Talking Mats® and involvement in decision making for people with dementia and family carers

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This study has shown that Talking Mats®, a low-tech communication tool, can help people with dementia and their family carers feel more involved in making decisions about managing their everyday life.

Government guidance recommends that people with dementia should be included in decisions about their care but often may have difficulty admitting they are having problems. Eighteen couples (person with dementia and a family carer) were asked to discuss how the person with dementia was managing daily living activities, using both Talking Mats® and other communication methods.

- People with dementia reported that Talking Mats® clarified their thoughts and enabled them to express themselves.
- Family carers reported that Talking Mats® made them feel more 'listened to' by the person with dementia.
- The findings contribute in a practical way to the current debate on how to meaningfully involve people with dementia and family carers in decisions about care.

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Executive summary

Background

The diagnosis of dementia is being made earlier now than previously, resulting in an awareness that people with early and moderate dementia should be enabled to retain as much autonomy as possible, for as long as possible, and the opportunity to play an active role in making decisions about their day-to-day life. Although autonomy is seen as being important in decision making, it is also acknowledged that people with dementia may have difficulty admitting they are having problems due to symptoms such as memory loss and communication difficulties, and many cannot manage their daily living without some support from others. Most family members want to involve their relative with dementia in decision making and care arrangements, but they struggle because of the communication and cognitive problems associated with the condition

Although there is now clear recognition that people with dementia should be encouraged to express their views and be included in decisions about their care, the methods employed to ascertain their views must address the difficulties described above. This project explores whether people with early and moderate stage dementia and their family carers can use Talking Mats®, a low-technology communication tool, to help them feel more involved in making decisions about managing their daily living activities.

Project overview

Eighteen couples (each comprising a person with dementia and a family carer) were asked to discuss how the person with dementia was managing four topics of daily living: 'personal care' (washing, dressing), 'getting around' (walking, using the stairs), 'housework' (cooking, making the bed) and 'activities' (watching TV, listening to music). Couples talked about the four topics using both the Talking Mats® framework and their usual communication methods. For each type of discussion, couples were asked to discuss two out of the four topics. For the discussion using usual communication methods, the researcher presented each option within a topic orally, one at a time in random order, and couples were asked to discuss whether the person with dementia was 'managing', 'needed assistance' or was 'not managing' each option. For the discussions using Talking Mats®, the options within each topic were represented in picture form and placed under a visual scale. After both types of discussion the couples were asked to complete a short questionnaire to determine how involved they felt in each type of discussion. Any additional comments were also recorded and field notes were taken.

Talking Mats® and involvement in decision making

Analysis of the data showed that, when compared to usual communication methods, the Talking Mats® framework can help people with dementia and family carers feel more involved in decisions about managing their daily living activities. They also feel more satisfied with the outcome of those discussions.

When questioned, the people with dementia reported that the Talking Mats® framework clarified their thoughts and enabled them to express their views. The framework allowed the people with dementia to convey their thoughts to their family carers, and helped them to reach a decision about how they were managing different aspects of their daily living.

The family carers acknowledged the value of the Talking Mats® framework in encouraging and maintaining communication, and stated that they felt the framework allowed for a better understanding of the views of the person with dementia that they cared for. An unexpected but interesting finding was that, although the people with dementia and family carers both felt more involved in discussions using Talking Mats®, the increased feeling of involvement was significantly

higher for the family carers. Family carers repeatedly reported feeling 'listened to' by the person with dementia and felt that their loved one could actually 'see' their point of view.

Talking Mats® and effectiveness of communication

Analysis of the data also revealed that the Talking Mats® framework can help people with dementia who are still living at home to communicate more effectively when compared to their usual communication methods. In particular, the improvement in communication was most evident in the level of engagement of the people with dementia, and the reduced instances of repetitive behaviours. This corroborates the findings from a previous research project (Murphy *et al.*, 2007), which established that the Talking Mats® framework significantly improves the overall effectiveness of communication in people with dementia living in care home settings, when compared to their usual communication method.

Implications for policy and practice

The findings in this report contribute in a practical way to the current debate on how to meaningfully involve people with dementia in decisions about their care. The Talking Mats® framework demonstrates an innovative and positive approach to obtain both the views of people with dementia and their family carers regarding managing day-to-day living. For the person with dementia and their family carer, living every day with dementia demands the ability to cope with constantly shifting needs and preferences. Talking Mats® provides a framework whereby the needs and views of the person with dementia and their family carer can be articulated, shared and reflected upon. By facilitating such conversations it may be possible to identify strengths and abilities, correct misperceptions, reduce anxiety on the part of the family carer, and offer both parties a method to voice their opinions in a safe, non-confrontational way. This in turn could improve the relationship between the person with dementia and the family carer, if all involved feel that the views of both parties have truly been acknowledged.

The findings in this report, added to those of Murphy *et al.* (2007), also have implications for the organisation, delivery, regulation and improvement of services to people with dementia. Recent guidance, from both the Department of Health and devolved governments, recommends that people with dementia should be involved in decision making about care options, and about key life transitions. Therefore, practitioners working in all sectors need the right attitudes, knowledge and skills to work effectively, not only with individuals with dementia, but also their family carers, to ensure their views are listened to. Having demonstrated that the Talking Mats® framework could allow people with dementia and their family carers to jointly discuss issues, using this approach could enable those involved to learn about each other's perspectives on managing day-to-day living, and some of the feelings around these ongoing daily transactions. The views of both parties can then be recorded in a way that can be used to clarify and enhance support planning, which is essential if personalised services and user and carer directed outcomes are to be achieved.

Future plans

Having established that the Talking Mats® framework can help people with dementia and their family carers feel more involved in making decisions, one of the research team's priorities will be to raise awareness of the Talking Mats® framework for families living with dementia, and carers working in this sector. This will be achieved by writing short articles for magazines/journals that are accessible to families and carers of people with dementia such as the Alzheimer's Society newsletter, the *Caring Times* and *Living with Dementia* etc. Awareness raising programmes are necessary in order for Talking Mats® to become a mainstream resource for families which includes a person with dementia. Health, social care, third sector, carers and advocacy organisations involved in offering information, support and services to people with dementia are in a position to make families aware that low-technology approaches to aid communication around everyday decision making are available.

A second priority will be to make the Talking Mats® framework available to people with dementia and their families, and to find ways of supporting/training couples and families to use the tool. It is hoped that the relevance of Talking Mats® to a wide range of people with disability may convince organisations working within this sector that supporting and training staff and families to use the tool is a practicable and effective way forward. The Talking Mats team have already run two training courses specifically for family members and would hope to run more. This could be achieved through organisations such as Alzheimer's Society, Alzheimer Scotland and Age UK. The Talking Mats Research and Development Centre already has a database of relevant organisations in place.

Further research

Based on the findings within this report, one possible focus for future research is to explore whether exposure to the Talking Mats® framework in the earlier stages of dementia can help the person with dementia at later stages when making key decisions about accepting care. This in turn could help determine whether enabling/encouraging people with dementia to be involved in early decisions about their daily life makes acceptance of care easier in the future.

1 Introduction

Background

The number of people with dementia in the UK is currently 700,000, with the figure forecast to rise to over a million by 2025 (Alzheimer's Society, 2007). The diagnosis of dementia is being made earlier now than previously, resulting in an awareness that people with early stage (and even moderate stage) dementia can give meaningful opinions and make decisions – or be included in making decisions – about their day-to-day care (Brod *et al.*, 1999; Mozley *et al.*, 1999). Consequently, professionals are now encouraged to involve people with dementia in discussions and decisions about their care (NICE and SCIE, 2006). In addition, the shift from a medical to a social model of dementia has resulted in an increased awareness of the insights, competence and rights of people with dementia (Horton-Deutsch *et al.*, 2007). Despite this awareness of the importance of protecting the rights and freedoms of people with dementia, there are few studies seeking people's opinions about day-to-day care (Tyrrell *et al.*, 2006). A process that listens to, and honours, the views and needs of the person with dementia is essential if rights are to be meaningful. However, although autonomy is seen as being important in decision making, it is also acknowledged that people with dementia may have difficulty admitting they are having problems due to symptoms such as memory loss, word finding difficulty, problems with reasoning, perseveration (repetition of previously used words, phrases or behaviour), lack of coherence, losing track of a topic and distractibility (Bayles, 1985; Bourgeois, 1991; Kempler, 1995; Whitehouse, 1999; Dijkstra *et al.*, 2004).

Recent studies relating to healthcare decisions found considerable discrepancies between family carers and people with dementia (Wackerbarth, 2002; Horton-Deutsch *et al.*, 2007). In a study of 3,500 older people living in 350 care homes in France, Somme (cited in Tyrrell *et al.*, 2006) reported only one third of the people with dementia felt that they had been actively involved in making decisions, and that family members made decisions for them (Somme, 2003). However, family carers' perceptions are not always a reliable indicator of the views of people with dementia. The views of people with early stage dementia and their family carers about freedom of choice were examined, and it was concluded that the opinions of people with dementia are 'often overlooked and their rights to information and free expression are fragile' (Tyrrell *et al.*, 2006, p 496). A conclusion from these studies is that 'People with dementia and their families should be encouraged to discuss preferences and, perhaps most importantly, reasons for their preferences' (Horton-Deutsch *et al.*, 2007, p 116).

Most family members want to involve their relative with dementia in decision making and care arrangements, but they struggle because of the communication and cognitive problems described above. There is now recognition of the contribution that family carers make and their own need for support (NICE and SCIE, 2006; Askham *et al.*, 2007). They may have considerable stress at many levels: they have to deal with the mental and often physical deterioration of their loved one, they want to protect the person with dementia while trying to maintain their relative's independence, and they have to make a series of challenging decisions as the illness progresses (Wackerbarth, 2002). This is all compounded for many by feelings of guilt that they are not truly involving the person with dementia and may be making decisions on their behalf. Some of the most difficult decisions that have to be made are related to the ability of the person with dementia to carry out tasks of daily living, such as cooking, washing, shopping, etc. Problems with these aspects of life are the main reasons for the person with dementia having to consider accepting care, whether it be in their own home, living with family members or moving into residential care.

The study undertaken by Somme (as cited in Tyrrell *et al.*, 2006) found that residents who felt included in decisions about their care showed increased wellbeing and positive adjustment

to living in residential care, compared to those who felt their family had made the decision for them (Somme, 2003). It is therefore important to start discussing management of daily living activities at an early stage, when the person with dementia can still share their views and understand the perceptions of their family. Thus, it may be advantageous to facilitate and record discussions about daily living, so that both the processes of involvement and the outcomes of such discussions can be carried forward as the condition progresses.

Policy and practice

A range of UK government reports and guidelines have included references to dementia, but it has taken some years for dementia to become a national priority in the UK. The voluntary sector has highlighted concerns over a number of years about severe inadequacies in the health and social care systems and services with regard to dementia (Age Concern, 2007; Knapp *et al.*, 2007). While the National Service Frameworks on older people, mental health and long-term conditions gave some recognition to dementia, these were not sufficient to achieve consensus on a defined care pathway nor to set clear targets to improve quality of care and outcomes (CSCI *et al.*, 2006; NAO, 2007).

A more integrated health and social care initiative resulted in the publication by the Department of Health and the Care Service Improvement Partnership of *Everybody's Business: Integrated Mental Health Services for Older Adults: A Service Development Guide* (DH & CSIP, 2005). This set out the essential components of a comprehensive mental health service for older people.

In the following year (2006), the National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence published a joint health and social care clinical guideline (NICE and SCIE, 2006). This report provided evidence-based good-practice advice to care practitioners and service commissioners across sectors for the care and management of people with dementia and family carers. The guideline clearly affirmed that people with dementia should:

- be involved and in control of their own living arrangements and support on a day-to-day basis;
- have their voice heard in person-centred care planning and reviews;
- have their voice heard in the regulation, development and improvement of services and support systems;
- be involved in decisions about key life choices and transitions;
- be involved in decisions about care and treatment.

However, serious concerns persisted and the Alzheimer's Society in England commissioned a wide-ranging report on the state of dementia care in the UK and the available evidence for effective services and outcomes (Knapp *et al.*, 2007). The two key recommendations in the published report were to make dementia a national health and social care priority, and to improve the quality of care of people with dementia and their carers.

Around the same time, a review of services for people with dementia and their families by the National Audit Office (NAO, 2007) criticised the quality of care received. The National Audit Office urged a 'spend to save' approach to investment, through earlier diagnosis and intervention and improved community services. The report argued that such an approach should enable better individual and national outcomes, by preventing unnecessary moves into care homes and hospitals and by shortening hospital stays.

England and the devolved governments have set about the task of creating strategic action plans in different ways, reflecting variations in local populations, existing strategic frameworks and targets, patterns of joint commissioning, service delivery and levels of resource. In England, extensive public formal consultation and widespread stakeholder involvement including people with dementia and family carers reached a broad consensus and resulted in the publication of *Living Well with Dementia: A National Dementia*

Strategy (DH, 2009a). The strategy is outcome focused around three main themes:

- raising awareness and understanding;
- early diagnosis and support;
- living well with dementia.

The strategy concludes that early diagnosis and intervention is essential for the person with dementia and family carers to maximise quality of life, to reduce and prevent harm, to enable them to make choices for themselves and to enable them to access help, support and treatment.

- Objective 6 in the strategy focuses on the improvement of community personal support services. This outcome requires access to a range of flexible and reliable services that are 'responsive to the personal needs and preferences of each individual and take account of broader family circumstances' (DH, 2009a, p 12).
- Objective 7 relates to the implementation of the National Carers Strategy (DH, 2008), and confirms that family carers are the most important resource for people with dementia and that an agreed plan to support their role is essential.

The National Dementia Strategy for England recognises that implementation presents major challenges for all parts of the health and social care systems, and that effective implementation will depend on dovetailing with other policy and service developments in the National Health Service (NHS) and regional and local government. Such policies include those on family carers, end-of-life care, long-term conditions, mental health and staying healthy. *Putting People First* (DH, 2007), the concordat signed up to by the NHS and national and local government in England, which sets out a personalised adult social care system to give more choice and control to people who use services, has a key place in this wider policy context.

Dementia is a national priority for the Scottish Government, with a number of measures and programmes already in place. In September 2009, the Scottish Government launched *The National Dialogue on Dementia: Dementia Strategy Consultation Paper* to encourage and support engagement by the wider community with the commitment to deliver a Dementia Strategy for Scotland by April 2010 (Scottish Executive, 2009). This work has been informed by the multi-representative Dementia Forum, which was set up in 2007. Five work streams are under way to develop the strategy: Treatment and Managing Behaviour; Assessment, Diagnosis and Patient Pathways; Improving the General Service Response to Dementia; Rights, Dignity and Personalisation; and Health Improvement, Public Attitudes and Stigma.

The Welsh Assembly Government commissioned an Expert Group to develop a *National Dementia Action Plan for Wales*. The Plan is out for public consultation, and the final report was expected in late 2009 (Welsh Assembly Government, 2009a). The Plan builds on current policies and strategies that seek to improve and change economic, cultural and environmental conditions by building supportive communities (*Fulfilled Lives, Supportive Communities*; Welsh Assembly Government, 2009b). Specific outcomes in the Plan include reducing the social isolation and stigma of people with dementia and their carers, support for people to live at home for longer, improving equality of access to services, initiatives to improve choice and control, and the personalisation of care.

The Northern Ireland Assembly Executive has committed to the development of a Dementia Strategy for Northern Ireland. The Department of Health, Social Services and Public Safety is leading a working group to produce the strategy, which got under way in autumn 2008. It appears that its report will now be ready for public consultation in February 2010. The Northern Ireland strategy builds on an earlier review of mental health services in Northern Ireland, as well as the research evidence base from the National Dementia Strategy for England and those of the other devolved governments. It is anticipated that research involving the views of people with dementia will inform the work of the group (Levenson and Williamson, 2009).

Implementation of the National Carers Strategy (DH, 2008) is a key component in ensuring effective outcomes for the various dementia plans and strategies, as family carers are the most important resource for people with dementia. Support for carers is to be 'tailored to meet individual needs', enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen (DH, 2008, p 7). The question of negotiating the right kind and levels of support that balance the needs and choices of both the person with dementia and their carer is explored more fully in Chapter 6.

Although there are some differences of emphasis and approach, the strategic direction with regard to dementia across the UK is clear – timely diagnosis and support, improving quality of life and care and raising awareness and understanding. The various strategies and policy guidance all indicate the need to draw together other national and regional legislation and policies, in order to maximise effective outcomes and make better use of resources at regional and local level. This means putting the person with dementia at the centre, a focus on the strengths of individuals, support for families and social networks, ensuring individualised responses across the course of the illness, while also ensuring that the workforce have the knowledge, understanding and skills to support dignity and equality. Essentially, this is about changing the culture of care and support, and corresponds with the move towards personalisation, equality of access and support for families and communities.

The Mental Capacity Act (2005) for England and Wales provides a framework to protect and empower people who may lack capacity to make some decisions for themselves, such as people with dementia (DH, 2005). The Act was fully implemented in October 2007. Similar legislation was already in place in Scotland (Adults with Incapacity Act (Scotland), 2000). The Act states that an individual has the capacity to make decisions about treatment and care, unless it can be demonstrated that this is not the case. The Act covers decisions relating to a person's property and financial affairs, healthcare treatment, place of residence and more everyday decisions such as personal care. Five main principles inform the Act and are briefly summarised as follows:

- Every adult has the right to make his or her own decisions, and capacity must be assumed unless this is proved not to be the case.
- A person must be given all practicable help to make their own decisions and to communicate those decisions.
- It should not be assumed that someone lacks capacity simply because their decision appears eccentric or unwise to others.
- If someone lacks capacity, any decision made on their behalf must be made in the person's best interests.
- Decisions or actions taken on behalf of the person who lacks capacity should be the least restrictive of their basic rights and freedoms, and all alternatives must be considered.

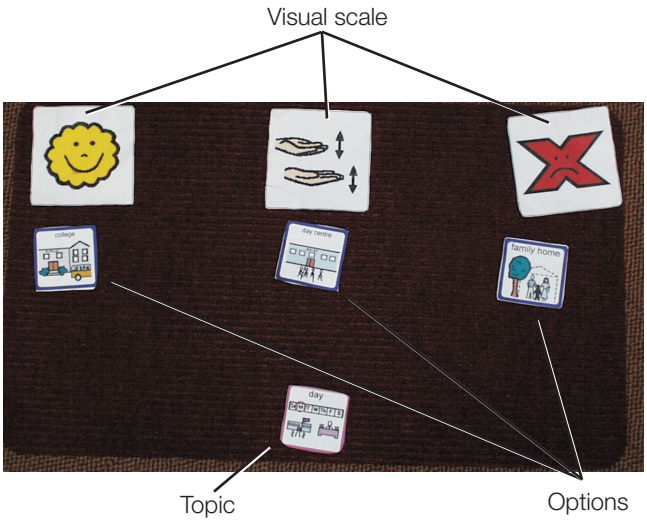
The right to receive reasonable help and support to make their own decisions, and to communicate those decisions by any possible means, is thus a key principle in the Act.

Talking Mats®

There is now clear recognition that people with dementia should be encouraged to express their views and be included in decisions about their care. They have a right to make decisions unless there is evidence of a lack of capacity. However, as people with dementia develop cognitive and communication difficulties, the methods employed to ascertain their views must address the difficulties described above.

One such method is the Talking Mats® framework. Talking Mats® is a low-technology communication framework, developed at the University of Stirling, to help people with communication difficulties to express their views. It uses a simple system of picture symbols, placed on a textured mat, that allow people to indicate their feelings about various options within a topic by placing the relevant image below a visual scale. The

Figure 1: Example of a Talking Mat®



Talking Mats® framework is accessible, inexpensive and can be used in any setting – although some training is required in order to ensure correct and effective use. An example of a Talking Mat® is shown in Figure 1.

A previous study undertaken by Murphy *et al.* (2007) found that the Talking Mats® framework could be used by many (although not all) people at all stages of dementia, and that it improved their ability to communicate compared with usual conversation. In particular, for people with early (and some with moderate) stage dementia, Talking Mats® increased the amount of time that their conversation stayed on track and the extent to which a communication partner understood their views. It appeared to help individuals to organise their thoughts and enhanced information exchange by providing visual cues, which the person with dementia could consider and express a view on. Unlike speech, this view remained visible and could be recorded, giving the communication partner the opportunity to observe and comment.

Based on this evidence, Talking Mats® could provide family carers with an effective tool to allow the person with dementia that they care for to communicate their needs and preferences more easily than through normal conversation. This in turn could help the person with dementia to remain in control of their own daily living activities, and ultimately could assist people with early (and perhaps moderate) stage dementia when they face difficult decisions such as accepting care (Murphy *et al.*, 2007).

Aims of the project

With this in mind, the central aim of the current project was to explore whether Talking Mats® can help people with dementia and family carers to feel more involved in decisions about managing their daily living.

2 Project overview

The project ran over a 15-month period from April 2008 to June 2009. This chapter describes the design and data collection methods employed in the study, including:

- determination of the topics for discussion;
- participants;
- fieldwork:
- the pilot study;
- the main fieldwork data collection phase.

Determination of the topics for discussion

The focus of discussions was how people with dementia and their family carers are managing activities of daily living such as washing, cooking, paying bills, etc. Problems with these aspects of daily living are often the reason that people with dementia require care, but are also frequently the most difficult to talk about. The choice of specific topics and range of options within each topic were identified using the World Health Organization's *International Classification of Functioning* (WHO, 2001) and relevant recent literature (Tester *et al.*, 2004). Guidance was also sought from the project advisory group, whose members included people with dementia and family carers.

The participant couples were asked to discuss four aspects of daily living:

- **personal care** (e.g. washing, washing hair, getting dressed appropriately): this topic offered couples the opportunity to discuss a topic that is often a problem for people with dementia, but can be difficult to broach;
- **getting around** (e.g. getting into/out of bed, walking, driving): this topic offered couples the opportunity to consider how the person with dementia was managing physically, and discuss any difficulties with mobility;
- **housework** (e.g. cooking, washing dishes, laundry): this topic allowed couples to discuss what household chores the participants with dementia were managing, and also provided a picture of the domestic workload of family carers;
- **activities** (listening to music, reading a book/ newspaper, watching TV): this topic allowed couples to consider how people with dementia like to fill their time and discuss the individual activities they specifically liked and disliked.

As the overall aim of the project was to determine whether Talking Mats®, compared to their usual communication methods, could help people with dementia and family carers feel more involved in decisions about managing their daily living, couples were asked to discuss two of the four topics under two different conditions: (1) using the Talking Mats® framework and (2) using their usual communication method, as described below:

- **Talking Mats®** – the topics and options were converted into Talking Mats® symbols and couples were asked to place each symbol under a visual scale (see Figure 2).
- **Usual Communication Method** – the researcher asked couples to verbally discuss each option within a topic.

The Talking Mats® condition used visual symbols created using Mayer-Johnson Boardmaker software.[1] As some people with mild Alzheimer's disease are known to have problems with some aspects of visual ability (Cronin-Golomb and Hof, 2004), care was taken to ensure that the symbols were easy to comprehend and highly visible:

Figure 2: Talking Mats® topic symbols

- Each symbol was larger than those ordinarily used in Talking Mats®: (9cm x 9cm vs 5cm x 5cm).
- Symbol titles were printed in Bold Arial font, point size 30.
- The background of each symbol was bold yellow, as previous research identified that the majority of people with dementia show a preference for this colour contrast when offered a choice (Murphy *et al.*, 2007) (see Figure 3).

Figure 3: Examples of Talking Mats® symbols

A full listing of options within each topic employed in the current project can be found in Appendix 1.

Participants

Participant recruitment

The original proposal required the recruitment of a minimum of 20 couples (a person with dementia and their family carer) from across Scotland and the North of England. On commencement of the project, a project advisory group, comprising experts in dementia as well as people with dementia and family carers, was formed to offer guidance to the project. Four members of the advisory group agreed to act as link people to help identify potential participants for the project, based on the following inclusion criteria:

- The person with dementia must be officially diagnosed with dementia, either of the Alzheimer type or dementia due to other causes.
- The person with dementia must be aware of their diagnosis and be comfortable with the terminology involved.
- The person with dementia should be at the early stages of the condition.
- The person with dementia must be living at home and have a relative or friend (unpaid family carer) who is knowledgeable about how they are managing their daily living activities and be able to discuss this with them.
- Both the person with dementia and the family carer should be native speakers of English and have the visual acuity to see the Talking Mats® symbols.

Members of the project advisory group were able to identify potential participants in the North of England who fitted the inclusion criteria. In order to access potential participants in Scotland, the researcher approached external agencies that offer support to people with dementia in the community. The researcher travelled throughout Scotland giving talks and presentations to inform the external

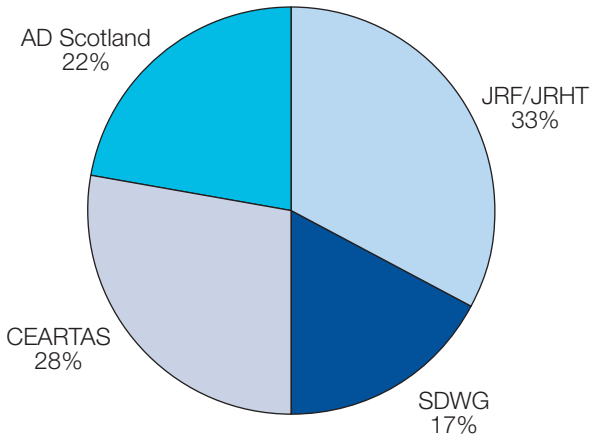
agencies about the project. Over 50 agencies were contacted including:

- Alzheimer Scotland Services: Aberdeen, Angus, Dumbarton, Dundee, Falkirk, Fife, Glasgow, Inverness, Lothian, Perth and Stirling;
- Alzheimer Scotland local branches: Alyth, Dundee, Falkirk, Perth and Stirling;
- Joint Dementia Initiative;
- Scottish Dementia Working Group;
- Princess Royal Trust for Carers: Arbroath, Dundee, Falkirk, Fife, Perth and Stirling;
- Help the Aged;
- Age Concern;
- independent advocacy organisations: Angus, Dundee, Falkirk, Fife, Forth Valley, Glasgow and Perth;
- home care delivery organisations;
- supported housing organisations;
- befriending organisations;
- specialist dementia day care facilities: Angus and Stirling;
- Joseph Rowntree Foundation (JRF) and Joseph Rowntree Housing Trust (JRHT).

Of the 50 agencies contacted, four agencies were involved in identifying potential participants as follows (also see Figure 4):

- Within each of the four agencies that offered assistance, a link person was identified, who received project information sheets describing the research project (see Appendix 2).
- Each link person was then asked to identify potential participants who fitted the inclusion criteria (see above) and to pass on the project information sheets.
- If interested, potential participants completed a tear-off slip with their contact details and returned this to the link person, who then forwarded it to the researcher in a stamped addressed envelope provided.
- The researcher then contacted the potential participant to arrange a convenient time for the initial consent visit.

Figure 4: Source of participants



Key: AD Scotland = Alzheimer Scotland, JRF/JRHT = Joseph Rowntree Foundation/Joseph Rowntree Housing Trust, SDWG = Scottish Dementia Working Group, CEARTAS = CEARTAS Advocacy, Kirkintilloch.

Demographic of participants

Initially, 22 couples (person with dementia and family carer) were identified and agreed to take part in the project. However, one person with dementia was unable to use Talking Mats®, two participants withdrew due to ill health, and unfortunately one person with dementia died midway through the fieldwork phase of the project. Thus, the findings in this report are based on results from 18 couples.

Six of the 18 couples lived in the North of England, with the remaining 12 couples living in a number of different regions within Scotland (see Figure 5).

- Eighteen people with dementia took part in the study – ten males and eight females. They had an average age of 77 years (range 60–86) (see Figure 6).

Figure 5: Country of origin of participants

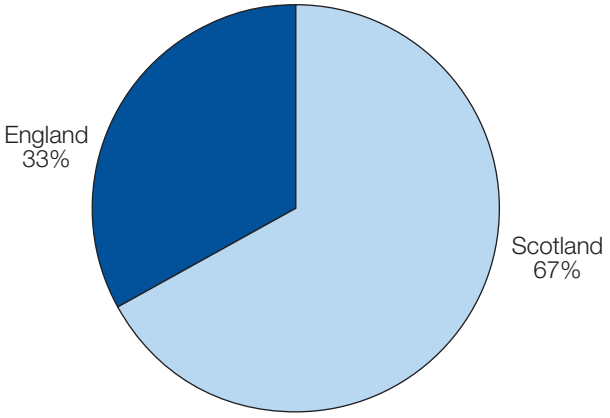
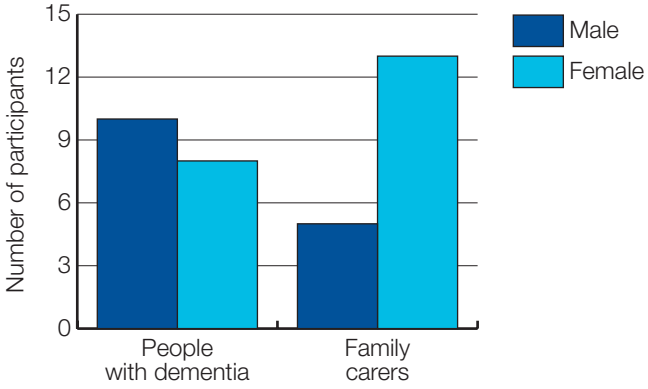


Figure 6: Gender of participants



- Eighteen family carers also took part in the project – five males and thirteen females. They had an average age of 69 years (range 44–89) (see Figure 6).

Relationship between participants with dementia and family carers

Just over half of the participants with dementia were male and were cared for by their spouse. The family carers were predominately female and either spouses or daughters (see Figures 7 and 8):

- Out of the ten male participants with dementia, nine were cared for by their wives and one was cared for by his daughter.
- Out of the eight female participants with dementia, five were cared for by their husbands and three were cared for by their daughters.
- No participant with dementia had a son for a carer.

Figure 7: Participants with dementia – relationship to family carers

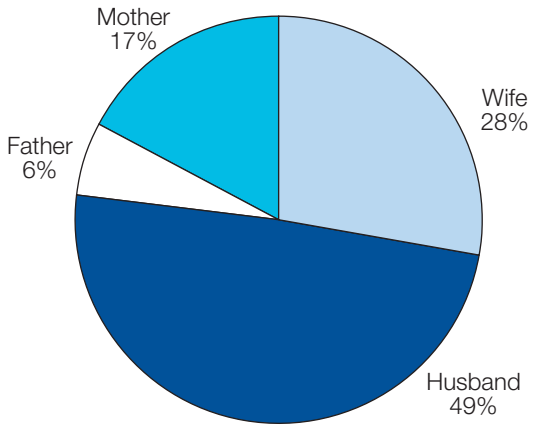
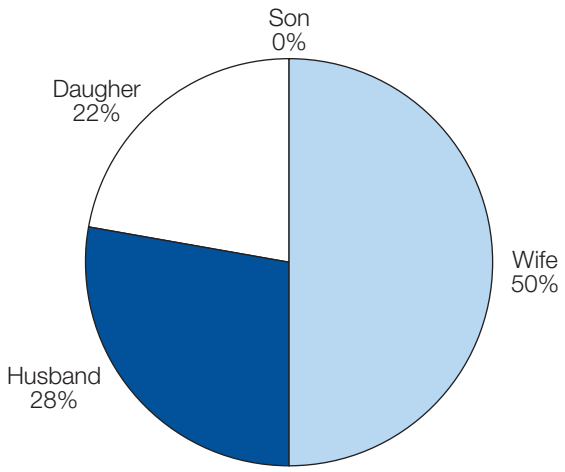


Figure 8: Family carers – relationship to people with dementia



Determining participant stage of dementia

One of the inclusion criteria for the research project was that the person with dementia should be at the early stages of the condition. How best to determine stage of dementia is a topic that has caused much debate. For the purposes of this project, stage of dementia was determined using scores obtained on the Communication Difficulties Scale (CDS), which was developed during a previous project funded by the JRF (Murphy *et al.*, 2007).

The CDS comprises 13 statements that are based on well-documented descriptions of the communication problems often experienced by people with dementia as the condition progresses, such as difficulty remembering words, losing track of a conversation, using filler words (e.g. thingy,

whatsit) in place of content words, repetition of words, etc. (Kempler, 1995; Dijkstra *et al.*, 2004).

The CDS requires a third party, such as a family carer who knows the person with dementia well, to assess various aspects of their communication. The family carer is asked to read each statement and circle one of five responses that best describes the communication ability of the person with dementia who they care for (see Figure 9).

Figure 9: Example of statement from the CDS

(2) They are likely to repeat things that they have just said				
Never	Sometimes	Often	Always	Says too little for me to judge

Each CDS option is assigned a score: for example in Figure 9, 'Never' = 0, 'Sometimes' = 1, 'Often' = 2, 'Always' = 3 and 'Says too little for me to judge' = 4. The total CDS score is calculated by totalling the scores for all 13 statements, thus scores can range from 0 to 39, with a higher score indicating a greater degree of communication difficulty.

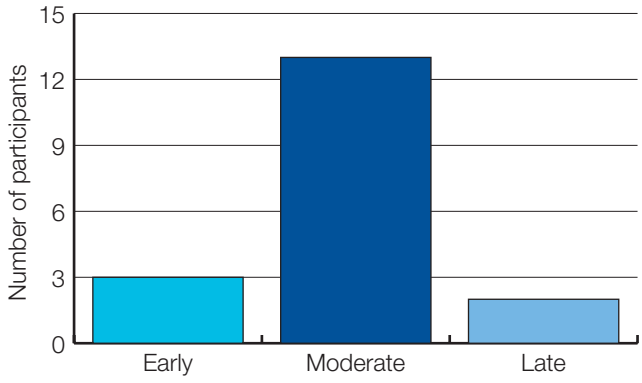
Recent research has shown that the CDS is a valid measure to estimate stage of dementia (Murphy *et al.*, 2007). Applying the method employed by Murphy *et al.*, a CDS rating of between 0 and 10.5 was defined as 'early stage', a rating between 11 and 19.5 as 'moderate stage' and a rating between 20 and 39 as 'late stage'. Although it was intended that the people with dementia who took part in the project would be at the early stages of the condition, the CDS ratings showed that this was not always the case, as most were at the moderate stages of dementia and some were even at the later stages, even though they were still living at home, as shown below (see also Figure 10):

- Three participants were judged to be at the early stage of dementia.
- Thirteen participants were judged to be at a moderate stage of dementia.
- Two participants were judged to be at the late stage of dementia.

Home care support from external agencies

The participants with dementia who took part in the current project were still living at home and were

Figure 10: Stage of dementia based on scores on the CDS

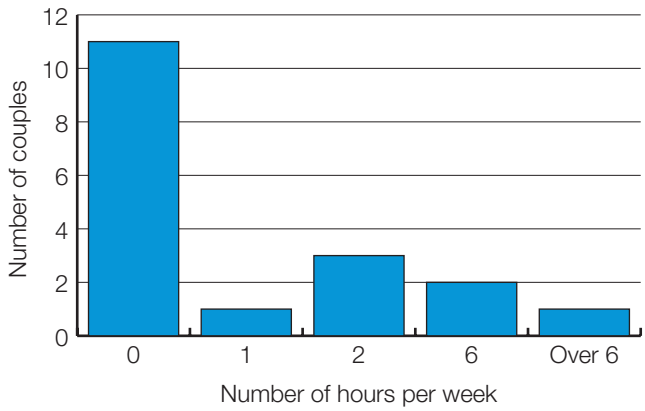


being cared for by a family carer. During the initial visit, family carers were asked some background questions about their situation. In order to gain a picture of what external support the people with dementia and family carers were receiving, the couples were asked how many hours per week of care from external agencies they received each week (see Figure 11).

As can be seen from Figure 11:

- 11 out of the 18 couples were receiving no support from external agencies;
- one couple received one hour of care per week;
- three couples received two hours of care per week;
- two couples received six hours of care per week;

Figure 11: Weekly hours of care received from external agencies



- one couple received over six hours of care per week (14 hours).

Fieldwork

The pilot study

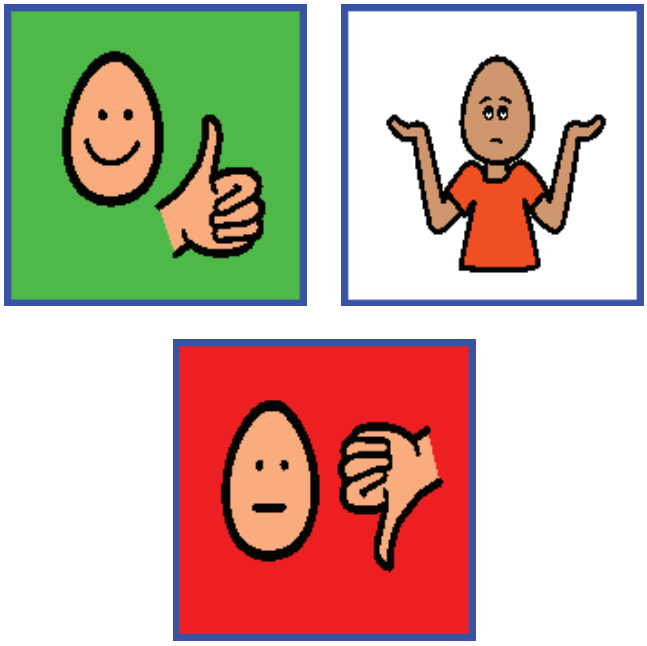
Prior to proceeding to the main fieldwork phase of the project, a short pilot study was conducted with four people with dementia and their family carers, who did not take part in the main study. All were diagnosed as being at early stage dementia, were living at home and had a family carer who was able to discuss with them how they were managing their daily living.

The pilot study identified a number of issues that were addressed prior to the main fieldwork data collection phase:

- First, it was apparent that the visual scale chosen for use in the Talking Mats® discussion was unclear and caused confusion. The visual scale comprised of three symbols representing 'managing', 'needing assistance' and 'not managing'. The 'managing' and 'not managing' symbols were shapes with happy and sad faces. Two participants in the pilot study were confused by the shapes used on these symbols, but stated that they understood the facial expressions. One family carer suggested that actual faces with happy and sad expressions should be employed, while a member of the project advisory group suggested that a green background should be used for the 'managing' symbol and a red background for the 'not managing' symbol. Adaptations to the usual visual scale were made to aid the comprehension of the people with dementia (see Figure 12).

- The second issue related to the methodology to be employed in the project. It was originally proposed that half of the couples would be asked to talk about how the person with dementia was managing activities of daily living using Talking Mats®, and the other half of the couples would discuss the issue using their usual method of communication. Owing to the difficulty in recruiting participants, it soon became clear that it would be extremely difficult to ensure that both groups of couples were matched to ensure fair comparison. Thus, it was decided that all couples involved in the project would be asked to discuss managing daily living activities using Talking Mats® *and* their usual method of communication.

Figure 12: Adapted visual scale



- An additional concern regarding the methodology was the role of the researcher when the couples were asked to discuss managing daily living. The project advisory group was invited to watch video recordings of the pilot study and expressed concern that the researcher was too involved in leading discussions. Thus, it was decided that the researcher's role was purely to facilitate discussions and provide guidance when necessary.

The main fieldwork data collection phase

The fieldwork phase of the project was originally timetabled for five months between July and November 2008. However, owing to the difficulty with participant recruitment, the fieldwork was delayed by two months and took place for a period of nine months from September 2008 to May 2009.

As outlined previously, participants were approached by a designated link person in an outside agency and were supplied with an information sheet about the project. On expression

of interest, permission was sought to forward their contact details to the researcher, who then made initial contact to arrange a convenient time to visit.

Each couple was visited three times. The purpose of the first visit was to provide some background information about the project and ask whether they would be willing to take part. When undertaking any research project, it is imperative that full and informed consent is obtained from any individual taking part. This particularly applies to research involving individuals with a cognitive or communication impairment. To make certain of this, the researcher followed the comprehensive consent procedure undertaken in a previous study by Murphy *et al.* (2007), ensuring that all documentation was adapted accordingly and explained thoroughly. Participants were also given the opportunity to become familiar with the equipment to be used and were made aware that future visits would need to be video recorded. Copies of all consent documentation can be found in Appendix 3. This initial visit was also important in allowing the researcher to obtain background information about the person with dementia and their family carer and offered time for the researcher and participants to get to know each other.

The second and third visits involved the collection of data. Each couple was asked to discuss how the person with dementia was managing daily living activities using Talking Mats® and using their usual communication method i.e. conversation. The order of the discussion types was counterbalanced; half of the couples used Talking Mats® during the second visit (TM condition) and their usual communication method (Usual Communication Method condition) during the third visit. The other half of the couples had the discussion using their usual method of communication first.

For each type of discussion, couples were asked to discuss two out of the four topics. The topics were grouped to control for complexity. 'Personal care' and 'activities' were always discussed during the same visit, and 'getting around' and 'housework' during the other visit. The order in which the topic groups were discussed was also counterbalanced across couples, with half discussing 'personal care and 'activities' first and half discussing 'getting around' and 'housework' first.

For both types of discussion, one member of the couple was invited to choose which topic to discuss first. The choice of whether this was to be the person with dementia or the family carer was also counterbalanced across couples: in half of the couples the person with dementia chose the first topic, and in the other half of the couples the family carer chose first. To ensure fairness, the order in which the chosen first topic was discussed was also counterbalanced across couples: for half of the couples the chosen first topic was discussed first and for the other half the chosen first topic was discussed second. Full details of the counterbalancing methods employed in the project can be found in Appendix 4.

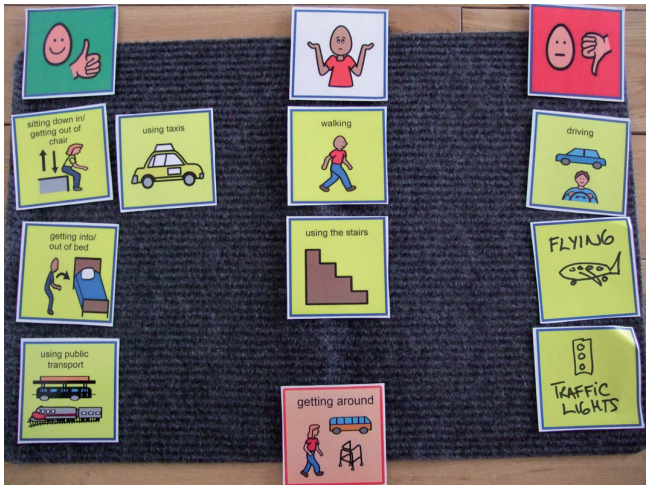
During both types of discussion, the focus was on how both members of the couple felt the person with dementia was managing the options within each of the four topics chosen for discussion. It was explained that the role of the researcher was to facilitate discussion by asking open-ended questions such as 'How are you managing washing your hair?', and that both members of the couple should discuss each option together and come to a decision.

For the Talking Mats® discussion, the option symbols within each topic were laid out and each member of the couple took it in turns to choose an option to discuss (see Figure 13). The researcher explained that the visual scale represented 'managing', 'needing assistance' and 'not managing', and couples were encouraged to come to an agreement, if possible, as to where each option symbol should be placed on the mat under the visual scale. Couples were encouraged to take ownership of the mat and place the symbols themselves. At the end of the Talking Mats® discussion, a photograph was taken of the mat to provide a record for later analysis (see Figure 14). For the discussion using usual communication methods, the researcher presented each option within a topic orally one at a time in random order, and couples were asked to discuss whether the person with dementia was 'managing', 'needed assistance' or 'not managing' each option.

For each type of discussion, couples were reassured that they did not have to discuss every

Figure 13: Participants completing a Talking Mat®

Figure 14: Photographs of completed Talking Mats®



option if they did not wish to do so. If any individual was tired or uncomfortable the visit was stopped. However, at no point was this necessary. At the end of each discussion, the researcher summarised what had been discussed, to confirm that both parties were happy with the views expressed. They were then asked if there were any additional options they would like to discuss to ensure that nothing important to each individual was omitted.

The focus of the current project was to determine whether Talking Mats® can help people with dementia and family carers feel more involved in decisions about daily living. In order to explore this, after each type of discussion both the person with dementia and the family carer were asked to complete the Involvement Measure, which is a short questionnaire asking how involved they felt in each type of discussion. Both parties completed the questionnaire independently to avoid biasing answers, and assistance was offered to the participants with dementia where necessary. A more detailed description of the Involvement Measure can be found in Chapter 3.

As a token of appreciation, a small gift and card were given to each couple at the end of the third visit. All 18 of the couples were also sent a debrief letter containing photographs of their Talking Mats® and a full summary of their views during both types of discussion (see Appendix 5).

Summary

- This chapter outlined the design and data collection methods employed in the project.
- The participants in the study were people diagnosed with dementia living at home, who had a family carer they could talk to about how they were managing different aspects of daily living.
- The researcher had great difficulty accessing people with dementia, despite seeking help from a number of agencies who offer support to people with dementia living in the community.
- The majority of the people with dementia who agreed to take part were at moderate stage dementia.
- Eleven of the 18 couples who took part in the project were receiving no home care support from external agencies.

- Each person with dementia and their family carer were asked to talk about how the person with dementia was managing four topics of daily living:
  - personal care;
  - getting around;
  - housework;
  - activities.

- Participants talked about the four topics using Talking Mats® and their usual communication method.

- After both types of discussion, each person with dementia and their family carer completed a questionnaire to compare how involved they felt in each type of discussion.

3 Talking Mats® and involvement in decision making

The primary focus of the current project was to determine whether Talking Mats® can help people with dementia and family carers feel more involved in decisions about managing their daily living than when using normal communication methods. This chapter describes the main findings regarding involvement.

In order to measure involvement, the participants with dementia and family carers completed the Involvement Measure after the Talking Mats® and Usual Communication Method discussions, to ascertain how involved they felt in each type of discussion. The Involvement Measure is a short questionnaire comprised of six questions that measure different aspects of involvement. It was devised in collaboration with the project advisory group using questions adapted from the 'Freedom of Choice Interview Schedule' presented by Frossard *et al.* (2001) (as cited in Tyrrell *et al.*, 2006), a measure specifically designed for people with dementia and their family carers to indicate how they felt about their involvement in a situation where they had to consider issues around care.

Care was taken to ensure that the Involvement Measure was adapted, using plain English and visual clues such as those in Figure 15, to make it accessible for people with communication or cognitive difficulties.

The Involvement Measure questions were:

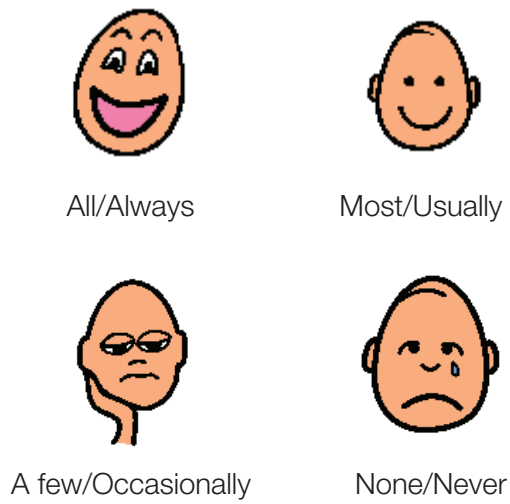
1. How many of the issues that are most important to you were covered?

2. How well do you think you were listened to?

3. How well do you think you were able to express your view?

4. Did you have enough time to express your view?

Figure 15: Examples of visual cues used to adapt the Involvement Measure



5. How involved in the conversation did you feel?

6. For the final question, participants were asked to rate how well they felt the conversation went using a seven-point likert scale, where 0 = not very well at all and 6 =very well indeed.

Questions 1–5 were assigned a score whereby 'All/Always' = 4, 'Most/Usually' = 3, 'A few/Occasionally' = 2, 'None/Never' = 1. All scores were totalled to quantify feelings of involvement, with a higher score indicating a greater degree of feeling involved in the discussion. Ratings for Question 6 were used to produce a global satisfaction score with a higher score representing greater satisfaction with the discussion.

Both the participants with dementia and their family carers completed the Involvement Measure after the Talking Mats® and Usual Communication Method discussions to ascertain how involved they felt in each type of discussion.

Involvement Measure results

All participants

- Scores on the Involvement Measure revealed that all of the participants felt significantly[2] more involved in discussions when using Talking Mats®, with a mean score of 18.2 out of 20 compared to their usual communication method, which had a mean score of 16.3 out of 20 (see Figure 16).

- Scores on the Involvement Measure revealed that all of the participants felt significantly[3] more satisfied with the discussion when using Talking Mats® with a mean score of 5.6 out of 6, compared to their usual communication method, which had a mean score of 4.5 out of 6 (see Figure 17).

Figure 16: Feelings of involvement during both discussion types for all participants

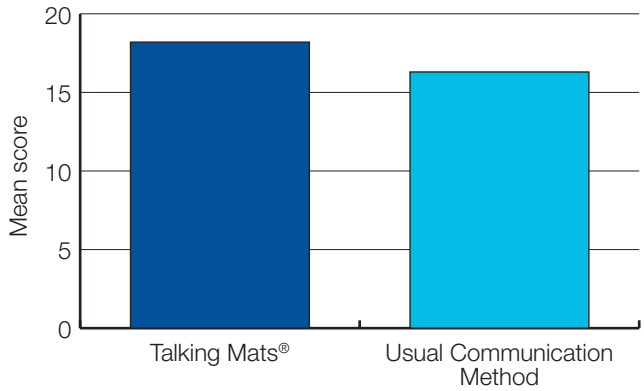
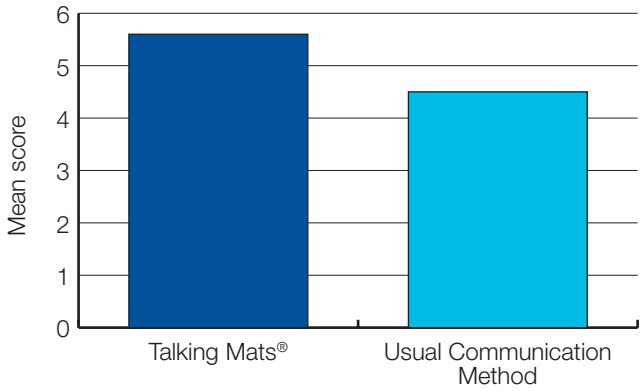


Figure 17: Feelings of satisfaction with both discussion types for all participants



Comparison of participants with dementia and family carers

Based on the overall results, it is clear that Talking Mats® can help people with dementia and family carers feel more involved in discussions about managing daily living when compared to usual communication methods. However, further analysis of the Involvement Measure results was necessary in order to answer the specific research questions i.e. to ascertain whether the people with dementia and family carers differed in their degree of feelings of involvement in each type of discussion.

- The participants with dementia had a mean score of 17.5 out of 20 and the family carers had a mean score of 19 out of 20 for feelings of involvement using Talking Mats® (see Figure 18).

- For the Usual Communication Method discussions, the participants with dementia had a mean score of 15.6 out of 20 and the family carers had a mean score of 16.9 out of 20 for feelings of involvement (see Figure 18).

- The participants with dementia had a mean score of 5.4 out of 6 and the family carers had a mean score of 5.7 out of 6 for satisfaction with the discussion when using Talking Mats® (see Figure 19).

- For the Usual Communication Method discussions, the participants with dementia

Figure 18: Feelings of involvement during both discussion types for participants with dementia and family carers

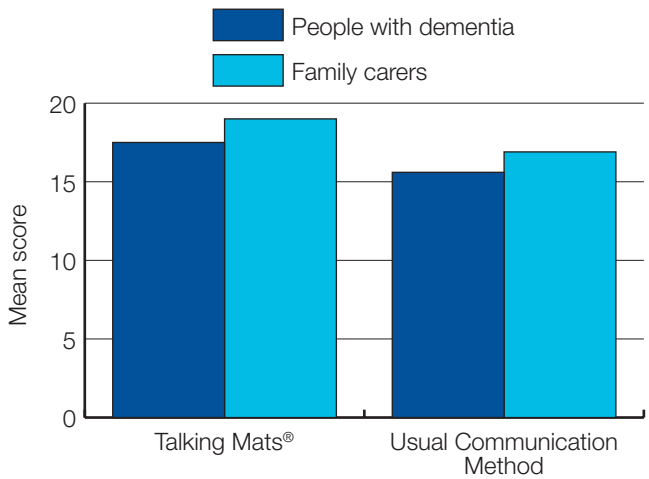
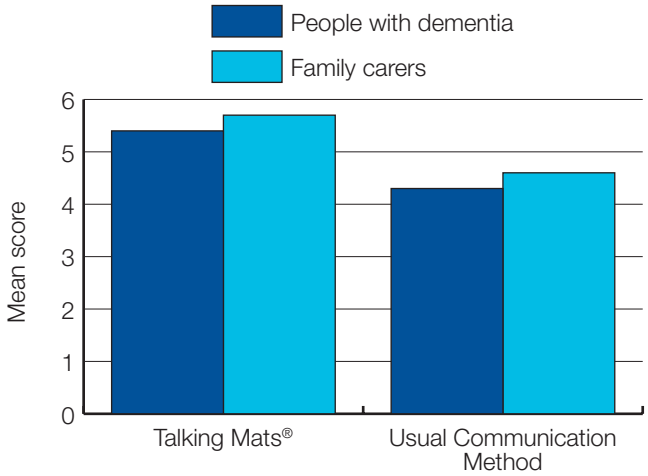


Figure 19: Feelings of satisfaction with both discussion types for participants with dementia and family carers



had a mean score of 4.3 out of 6 and the family carers had a mean score of 4.6 out of 6 for satisfaction with the discussion (see Figure 19).

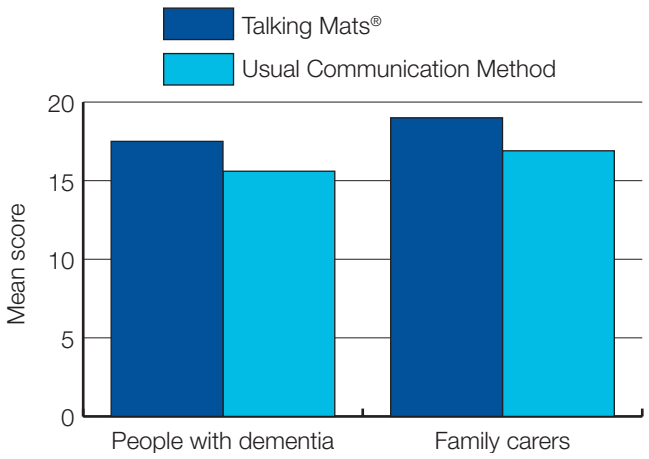
It is clear that Talking Mats® can significantly increase feelings of involvement and overall satisfaction with the discussion, for both people with dementia and family carers. Previous research has shown that Talking Mats® are significantly more effective than usual communication methods in helping people with dementia to express their views, thus it was hoped that Talking Mats® could also help them to feel more involved in important discussions with their family carer about their daily life.

An interesting but unexpected finding was that, although the family carers also felt more involved in the discussion using Talking Mats® compared to usual communication methods, the degree of increased feeling of involvement was significantly higher[4] than for the people with dementia who they cared for (see Figure 20).

What do people with dementia and family carers think about Talking Mats®?

To gain further insight into reasons behind this significant increase in feelings of involvement, the people with dementia and family carers were asked how they felt about using Talking Mats®. Below are some of their replies.

Figure 20: Comparison of feelings of involvement for people with dementia and family carers



Comments from people with dementia

- *"It [Talking Mats®] helped me remember what we were talking about."*
- *"I found it [Talking Mats®] a big help, sometimes I get the words muddled and can't get out what I am trying to say."*
- *"The pictures are really clear; they helped me to remember when I couldn't find the right word."*
- *"The mat shows that I am able to do much more than I thought."*
- *"That is what I think, right in front of me; I don't have to rack my brain to remember."*
- *"I had forgotten all the things I like to do."*
- *"I didn't realise how much she is doing in the house."*
- *"We could use it with the grandchildren, like a game but one that I can play too."*
- *"It was nice to talk about things. We never seem to do that anymore but the pictures really helped us do it."*
- *"It is so difficult to tell [my wife] what I think when I can't remember the words, the pictures could help me a lot."*

Comments from family carers

- *"It [Talking Mats®] really feels like he is listening to my point of view, even for that moment."*
- *"Meals are a problem, I'm not sure if he likes what I give him, but it is so hard to know. We could use pictures of different foods and decide what we are going to have for tea each night."*
- *"Feels less confrontational, we didn't argue."*
- *"I wouldn't say that we are at the stage that we need it [Talking Mats®] to communicate every day, but we could use it when deciding on what we wanted to do each day, or even what TV programmes we want to watch."*
- *"She can see how much I actually do."*
- *"It [Talking Mats®] gives a focus to your conversation, it can be so difficult sometimes to find out what he feels."*
- *"It never seems like he is listening to me, with this I can make him sit down and look at symbols and get him to understand what I am trying to say."*
- *"I can talk away and she's nodding away, but she's not taking it in. At least with the mat she can see and hear what I am trying to say."*
- *"I can definitely see a place for it [Talking Mats®] when communication really becomes a problem."*
- *"He can't say he has forgotten what we agreed, it's right there in the pictures in front of him."*

Summary

This chapter addresses the principal research questions of whether Talking Mats® can help people with dementia *and* family carers feel more involved in decisions about managing their daily living than when using usual communication methods.

The key findings are:

- Talking Mats® can help people with dementia feel more involved in decisions about managing their daily living than when using usual communication methods.
- Talking Mats® can help family carers feel more involved in decisions about how the person with dementia who they care for is managing daily living than when using usual communication methods.
- An interesting but unexpected finding was that, although both the people with dementia and family carers felt more involved in discussions using Talking Mats®, the increased feeling of involvement was significantly higher for the family carers.

Previous research has shown that Talking Mats® are significantly more effective than usual communication methods in helping people with dementia to express their views (Murphy *et al.*, 2007). The results from the current project extend this previous research and demonstrate that Talking Mats® can help both people with dementia *and* family carers feel more involved in important decisions about managing everyday living activities.

4 Talking Mats® and effectiveness of communication

The results reported in the previous chapter determined whether Talking Mats® can help people with dementia and family carers feel more involved in decisions about managing daily living compared to usual communication methods. However, the researchers were also interested to determine whether the Talking Mats® framework could help the participants with dementia to communicate more effectively. A previous project found that Talking Mats® improved the ability of people at early, moderate and even late stages of dementia living in a care setting to communicate more effectively compared to usual communication methods (Murphy *et al.*, 2007). Thus, it was of interest to determine whether this improvement in communication would also be evident in people at varying stages of dementia who are still living at home with a family carer.

During the main data collection phase of the project, the researcher video recorded the discussions between the participants, both with and without the Talking Mats®, to allow for later analysis. On completion of the fieldwork phase, the videotapes of each type of discussion were scored to determine effectiveness of communication. This chapter describes the findings related to effectiveness of communication and the methodology employed to ensure that the scoring of the video recordings was consistent and reliable.

Consensus approach to obtaining inter-rater reliability

Following the method employed in a previous project undertaken by Murphy *et al.* (2007), a consensus approach was taken to rate the effectiveness of communication. Three raters from differing professional backgrounds, comprising of the fieldwork researcher, a speech and language therapist and a psychology undergraduate, scored the video recordings. The following strategies were employed when scoring the videos to ensure consistency:

- The raters watched several pilot tapes to ensure that the criteria used for scoring were clearly defined.
- The videos were always rated in the same setting of the AAC Research Unit at the University of Stirling.
- Most importantly, the raters always watched the videos together and used a three-stage consensus approach to scoring, as outlined comprehensively in Murphy *et al.* (2007). The three stages were:
  - *stage 1: independent scoring* – the three raters watched each video together, but scored each indicator independently without any consultation;
  - *stage 2: consultation* – the three raters then revealed their scores to each other and discussed the reasons behind their decision;
  - *stage 3: adjustment* – if a difference of opinion occurred, each rater took into account their colleagues' justification of their decision before deciding whether to adjust their own score.
- The raters were not required to reach consensus if, after consideration, their views still differed from that of their colleagues.

Assessment of the consensus approach

All instances of inter-rater agreement and disagreement were recorded for both the Talking Mats® and Usual Communication Method discussions, to examine the efficacy of the consensus approach. The overall average inter-rater agreement after consultation was 80%, which is well above the accepted lower bound level for agreement (Aspland and Gardner, 2003) and was found to be highly reliable.[5] The average inter-rater agreement after consultation for the Talking Mats® discussions was significantly higher at 88%, compared to 71% for the Usual Communication Method discussions, as raters found it harder to score these videos and increased consultation was often necessary.

How best to measure effective communication?

Judging the effectiveness of an interaction is by its very nature subjective and there is no gold standard tool to enable comparative judgements to be made about the quality of interactions between two people (Barlett and Bunning, 1997; Grove *et al.*, 2000; Kagan and Gailey, 2001). In order to assess the effectiveness of communication in the current project, the video recordings of each discussion were scored using a refined version of the Effectiveness Framework of Functional Communication developed within the AAC Research Unit at the University of Stirling. The coding framework has been developed through a process of literature review, video observation and peer discussion and has been employed in a number of studies, which have shown it to be a reliable and consistent method to measure the effectiveness of functional communication (Murphy *et al.*, 2007; Murphy and Cameron, 2008).

The version of the effectiveness coding framework employed in the current project looked at five important indicators of effective communication:

- **the participant's understanding of the topic for discussion** – based on verbal and non-verbal responses;
- **the participant's engagement with the process** – this reflects the social closeness that is established in the interaction and maintained through rapport and joint attention;
- **whether the participant keeps on track** – the amount of time during the discussion that the content of the participant's communication was 'on track' – 'on track' meaning that the participant's verbal and non-verbal responses were relevant to the topic being discussed;
- **the researcher's understanding of the participant's views** – shown by the non-verbal and verbal responses of the researcher;
- **the participant's confidence level in responding –** this was demonstrated by the manner in which the participant responded and the pattern of responses e.g. low confidence was demonstrated by hesitancy in articulating views.

For the purpose of the analysis, the first four options within each of the four topics presented to the participant were studied for both the Talking Mats® and Usual Communication Methods discussions. After watching the video recordings of the discussions, all three raters assigned a score for each of the five indicators described above, choosing between 4 = 'always', 3 = 'often', 2 = '50:50', 1 = 'occasional', 0 = 'never' (see Figure 21).

Do Talking Mats® help people with dementia communicate more effectively?

In order to ascertain whether effective communication was achieved in each type of discussion, the adjusted scores of the three raters were averaged, and the five indicator scores were totalled to produce an overall effectiveness of communication score out of 20, with a higher score indicating a greater degree of effectiveness. Following the method employed by Murphy *et al.* (2007), a total score of 15 or more was considered to be evidence of effective communication.

Figure 21: Effectiveness coding framework

	4 Always	3 Often	2 50:50	1 Occasional	0 Never
Participant's understanding of issue for discussion					
Participant's engagement with process					
Participant keeps on track					
Researcher's understanding of the participant's views					
Participant's confidence level in responding					
Comments:					

- The mean score for overall effectiveness of communication was 15.7 for the Talking Mats® discussion and 14.5 for the Usual Communication Method discussions.

- Talking Mats® significantly improved the effectiveness of communication in people with dementia when compared to their usual communication method [6].

- An effective level of communication was only achieved when Talking Mats® were used (see Figure 22).

Individual effectiveness indicators

Having established that Talking Mats® did improve the overall effectiveness of communication in the participants with dementia, the following sections outline the results for each of the individual effectiveness framework indicators, to determine which of these key components of communication was improved when using Talking Mats®. For each indicator, the adjusted scores of the three raters were averaged to produce a mean score out of 4, with a higher score signifying increased evidence of that particular aspect of effective communication.

Participant understanding

- The mean score for participant understanding was 3.3 for the Talking Mats® discussions and 3.4 for the Usual Communication Method discussions (see Figure 23).

- There was no significant difference between mean scores for participant understanding when using Talking Mats® and Usual Communication Methods.[7]

- As the majority of the people with dementia were at the early to moderate stages of the condition, most had a good understanding of the topics under discussion.

Figure 22: Mean scores for overall effectiveness of communication

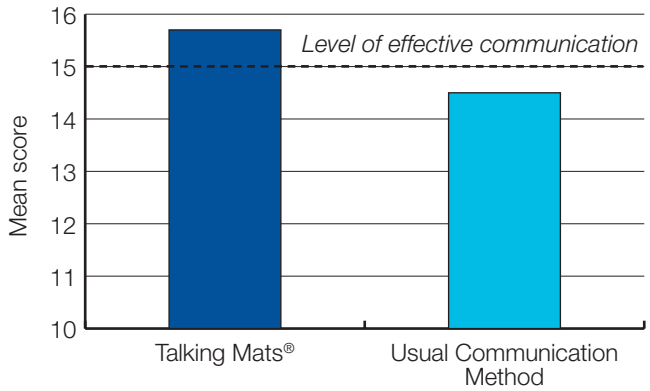
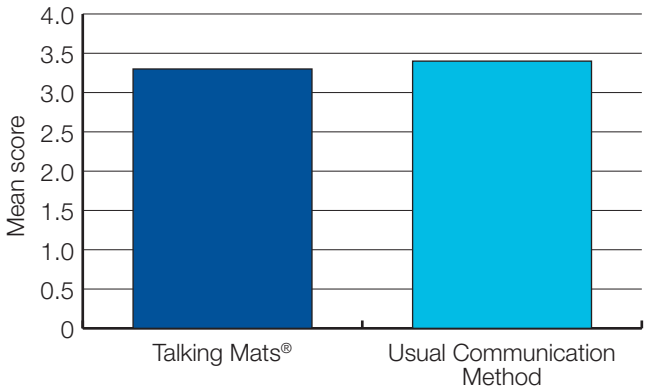


Figure 23: Mean scores for participant understanding



Participant engagement

- The mean score for participant engagement was 3.2 for the Talking Mats® discussions and 2.7 for the Usual Communication Method discussions (see Figure 24).

- The people with dementia were significantly more engaged when using Talking Mats® compared to their usual communication method.[8]

- Talking Mats® clearly encouraged the participants with dementia to engage more in the discussions about managing daily living. This was demonstrated by changes in body language and the level of interaction with family carers and the researcher.

Participant on track

- The mean score for participant on track was 3.2 for the Talking Mats® discussions and 3.1 for the Usual Communication Method discussions (see Figure 25).

- Talking Mats® marginally encouraged people with dementia to keep their conversation on track when compared to their usual communication method, but the difference between mean scores did not reach statistical significance.[9]

- As the majority of the people with dementia were at the early to moderate stages of the condition, it would appear that they possessed the ability to inhibit irrelevant responses and remain on track during discussions.

Figure 24: Mean scores for participant engagement

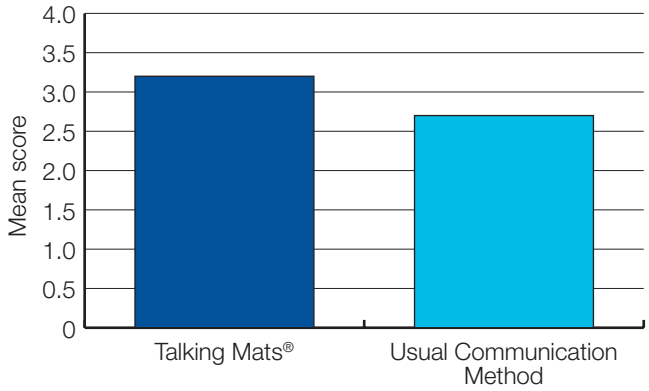
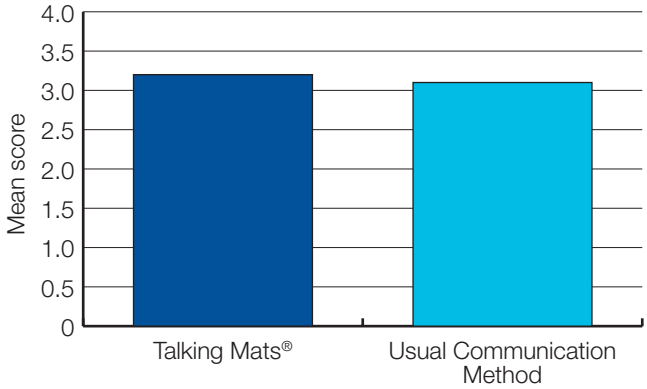


Figure 25: Mean scores for participant staying on track



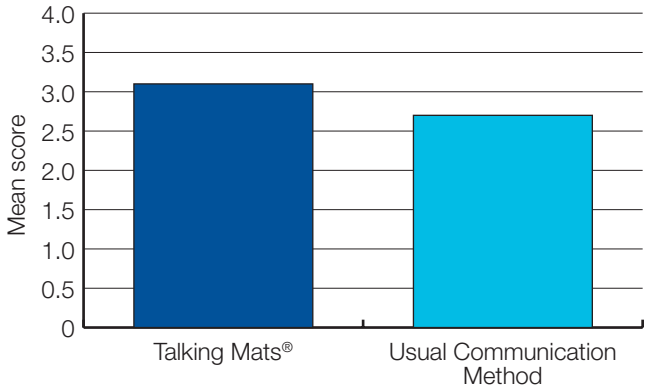
Researcher understanding of participant views

- The mean score for researcher understanding was 3.1 for the Talking Mats® discussions and 2.7 for the Usual Communication Method discussions (see Figure 26).

- Using Talking Mats® did improve the extent to which the views of people with dementia were understood when compared to their usual communication method, although the improvement failed to reach statistical significance.[10]

- Talking Mats® clearly enhanced the researcher's understanding of the views of the people with dementia, but, as the majority of

Figure 26: Mean scores for researcher understanding of participant views



the participants were at the early to moderate stage of the condition, most did possess the capability of verbally expressing how they felt, both with and without the use of Talking Mats®.

Participant confidence in responding

- The mean score for participant confidence level in responding was 2.9 for the Talking Mats® discussions and 2.6 for the Usual Communication Method discussions (see Figure 27).

- Talking Mats® did increase confidence in responding for the people with dementia when compared to their usual communication method, although this increase did not reach statistical significance.[11]

- As will be discussed in the following section, some of the participants with dementia were less confident in expressing their views during discussions, as a number of the family carers took the lead in discussions.

Additional aspects of effective communication

The findings reported in this chapter so far have established which primary indicators of effective communication were improved when using Talking Mats®. In addition to these primary indicators, several other factors were also considered to explore how the participants with dementia communicated, including perseveration, and the interaction between participants, as measured by the symmetry of the conversation and placing of the Talking Mats® symbols.

Perseveration

Perseveration is the term used to describe the uncontrollable tendency to continue or repeat an act or activity (Lezak *et al.*, 2004). It is well documented that people diagnosed with dementia often exhibit perseverative behaviours, such as repeating words, phrases or gestures, for example wringing their hands or playing with the hem of a skirt (Bayles, 1985; Guarda *et al.*, 2008). A previous study by Murphy *et al.* (2007) found that Talking Mats® reduced the instances of perseveration during discussions when compared to usual communication methods. To ascertain whether the same pattern of results would be evident in the current project, the videos were scored using the method described previously, whereby the adjusted scores of the three raters were averaged to produce a mean score out of 4, with a higher score signifying increased evidence of perseveration.

- The mean score for participant perseveration was 0.2 for the Talking Mats® discussions and 0.7 for the Usual Communication Method discussions (see Figure 28).

- Talking Mats® significantly reduced the instances of perseveration in people with dementia when compared to their usual communication method.[12]

- As can be clearly seen in Figure 28, when participants with dementia were using

Figure 27: Mean scores for participant confidence in responding

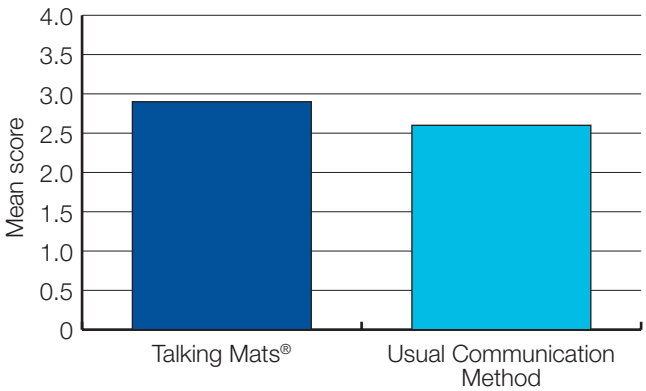
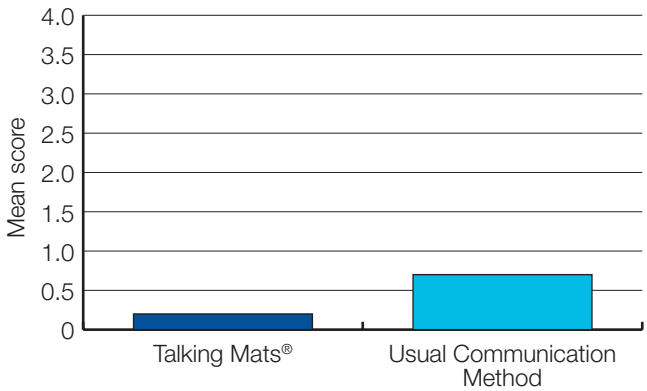


Figure 28: Mean scores for participant perseveration



Talking Mats® they were less likely to display perseverative behaviours, suggesting that they were able to concentrate on the interaction and stay focused to a greater extent than when using their usual communication method.

Interaction between participants with dementia and family carers

Having established which primary and secondary indicators of effective communication were improved using Talking Mats®, attention then turned to the interaction between the participants with dementia and the family carers when using Talking Mats® and their usual communication method.

Symmetry of conversation

In order to determine the symmetry of conversation, the raters used a likert-type scale to record which conversation partner in each couple was more verbal during discussions (see Figure 29).

- In four out of the 18 couples, Talking Mats® allowed for a balanced discussion between people with dementia and their family carers, compared to three out of 18 couples when employing their usual communication method (see Table 1).

Figure 29: Symmetry of conversation scale

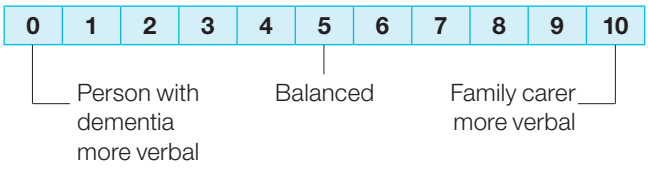


Table 1: Symmetry of conversation during both types of discussion

	Talking Mats®		Usual communication	
	No. of couples	%	No. of couples	%
Person with dementia more verbal during discussion	1	6	6	33
Balanced discussion	4	22	3	17
Family carer more verbal during discussion	13	72	9	50

- The people with dementia were more verbal during the discussion in one out of 18 couples when using Talking Mats®, compared to six out of 18 couples when employing their usual communication method.

- Family carers were more verbal during both types of discussion (see Figure 30), but this was far more evident when using Talking Mats®, as in 13 out of the 18 couples, the family carers were more vocal. These findings lend support to the Involvement Measure data discussed in chapter 4, which showed that family carers felt the Talking Mats® framework allowed them to express their opinions and to be heard by their relative, whereas they felt less involved in discussions using usual communication methods.

Talking Mats® symbol placement

To examine to what extent the participants with dementia were able to assume ownership of the placement of the Talking Mats® symbols, a likert-type scale was used to record which conversation partner decided where the option symbols would be placed (see Figure 31).

- Just over 20% of the people with dementia were able to take ownership of the mat and place

Figure 30: Symmetry of conversation for both types of discussion

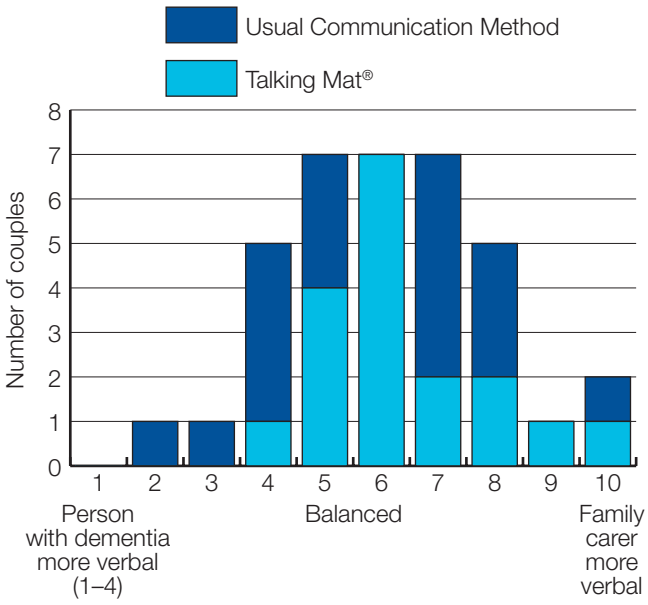


Figure 31: Talking Mats® symbol placement scale

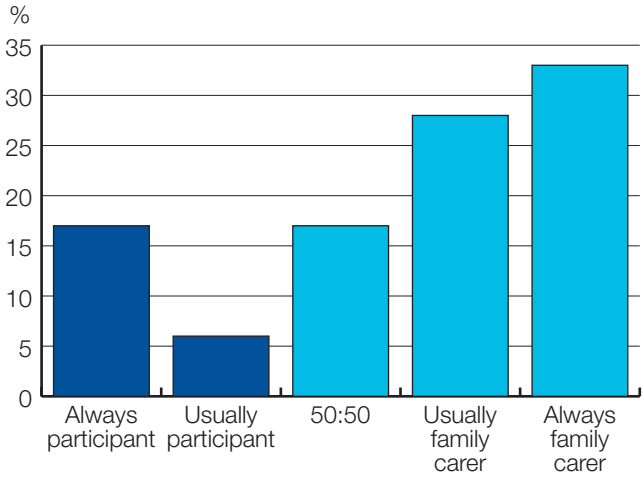
4	3	2	1	0
Always participant	Usually participant	50:50	Usually caregiver	Always caregiver

the Talking Mats® symbols themselves (see Figure 32).

- In just under 20% of cases the placement of the Talking Mats® symbols was a joint effort.

In 60% of cases the family carer placed the symbols (see Figure 32). The previous project found that the placing of the symbols can cognitively overload some people with dementia, as having to both 'think' and 'do' is too demanding. For some people with dementia it is therefore preferable for the carer to place the symbols for them, once they have indicated their views either verbally or non-verbally. The fact that the majority of family carers placed the symbols also lends support to previous observations regarding their increased feelings of involvement and the asymmetry of conversations when using Talking Mats®.

Figure 32: Placement of Talking Mats® symbols



Summary

This chapter addresses the question of whether Talking Mats® can help people with dementia communicate more effectively than usual communication methods when making decisions about how they are managing activities of daily living. The key findings are:

- Talking Mats® significantly improves the overall effectiveness of communication in people with dementia when compared to their usual communication method.
- The improvement in communication was most evident in the level of engagement of the participants with dementia and the reduced instances of repetitive behaviours.
- As the majority of the people with dementia in the study were at the early to moderate stages of the condition, they were able to stay on track, understand what was being discussed and make their views known to others both with and without the use of Talking Mats®.
- Talking Mats® did increase confidence in responding in people with dementia, but this increase was often masked by the fact that many of the family carers felt that the Talking Mats® discussions were the only way to ensure that their own views were heard.
- This was mirrored by the observation that the family carers were more vocal during the Talking Mats® discussions and were also more likely to place the symbols on the mat.

5 Supplementary findings of interest

The primary focus of the current project was to determine whether the Talking Mats® framework can help people with dementia and family carers feel more involved in decisions compared to usual communication methods. Although not central to the issue under investigation, in the process of determining the answer to the research question, detailed notes were taken which document how the individuals with dementia and their family carers who took part in the study felt they were managing the daily living activities discussed.

A number of interesting findings arose from analysis of the discussions and were explored further. These included:

- which daily living activities the people with dementia who took part in the study were managing/not managing;
- the differences in how people at differing stages of dementia felt they were managing in relation to daily living activities;
- the differences in opinion between the family carers who were spouses and those who were daughters.

The findings outlined in this chapter relate only to the participants who took part in this study, and as such cannot be generalised to the wider population of people living with dementia and their family carers. The small number of participants and uneven group sizes involved in the study limit the strength of conclusions that can be drawn. However, the findings do provide a picture of how people with dementia at differing stages of disease progression, and family carers, feel they are managing four aspects of their daily living activities, and provide a basis for future research.

Dementia and managing activities of daily living

The results from the Talking Mats® and Usual Communication Methods discussions were combined to provide an overview of the discussions between the participants with dementia and their family carers. Each of the four topics discussed were then analysed at the individual option level to provide a detailed picture of exactly how the people with dementia in the study were managing the range of daily living activities discussed. Verbatim quotes from the discussions from both the people with dementia and family carers are included. Where necessary, to improve understanding, additions to the quotes have been made in brackets. Each quote is followed by: details of the author – family carer (FC) or person with dementia (PWD); the type of discussion – Talking Mats® (TM) or Usual Communication Methods (UCM); and the option being discussed e.g. watching TV.

Personal care

The people with dementia who took part in the study were generally managing tasks such as eating, drinking, shaving, brushing teeth and going to the toilet independently:

> *"You can manage to shave yourself no problem."*
>
> (FC 20, TM, shaving)

> *"I have false teeth. Take them out and brush them."*
>
> (PWD 15, UCM, brushing teeth)

Most needed some level of support with washing and getting dressed or undressed:

> *"They [clothes] magically just appear … [laughter] I lay them out at night!"*
>
> (FC 18, UCM, medication)

"I've sometimes to help him with putting on shirts and that."
(FC 1, TM, getting dressed appropriately)

to which her partner replied:

"Getting them on the right way."
(PWD 1, TM, getting dressed appropriately)

"I was on the phone, he put his [pyjama] bottoms on, but the top was on top of his day clothes. He wasn't a happy bunny when I suggested taking them off."
(FC 8, UCM, getting ready for bed)

"She can get them [clothes] off but if she could just wear her vest and pants she'd go to bed like that."
(FC 13, TM, getting ready for bed)

Taking medication caused the greatest degree of difficulty for the people with dementia in the current study, and assistance from a family carer was usually required:

"Would you be able to manage this if I wasn't here? Would you remember it? You get mixed up about it."
(FC 7, TM, medication)

"I give her her medication. She's on Aricept, one each night. That's part of my job."
(FC 13, UCM, medication)

"Would you remember your tablets in the morning if I didn't put them out for you? ... I'd say you would forget them."
(FC 20, TM, medication)

Getting around

The people with dementia who took part in this study were relatively mobile and were managing walking, using the stairs and getting into/out of chair and bed:

"He takes the dog for a walk."
(FC 20, UCM, walking)

"I just get up straight away."
(PWD 13, UCM, getting into/out of bed)

"I just get in and oot it, that's that."
(PWD 11, UCM, getting into/out of bed)

The greatest problems related to getting around outside the home, as many couples were reluctant to use public transport, and rarely used taxis owing to a reported loss of confidence and the expense involved:

"Too difficult to get on and off!"
(FC 19, TM, using public transport)

"I find it difficult as I can't stand and wait because of my back."
(FC 2, TM, using public transport)

"too expensive!"
(PWD 1, UCM, using taxis)

"can't afford them!"
(PWD 20, UCM, using taxis)

Driving was the issue that caused much distress and frustration for people with dementia in the current study, and many verbalised feeling 'angry' and 'betrayed' at having to give up their licence upon diagnosis:

"Something dear to my heart … I feel I could still drive but they took my licence off me six years ago. When I'm sitting in the car with [wife's name] I can still tell what she's doing wrong."
(PWD 14, TM, driving)

"I didna kill anyone. I can still drive."
(PWD 1, UCM, driving)

"I don't have a car. They stole it from me.… Part of your life is gone."
(PWD 20, UCM, driving)

"Perhaps one of the biggest shocks of my life. I used to be an advanced driver; I now depend on [family carer's name]."
(PWD 3, TM, driving)

Housework

Most of the people with dementia in the current study were dependent on their family carers for the vast majority of household chores, although some could manage straightforward tasks such as making the bed and washing dishes:

"He washes the dishes in the morning. I do it the rest of the day."
(FC 20, UCM, washing the dishes)

"You still make an attempt at it. Do it better than me probably."
(FC 19, TM, making the bed)

However, most were wholly dependent on family carers for cooking and cleaning:

"She cuts up the vegetables for soup but not main meals. I do that now."
(FC 7, UCM, cooking)

"Can open a tin of soup. If she wasn't here I'd have a packet of biscuits."
(PWD 14, UCM, cooking)

"He wouldn't know where to start!"
(FC 14, TM, cleaning the kitchen/bathroom)

"Oh that's you; I don't think I do any cleaning."
(PWD 3, TM, cleaning the kitchen/bathroom)

Financial matters/paying bills and using the telephone were the housework tasks that caused the greatest degree of difficulty for the participants with dementia who took part in the study:

"Counting cash, counting money is a major problem."
(PWD 14, TM, taxis)

and

"No, my sense of money values has gone. [Family carer's name] has taken this over completely."
(PWD 14, TM, financial matters/paying bills)

"She gets confused with money."
(FC 7, UCM, financial matters/paying bills)

"You always did the financial side in this house. I paid the bills. Things have changed now. I do all the financial matters and all the bills."
(FC 8, TM, financial matters/paying bills)

"Do you think you avoid doing it because sometimes you're not exactly sure what to do or who's talking? Definitely you're avoiding it because of the situation you are in memory wise."
(FC 8, TM, using the telephone)

"He picks the phone up the wrong way."
(FC 1, UCM, using the telephone)

"I couldn't dial, don't remember the numbers."
(PWD 7, UCM, using the telephone)

Activities

The people with dementia in the current study were, however, still managing to partake in a number of different activities. Most were relatively mobile, and socialised outside the home including eating out, attending clubs or going on trips with support:

"[I go to] Bowling club, art club."
(PWD 20, TM, clubs and groups)

"Often we'll take the car and go out and go for a meal and that."
(FC 7, TM, going on trips)

"We started going out for lunch on Saturdays about a year ago, couldn't afford it when the children were younger."
(PWD 14, UCM, eating out)

"People from their old church come and collect them. And she goes down to my church on a Monday night to a club with my cousin."
(FC 18, UCM, church)

"[She goes to] Two smaller groups on a Sunday. They take care of her."
(FC 15, UCM, clubs and groups)

Some were also managing a number of activities within the home such as listening to the radio, doing games/puzzles or watching television:

> *"Never did it before but I started four years ago [in order] to exercise my brain."*
> (PWD 14, UCM, puzzles and games)

> *"Gave up reading for a while because I forgot what the book was about. [I now] Read* Reader's Digest *– 4 short stories, short enough to read and remember it."*
> (PWD 14, UCM, reading)

> *"I like factual stuff. We look at the TV magazine and mark off what we want to watch."*
> (PWD 15, UCM, watching TV)

On a positive note, the people with dementia who took part in the study were managing to enjoy many more activities than originally envisaged, including painting, singing, bowling and playing the drums!

> *"He cannae write the same but he can still paint, do his oil painting."*
> (FC 20, TM, writing)

> *"I go with the ladies to do singing in the church."*
> (PWD 6, UCM, singing)

Comparison of the views of people at different stages of dementia

In an attempt to gain a picture of what people at differing stages of dementia – who are still living at home – are managing in relation to daily living activities, the 18 people with dementia who took part in the study were divided into three groups based on their scores from the Communication Difficulties Scale (CDS) as previously described in Chapter 2. Based on these scores, three were estimated to be at early stage dementia, 13 were estimated to be at moderate stage dementia and two were estimated to be at late stage dementia. The views of those at early, moderate and late stage dementia and their family carers were then compared for each of the four topics discussed:

Personal care

The people estimated to be at early stage dementia who took part in the study were managing the majority of their 'personal care', with minimum assistance. Those estimated to be at moderate and late stage dementia had more difficulty as they were managing around half of the 'personal care' tasks discussed.

Getting around

The participants with dementia who took part in the study were managing many of the tasks related to 'getting around'; regardless of the stage of dementia they were estimated to be at. However, for those estimated to be at the moderate and later stages of dementia, the percentage of topics not discussed was higher, as many of the couples refused to talk about 'driving' as they found it a highly emotive topic.

Housework

Regardless of the stage of dementia, the people with dementia who took part in the study relied heavily on their family carer to carry out household tasks, and were unable to manage over half of the tasks discussed. As noted previously, the tasks that caused the greatest difficulty were financial matters/paying bills and using the telephone.

Activities

All of the individuals with dementia were still managing to partake in half of the activities discussed. However, those estimated to be at late stage dementia chose not to discuss nearly one fifth of the activities, as they felt it was no longer appropriate to their circumstances.

Comparison of the opinions of spouses and daughters who are family carers

Of the 18 family carers who took part in the project, 14 were spouses (nine wives and five husbands), all of whom lived with the person with dementia who they cared for. Four of the family carers were daughters, half of whom lived with their parent with dementia. During the analysis of the discussions between the people with dementia and family carers, it soon became clear that the daughters

who were family carers had different opinions from those family carers who were spouses, regarding what the person with dementia was managing in relation to their activities of daily living. The daughters also differed in the strength of their opinions, depending on whether they lived with their parent.

From analysis of discussions, it was clear that the family carers who were spouses felt that the person with dementia was managing more of their daily living activities, when compared to family carers who were daughters. When compared to spouses, all of the daughters agreed that their parent was managing less of their daily living activities, although they differed in their opinion as to how much their parent was actually managing. The daughters who were not living with their parent felt that the person with dementia was able to manage less of their daily living activities compared to the family carers who were spouses. However, the daughters who were actually living with their parent felt that their parent was having even more difficulty.

Clearly, the greatest difference in opinion was most apparent when the daughters were actually living with their parent with dementia. The family carers who were spouses were actually caring for people estimated to be at a more advanced stage of dementia, yet they felt that the person with dementia was able to manage more of their daily living activities. The exact reasons behind this anomaly are unclear, but it could be suggested that spouses make more allowances for their partners, as they have an understanding of, and can adjust to, the gradual deterioration in ability as a result of advancing age. Of course, the small and uneven group sizes limit the strength of conclusions that can be drawn from this analysis; however, they do offer insight into the experiences of two different types of family carers of people with dementia, and highlight the need for a systematic exploration of their differing views.

Summary

This chapter outlines a number of interesting supplementary findings that arose from an analysis of the detailed notes taken during the course of the project. Owing to the small number of participants, these findings can only be seen as exploratory, and relate only to the participants who took part in the study. However, they do provide a basis for further research, and highlight the need for a more systematic investigation.

Key findings

Dementia and managing activities of daily living

- The people with dementia who took part in the study were managing some of their personal care, but needed assistance with washing and dressing, and maximum assistance with taking their medication.
- Most of the people with dementia who took part in study were still mobile within the home, but the majority needed assistance using public transport, and were unable to drive.
- Most of the people with dementia who took part in the study were dependent on their family carers for the vast majority of household chores, with the most difficult tasks being financial matters/paying bills and using the telephone.
- On a positive note, the majority of the people with dementia who took part in the study were still managing to enjoy a number of activities ranging from eating out to singing and playing the drums.

Comparison of the views of people at different stages of dementia

- The people estimated to be at early stage dementia who took part in the study were managing the majority of their personal care, but those at later stage dementia needed more help from their family carers.
- The people with dementia who took part in the study were managing most tasks related to ‘getting around’ regardless of the stage of dementia they were estimated to be at. However, many of those at later stage dementia declined to talk about emotive topics such as driving.

- The people with dementia who took part in the study were unable to manage many household tasks, and relied heavily on their family carers regardless of the stage of dementia they were estimated to be at.

- All of the individuals with dementia were still managing to enjoy over half of the activities discussed, although those estimated at later stage dementia declined to discuss more of the included activities.

Comparison of the opinions of spouses and daughters who are family carers

- The family carers differed in their opinions regarding what the person with dementia was managing in relation to their daily living activities.

- The family carers who were spouses felt that the person with dementia was managing more of their daily living activities, when compared to family carers who were daughters.

- The daughters also differed in the strength of their opinions, as those who lived with their parent felt they were having even greater difficulty managing daily living tasks.

- As the family carers who were spouses were caring for people at later stage dementia, it was suggested that they make more allowances for their partners. However, a more systematic investigation is needed to explore the reasons behind these differences in opinion.

6 Discussion and conclusions

The central aim of the current project was to explore whether the Talking Mats® framework can help people with dementia and family carers to feel more involved in decisions about managing their daily living than usual communication methods.

Talking Mats® and involvement in decision making

The key findings have shown that people with dementia feel more involved in discussions about how they are managing their daily living when using the Talking Mats® framework, compared to their usual communication method. They also feel more satisfied with the outcome of those discussions. When questioned, the people with dementia reported that the Talking Mats® framework clarified their thoughts and enabled them to express their views. The framework allowed the people with dementia to convey their thoughts to their family carers, and helped them to reach a decision about how they were managing different aspects of their daily living.

A similar pattern was also evident in the responses from the family carers, who also reported feeling more involved in discussions and more satisfied with the outcome when using Talking Mats®. When questioned, family carers often acknowledged its value in encouraging and maintaining communication. It is evident that family carers felt that the Talking Mats® framework can allow for a better understanding of the views of the person with dementia for whom they care. This clearly has implications for the stress and guilt often associated with having to make decisions for their loved one, not only those made on a day-to-day basis, but also those related to their future care.

An unexpected finding was that, although the people with dementia and family carers both felt more involved in discussions using Talking Mats®, the increased feeling of involvement was significantly higher for the family carers. Family carers repeatedly reported feeling 'listened to' by the person with dementia and felt that their loved one could actually 'see' their point of view. The family carers' increased feelings of involvement when using Talking Mats® were mirrored by their propensity to be more vocal during the Talking Mats® discussions and to take charge of placing the symbols. When put together, it is clear that the desire for one's view to be heard was of great importance to the family carers of people with dementia, and that the Talking Mats® framework afforded them the opportunity to achieve this.

The tendency for people to talk over individuals with communication difficulties is well recognised, and it could be suggested that the family carers dominated the discussions using Talking Mats® at the expense of the person with dementia. An alternative interpretation is that the framework has the ability to alter the dynamics of relationships, and enhance the interaction between the person with dementia and their family carer. Many family carers stated that often they choose not to say something that is going to inflame a situation, so instead they say nothing at all. In contrast, they felt that the Talking Mats® framework allowed them time and space to have their say, and helped to organise and structure their conversation with the person with dementia for whom they cared.

Talking Mats® and effectiveness of communication

Although the central aim of the project was to determine whether Talking Mats® can help people with dementia and family carers *feel more involved* in decisions about managing daily living activities, the researchers were also interested in determining whether the Talking Mats® framework could help people with dementia to *communicate more effectively*. Previous research had shown that the Talking Mats® framework improved the ability of people at early, moderate and even late stages of

dementia living in a care setting to communicate more effectively (Murphy *et al.*, 2007). Thus, the current project explored whether this improvement in communication would also be evident in people at differing stages of dementia who were still living at home.

The results corroborate the findings from the previous research (Murphy *et al.*, 2007), as they show that Talking Mats® significantly improved the overall effectiveness of communication in people with dementia when compared to their usual communication method. The improvement in communication was most evident in the level of engagement of the participants with dementia and the reduced instances of repetitive behaviours. Engaging in interaction and maintaining social closeness are important factors in sustaining any form of relationship (Light, 1988; Locke, 1998), and Talking Mats® could clearly play a role in ensuring that people with dementia are able to engage more with the people in their life. Moreover, the ability of the Talking Mats® framework to reduce perseveration has the potential to further enhance this interaction, as it allows the person with dementia to stay more focused than when using their usual communication method.

Supplementary findings of interest

Based on the results discussed thus far, it is clear that the Talking Mats® framework can help people with dementia and family carers feel more involved in decisions, and allow for more effective communication compared to usual communication methods. However, the actual content of the discussions also allowed for exploration of a number of interesting areas.

Dementia and managing activities of daily living

Chapter 5 began by outlining how well the people with dementia and family carers felt that the person with dementia was managing each of the four topics under discussion, namely 'personal care', 'getting around', 'housework' and 'activities'. The results suggest that the activities that caused the greatest difficulty were taking medication, driving and financial matters/paying bills.

Comparison of the views of people at different stages of dementia

Chapter 5 then compared the views of people at early, moderate and late stage dementia and their family carers. The comparisons mirrored the overall responses from all the participants, but suggested that as dementia progresses, more assistance is needed with personal care and household chores, and there is a reluctance to discuss emotive topics such as driving.

Comparison of the views of spouses and daughters who are family carers

The final section of Chapter 5 compared the views of family carers who were spouses and those who were daughters. From an analysis of the discussions it was clear that the daughters and spouses differed in their opinion of how well they felt the person with dementia was managing. The daughters felt that the degree of support required was much greater, and that they were responsible for much more of their loved one's care, most especially when they were living with their parent.

It is important to note that the findings outlined in Chapter 5 relate only to the participants who took part in this study, and as such cannot be generalised to the wider population of people living with dementia. The small number of participants and uneven group sizes involved in the study limit the strength of conclusions that can be drawn, and as such these findings can only be seen as exploratory. However, they do provide a picture of how people with dementia at differing stages of disease progression, and family carers, feel they are managing four aspects of their daily living activities, and provide a basis for a more systematic investigation in future research.

Additional points of interest

In addition to the findings discussed thus far, a number of other issues were uncovered during the project, which warrant discussion. One of the greatest obstacles throughout the project was the difficulty in recruiting participants. The researcher sought assistance from over 50 agencies in Scotland who offer support to people with dementia living in the community. Of

these 50 agencies, four passed on information about the project to potential participants. On further investigation into the reasons why only a small number of agencies were able to identify participants, it would appear that many of the agencies whose role it is to provide support to people with dementia and their carers have no contact with people recently diagnosed, or even with those at the moderate stages of the illness still living at home.

Based on the comments from family carers, this situation arose due to a combination of a lack of knowledge of the help available, and also how best to make their needs known. Eleven out of the 18 couples who took part in the study told the researcher that they received no help from any external agency. Perhaps one of the most disturbing consequences of this lack of intervention was that the majority of the people with dementia who took part in the study were very clearly in the moderate and even later stages of dementia, and were still living at home with family carers as their sole means of support. Many of the family carers were themselves older, with several affected by a variety of age-related health problems, and the tremendous stress of being the sole carer of a family member with dementia was clearly evident. Family carers repeatedly cited the gradual decline in communication as one of the most distressing aspects of caring for their loved one. Until early intervention and a support framework are put in place, and strategies are sought to aid communication, this alarming pattern is set to continue. As one carer said, *"the daily struggle is like swimming in soup".*

How can the findings from the Talking Mats® research project inform and impact on practice and the policy implementation?

The Talking Mats® framework demonstrates an innovative and positive approach to helping carers and people with dementia discuss the management of everyday living. For both, 'living well with dementia' involves a complex balancing act to negotiate a way through changing needs and preferences in everyday living, and choices about current and future support. Talking Mats® provides a framework whereby the needs and views of the person with dementia and their carer can be articulated and shared. By facilitating such conversations it may be possible to identify strengths and abilities, correct misperceptions about abilities and preferences, reduce anxiety on the part of both the person with dementia and their carer, and give expression to their concerns in a safe, non-confrontational way.

The demonstration that the Talking Mats® framework could enable people with dementia and their family carer to jointly discuss and make decisions about how people are managing daily living is important for health, care and other staff such as Housing and Benefit Agency staff, in assessing needs and providing care and support. Staff working within these sectors must be able to not only identify the specific needs and preferences of people with dementia, but also take into account the views of family members and work with them. Innovative and creative methods such as the Talking Mats® framework can not only contribute to the process of negotiation in day-to-day decision making, but also offer a method for recording views to inform later decision making with members of the wider support community.

With regards to policy implementation, government policy guidance seeks to ensure that the principles and objectives described in their strategies are translated into high-quality services that can demonstrate effective outcomes. Government policy also advocates that users and carers should be at the centre of determining outcomes of the implementation of government strategies and targets. The findings from this study suggest that Talking Mats® can support people with dementia and their carers to express their views about services. By supporting people with dementia and their carers to feel more involved in discussions about how they are managing their daily living, Talking Mats® is a significant tool that can be of help to those who have to implement policy and change practice.

Table 2 highlights some of the recommendations and guidelines described in government documents for which the Talking Mats® framework has relevance.

Effective policy implementation and development of appropriate services also requires

Table 2: Relevance of Talking Mats® to government recommendations and guidelines

Document	Recommendations/guidelines
Adults with Incapacity (Scotland) Act (2000) (Scottish Executive, 2000); *Mental Capacity Act (2005)* (DH, 2005)	• Involvement of people with dementia in decision making • Rights of individuals to be supported to make own decisions • Alternative methods of communication should be used
NICE and SCIE (2006)	• People with dementia should: – be involved and in control of their own living arrangements and support on a day-to-day basis – have their voice heard in person-centred care planning and reviews – have their voice heard in the regulation, development and improvement of services and support systems – be involved in decisions about key life choices and transitions – be involved in decisions about care and treatment • Professionals are encouraged to involve people with dementia in discussions and decisions about their care • Recognition of the contribution that family carers make and their own need for support
CSCI (2006); NAO (2007)	• Defined care pathway and set targets to improve quality of care and outcomes
Putting People First (DH, 2007)	• Giving more choice and control to people who use services
Carers Strategy (DH, 2008)	• Need to negotiate the right kind and levels of support that balance the needs and choices of both the person with dementia and their carer
A National Dementia Strategy (DH, 2009a)	• This strategy is outcome focused around three main themes, which involve the inclusion of the views of people with dementia and their carers: – raising awareness and understanding – early diagnosis and support – living well with dementia – services should be responsive to the personal needs and preferences of each individual and take account of broader family circumstances (Objective 6) – family carers are the most important resource for people with dementia and an agreed plan to support their role is essential (Objective 7)
Dementia Strategy Consultation Paper (Scottish Executive, 2009)	• Focus on rights, dignity and personalisation
National Dementia Action Plan for Wales (Welsh Assembly Government, 2009a)	• Initiatives to improve choice and control, and the personalisation of care
Alzheimer's Society Northern Ireland consultation (2009)	• Research involving the views of people with dementia will inform the work of the group

a significant effort in improving the knowledge and skills of the workforce. It is critical for local commissioners, practitioners and support staff to know about, and have access to, tools and approaches that enable people with dementia to express their views even though verbal communication skills have deteriorated. The *Joint Commissioning Framework for Dementia* in England (DH, 2009c) – the commissioning guidance associated with the National Dementia Strategy – makes it clear that the workforce requires skills to work effectively with people with dementia and their carers. Innovative practice is needed to facilitate communication, including non-verbal forms, in order to assist people with dementia and their carers to express their views about daily living in a way that maximises abilities and promotes dignity.

Practitioners across all sectors need the right attitudes, knowledge and skills to work effectively with individuals with dementia and their carers and to ensure dignity, choice and control for both. Approaches such as the Talking Mats® framework enable those involved to learn about each other's perspectives on managing day-to-day living, and some of the feelings around these ongoing daily

transactions. Talking Mats® is a proven innovative method to facilitate and improve communication between carers and the person with dementia. Views can be recorded in a way that can be used to clarify and enhance support planning, which is essential if personalised services and user and carer directed outcomes are to be achieved.

Future plans

Having established that the Talking Mats® framework can help people with dementia and their family carers feel more involved in making decisions, one of the research team's priorities will be to raise awareness of the Talking Mats® framework for families living with dementia, and carers working within this sector. This will be achieved by writing short articles for magazines/journals that are accessible to families and carers of people with dementia such as the Alzheimer's Society newsletter, the *Caring Times* and *Living with Dementia*. Awareness raising programmes are necessary in order for Talking Mats® to become a mainstream resource for families, which includes a person with dementia. Health, social care, third sector, carers' and advocacy organisations involved in offering information, support and services to people with dementia are in a position to make families aware that low-technology approaches to aid communication around everyday decision making are available.

A second priority will be to make the Talking Mats® framework available to people with dementia and their families, and to find ways of supporting/training couples and families to use the tool. It is hoped that the relevance of the Talking Mats® framework to a wide range of people with disabilities may convince organisations working within this sector that supporting and training staff and families to use the tool is a practicable and effective way forward. The Talking Mats team have already run two training courses specifically for family members, and would hope to run more. This could be achieved through organisations such as Alzheimer's Society, Alzheimer Scotland, Age UK and Carers UK. The Talking Mats Research and Development Centre already has a database in place of relevant organisations.

Further research

Based on these findings, there are a number of other research questions that warrant further investigation:

1. Could becoming familiar with the Talking Mats® framework in the earlier stages of dementia help the person to use Talking Mats® at a later stage, when making key decisions about accepting care?

2. Does enabling/encouraging people with dementia to be involved in early decisions about their daily life make acceptance of care easier in the future?

3. Could the Talking Mats® framework help with conflict resolution?

Conclusions

The current project has shown that people with dementia and family carers can use the Talking Mats® framework to feel more involved in making decisions about managing daily living. It is clear that the framework can also help people with dementia to communicate more effectively, by increasing their level of engagement with others and helping to maintain attention.

The Talking Mats® framework could also result in increased well-being and positive adjustment to accepting increasing levels of care for people with dementia. Lastly, and perhaps most importantly, it could improve the relationship between the person with dementia and family carers, if all involved feel that the views of the person with dementia and the family carer have truly been acknowledged.

Having established that the Talking Mats® framework is a valuable tool in helping people with dementia to make decisions about their daily life, the next step must be to put this knowledge into practice. If, as the policy-makers suggest, the focus is now to truly engage and maximise the involvement of people with dementia in decisions about their care, it is clear that the Talking Mats® framework offers an effective way to allow the views of people with dementia and their family carers to be heard.

Notes

1 The Picture Communication Symbols (PCS) are ©1981–2009 Mayer Johnson Co. and are used with permission – Mayer-Johnson Co., P.O. Box 1579, Solana Beach, CA 92075, USA.

2 Wilcoxon signed-rank test, $z = -3.83$, $p < 0.01$, $r = -0.45$

3 Wilcoxon signed-rank test, $z = -3.46$, $p < 0.01$, $r = 0.41$

4 Mann-Whitney test, $z = -2.12$, $p < 0.05$, $r = 0.35$

5 Intraclass correlation = 0.99

6 Wilcoxon signed-rank test $z = -2.40$, $p < 0.05$, $r = 0.40$

7 Wilcoxon signed-rank test, $z = -0.36$, $p > 0.05$

8 Wilcoxon signed-rank test, $z = -2.20$, $p < 0.05$, $r = 0.36$

9 Wilcoxon signed-rank test, $z = -0.36$, $p > 0.05$

10 Wilcoxon signed-rank test, $z = -1.27$, $p > 0.05$

11 Wilcoxon signed-rank test, $z = -1.46$, $p > 0.05$

12 Wilcoxon signed-rank test, $z = -2.70$, $p < 0.05$, $r = -0.45$

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Appendix 1
Full listing of options for discussion

Personal care
- Washing
- Washing hair
- Brushing teeth
- Make-up
- Shaving
- Getting dressed appropriately
- Getting ready for bed
- Eating
- Drinking
- Glasses/hearing aid
- Toilet
- Medication

Getting around
- Walking
- Sitting down in/getting out of chair
- Getting into/out of bed
- Stairs
- Driving
- Using public transport
- Using taxis

Housework
- Cooking
- Washing dishes
- Hoovering/dusting
- Cleaning bathroom/kitchen
- Making the bed
- Laundry
- Ironing
- Food shopping
- Financial matters/paying bills
- Using the telephone
- Writing
- Caring for pets

Activities
- Reading a book/newspaper
- Listening to music
- Watching TV
- Looking at photographs
- Listening to the radio
- Puzzles/games
- Going for a walk
- Seeing friends
- Going on trips
- Eating out
- Clubs/groups
- Dancing
- Cinema/theatre
- Church
- Gardening

Appendix 2
Project information sheets

Talking Mats® and involvement in decision making for people with dementia and family carers

General Information Sheet for Family Carers

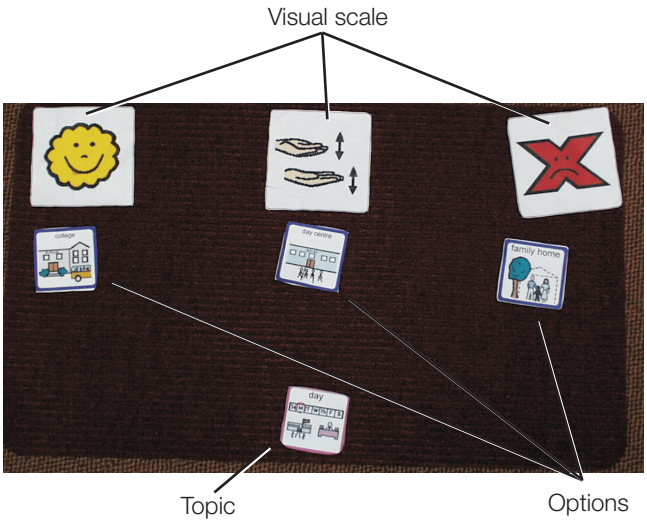
Joan Murphy (Research Speech and Language Therapist) has received funding from a major UK charity, the Joseph Rowntree Foundation, to undertake a project with people with dementia and their caregivers. We are writing to ask if you would be interested in taking part in this study.

Talking Mats®: a tool to help people with dementia have their say?

The deterioration of communication between people with dementia and their relatives and carers is one of the most difficult aspects of the illness. It becomes increasingly difficult to ensure that the views of the person with dementia are included, and that decisions are made with their involvement. Nevertheless, it is important to enable people with dementia to be more actively involved in expressing their views about aspects of their life, such as their relationships, their surroundings and their daily living activities in order to improve their quality of life.

There are several factors which could improve communication for people with dementia. These factors include the use of carefully chosen pictures, making use of both verbal and non-verbal communication, giving people opportunities to talk in indirect ways, and providing resources to help family and carers communicate with people with dementia. Talking Mats® is an innovative communication tool that makes use of all of the above. Since it was developed in 1998 by Joan Murphy, a Research Speech and Language Therapist, Talking Mats® has been used with many people with a wide range of communication difficulties to help them express their thoughts and feelings.

Talking Mats® uses 3 sets of picture symbols:



1. **Topics** that are relevant to the problem explored (e.g. pictures symbolising *where you want to live, what do you want to do during the day*, and so on).

2. **Options** relating specifically to each topic (e.g. *whether you wish to have your own home or live in a family home*, and so on).

3. **Visual scale** in order to allow participants to indicate their general feelings about each topic and option (e.g. *happy, unsure* or *unhappy*).

Our previous work has indicated that Talking Mats® helped people with dementia express their opinions, and that it improved their ability to communicate compared with usual conversation. We believe the Talking Mats® framework could also help the person with dementia to discuss, and make choices about, how they manage their own daily living activities. This is the focus of the research study that we are hoping that you, and the person with dementia that you are care for, might become involved in.

We are aiming to recruit 40 people in total (20 people at the early stages of dementia, and 20 family carers) to take part in the research. We will meet with each participant and their family carer on three occasions, at a place where they feel comfortable (usually their own home). During the first visit, we will explain the project to both parties, introduce them to Talking Mats®, and ask them if they would be happy to take part. On the second

and third visits, we will ask the participants and their family carers to discuss how the person with dementia is managing their daily living activities, such as dressing or getting around. One of these visits will involve a normal face-to-face conversation; during the other visit each pair will be helped to have the conversation using Talking Mats®. At the end of each type of conversation, each pair will be asked to complete a simple questionnaire to find out how both felt about their *involvement* in these discussions. Both types of conversation will be videotaped so that we can later assess if Talking Mats® helps people with dementia and their family carers to feel more involved in discussions about managing daily living activities.

We very much hope that both you and the person with dementia that you care for will be able to help in the study. Previous work suggests that most people with dementia enjoy the experience of using Talking Mats®. We would be delighted to answer any questions or queries that you might have about the project. Please feel free to contact us.

Joan Murphy
joan.murphy@stir.ac.uk

Tracey Oliver
t.m.oliver@stir.ac.uk

AAC Research Unit
University of Stirling
Stirling FK9 4LA
Tel: 01786 466370

If you would like to take part in this study, please complete and return the slip overleaf and we will contact you to arrange a time to visit and discuss the study further. Thank You!

Talking Mats® and involvement in decision making for people with dementia and family carers

We are interested in finding out more about the Talking Mats® and Involvement in Decision Making project. Please contact us to arrange a time to visit to discuss this further.

Participant Name: .....

Address: .....

.....

.....

Contact Telephone Number: .....

The best time to call is: .....

Family Carer Name: .....

Address: .....

.....

.....

Contact Telephone Number: .....

The best time to call is: .....

Please return the above slip in the enclosed envelope to:

Tracey Oliver
AAC Research Unit
University of Stirling
Stirling FK9 4LA
Tel: 01786 466370

Talking Mats® and involvement in decision making for people with dementia and family carers

Information Sheet for Participants and Family Carers

We are carrying out a study to find out how we can help people with memory problems to discuss and make choices about how they manage their own daily living activities.

The study is looking at:

- How people with memory problems manage everyday activities such as dressing or getting around.
- How people with memory problems can discuss any difficulties doing these activities with their family carers.
- How to help people with memory problems and family carers feel more involved when making decisions about coping with these activities.

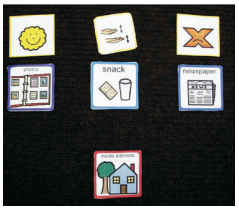
I would like you to help me.

If you agree to help me, on one occasion I come to see you I will help you and your family carer to have an informal chat about how you are managing your everyday activities.

On the other occasion I come to see you I will use ***Talking Mats***® to help you and your family carer discuss how you are managing your everyday activities.

This is a picture of someone using ***Talking Mats***®.

I will not share your views with anyone unless you want me to.



You will get a photograph of your ***Talking Mats***® and a summary of your conversation to keep.

	If you agree to help, I will meet you today and on two other occasions.
	I will always see you at a place that is comfortable and familiar to you.
	When I come back to see you, I will help you and your family carer to discuss how you are managing everyday activities using normal face-to-face conversation and also ***Talking Mats***®.
	I will video your conversations.
	If you change your mind at any time you can tell me to stop.

You can contact me at:

Tracey Oliver
AAC Research Unit
University of Stirling
Stirling FK9 4LA
Telephone: 01786 466370
t.m.oliver@stir.ac.uk

Appendix 3
Consent documentation

Obtaining Consent from People with Dementia

Potential participants will be identified by a link person who will be given a general information sheet to pass to potential participants and their family carers. If they wish to take part, family carers will be asked to complete and return a slip with contact details for both parties, at which time the research team will make contact to arrange an initial visit.

Initial Consent Visit – with potential participant and family carer

1. An information sheet will be discussed (and left) with participants and their family carers. Both parties will also be encouraged to familiarise themselves with Talking Mats® symbols and mats and video equipment.

2. Participants and family carers will only be asked to sign the consent forms if they have answered in the affirmative to all questions.

3. The researcher will explain that the video tape will be kept for a specified period for research purposes, and that none of the images will be disseminated unless consent is given. Participants and family carers will be asked to sign a consent form specifying whether (and how) they will allow their tape to be used.

4. Both parties will be asked to specify which time of day would suit them for the following visits.

Subsequent Visits – ongoing consent

1. The research group will telephone each participant and their family carer to confirm the time and date for the second and third visits. Several days before each subsequent visit, both parties will receive an appointment letter.

2. On the day of the visit, efforts will be made to ensure that both parties are happy for the visit to proceed on that day.

3. Before the interviews begin, both parties will be reminded of the purpose of the interview, asked if they are happy to proceed with the research, and reminded that they are free to stop at any point.

Debriefing

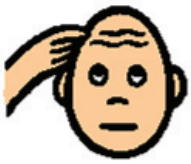
1. Following the interviews, participants and family cares will be sent photographs of their Talking Mats®, as well as a summary of the discussion they had using their usual method of conversation.

2. Following the conclusion of the study, the researchers will present their anonymised results to groups of participants and family carers in an accessible fashion.

Participant No: _____
Date: _____

Talking Mats® and involvement in decision making for people with dementia and family carers

Participant Consent Form

	Have you read the information sheet, or had it explained to you?	YES	NO
	Have you been able to ask questions and talk about the study?	YES	NO
	Are you happy with the answers you have been given?	YES	NO
	Do you understand that it is your choice to take part in the study?	YES	NO
	Do you understand that I will use video as part of the study?	YES	NO
	Do you understand that you can stop at any time? (You do not have to say why you want to stop).	YES	NO
	Are you happy to take part in the study?	YES	NO

Name .....
Signature.....
Date .....

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Video Consent Form – Participant

I agree to video and photographs being recorded on the understanding that the material will be retained securely and only be used for the current study and for the following:

	Yes	No
Teaching and carrying out research in the university		
Teaching and carrying out research outside the university		
Professional journals (magazines)		
Newspapers and magazines		
Exhibitions/displays/presentations		
Future research		

Timescale.....

We will contact you prior to using any videos and photographs to check that you are happy for us to do so.

I understand that my full identity will not be revealed

Signature of participant

.....

Date .....

Participant No: _____
Date: _____

Talking Mats® and involvement in decision making for people with dementia and family carers

Video Consent Form – Family Carer

I agree to video and photographs being recorded on the understanding that the material will be retained securely and only be used for the current study and for the following:

	Yes	No
Teaching and carrying out research in the university		
Teaching and carrying out research outside the university		
Professional journals (magazines)		
Newspapers and magazines		
Exhibitions/displays/presentations		
Future research		

TIMESCALE.....

We will contact you prior to using any videos and photographs to check that you are happy for us to do so.

I understand that my full identity will not be revealed

Signature of family carer

.....

Date .....

Relationship to participant.....

Appendix 4
Counterbalancing methods employed in the project

Dyad	Participant ID	Data collection visit 1 or 2	Topic choices	P or C 1st choice	1st choice discussed 1st or 2nd	Order of conversation type
1	1a & 1b	Data 1	1 & 2	P	1st	TM
		Data 2	3 & 4	C	2nd	Non-TM
2	2a & 2b	Data 1	3 & 4	P	1st	TM
		Data 2	1 & 2	C	2nd	Non-TM
3	3a & 3b	Data 1	1 & 2	P	2nd	Non-TM
		Data 2	3 & 4	C	1st	TM
4	4a & 4b	Data 1	3 & 4	P	2nd	Non-TM
		Data 2	1 & 2	C	1st	TM
5	5a & 5b	Data 1	1 & 2	P	1st	TM
		Data 2	3 & 4	C	2nd	Non-TM
6	6a & 6b	Data 1	3 & 4	P	1st	TM
		Data 2	1 & 2	C	2nd	Non-TM
7	7a & 7b	Data 1	1 & 2	P	2nd	Non-TM
		Data 2	3 & 4	C	1st	TM
8	8a & 8b	Data 1	3 & 4	P	2nd	Non-TM
		Data 2	1 & 2	C	1st	TM
9	9a & 9b	Data 1	1 & 2	P	1st	TM
		Data 2	3 & 4	C	2nd	Non-TM
10	10a & 10b	Data 1	3 & 4	P	1st	TM
		Data 2	1 & 2	C	2nd	Non-TM
11	11a & 11b	Data 1	1 & 2	P	2nd	Non-TM
		Data 2	3 & 4	C	1st	TM
12	12a & 12b	Data 1	3 & 4	P	2nd	Non-TM
		Data 2	1 & 2	C	1st	TM
13	13a & 13b	Data 1	1 & 2	P	1st	TM
		Data 2	3 & 4	C	2nd	Non-TM
14	14a & 14b	Data 1	3 & 4	P	1st	TM
		Data 2	1 & 2	C	2nd	Non-TM
15	15a & 15b	Data 1	1 & 2	P	2nd	Non-TM
		Data 2	3 & 4	C	1st	TM
16	16a & 16b	Data 1	3 & 4	P	2nd	Non-TM
		Data 2	1 & 2	C	1st	TM
17	17a & 17b	Data 1	1 & 2	P	1st	TM
		Data 2	3 & 4	C	2nd	Non-TM
18	18a & 18b	Data 1	3 & 4	P	1st	TM
		Data 2	1 & 2	C	2nd	Non-TM
19	19a & 19b	Data 1	1 & 2	P	2nd	Non-TM
		Data 2	3 & 4	C	1st	TM
20	20a & 20b	Data 1	3 & 4	P	2nd	Non-TM
		Data 2	1 & 2	C	1st	TM

Notes:
1. Topic choices for each data collection visit will be counterbalanced – topics are divided into topics 1 & 2 and 3 & 4 to control for complexity of topics.
2. Person with dementia (P) or carer (C) choosing first topic will be counterbalanced across dyads.
3. The order in which 1st choice is discussed will be counterbalanced across dyads.
4. The order of administration of each conversation type will be counterbalanced across dyads.

Results in 4 possible combinations:

Combination	Dyad numbers		Topics	P or C 1st Choice	1st choice discuss 1st or 2nd	Conversation type
1	Dyads: 1 5, 9, 13, 17	Data visit 1	1 & 2	P	1st	TM
		Data visit 2	3 & 4	C	2nd	Non-TM
2	Dyads: 2, 6, 10, 14, 18	Data visit 1	3 & 4	P	1st	TM
		Data visit 2	1 & 2	C	2nd	Non-TM
3	Dyads: 3, 7, 11, 15, 19	Data visit 1	1 & 2	P	2nd	Non-TM
		Data visit 2	3 & 4	C	1st	TM
4	Dyads: 4, 8, 12, 16, 20	Data visit 1	3 & 4	P	2nd	Non-TM
		Data visit 2	1 & 2	C	1st	TM

Notes: P = Person with dementia, C = family carer.

Appendix 5
Example of participant debrief letter

UNIVERSITY OF STIRLING
DEPARTMENT OF PSYCHOLOGY

Tracey Oliver
AAC Research Unit
University of Stirling
Stirling FK9 4LA

Telephone: 01786 466370
Mobile: 07922 436748

Email: t.m.oliver@stir.ac.uk

Mr & Mrs X
Any Street
Any Town
Any Postcode

7th April 2009

Dear Mr & Mrs Bloggs

Talking Mats® and involvement in decision making for people with dementia and family carers

I am writing to thank you for taking part in the Stirling University research project looking at how we can help people with memory problems to discuss and make choices about how they manage their daily living activities.

During my recent visits you had a conversation and also used **Talking Mats®** to discuss how you both felt X is managing everyday activities. I took photographs of your Talking Mats® and some written notes of what you said and enclose a copy of these for you to keep. I hope you both find them helpful.

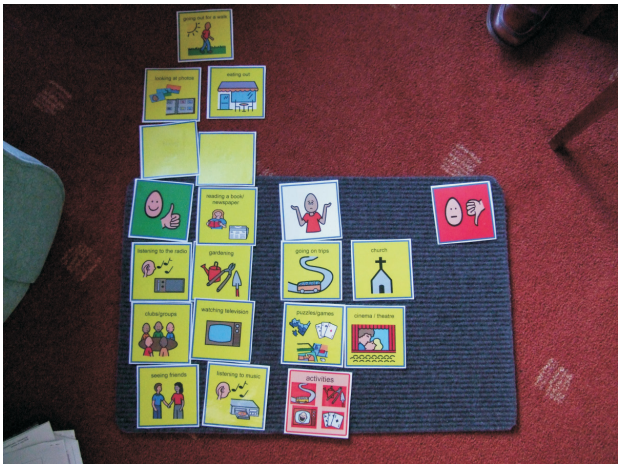
When we have completed the project, we will send you both details of what we found in the research project so you know how important your taking part has been.

With all best wishes

Tracey Oliver

You used **Talking Mats®** to discuss how X was managing his personal care and the activities he likes to do.

Topic: Personal Care	
Your Talking Mat:	
You both agreed X is managing:	Washing, washing hair, brushing teeth, shaving, getting ready for bed, eating, drinking, going to the toilet, taking medication, looking after his glasses
You both agreed X needs a little help with:	Getting dressed appropriately
You both agreed X is not managing:	There is nothing about personal care that X is not managing

Topic: Activities	
Your Talking Mat: 	
You both agreed X enjoys:	Reading a newspaper, listening to music, watching TV, looking at photographs, listening to the radio, going for a walk, seeing friends, eating out, clubs and groups, gardening
You both agreed X sometimes enjoys:	Puzzles and games, going on trips, cinema/theatre, church
You both agreed X does not enjoy:	There was no activity that you discussed that X did not enjoy
Other activities that X enjoys include:	Babysitting and bowling

You also both had a chat about how X was managing getting around and housework.

Topic: Getting Around	
You both agreed X is managing:	Walking, sitting down in and getting out of a chair, getting into and out of bed, using the stairs
You both agreed X needs help with:	There was nothing about getting around that X needs help with
You both agreed X is not managing:	Driving

Topic: Housework	
You both agreed X is managing:	Washing the dishes, making the bed
You both agreed X needs help with:	Cooking, food shopping, using the telephone
You both agreed X is not managing:	Hoovering and dusting, cleaning the bathroom and kitchen, laundry, ironing, financial matters and paying bills, writing

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Sylvia Cox is an experienced social care consultant and has been involved in working on commissions across the boundaries of the social work, health and housing sectors. She has been involved in policy development and strategic planning at national and local levels. She has evaluated housing and care projects and undertaken consultancy around the assessment and delivery of health and social care in residential and community care settings. She has worked with both commissioners and providers developing quality services and effective outcomes. She is committed to the involvement of people and communities in the planning and delivery of good quality services and in their own care and support.

Tracey M. Oliver is a researcher in the Talking Mats Research and Development Centre at the University of Stirling. She has a background in psychology and has been involved in a number of projects involving people living with dementia and Parkinson's disease. She has a particular interest in exploring ways to help maintain communication between people living with long-term conditions and their carers/families.