. (2014). Help yourself: Perspectives on self-management from people with dementia and their caregivers. *Qualitative Health Research*, *25*(1), 87-98. doi:10.1177/1049732314549604

Goal Attainment Scaling (GAS) is a well-established tool for assessing the progress that patients make on attaining their goals[8]. Here we used the GAS-light verbal scoring system, which is shown below:

				Computerisation	
At Baseline	With respect to this goal do they have?	Some function	❑	-1	
		No function (as bad as they could be)	❑		-2
At Outcome:	**Yes**	A lot more	❑	+2	+2
		A little more	❑	+1	+1
		As expected	❑	0	0
Was the goal achieved?	**No**	Partially achieved	❑	(-1)	-1
		No change	❑	-1	-2
		Got worse	❑	-2	

Fig 6. Gas light verbal scoring system

Given that all our patients with MCI had comparatively mild disabilities we have always used -1 as the baseline. To measure progress we used a simplified Goal Attainment Scaling calculator (i.e. where levels of importance and difficulty are not measured and counted as a standard of 1 each) which is available from the King's College London website[9].

The statistical evaluation of GAS has proved to be somewhat controversial. In her practical guide on GAS, Turner-Stokes asserts that the T-scores obtained are normally distributed[10]. However, whilst the use of GAS scores as a clinical outcome measure was supported in a follow-up letter by Kerckhofs[11], her formula and the implication that they can be analysed by the use of parametric statistics were criticised. We were able to get information on 48 group attendees who completed at least two goals and found that our results were approximately normally distributed, hence we felt that we could use a t-test. This showed a highly significant result as shown in the graph below (The mean of GAS scores at start minus GAS scores at

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[8] Kiresuk, Smith and Cardillo. Goal Attainment Scaling: Applications, Theory, and Measurement Psychology Press, 1994. ISBN-10: 0898598893
[9] http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/resources/tools/gas.aspx
[10] Turner-Stokes L., Goal Attainment Scaling (GAS) in Rehabilitation: A practical guide, *Clinical Rehabilitation* 2009; 23(4): 362-70.
[11] Kerckhofs, E., Ordinal goal attainment scores are not suited to arithmetic operations or parametric staistics. *Clinical Rehabilitation* 2010; 24:479.

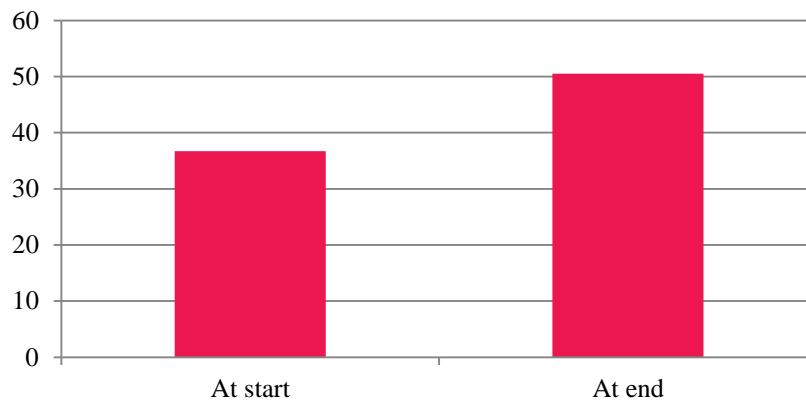end equals -13.8210375669, 95% confidence interval -15.9127739333 to -11.7293012004. p<0.0001).

Fig 7. Bar chart of average Goal Attainment score at beginning and end of THYMe groups

Awareness of risk factors for developing dementia

A key outcome for us in running the groups was to raise awareness of the modifiable risk factors for developing a dementia such as obesity, smoking and lack of exercise. People need to understand these risks if they are going to make active steps towards reducing them. Group attendees were presented with a list of lifestyle-related modifiable factors and asked at the beginning and end of each group which they thought were risk factors for developing dementia. Group attendees significantly increased their knowledge of risk factors. At the beginning of the course they correctly identified an average of **56.3%** of potentially modifiable risk factors for dementia compared to **96.6%** at the end of the course. This clearly demonstrates that the course is successful at educating attendees about the modifiable risk factors for developing dementia.