

My name is not dementia

People with dementia
discuss quality of life
indicators

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Preface

In October 2008 Alzheimer's Society published 'Dementia: out of the shadows'. The report gave an opportunity to those living with dementia to speak out about their lives, before and after receiving a dementia diagnosis; the problems they encountered and the changed relationship with family and friends.

In a foreword to the report, Sir Terry Pratchett said he believed it better to know about having the condition but that when you do 'come out' the attitude of others changes dramatically. People are embarrassed and one person quoted in the report said that friends he had known for many years now 'crossed the road' to avoid meeting him.

People with dementia often feel that dementia becomes the only thing others know about them. But they remain individuals in their own right and dementia is not the most important thing about them. Many are still able to do what they did before despite their life changing and some things becoming increasingly difficult to do.

The ability to lead a fulfilled life doesn't stop on diagnosis. A good quality of life can be maintained and that is what this report will help us to understand.

Many people have given thought to how we measure the quality of our lives. By listening to those who live with dementia, this piece of work begins to bring together what they think is important. We have gone out and spoken to those who are living with dementia, but also those whose voices are rarely heard. Some are a lot further into the dementia journey than others and some can no longer be cared for at home but are in a care home.

The Society now intends to talk with others about what factors influence quality of life and how they can be measured. We hope it will be possible to monitor quality and, through public policy and by changing the attitudes of society, we aim to make sure that it is all up from here.

Ruth Sutherland
Acting Chief Executive

Foreword by Sir Terry Pratchett

Out of the shadows, blinking in the light

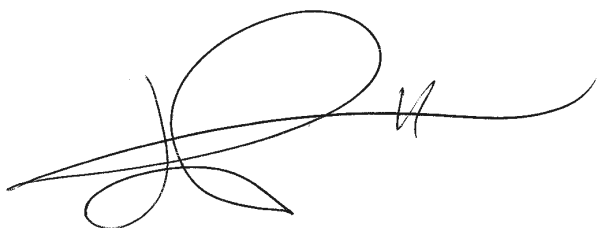
Once upon a time, but not that long ago, Alzheimer's was the disease that did not get talked about; now, it sometimes seems to me that people talk about nothing else!

Since Alzheimer's Society published 'Dementia: out of the shadows' in October 2008 the nation has realised that the disease, suffered by victims, relatives and carers, is in fact a plague. For those who live beyond the age of 65, one in every three of us will have dementia before they die.

It's not hidden any more. It can't be shrugged off any more. Comedians' jokes about granddad 'going mental' aren't funny any more, if they ever were. In short, people are frightened about the future. And, because the baby boomers don't like being frightened, they tend to get angry too. They are ready to believe stories about someone's relative's treatment in a not very caring 'care home', they see in documentaries the hopeless elderly vegetating in chairs, they read Sir Michael Parkinson's vehement attack on the waiting rooms for death. They are not as compliant as their ancestors who went through a world war, and suddenly we find a growing interest in assisted dying. Fear is the spur, fear of hell before death.

It is a tragedy that this is so, and a tragedy, too, that sometimes their fear is well founded. The care industry has a lot of work to do. Dementia is all too often a fact of life, and no longer out of sight and out of mind. And it requires not just care but also understanding and, to be frank, policing as well. There is an opportunity here to give the lie to some of the clichés of care. We have to learn to be good at it.

Thank goodness for Alzheimer's Society.
I commend this report.

A handwritten signature in black ink, consisting of a large, stylized 'T' and 'P' followed by a long horizontal line and a small flourish at the end.

Terry Pratchett OBE
Author

Executive summary

In 2009/10 the Mental Health Foundation carried out a research project for Alzheimer's Society with the aim of better understanding key quality of life indicators for people with a dementia diagnosis, using evidence that drew directly on their own views and experiences as well as building upon existing quality of life indicators and measures. A particular focus of the research was, if possible, to collect the views of people with dementia from so-called 'seldom heard' groups, including people from black and minority ethnic groups and people with more severe dementia living in care homes. In time Alzheimer's Society hopes to build consensus on what important quality of life indicators might be and how they might be measured on a population wide basis in order to understand whether quality of life for people with dementia is improving or not.

The research used a mixed methodology including a literature review, interviews, focus groups and a postal survey. The project was successful in carrying out the research with 44 people with dementia including significant numbers from black and minority ethnic communities and people with more severe dementia living in care homes.

Some challenges were encountered in developing the indicators, finding organisations and individuals willing to be involved, and the innovative methodology that was used. These had an impact on the original timeline for delivering the project and raised some questions about the validity and reliability of the indicators and measures. It was not possible to recruit people with dementia who also had learning disabilities, or sufficient numbers of people with dementia from the lesbian, gay, bisexual or transgender communities.

However, very consistent themes emerged from the research about what was important in people's quality of life and the methodology proved successful enough to indicate that it could be used on a much bigger scale, with some refinements, to gather information about quality of life, especially from people with more severe dementia.

The key quality of life indicators and findings, in order of importance, that came out of the research were:

1. Relationships or someone to talk to
2. Environment
3. Physical health
4. Sense of humour

5. Independence
6. Ability to communicate
7. Sense of personal identity
8. Ability or opportunity to engage in activities
9. Ability to practise faith or religion
10. Experience of stigma

Overall findings about quality of life arising from the project

Determining quality of life for people with dementia is a complex, ongoing multi-dimensional, multi-perspectival process. Considerable work has been done in this field which this project has tried to build upon but its findings should be treated with caution because of the methodological challenges involved in such a complex field. Four overall findings emerged from this project.

1. People with dementia, including people with more severe dementia, are able to express their views about what is important to their quality of life.
2. The domains that feature in generic quality of life measures may be of just as much relevance to people with dementia, including those with more severe dementia, as the more dementia-specific domains in health-related quality of life measures for people with dementia.
3. Maintaining a good quality of life is perfectly possible following a diagnosis of dementia. Services for people with dementia, and the wider community, should not make assumptions that following a diagnosis of dementia support to improve a person's life is pointless because it will have no impact on quality of life. There are many factors outside a person's dementia that affect their quality of life and this indicates that services should develop so that they can address these wider quality of life issues. Despite being a progressive, terminal condition that severely affects a person's mental functioning, dementia may not affect a person's quality of life in respect of emotions, feelings and mental well-being in ways that one would expect. Quality of life is defined primarily by the person, as a person, and their circumstances, not their dementia.
4. People with dementia have a clear need for regular, everyday, one to one social interaction and this will have significant benefit to their quality of life and social inclusion.

Quality of life findings for people in seldom heard groups and other specific groups

There are significant differences about quality of life among people with dementia from seldom heard groups, including people of different ethnicities, and between the views of people with dementia and their family members and carers.

People with more severe dementia and people with dementia living in care homes are able to express their views about their quality of life and these differ significantly from people living in their own homes in the community and those with less severe dementia. Quality of life measures for people with dementia need to be sufficiently sensitive to enable these differences to be identified.

Using picture cards to measure quality of life

It appears that even people with more severe dementia are able to express their views about quality of life issues using a picture card exercise approach.

The picture card exercise approach has the potential to be developed into a valid and reliable method of measuring quality of life for people with dementia of varying degrees of severity and for whom English may not be their first language.

Recommendations

1. The research described in this report found consistent themes about what is important in the quality of life of people with dementia. It reviews the considerable body of work that exists in this area and brings the perspective of those living with dementia firmly into focus. We recommend that, using the findings from this report and the existing body of knowledge regarding quality of life in dementia, work be taken forward to explore the possibility of developing a monitor of quality of life for people with dementia. This monitor could capture what quality of life is like for people with dementia across the UK. It could explore whether quality of life is improving or declining over time and provide information on what factors might explain any observed changes.

Alzheimer's Society considers that such a monitor would provide vital information regarding the relative success of public policy in effectively supporting people with dementia. Given the focus quite rightly applied to dementia by public policy in recent years, it is particularly important to understand its impact on quality of life for those living with the condition.

2. This report highlights a range of issues regarding the understanding and measurement of quality of life for people with dementia. We recommend that these be used to inform future work on quality of life in dementia and dementia services and policy in general. These issues include:
 - the possibility of developing methodologies such as Talking Mats to gather the views of people in the later stages of dementia
 - the importance of developing methodologies that include both generic and health-specific quality of life indicators
 - the discrepancy between the views of people with dementia and those caring for them, in terms of what is most important to quality of life
 - the research suggests that different communities of people with dementia consider different things to be most important to their quality of life, for example those in care homes and those from black and minority ethnic communities.
3. This study highlights the range of issues that must be addressed in order to support the maintenance and promotion of quality of life. It re-emphasises the need for policy makers, service providers and regulators to focus on the things of most importance to the quality of life of people with dementia. We recommend that these bodies (policy makers, regulators, services providers) ensure they consider the breadth of factors that impact on quality of life throughout the course of developing and implementing their work. This must include consideration of factors that may not have previously been considered as relevant to these organisations, for example relationships and spirituality.
4. The report highlights that quality of life is possible following a diagnosis of dementia. We recommend that recognition of this informs all of the dementia-related work of policy makers and service providers. The finding that there are many factors outside the person's dementia that affect their quality of life provides further incentive to ensure services are developed that address a wide range of aspects of people's lives. It demonstrates the importance of avoiding assumptions that, following a diagnosis of dementia, support to improve other aspects of a person's life is pointless because it will have no impact on quality of life.

Introduction

This report describes a research project carried out by the Mental Health Foundation on behalf of Alzheimer's Society with the original aim of establishing key quality of life indicators for people with a dementia diagnosis, using evidence that drew directly on their own views and experiences.

The project was carried out in 2009 and early 2010. It consisted of several research 'strands', together with a literature review (see Appendix 1).

The report begins by briefly describing some key background issues relating to quality of life and dementia, existing quality of life instruments for people with dementia, and involving people with dementia in developing quality of life instruments and measures. It then goes on to describe the approach taken to this particular project including aims, methodology and participants. The project had a special focus on people with dementia from seldom heard groups including those from black and minority ethnic groups and people with more severe dementia and engaging individuals from these groups is also explained. There is a description of how ethical issues were tackled and the development of a specific methodology involving a picture card exercise for interviews and focus groups.

The report then describes the quality of life indicators that emerged from the research as being the most important, illustrated with quotes from the participants. This is followed by an analysis and discussion of the key findings. There is then a more detailed analysis that examines differences between different seldom heard groups including people in different care settings, people of different ethnicities, and the views of family members and carers as compared with the views of people with dementia.

The penultimate section discusses the additional findings that were obtained through the methodological approach used and how effective this was in getting the views of people with more severe dementia.

1. Background

Dementia in the UK

Dementia is one of the biggest challenges facing health and social care in the UK. There are a number of different types of dementia of which Alzheimer's disease is the most common (62 per cent of all people with dementia), followed by vascular dementia (27 per cent). Although there are variations in symptoms between the different types of dementia they all result in a progressive deterioration, usually over several years, in a person's cognitive and physical functioning, leading ultimately to the person's death. Currently there are no cures or disease modifying treatments for any type of dementia.

In the UK there are currently 750,000 people who have dementia although this figure is expected to double to 1.4 million in the next 30 years (Alzheimer's Society 2007). The 'Dementia UK' report estimated that about 575,000 live in England. With an ageing population that is also living longer than ever before this figure is estimated to rise to 940,000 by 2021 and over 1.7 million by 2051. In 2009 the Department of Health in England responded to this challenge by publishing the first ever national dementia strategy, a five year plan with 17 key objectives and £150 million attached to it for the purposes of implementation over the first two years (Department of Health 2009). Strategies for dementia are also being developed in Scotland, Wales and Northern Ireland but references in this report to policy and service development relate primarily to the situation in England.

Quality of life and dementia

Perhaps partly because no cure or universally effective treatment has yet been discovered there has been considerable attention paid by both professionals and researchers to quality of life issues for people with dementia. Over the last few years very important, high quality research has been carried out on quality of life issues for people with dementia, as well as their families.

However, not only is the concept of 'quality of life' difficult to define and the subject of much debate, there are also major challenges posed when it is applied to people with dementia. The literature review commissioned specially for this project discusses these in considerable detail and several points that emerge from the review are noted below.

Quality of life and health-related quality of life

A distinction can be drawn between 'quality of life' and 'health-related quality of life'. Although the following definition of quality of life comes from the World Health Organization it could clearly apply to anyone, irrespective of their health status, ie whether or not they have a disability or long term condition like dementia:

an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL 1995)

By contrast, 'health-related quality of life' primarily looks at quality of life through the perspective of a person's health status and/or impact of a person's health condition or disability. As the authors of literature review point out much of this work has been developed in relation to people with long term physical conditions (particularly where chronic pain is involved). Understandably, this assumes that the condition automatically represents a deficit in a person's quality of life. However, with dementia this can potentially skew the view of the person's quality of life because the dementia may mask many of the authentic issues that continue to be a cause of concern (or happiness) for the person. These may be very similar to those of people who do not have dementia, for example relationships or financial matters. Health status and consequences of health problems are likely to remain important factors in a person's quality of life, but the degree of importance will vary from individual to individual and a wide range of other factors (such as social relationships, participation in meaningful activity or receipt of care) are also likely to be important, irrespective of a person's health status.

A complex range of factors affect quality of life

A person's quality of life is the result of, and mediated by, a complex range of factors. These factors will always be particular to that individual and their circumstances (including gender, ethnicity and social class) at any given time, though almost certainly there will be commonalities over time, and with the experiences of others. However, for people with dementia additional factors, such as the impact of stigma and the changes in mental and physical functioning resulting from the condition itself, may also play an important role. The literature review revealed:

- A person's quality of life can be seen to have objective characteristics which can be measured by the observations of a professional or other proxy (for example a family carer).
- If a person's health status and consequences of health problems are considered central to a person's quality of life then the quality of life of a person with dementia is likely to deteriorate if measured objectively, as the condition progresses.

- If other factors (known as ‘domains’) are incorporated into a quality of life measure then the quality of life of a person with dementia is likely to change significantly as the condition progresses but may not deteriorate in all domains (for example participation in activities may decline but receipt of care may improve).
- A person’s quality of life can be seen to have subjective characteristics which can be measured by the first hand account (‘self-report’) of the person themselves.
- It is not clear whether the important themes in terms of quality of life for people with dementia are significantly different from those for people without dementia.
- People with severe dementia can provide meaningful self-reports about their quality of life.
- Where quality of life is rated by both a proxy and the person with dementia, agreement is often rated as poor to moderate and the gap widens as the person’s dementia becomes more advanced – the proxy is likely to give the person’s quality of life a lower rating than the person with dementia themselves.
- It is unclear how far the quality of life for a person with dementia is affected by the stage that the dementia has reached and the type of care they are receiving and whether different factors come into play – for example, comparing a person who is in the early stages of dementia and still quite independent with a person with more severe dementia living in a care home.

Existing quality of life measures for dementia

The literature review identified a number of existing quality of life instruments that have been developed over recent years by professionals and researchers working in the field. Not included in the literature review but also considered as part of the research was work carried out around goal attainment scaling and goal setting (Bouwens et al 2008) and the recent work around population-level frameworks (ADI-QOL) for addressing quality of life for people with dementia (Banerjee et al 2010).

Several quality of life instruments have been developed in ways that incorporated the views of people with dementia as well as incorporating self-reports by the person with dementia (for example DQoL, QoL-AD, DEMQOL – see Chapter 1 of the full literature review accompanying this report). Development of the DEMQOL measure is of particular note as people with more severe dementia were included in its development, although it is explicitly described as a measure to assess health-related quality of life with dementia.

Given the existence of a range of quality of life instruments the question of why it was felt important to develop another quality of life measure for people with dementia might be asked. There are several reasons.

Firstly, as Banerjee et al point out, despite all the work that has been done around quality of life and dementia there are still significant gaps in knowledge and areas requiring attention (Banerjee et al 2008). Two areas of particular note are:

- quality of life variations by ethnicity
- differences in quality of life in different settings (eg in care homes and in the community).

Secondly, with the exception of DEMQOL, it was not clear how far people with more severe dementia had been involved in the development of the instruments, and therefore how far they really reflected what might be important to someone with more severe dementia. Furthermore, while instruments such as ADRQL and DEMQOL are intended for use with people with more severe dementia, most instruments were not developed with this group in mind.

Thirdly, it was not clear how far people with dementia from seldom heard groups had been involved in the development of the instruments, and therefore how far they really reflected what might be important to people from these groups. Seldom heard groups is a loose term used to denote groups and communities who for varying reasons have experienced exclusion or marginalisation from mainstream society (including access to health and social care). These groups include:

- black and minority ethnic groups
- people with learning disabilities
- lesbian, gay, bisexual or transgender people

People with other long terms conditions, illnesses and disabilities (including people with dementia themselves) are often included as a 'seldom heard' but people with learning disabilities are of particular relevance here because they experience high prevalence rates of dementia.

Fourthly, while instruments aimed at people with more severe dementia do exist, they still have some limitations. For example, the ADRQL does not include a self-report element while the DEMQOL assesses health related quality of life which could exclude domains that do not necessarily link directly to health status or consequences of dementia, such as the external environment in which a person is living, or their faith or spirituality.

It therefore appears that despite the amount of work carried out in this field there is still important work to be done, using existing evidence and knowledge, to develop quality

of life indicators and measures that might be a synthesis or hybrid of existing indicators. Such indicators would need to:

- include as wide a range of quality of life domains as possible, and focus not only on health status, cognitive functioning, ability to socially interact and communicate, or other problems for the person caused by their dementia
- include domains that reflect what is important to people with dementia from seldom heard groups and people with more severe dementia
- include self-reports from people with more severe dementia.

This is of particular relevance given the ‘National Dementia Strategy for England’ that is currently being implemented in England. Evaluating the implementation of the strategy will be crucial and nowhere will this be more important than the impact it has on the lives of people with dementia and their families. In the absence of a cure for dementia, or disease modifying treatments, quality of life and well-being issues for people with dementia therefore have a particular significance.

Involving people with dementia in developing indicators and measures and monitoring quality of life

Over the last few years the voices of people with a dementia diagnosis have become much more audible, placing them as key stakeholders at the centre of good dementia care alongside professionals, service providers and family carers (Cantley et al 2005; Care Services Improvement Partnership 2007). For example, people with dementia were on the reference group and working groups that developed the ‘National Dementia Strategy for England’. Shortly before the national dementia strategy was published, Alzheimer’s Society published ‘Dementia: out of the shadows’, a piece of qualitative research undertaken by the Mental Health Foundation that explored the views and experiences of people with dementia about diagnosis and living with dementia (Alzheimer’s Society 2008). A number of quotes from the research by people with dementia were included in the ‘National Dementia Strategy for England’.

The increasing involvement of people with dementia in research and service development and the growth in evidence from them about living with the condition, and their experiences of health, social care and housing services, has therefore increased opportunities to complement work done elsewhere on quality of life and well-being issues. As has already been pointed out, people with dementia were involved in developing some of the existing quality of life indicators and measures. Their active involvement in research projects such as ‘Dementia: out of the shadows’ also provides

important evidence for developing indicators and measures. But projects such as 'Dementia: out of the shadows' were not designed to explore quality of life issues per se and therefore provide only partial evidence for what these indicators might include.

However, compared with other disability groups, the involvement of people with dementia is still at a fairly early stage. Studies involving in-depth qualitative research with people with dementia remain the exception and studies involving people with dementia from seldom heard groups are even rarer. And unlike virtually all other conditions the progressive nature of dementia, particularly on a person's cognitive functioning and ability to communicate, pose real challenges to the involvement of people with more severe dementia and the ability to draw firm conclusions from information that is obtained from them. Thus, while 'Dementia: out of the shadows' provided important information about the experiences and views of people who had been diagnosed with dementia, most of them were in the mild to moderate stages of dementia.

The increasing involvement of people with dementia provides a clear imperative for further development of quality of life indicators and measures. For any hybrid set of indicators and measures to have validity (as well as credibility) the challenge of including people with dementia in their development must be met, and ways of involving people with dementia from seldom heard groups, and with more severe dementia, must also be found.

2. Aims

The original aims of the project were as follows:

1. Identify any existing relevant quality of life indicators, measures and instruments by drawing upon research literature already available, including research that has gathered the views of people with a dementia diagnosis.
2. Where there are gaps (for example, with people with a dementia diagnosis from seldom heard groups), to identify potential quality of life indicators that are relevant to their specific experiences through qualitative research with such groups.
3. Produce draft quality of life indicators and 'road test' these with key stakeholder groups, including people with a dementia diagnosis, commissioners and service providers and policy makers.
4. Make recommendations on how further work can be taken forward to put the quality of life indicators into practice.

However, during the course of the project an innovative methodology using an adapted version of Talking Mats (Murphy et al 2007) to obtain the views of people with more severe dementia was developed and this was subsequently applied across the project. While this was not one of the original aims of the project and the methodology would certainly need refining (see Appendix 4), it generated very important findings about successfully communicating with people with more severe dementia, obtaining meaningful information about what is important to them in relation to their quality of life, and therefore being used as a potential instrument for measuring quality of life in the future. The Findings section reports on how this process developed and what the outcomes were.

3. Methodology

Mental Health Foundation

The research was carried out on behalf of Alzheimer's Society by researchers from the Mental Health Foundation. The Mental Health Foundation is a UK charity that undertakes research and development projects on mental health and well-being, and issues affecting people with mental health problems of all ages. It provides information to people with mental health problems, people with dementia, their families, and practitioners involved in their care as well as the general public. It also undertakes campaigning and lobbying work on mental health issues. The Foundation particularly values the direct experience of people with mental health problems and conditions such as dementia, and tries to place them at the centre of all its work.

The Foundation has its own programme of work on issues affecting people with a dementia diagnosis and has produced both research reports and information for people affected by dementia (Mental Health Foundation 2001; 2005; 2007). However it is also pleased to be able to work in partnership with organisations such as Alzheimer's Society and has recently carried out two major pieces of work for the Society (Alzheimer's Society 2008; 2009).

Steering group

A small project steering group was established with the following membership:

Andrew Ketteringham

Director of External Affairs
Alzheimer's Society

Samantha Sharp

Senior Policy Officer
Alzheimer's Society

Andrew Chidgey

Head of Policy and Public Affairs
Alzheimer's Society

Toby Williamson

Head of Development and Later Life
Mental Health Foundation

The group was joined from time to time by the following people:

Professor Clive Ballard

Director of Research
Alzheimer's Society

Dr Eva Cyhlarova

Head of Research
Mental Health Foundation

Dr Nori Graham

Old Age Psychiatrist and Vice President
Alzheimer's Disease International

Lynsey Roberts

Press Officer
Alzheimer's Society

Overall approach

There were four key elements to the research.

1. A literature review, including qualitative studies involving the views of people with dementia and, where appropriate, studies involving the views of other similar disability groups (eg long term conditions) on quality of life issues.
2. Piloting some small scale primary research to gather the views of people with dementia from seldom heard groups and people with more severe dementia.
3. Based upon the literature review and the primary research, developing a first draft of the quality of life indicators, and consulting people with dementia more widely through a postal survey carried out via local branches of Alzheimer's Society.
4. Developing a second draft of the indicators and consulting with key stakeholders, including people with a dementia diagnosis and family carers, at a small 'listening' event in November 2009.

Because of the relative complexity of the project, particularly the challenge of collecting information from people whose cognitive functioning and ability to communicate could potentially be quite limited, a mixture of data collection methods was proposed including one to one interviews, focus groups and a postal survey.

The four elements were originally intended to take place sequentially but the project was delayed significantly because of difficulties in recruiting participants from seldom heard groups and with more severe dementia (see below). As a result, the data collection phase was compressed and the primary research with seldom heard groups took place concurrently with the postal survey and the listening events in November 2009.

Seldom heard groups and people with more severe dementia

Three seldom heard groups were identified to be included in the research, as well as people with more severe dementia. These groups were:

1. people with dementia from different black and minority ethnic groups
2. people with learning disabilities and dementia
3. lesbian, gay, bisexual or transgender people

Although it was recognised that many people with more severe dementia continue to live in the community it was decided to focus on people at this stage of the condition who were living in care homes. This had the added advantage that it would be possible to compare their views on quality of life with people living in the community in their own homes.

Recruitment of participants

Recruitment of participants was planned through a number of routes as follows:

People with more severe dementia

Several care homes and care home providers in London providing care to people with dementia were approached. Three care homes agreed to participate.

People with dementia from different black and minority ethnic groups

Several local organisations working directly with people with dementia from black and minority ethnic groups were approached. Two organisations, one in Bristol and one in West London, assisted in helping to identify and facilitate contact between the researchers and people with dementia from different black and minority ethnic groups. In addition, some of the research participants living in care homes were from black and minority ethnic groups.

People with learning disabilities and dementia

Contact with individuals and organisations working with people with learning disabilities was made via the Foundation for People with Learning Disabilities, which is part of the Mental Health Foundation. Only one organisation agreed to assist with the research and facilitate contact with a group of older people with learning disabilities who did not have

dementia but had direct experience of supporting other people with learning disabilities and dementia.

Lesbian, gay, bisexual or transgender people

A number of health and social organisations working with older lesbian, gay, bisexual and transgender people were contacted, including Alzheimer's Society's own lesbian, gay, bisexual and transgender network, but there was no expression of interest to participate in the research. An advert was placed on Alzheimer's Society's web forum, Talking Point, and one response was received, leading to contact being made with a gay man willing to be interviewed.

Postal survey

Four local branches of the Alzheimer's Society which expressed interest in supporting the research were each sent 120 copies of a questionnaire designed for the research, which they then distributed at their branch cafes, day centres, etc.

Listening event

An invitation was sent out by Alzheimer's Society to all members of their Living With Dementia Group (made up of people with dementia) and some local branches of the Alzheimer's society were also contacted to see if they had members interested in attending.

Table 1 below gives an overall breakdown of participants. A total of 44 people with dementia participated in the research. Five family carers participated in the event in November 2009 and six people with learning disabilities who did not have dementia participated in a focus group (see below).

Table 1 Participants in primary research, listening event and postal survey by research category

	People with dementia	Family carers	People with learning disabilities
Seldom heard groups in primary research	22 (13 men)	–	6 (4 women)
Participants at listening event	6 (5 men)	5 (4 women)	–
Postal survey responses	16	–	–

Table 2 gives a breakdown of participants from seldom heard groups.

Table 2 Breakdown of participants from seldom heard groups in primary research

Group	Numbers (with indication of largest gender group)
People from black and minority ethnic communities	Total 16 (includes 5 people with more severe dementia) African-Caribbean 5 (3 women) South Asian 5 (4 men) Chinese 3 women Jewish 3 women
People with more severe dementia	Total 10 (5 women, 5 men) (including 5 people from BAME communities)
Lesbian, gay, bisexual or transgender people	1 gay man
People with learning disabilities and dementia	–

Ethical issues

All participants were given comprehensive information about the research and asked to give their consent to participating in the focus groups or interviews and were free to withdraw at any time. It was recognised at the beginning of the project that there would be particular challenges in involving people with more severe dementia. Both Alzheimer's Society and the Mental Health Foundation were satisfied that the research design met appropriate ethical requirements but formal ethics approval was not sought from an NHS or Social Care Ethics Committee. It was therefore not possible to involve anyone who lacked the mental capacity to give their consent to participate. This meant that people with very severe dementia were not included in the research.

However it was possible to include people with relatively severe dementia who had been identified by the recruiting organisation as potential participants by providing a very simple, illustrated information sheet and verbal explanation of the research, and seeking their consent on the day of the interview. The researchers also advised the recruiting organisations to inform the families of potential participants of the research and in some cases additional agreement was provided by families for the person to participate. No families objected to their relative participating. Two potential participants clearly

indicated that they were not willing to participate in the research and they were not interviewed. To indicate their consent all participants signed a simple, consent form (for people whose first language was not English translated versions of the information and consent form were provided).

Some family members sat in on interviews with their relatives, with their agreement, and occasionally assisted the person with answering a question. Some of the interviews with people from black and minority ethnic communities also involved the use of interpreters.

None of the participants withdrew their consent or withdrew from the research.

All the interviews and focus groups were recorded and three of the interviews with people in care homes were filmed. All the data collected was treated confidentially and stored securely in accordance with the Mental Health Foundation's research policies and procedures.

Data collection

For all the participants in the seldom heard groups and people with more severe dementia two main lines of investigation were used in the collection of data:

- They were asked what was important or not important in their lives at present, and what helped them if they were confused or forgetful.
- They were asked to rate a series of items according to their importance in their lives. The list of items was based upon a synthesis of the key indicators and domains drawn from existing quality of life instruments. The full list of 37 items and rating scale can be seen at Appendix 2. There was some variation in which items were used depending upon whether people lived in a care home or in the community in their own home.

A similar approach was used for the listening event (where people with dementia and family carers were divided into two separate focus groups) and the postal survey. An abbreviated, summarised list of items was used for both of these, based partly on the initial findings from the research carried out with seldom heard groups (see Appendix 3). In addition, the focus groups involved a more open discussion about what quality of life meant to participants, including how they viewed their own quality of life in relation to others.

Use of picture cards

It was recognised from the start that some participants, particularly those with more severe dementia, might have difficulties with conventional interview or focus group formats involving verbal questioning or discussion. This would potentially be made more difficult by some of the more abstract concepts involved, such as 'quality of life'. It was therefore decided to develop a set of simple picture cards to represent key quality of life indicators and domains, based upon key quality of life domains drawn from the existing literature. Each indicator or domain had its own card. Participants were given or shown each card and asked to place it on piece of marked paper according to its importance to them with a choice of three options – 'very important', 'quite important', 'not important'. If participants did not understand the item it would be omitted.

In developing this approach it immediately became apparent that this could potentially be a simple but effective way of getting all participants to rate quality of life indicators according to their importance, so the approach was used in all the interviews and focus groups with seldom heard groups. An adapted version of the approach was also used at the listening event with the abbreviated, summarised list and the picture symbols from this were also used in the postal survey.

The approach was based upon the Talking Mats approach developed by the University of Stirling which has been shown to be an effective way of communicating with people with moderate and severe dementia, as well as an adapted version used by Blackpool Council in a project they carried out in 2009 with people with dementia in care homes (Neale K 2010).

Data analysis

Responses to the picture card exercise and survey were entered into SPSS V.18 (a standard software data analysis package) for analysis. When analysing the interview and focus group transcripts, researchers noted anything participants mentioned that affected their quality of life. This could include something that was important to them, which upset them or anything they particularly enjoyed. Quality of life indicators were weighted according to how important they were to the participant. This was indicated by what people said about this aspect of their life and how many times it was mentioned during the interview or focus group.

The five quality of life indicators that were most frequently identified as 'very important' were selected from both picture card exercises and the qualitative data analysis, giving a total of 15 possible indicators. Some of the most important indicators, however, were the same across these analyses giving an overall total of 10 indicators of quality of life (see Findings, p17).

4. Findings

Key quality of life indicators

Based upon an analysis involving both the picture card exercises and the qualitative data from the interviews and focus groups the following ten key quality of life indicators were identified. They are ranked in order of importance and illustrated by quotes from people with dementia who participated in the research.

1. Relationships or someone to talk to

This category included family, friendships, and relationships with paid carers.

‘Quality of life is living with your family – circle of friends and family’

‘Very important, very important, I’ve got wonderful friends. I’ve got people who will put themselves out for all kinds of things just for sheer friendship and I feel guilty always so don’t let’s do that, we won’t do that and so on and so forth but you’d be amazed how people want to help their friends’

‘Family, family is very, very, very special’

‘Friendship is good. Very important to have friends’

‘How another person reacts to you can make you very unhappy’

‘I feel lonely because I cannot speak English and I do not know how to communicate with them [neighbours]’

‘I like to know that people are friendly and good friends with me and I try to be good friends with them’

‘What upsets me tremendously is when I see other people who are being taken advantage of by the people around them’

‘I would be lost without my wife, my wife is everything, so is my family’

really. My wife has to do everything for me...when she is not there I miss her, I hate it when she goes out, I can't wait for her to come home and that's the same as the family, I would be lost without my family. Definitely'

2. Environment

This included physical aspects of the environment such as it being safe and secure as well as more ambient aspects such as peace and quiet.

'Oh there's nothing better than peace and quiet to be happy and comfortable but if you ain't got peace you're upset and when you've got peace and quiet you've don't have nothing in the mind'

'If you ain't contented you are miserable about everything'

'To feel safe, I've lived here for about two years and feel secure and safe. No accidents. This is important'

'You have got to have an environment what you know'

'I want to keep my own environment that I am in because I am familiarised with it'

'It's not just the environment in the house, it's when you go out...in the bank, environment in the shops you go into, or restaurants is another environment which you have got to overcome'

3. Physical health

'Physical health to me is very important. I can do things on my own like go out, I can get the bus, I can go to Brighton, I go to Eastbourne I even take my grandson out on my own and at the moment physical health is more important because of my grandson because he is three and I want to see him get older and older'

'I think your health is very important because even though... I've got problems in myself, with my brain through my vascular dementia...I feel that if you have got your physical fitness then it still gives you that form of independence that you can still do things like, I can still go the

bathroom and shave and do things like that, where if you haven't got good health, and you start having problems as well, it must be horrendous'

'I am very conscious of keeping fit, I mean I do yoga...we try to get out and walk every day...so I am very conscious of the fact that keeping the body in a fit state is important'

4. Sense of humour

'It is very important to have a laugh and have a joke'

'Oh it is very important to have a laugh. Something that can make you laugh and being made to laugh is very important'

'I strongly believe that humour with people...is important, if you can enjoy a joke or a pleasantry with people, that's a lift you know, to me'

5. Independence

This category included practical issues such as being able to look after oneself and exercise choice as well as the feeling of being independent.

'I think it is very important because if you have your own independence then you feel that you are not depending on other people, and it is good to know that you have got that form of independence. I mean I go out and I still drive and it is nice to have that freedom'

'Yes I like looking after myself, doing things for myself. Seeing that I'm respectable'

'Very important, you can look after yourself because if you do, you don't have no problems but if you can't look after yourself, you've got problems. Someone has to look after you'

'Yeah, important if you're free to do what you want, you can do things. Otherwise you can't do nothing'

But there was recognition of the risks and responsibilities that having independence carried:

‘I have got a desire to have more freedom, but something would happen and it would be chaos in the end...I would go to the football matches and do everything I used to do and that would be a right mess’

‘When the day comes that I have got to start asking for help...[and]...if that independence is taken away...then I hope its only taken away from me in the right way...I would like to think that I could still be consulted and still have some say in my independence’

6. Ability to communicate

This category included issues such as being listened to and being understood.

‘My psychiatrist asked me a question and I am trying to find answers to sort out my brain and he just said “stop there, stop now. All I want from you is yes or no I don’t want waffle”. People like myself cannot give an answer in a yes or no, you need the time to try and think [through] the question and believe it or not after somebody has asked the question you might have forgot half the question they have asked you. So communicating I think it’s very important’

‘I think it would be nice if people gave you the courtesy of time to finish what you are trying to say...so communicating I think it’s very important but [I] think it’s nice if people give the benefit’

7. Sense of personal identity

This category included how the person would describe themselves, their expectations and hopes, for example.

‘Because I have got this vascular dementia, I am not suddenly altering my ways, I am still x, I am still loving, caring and I still have feelings, like we have talked about and [I] would like to think that [I] haven’t changed in [myself]’

‘I think some people wear dementia like a coat, they have a big banner across them saying “I have dementia”...I think people should put dementia to one side, focus on something they would like to be’

8. Ability or opportunity to engage in activities

This category included being able to help out or be busy with activities.

‘I think you people should put dementia to one side, focus on something they would like to be and I know I do painting, 10 years ago I couldn’t paint a ceiling. So focus on a skill and say that’s me, I am a sidesman at the church...that’s important to me’

‘I’d like to do it because I’ve always worked and the devil makes work for idle hands. I would like to be able to work even though I am 73 years of age. I would like to work’

‘Enjoyable things to do. Oh yes I think it’s most important to be able to enjoy things you do in your life’

‘Another way to look at it would be what would happen if you weren’t busy at all. What would you be doing? You would have to be looking for fun or looking to do things’

9. Ability to practise faith or religion

‘I really need the church, I love the church and I feel happy, I see God’

‘Very important, cos if you gonna do something and have no faith in what you are doing you might as well don’t do it. That is to me right.’

‘Oh yes, definitely. I have got a firm belief in God and I pray to him’

10. Experience of stigma

This included some negative experiences of stigma as well as the desire to be treated fairly.

‘It would be nice if a lot of people had more understanding and appreciate what you have got...like I was in town the other Saturday and this other lady started laughing because the way I was trying to struggle to talk and that started to make me feel uncomfortable and I thought if only she understood, then perhaps she wouldn’t stand there and laugh’

‘People think, as soon as you mention dementia, they look at you and go there’s nothing wrong with him, he’s fiddling the system, they look at me and think I am fiddling the system, they don’t know what is going on’

‘If you say to someone, “can you wait a couple of minutes, I’ve got dementia and I want to explain” they look at you and think there is nothing wrong with you, you should be able to talk...then again you get some who go “HOW – ARE – YOU?” and you think, “grrr, I’m not that bad”’

‘I have got two daughters and a son, one [daughter] is still on the border of denial, but friends, well you think they are your friends...You walk down the road and they will walk over the other side and you walk in a pub and they walk down the other end of the bar’

‘It is very, very important because to me, that is what everyone wants and it is important to be treated fairly’

Comments – a social inclusion message?

These indicators need to be treated with some caution for the methodological reasons set out in Appendix 4. However, as indicated in the section below (Ways of measuring quality of life) there are grounds for believing that these genuinely represent the views of people with dementia, certainly at the time when the data was gathered.

The indicators reinforce the findings from other dementia quality of life work that emphasise the impact of a wide range of domains on the quality of life for people with dementia. While the condition undoubtedly affects how people experience relationships, the environment around them, their own physical health and so on, it does not appear that crucial life domains such as these become irrelevant or incomprehensible to the person, even when they may be in a more severe phase of the condition.

Thus, the importance of relationships and someone to talk to is a basic human need and there is no particular reason to think that dementia would change this – the research clearly reinforces this. Together with other indicators such as sense of humour, ability to communicate and sense of personal identity, and other evidence we have about the lives of people with dementia (particularly in care homes and other institutional settings) this clearly indicates both the need, and benefit of human interaction for people with dementia. The importance of physical health, the environment, independence and the ability or opportunity to engage in activities are

also fairly universal in their importance. A strong sense emerges that what is important for the quality of life for people with dementia is perhaps not very different from those without the condition.

This reignites the discussion around the relative merits and drawbacks of having generic quality of life measures as opposed to health related quality of life measures specifically for people with dementia. Certainly the former may not always be sufficiently sensitive to pick up key issues for people with dementia. However, the latter can run the risk of becoming overly focused on the condition and its potential deficits and negative consequences. They may thereby potentially exclude or pay insufficient attention to generic life domains which may well remain crucially important to the person, and the source of positive experiences in the person's life. This in turn could lead to policies, strategies and services missing opportunities to develop socially inclusive ways of working with people with dementia that support their quality of life in these domains, including a focus on a person's strengths, aspirations and abilities, in addition to their potential needs for care and treatment.

Even with indicators such as the experience of stigma, that are clearly more particular to people with dementia, one can also view these as involving wider issues of rights, citizenship and social inclusion that are very much part of an inclusion agenda. Thus, as the authors of the literature review suggest, it would appear that quality of life for people with dementia must be understood as being multi-dimensional. It should not be viewed only through a lens focusing on health, any more than it should be viewed only through a lens with social interaction, for example, as its focus.

Perhaps one area that might cause some surprise is the importance of having the ability to practise one's faith or religion. This is partly a reflection of the relatively high numbers of people from black and minority ethnic groups where faith communities and organised religion continue to be significantly larger than in other communities. It is also partly a reflection of the age of participants, particularly those from black and minority ethnic groups and with more severe dementia, most of whom were in their 70s and 80s. Membership of a faith community or organised religion tends to be higher among this age group than among people in their late 50s and 60s. Although the numbers of people practising a faith or religion may diminish as dementia affects a younger generation, it is clear from this research that for large numbers, particularly people from seldom heard groups and with more severe dementia, it continues to be important. Supporting people with dementia to continue to practise their faith or religion is therefore an important task for paid care staff and other carers.

Feelings, emotions, mental health and well-being

Very notable by their absence from the findings are factors directly involving people's feelings, emotions, mental health or mental well-being. This may appear odd given the potentially devastating affect that being given a diagnosis of dementia could have on a person and that dementia is a condition which has an impact on people's mental functioning. Indicators associated with these factors were quite explicitly included in the research and the fact that they do not appear in the list above does not mean that they weren't considered important, but other factors were rated as being more important. Furthermore, quite clearly, the factors listed above would all have an impact on a person's emotions, feelings and mental health and evidence from elsewhere supports this.

However, perhaps what this suggests, and is potentially worth emphasising is that people with dementia, even those with more severe dementia, do not automatically find their lives dominated by the condition itself and the impact that it has on their mental functioning. As with other disabilities, it would appear that people can adjust to a diagnosis of dementia both consciously, and perhaps unconsciously for people with more severe dementia, as indicated by these two quotes from participants:

'I just think, well, I am quite healthy, as I said, it's just my brain. She [friend] has got cancer and there are various people that have got heart problems and things like that so I have never sort of been down about what I've got. I look at it that as you are getting older anyway, at some stage you are going to change or you might have an illness'

'It's not important to me who you are because you have failed in a way, medically...you just accept it'

This finding is supported by the literature review. Everyday factors that affect people's quality of life become, or continue to be important irrespective of the dementia, even though the condition will have an impact on those factors. If this is the case there are very significant messages for both health and social care services, and society at large, about respect, citizenship, and inclusion in the way people with dementia are perceived and treated. The title of this report is therefore a very fitting one – quality of life is defined primarily by the person and their circumstances, not the dementia.

Determining quality of life for people with dementia is a complex, ongoing multi-dimensional, multi-perspectival process. Considerable work has been done in this field which this project has tried to build upon but its findings should be treated with caution because of the methodological challenges involved in such a complex field. These findings below observe that quality of life is affected by many aspects of life.

Summary of findings

- People with dementia, including people with more severe dementia, are able to express their views about what is important to their quality of life.
- The domains that feature in generic quality of life measures may be of just as much relevance to people with dementia, including those with more severe dementia, as the more dementia-specific domains in health-related quality of life measures for people with dementia
- Maintaining a good quality of life is perfectly possible following a diagnosis of dementia. Services for people with dementia, and the wider community, should not make assumptions that following a diagnosis of dementia support to improve a person's life is pointless because it will have no impact on quality of life. There are many factors outside a person's dementia that affect their quality of life and this indicates that services should develop to address these wider quality of life issues. Despite being a progressive, terminal condition that severely affects a person's mental functioning, dementia may not affect a person's quality of life in respect of emotions, feelings and mental well-being in ways that one would expect. Quality of life is defined primarily by the person, as a person, and their circumstances, not their dementia.
- People with dementia have a clear need for regular, everyday, one to one social interaction and this will have significant benefit to their quality of life and social inclusion.

Comparing direct responses from different groups involved in the research

1. Quality of life indicators for people in different care settings and at different stages of dementia

'A nice place to live. No worries no problems' – person with dementia living in a care home

'Meeting nice people, not necessarily nice people but meeting people that are interesting to me. They don't have to have the greatest of backgrounds, they don't have to have the greatest education as long as they come over to me in a way that I can relate to and understand. They might not always go along with what I see or believe in but at least I can communicate and I can understand' – person with dementia living in a care home

‘Yes it is important... but I am as you know...not physically well and there are things that I can’t do but I do manage up to a point to do the things that I want to do’ – person with dementia living in a care home

‘Feeling safe and secure, yes that’s what I like about this place, feeling safe and secure. People look after me here, you know. Quite happy with that’ – person with dementia living in a care home

‘Ah, that’s a very important thing. Some people don’t like peace and quiet and I understand their life is quiet when they are sleeping or when they’re dead. I think it is very good to have peace sometimes’ – person with dementia from a seldom heard group living in the community

‘Physical health is very important, there is nothing really wrong with me apart from my legs...and my brain. I have got to try and keep exercising my legs’ – person with dementia living in the community

‘I think it is very important because if you have your own independence then you feel that you are not depending on other people’ – person with dementia living in the community

‘Anybody with...dementia...like a road accident...that person is not going to be the same and the whole family is going to have to change, adjust and develop to the new situation’ – person with dementia living in the community

‘I think most of the things I put down as important, the older I get they are still going to be important to me’ – person with dementia living in the community

Responses from people with dementia living in care homes were compared with those from people with dementia living in the community in their own homes. The results giving the top five most important indicators for each group are shown in Table 3 opposite.

Table 3 Top five quality of life indicators for people in different care settings and at different stages of dementia

	People living in care homes	People from seldom heard groups living in the community	Other people with dementia living in the community
Number of respondents	10	12	22
Most important quality of life indicators	Nice place to live Someone to talk to Feeling fit and well Having a laugh Feeling safe and secure	Peace and quiet Feeling safe and secure Faith or religion Friendship	Family Physical health Independence Relationships Communication Who I am

Responses according to living situation

The table shows some interesting differences across the three groups. There is a significant contrast in emphasis between people living in care homes and people living in the community, particularly those not from seldom heard groups.

For those people living in care homes, who were in the more severe stages of dementia, the focus appears to be on more immediate, tangible aspects of their lives, particularly relating to the environment and situation they were living in. By contrast, people not from seldom heard groups placed much more emphasis on quality of life factors that could be interpreted as expressions of maintaining control or compensating for the dementia (for example by trying to retain good physical health, and independence). One likely reason for this is that those who were not living in care homes were probably at a less severe stage of their dementia, as indicated by the fact that they were still living in the community and that they were more proactive in participating in the research (ie by attending a focus group or by completing a questionnaire).

While there are some similarities between people from seldom heard groups and other people living in the community (for example the importance of relationships) there are also significant differences, with a greater emphasis among the former on the environment they lived in and both human and spiritual relationships. These differences may in part be a reflection of the fact that nearly all the people from seldom heard groups in the community were from black and minority ethnic communities.

This analysis shows how factors affecting quality of life are likely to change depending upon both a person's circumstances and the severity of their dementia. This gives an indication of how health and social care services might concentrate their activities differently in order to support good quality of life for people with dementia, depending upon where they are living.

However it is difficult to know whether some of these factors may be a consequence of being in a care home and would be different if the person was still being cared for in their own home. Although 'feeling safe and secure' appears on two lists it is also difficult to know whether this may also have been interpreted differently by the two groups, particularly given the large numbers of people from black and minority ethnic groups in the seldom heard group (see next section).

2. Quality of life indicators for people with dementia of different ethnicities

'Yeah, if you feel safe and secure you feel happy but if not safe and secure you're not going to' – person with dementia from a black or minority ethnic group living in the community

'Oh it is very important to have a laugh... Something that can make you laugh and being made to laugh is very important' – person with dementia from a black or minority ethnic group living in a care home

'If I am happy inside [physically] it really makes me very good' – person with dementia from a black or minority ethnic group living in the community

'Going to the church, I sing, makes me happy. I miss my church, now I can't sing, can't go to church' – person with dementia from a black or ethnic minority group

'I think the environment of where you live is important because, you know, we are lucky because we have got nice neighbours' – person with dementia not from a black or minority ethnic group living in the community

'Oh yes it is sometimes you have got to make a decision to do something or other and you are not quite sure whether you should so you need a very good friend to help you to go through it' – person with dementia not from a black or minority ethnic group living in the community

‘I think it is nice to feel contented but to actually feel it might only be a brief moment in one day and the rest of the week you are running around to get back that wonderful feeling’ – person with dementia not from a black or minority ethnic group living in a care home

Responses from people with dementia from black and minority ethnic communities were compared to those of people from white British or Irish communities (where known). Because all three Jewish participants were living in a care home specifically for the Jewish community it was decided for this purpose to include them with other black and minority ethnic communities. The results giving the most important indicators are shown in Table 4 below.

Table 4 Most important quality of life indicators for people with dementia of different ethnicities

	People from black and minority ethnic communities	White British or Irish
Number of respondents	16	9
Most important quality of life indicators	Feeling safe and secure Having a laugh Feeling fit and well A good night's sleep Faith or religion	Nice place to live Someone to talk to Feeling contented Good food Being outside Being listened to Feeling you are important Feeling safe and secure People knowing you well

Notes

- Participants at the listening event and survey respondents are not included.
- People from a white British or Irish background identified many things as very important so it was not possible to identify the top five most important indicators.

Comparing the views of people with dementia and family members or carers

There are some interesting contrasts, particularly the surprising absence of relationships/someone to talk to for people from black, and minority ethnic groups. This may in part be a reflection of some black and minority ethnic group participants (notably some female participants) having led quite isolated lives for some time and having resigned themselves to this, particularly because the group included people with dementia from black and minority ethnic groups living in care homes. Another factor, which arose for a few of the male participants from black and minority ethnic groups, was an apparent disinterest in social interaction. It would appear that feeling safe and secure, and the role of faith or religion play important roles in providing quality of life for people from black and minority ethnic groups. For white British or Irish participants there was a much greater emphasis on social interaction and relationships, as well as a sense of oneself as an individual.

How far these factors are influenced or mediated by dementia would require further research including people from different ethnic backgrounds who did not have dementia. However it would certainly point to the importance of recognising that people with dementia from black and minority ethnic groups may have very different concerns regarding quality of life when compared to white British or Irish people. There may also be further differences between different ethnic minority groups (including people of Irish origin).

General comments – care settings, severity of dementia, and ethnicity

If the overall findings from this research contain important messages about the relationship between social inclusion and quality of life for people with dementia, the message from the more detailed analysis of the two main sub-groups is that quality of life is clearly affected by the individual and their particular circumstances, including ethnicity and the setting in which they live. In as much as the care setting people are in may also be a reflection of the stage of their dementia, it would also appear that factors influencing quality of life change over time and in terms of importance to them.

This does not however necessarily negate the importance of making quality of life measures as inclusive as possible; on the contrary, it emphasises further the need for such measures to be both comprehensive enough and sensitive enough to be meaningful to people with dementia from diverse communities, living in different care

settings, and at different stages of the condition. The conclusion drawn by the authors of the literature review is of particular relevance here where they state that:

Quality of life is not just multi-dimensional, it is **multi-perspectival**. In other words, how quality of life is understood **depends on where you are looking from** [authors' original emphasis]

This further indicates the importance of a hybrid approach to quality of life measures for people with dementia that incorporate both the health sensitive aspects of dementia-specific instruments, together with a more socially nuanced approach that may be contained in more generic instruments.

Quality of life indicators for people with dementia and as defined by family members and carers

'It's their quality of life that's being taken away, not ours' – family member/carer

'I mean like relationships, family is important but not as important as just me and him' – family member/carer

'Well communicating, they get slow on communicating' – family member/carer

'It's still important that they know that they are a person in their own right' – family member/carer

Overall responses from people with dementia (as well as specifically those who participated in the listening event and postal survey) were compared with those of carers. The three most important indicators for each group are shown in Table 5.

The table shows an interesting contrast but because of the small number of carers these findings should be treated with some caution. People with dementia and carers identified relationships as being of great importance but quality of life factors reflecting people's environment and circumstances, together with factors that could be interpreted as expressions of maintaining control or compensating for the dementia (for example by trying to retain good physical health, and independence) were not identified as being of importance by carers. Instead, carers emphasised that factors concerning the ability to interact, such as communication and being the 'same' person, as the quality of life factors they believed to be most important for the person with dementia.

Table 5 Quality of life indicators for people with dementia and as defined by family members or carers

	All participants with dementia	People with dementia who participated in the listening event and postal survey	Carers
Number of respondents	44	22	5
Most important quality of life indicators	Relationships Environment Physical health	Physical health Independence Relationships	Relationships Communication Who I am (ie the person with dementia)

Perhaps this reflects carers' concerns about the impact the dementia is having on their relationship with the person, whereas the person themselves, while recognising the importance of relationships, emphasises other life domains that may feel more tangible to them. Irrespective of the reasons that may lie behind these different responses, they clearly show the importance of carers (and paid staff) finding out what is important to the person with dementia and not making assumptions. It would also appear to reinforce evidence from the literature review that ratings of quality of life by proxies (ie family members and carers, etc) may be quite different from self-reports by the person with dementia.

Interestingly, several people with dementia who participated in the focus group identified relationships as the factor they thought their partner or carer would consider to be most important.

Quality of life indicators for lesbian, gay, bisexual and transgender people

Because only one gay man participated in the research it has not been possible to identify any findings that are specific to lesbian, gay, bisexual and transgender people with dementia although his responses to the interview have been included in the general analysis.

Quality of life indicators for people with learning disabilities and dementia

Because no people with learning disabilities and dementia participated in the research it has not been possible to clearly identify any findings that are specific to people with learning disabilities and dementia. However the findings from the focus groups with six older people with learning disabilities who had experienced supporting other people with learning disabilities who also had dementia were analysed.

In line with the findings from other parts of the study, relationships were identified as the factor members of the focus group thought had been very important for the quality of life of people who they knew who had learning disabilities and dementia.

‘I think x likes the company more than anything else and she seemed to be very pleased to see a lot of us down at her birthday party anyway’

‘As long as you’ve got good friends...and a nice garden to get fresh air, you’ve got everything’

Other, quite practical factors were identified by the group as also being important for quality of life including eating well, appearance, hobbies and activities.

Summary of quality of life findings for people with dementia in seldom heard groups and the views of family members or carers

There are significant differences about quality of life among people with dementia from seldom heard groups, including people of different ethnicities, and between the views of people with dementia and their family members and carers.

People with more severe dementia and people with dementia living in care homes are able to express their views about their quality of life and these differ significantly from people living in their own homes in the community and those with less severe dementia.

Quality of life measures for people with dementia need to be sufficiently sensitive to enable these differences to be identified.

Ways of measuring quality of life (based upon research methodology)

Although the project did not have the development of a specific quality of life measure (or 'instrument') as one of its original aims the research required a methodology with which people with more severe dementia could engage. As has already been described, an adapted version based upon the Talking Mats approach involving the picture card exercise was used to achieve this, and was also used in other parts of the research.

Although this research methodology was being used for the first time, and because of this had some limitations (see Appendix 4) both in its actual use with participants and in the findings it generated, there is good evidence to indicate it as a potentially valid and reliable method of measuring quality of life.

Virtually all the participants with more severe dementia living in care homes showed very significant signs of confusion and disorientation in terms of time, place and people, both prior to and during the interviews. This also applied to several participants from black or minority ethnic groups who were living in the community in their own homes, particularly where the process of interview was complicated because of the need for language translation. Several participants had difficulty understanding and answering the opening questions of the interview (not involving the picture card exercise) about what was important or not important in their lives at present, and what helped them if they were confused or forgetful.

However, nearly all these participants were able to actively engage with the picture card exercise and all of them were able to complete this part of the interview. Of particular note was that despite their dementia causing some confusion and disorientation, most participants were still able to express their views, and differentiate and rate in order of importance items they were shown as part of the exercise. An analysis of a small sample of the transcripts of the interviews with people with more severe dementia was carried out and each response was categorised in terms of how far it appeared that that the person was responding in a clear, unambiguous, and unprompted way to the question. Four out of the five interviews were with people living in care homes. The analysis included two interviews involving participants who were identified on first reading from the transcripts as providing some of the most confused answers as well as two participants from black and minority ethnic groups (one of whom had an interpreter as well, but lived in her own home in the community). The results are shown in Table 6.

Table 6 Clarity of response from participants to picture card assisted interview

	Clarity of responses in participant transcripts (%)					
	Person A	Person B	Person C	Person D	Person E	Average
Clear, unambiguous, unprompted response	83	63	55	38	28	53
Ambiguous response, or response possibly prompted (led) by the question	17	32	41	52	50	38
Confused, response, no clear link to question	–	5	4	10	22	8

The analysis shows that on average 53 per cent of the responses given were clear, unambiguous and unprompted and for one participant 83 per cent of her answers fell into this category with no confused responses whatsoever. Even for the participant (Person E) who seemed most affected by their dementia, 28 per cent of their responses were clear, unambiguous and unprompted, indicating an ability to engage meaningfully with the picture card exercise. For three participants (Persons A, B and C) over 50 per cent of their responses fell into this category. For all the participants, responses which were confused or had no clear link to the question constituted less than 25 per cent of their total responses and on average only 8 per cent of response were in this category. While for two participants (Persons D and E) 50 per cent or more of their responses were ambiguous or could have been led by the question, on average only 38 per cent of responses fell into this category.

This analysis would therefore indicate that the picture card exercise has potentially a good degree of validity as a way of collecting quality of life information from people with more severe dementia, including people whose first language is not English. Although there were significant methodological limitations in using this approach (see Appendix 4) these results would suggest that a more rigorous use of this methodology to ascertain its validity and reliability would potentially be of great benefit.

While more testing of this approach would be required to demonstrate its validity and reliability, the initial findings would indicate that it does elicit meaningful responses from people with dementia that are in most cases good reflections of the views and opinions of the person. This also applies to some of the participants from black and minority ethnic communities for whom English was not their first language. The consistency with which 'relationships or someone to talk to' cropped up for all participants would appear to support this. This would therefore clearly support the point that the authors of the literature review make in their conclusion in emphasising the importance of including the perspective of people with dementia in any assessment of their quality of life, as well as suggesting another way (in addition to those that have already been developed) of actually doing this.

Summary of findings about ways of measuring quality of life (based upon research methodology)

It appears that even people with more severe dementia are able to express their views about quality of life issues using a picture card exercise approach.

Using a picture card exercise approach has the potential to be developed into a valid and reliable method of measuring quality of life for people with dementia of varying degrees of severity and for whom English may not be their first language.

5. Conclusions

In undertaking this work Alzheimer's Society and the researchers from the Mental Health Foundation have covered ground that has been covered by many others. However, it was felt necessary to get a perspective from those living with dementia and with that in mind arrive at a set of criteria that can be widely agreed. Following that Alzheimer's Society believes that there would be great merit in trying to determine a way of measuring the criteria and thus monitoring the changes in quality of life for the population of people living with dementia as a whole. With more public policy being aimed at combating the impact of dementia there would be benefit in determining how successful that policy is. This will require further work and co-operation between many of those who have been involved. We seek for that to happen as soon as possible. This work is important and Alzheimer's Society is prepared to lead that work and call together interested parties into a consultation period with the aim of developing a quality of life monitor that can become widely accepted.

If the quality of life of those living with dementia is to be defined by the person and their circumstances then both the public, private and not for profit sectors have to review their attitudes to, and policies for, dementia. Just as 30 years ago we as a nation started to understand the needs of the disabled and enable them to access all the services available to the able bodied, the same must begin now for those with dementia.

In recent times there has been a much better understanding by government of the needs of people living with dementia. The Department of Health in England has implemented a national dementia strategy. The corresponding departments in Wales and Northern Ireland are to do the same and the Scottish government is treating it as a national priority. But if those strategies are to be successful then the lead given by each department must be equally strong at local level. Alzheimer's Society made that point recently, when the National Audit Office (National Audit Office 2010) published a report on the first year of the English strategy. What we have learnt from undertaking this work has reinforced our view that this is vital. If those charged with implementing dementia strategies are not giving that leadership then they must listen to what is being said and respond.

6. Recommendations

1. The research described in this report found consistent themes about what is important in the quality of life of people with dementia. It reviews the considerable body of work that exists in this area and brings the perspective of those living with dementia firmly into focus. We recommend that, using the findings from this report and the existing body of knowledge regarding quality of life in dementia, work be taken forward to explore the possibility of developing a monitor of quality of life for people with dementia. This monitor could capture what quality of life is like for people with dementia across the UK. It could explore whether quality of life is improving or declining over time and provide information on what factors might explain any observed changes.

Alzheimer's Society considers that such a monitor would provide vital information regarding the relative success of public policy in effectively supporting people with dementia. Given the focus quite rightly applied to dementia by public policy in recent years it is particularly important to understand its impact on quality of life for those living with the condition.

2. This report highlights a range of issues regarding the understanding and measurement of quality of life for people with dementia. We recommend that these be used to inform future work on quality of life in dementia and dementia services and policy in general. These findings include:
 - the possibility of developing methodologies such as Talking Mats to gather the views of people in the later stages of dementia
 - the importance of developing methodologies that include both generic and health-specific quality of life indicators
 - the discrepancy between the views of people with dementia and those caring for them, in terms of what is most important to quality of life
 - the suggestion that different communities of people with dementia consider different things to be most important to their quality of life, for example those in care homes and those from black and minority ethnic communities.
3. This study highlights the range of issues that must be addressed in order to support maintenance and promotion of quality of life. It re-emphasises the need for policy makers, service providers and regulators to focus on the things of most importance to the quality of life of people with dementia. We recommend that

these bodies (policy makers, regulators, service providers) ensure they consider the breadth of factors that impact on quality of life throughout the course of developing and implementing their work. This must include factors that may not have previously been considered as relevant to these organisations, for example relationships and spirituality.

4. The report highlights that quality of life is possible following a diagnosis of dementia. We recommend that recognition of this informs all of the dementia-related work of policy makers and service providers. The finding that there are many factors outside the person's dementia that affect their quality of life provides further incentive to ensure services are developed that address a wide range of aspects of people's lives. It demonstrates the importance of avoiding assumptions that, following a diagnosis of dementia, support to improve other aspects of a person's life is pointless because it will have no impact on quality of life.

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Appendix 1

Literature review – executive summary

The literature review was written by Joanne Warner, Alisoun Milne and Julie Peet from the School of Social Policy, Sociology and Social Research, University of Kent. The full literature review is published separately and also available online at alzheimers.org.uk/qollitreview

Background and introduction

This literature review forms the first part of a research project which sets out to establish key quality of life indicators for people with a diagnosis of dementia using evidence that draws directly on their own views and experiences. A central aim in developing these indicators is to provide commissioners, service providers, unpaid carers and people with dementia themselves the means to evaluate quality of life and well-being in relation to the services they are providing or receiving.

The project took place shortly after the publication by the government of the first 'National Dementia Strategy for England' (Department of Health 2009). This sets out three key steps in terms of improving quality of life for people with dementia and their carers: public education; proper and timely diagnosis of dementia; and development of appropriate services for people who have dementia and their carers. It is likely that the indicators developed through the research of which this review forms a part will include measures that reflect these three key elements of the dementia strategy and may help in monitoring its effectiveness.

Dementia is an umbrella term used to describe a group of brain disorders that involve a progressive deterioration in cognitive function, resulting eventually in severe cognitive impairment. The individual with dementia experiences a gradual decline in their ability to understand, remember, reason, communicate and use learned skills; mood changes are also common as the part of the brain that controls emotion is affected by the disease (Alzheimer's Society 2007).

In the UK there are currently 750,000 people who have dementia although this figure is expected to double to 1.4 million in the next 30 years (Alzheimer's Society 2007). It is

anticipated that the current annual costs associated with dementia in the UK will almost treble during the same period, to over £50 billion (Department of Health 2009). People with mild to moderate dementia constitute the larger proportion of this figure, whereas people with severe dementia make up approximately 12.5 per cent of the total (Alzheimer's Society 2007).

The growing interest in quality of life and dementia reflects a wider ranging interest in quality of life as a concept. However, there is no definitive consensus about exactly what 'quality of life' is, what it means and, therefore, how it might be measured or assessed. In simple terms, there are three ways of approaching quality of life that are each reflected in the literature we have reviewed. Firstly, it can be viewed as something that can be 'measured' objectively by others, such as clinicians or carers; secondly, it can be regarded as something that is by definition a subjective phenomenon and therefore can only be meaningfully evaluated through self-report by the person concerned; thirdly, there is the approach to quality of life which tries to synthesise these two broad approaches to develop relevant and meaningful indicators based on self-report, observations and other evidence.

For a definition of quality of life that appears to capture its complexity and the importance of the interplay between various factors, the following from Bowling and Gabriel (2004) is more than adequate for our present needs:

Quality of life, then, is a multidimensional collection of objective and subjective areas of life, the parts of which can affect each other as well as the sum. It is also a dynamic concept, reflecting values as they change with life experiences and the process of ageing (p3).

The trend towards greater involvement of people with dementia in service planning and delivery and in research is mirrored in an increased focus on capturing their perspectives on quality of life. At the same time, confidence in the possibility of obtaining reliable information directly from people with dementia has increased significantly. As the idea of subjective evaluations of quality of life has gained currency, the question of how to assess it when the person concerned is unable to provide a self-report, such as when they have severe dementia, becomes central. The literature that addresses these key issues forms a central focus of this review.

Defining and measuring quality of life in dementia

There are two broad categories of relevant literature in terms of approaches to defining and measuring quality of life. The first is largely medical or health-related and tends to take a 'traditional' approach to measuring quality of life. This means the emphasis is

often on 'objective' measures using clinician or carer observations, where reports by 'proxy' respondents often replace self-reports. Where the self-report of the person with dementia is incorporated, it is more often as an adjunct to the objective measure of their quality of life. More often than not, however, such self-reports are not included and this is especially true where the quality of life of people with severe dementia is concerned.

The implicit working assumption that often underpins this literature is that someone's quality of life will correspond closely to the state of their health and to what they can do in terms of everyday living. It is often assumed that living with a chronic condition of any form will correspondingly mean a reduced quality of life. 'Objective' instruments have been developed that appear to show moderate to good levels of reliability and validity in research terms. However, questions remain about the extent to which such measures can provide a 'true' reflection of an individual's quality of life if they do not incorporate an account by the individual concerned. One major basis for this doubt is the fact that agreement between proxies and the person with dementia is often rated as poor to moderate, and that the gap widens as dementia becomes more advanced. Quality of life is generally rated as being lower by carers than by the person with dementia themselves. It is therefore debatable whether it is appropriate to substitute proxy-reports for self-reports at all.

The second category of literature implicitly or explicitly conceptualises quality of life as a subjective phenomenon. In this literature, the first-hand accounts of people with dementia are often regarded as providing the most authentic account of that individual's quality of life. This increased focus on capturing the perspectives of people with dementia on their quality of life is a reflection of the wider trend towards greater involvement of people with dementia in service planning and delivery and in research.

The core dilemma inherent in assessing quality of life in people with dementia from this perspective is the fact that dementia is defined by deterioration of the means to comprehend and communicate. For this reason, assessing quality of life in people with severe dementia is usually considered a very different undertaking compared to assessing it in people with mild to moderate dementia because of the effect that severe dementia is assumed to have on the ability to comprehend and communicate. Despite the challenges however, a growing amount of research evidence suggests that people with severe dementia can indeed provide meaningful self-reports about their quality of life.

Evidence based on assessing quality of life from the perspective of the person with dementia suggests that what is important for quality of life for someone with dementia is in many respects the same as that for someone who does not have dementia. Positive social relationships, psychological well-being, independence and financial security are

things that most of us need in order to feel we have a good quality of life. However, some research highlights certain areas that appear to have greater significance for someone with dementia. These areas include being of use and giving meaning to life, security and privacy, and self-determination. Also included in one study is a domain of 'self-concept', which is believed to be unique to dementia and which incorporates stigma-related concepts such as embarrassment and self-esteem.

There is also a range of psychosocial issues that are thought to be relevant to understanding the experience of people with dementia and quality of life. The concept of psychosocial well-being, the different coping styles that individuals might adopt in response to developing dementia, the degree of resilience they have, social comparison theory, stigma and self-stigmatisation have all been found to be important and have added to our understanding.

Outcomes and quality of life indicators

There is an important, albeit limited, literature based on research carried out in relation to a range of groups that have relevance for understanding quality of life from the perspective of people with dementia. People with dementia from 'seldom heard groups' are frequently marginalised and their voices silenced, as the phrase suggests. However, there are sufficient studies to indicate that quality of life is mediated in complex ways by an individual's 'race', ethnicity, social class, age and gender. In simple terms, quality of life for a woman with dementia may mean something quite different compared to a male counterpart. Similarly, quality of life for someone of limited financial means may be defined differently compared to someone who is well off. What this literature demonstrates is the serious problem with the fact that 'dementia', once diagnosed, is all too quickly perceived to be the all-consuming feature of a person's identity. The reality is that people remain complex and multi-faceted and their quality of life is no less complex. The literature reviewed here suggests that the development of appropriate domains and indicators to assess quality of life needs to reflect this diversity and complexity rather than assume a degree of homogeneity which does not exist.

In terms of service settings, the review focuses on two main areas: early interventions for diagnosis and care home settings. A great deal of attention has recently been paid to the importance of early diagnosis of dementia and the improvements that can be made to people's quality of life if diagnosis is made early. This emphasis is reflected in the 'National Dementia Strategy for England' (Department of Health 2009), where the widespread adoption of memory services is intended to lead to improvements in people's experiences of services at this stage. There is clearly strong evidence that improving the process through which people are diagnosed and widening access to a high level of support at a relatively early stage of the illness is beneficial.

At the same time, the literature on developing quality of life measures for people with dementia in care homes is significant. The treatment of people in care home settings has been found to be sub-standard in a number of important respects, with evidence that this is a widespread problem rather than restricted to small areas. Studies that are reviewed demonstrate the central importance of understanding the subjective experience of the person with dementia as a fundamental dimension of enhancing care practice, developing appropriate interventions and increasing understanding.

In addition to the work reviewed here on quality of life and dementia, there have been significant developments in exploring the quality of life of people in other key groups that are relevant for this review, including older people, people with mental health needs, and people with learning disabilities. An important range of studies has investigated quality of life in older people, particularly from the perspective of older people themselves. Some of the most significant studies emphasise the importance of considering inequality between groups in understanding quality of life and how it should be assessed. More specifically, it is the consequences of inequality that are of concern; in particular, the capacity of inequality to constrain and limit quality of life.

The orientation of the research reviewed from the mental health field comes from a different evidence base compared to that from people with dementia and older people, with a focus on 'patient outcome measures' rather than 'quality of life'. However, its specific contribution is an important one as it serves to highlight the importance of user perspectives and participatory approaches. The concept of quality of life has become an increasingly important feature of the learning disability field. It is characterised by a 'rights based' approach where quality of life issues are viewed in the context of a strong tradition of user involvement and giving 'a voice' to service users. This strong value base reflects the history of the learning disability movement.

Conclusion and key recommendations of the literature review

The focus of this review has been the development of quality of life indicators in relation to dementia. What has become clear in the process of reviewing the relevant literature is that we still know very little about quality of life in this area.

From the evidence reviewed it is clear that the perspective of the person with dementia has for too long been omitted or ignored compared to other perspectives on quality of life, particularly formal, theoretical or medical perspectives. The 'disease-oriented' measures that have been dominant are not as helpful as once thought and, specifically, the assumption that dementia inevitably results in poor quality of life from the perspective of the person with dementia is faulty.

From the evidence reviewed, it should be emphasised that quality of life is not just multi-dimensional, it is multi-perspectival. In other words, how quality of life is understood depends on where you are looking from.

The idea that a single instrument could be used to assess quality of life at each stage of development of an illness such as dementia is almost certainly redundant and much more dynamic approaches to the task are required. In particular, the development of methodologies to enable the assessment of quality of life from the perspective of someone with severe dementia is of central importance. Any steps to make further progress in developing this work should be welcomed.

Positive social relationships, psychological well-being, independence and financial security are things that most of us need in order to feel we have a good quality of life. These factors have been found to be no less important for people with dementia. Being of use and giving meaning to life, security and privacy, and self-determination are some of the areas that appear to have greater significance for someone with dementia. The domain of 'self-concept' in one study is of great interest and work in this area could be developed further, particularly as it incorporates stigma-related concepts such as embarrassment and self-esteem.

The evidence is clear that stigma and discrimination have a serious and detrimental effect on the quality of life of people with dementia. The impact of 'personhood' in dementia has led to a paradigm shift in the way the perspectives of people with dementia are understood and increasingly incorporated. The argument that a further shift towards incorporating notions of citizenship for people with dementia may help address stigma and discrimination is compelling.

The population of people with dementia, like any other population, is heterogeneous in terms of individual biography, life course factors, 'race', social class, gender and sexuality. There is strong evidence that such factors mediate in significant ways in terms of the individual experience of quality of life. Some of the most significant studies stress the importance of considering inequality between groups in understanding quality of life and how it should be assessed. The future development of approaches to assessing quality of life must engage with and reflect this diversity if they are to be effective and experienced as authentic and meaningful by people with dementia.

Appendix 2

Quality of life indicators for seldom heard groups and people with more severe dementia

Picture cards were used with respondents for all the listed quality of life indicators other than where indicated by the footnotes.

- Good food
- A good night's sleep
- Nice place to live
- Enjoyable things to do
- Being outside
- Animals
- Faith or religion
- Having enough money
- Doing things for fun
- Looking good
- Choosing everyday things¹
- Looking after yourself¹
- Helping out¹
- Being busy²
- Family
- People you are close to²
- Friendship
- Everyone getting on¹
- Other people who live here¹
- Kind staff¹
- A helping hand²
- Giving to other people
- Someone to talk to
- Being listened to
- Communicating your thoughts and feelings

- Understanding what is going on
- People knowing you well
- Being treated fairly
- Feeling fit and well
- Feeling free to do what you want
- Feeling safe and secure
- Feeling you belong
- Feeling you are important
- Affection
- Feeling contented
- Peace and quiet
- Having a laugh

1 These symbols were only used with people with more severe dementia living in care homes.

2 These symbols were only used with people from seldom heard groups living in the community in their own homes.

Appendix 3

Quality of life indicators used for the listening event and postal survey

- My physical health
- My independence
- How I feel
- Who I am
- Paid care I receive
- How I think and communicate
- My relationships with other people
- My environment and surroundings
- My personal beliefs/faith/spirituality

Appendix 4

Methodological limitations

This was a complex piece of research and therefore almost inevitably there were a number of methodological limitations.

The overall sample was small and because it was divided up into particular sub-groups the findings should be treated with caution. It was not possible to recruit any people with learning disabilities and dementia and only one gay man in respect of lesbian, gay, bisexual and transgender people. There were no findings therefore about quality of life from the former and it was not possible to draw any conclusions from the latter.

The project was relatively successful in recruiting participants from black and minority ethnic groups given the difficulties that are often encountered in involving people from these groups in research. This therefore was a very positive achievement for the research that was of significance in terms of the findings. Nevertheless, because nearly half the sample were from black and minority ethnic groups it was not a representative demographic sample of the population in England or the UK.

Time, resources and ethical issues did not permit the research to be carried out with people with dementia from other seldom heard groups such as those from rural communities or people who lacked capacity to consent. It was therefore not possible to draw any conclusions about quality of life for people with dementia from these groups.

For the reasons described the research involved mixed methods of investigation. This included some variations in the quality of life indicators used, and an action research element in as much as the quality of life indicators were refined for the listening event and postal survey. This meant that it was not always easy to make direct comparisons between the different elements of the research and the different groups. It was also not possible to make comparisons based upon age or type of dementia as this information was not routinely collected, and comparisons between participants at different stages of dementia should be treated with great caution because detailed information about the stage or severity of dementia also was not routinely collected.

Time and resources did not permit the validity or reliability of the data collected to be tested. Participants were only seen once so changes over time were not measured. Particularly for individuals with more severe dementia where cognitive difficulties may

have effected their understanding of the questions and picture card exercise, and their ability to communicate may have effected their answers, it is difficult to know how valid and reliable their responses were. To do this would require a different researcher repeating the same exercise with each individual, as well as asking a family member or staff member to give their view about the relative importance of quality of life for the individual in question, and comparing the answers.

Use of terms such as 'good' and 'nice' to describe some of the items on the picture card exercise may have unduly influenced how people rated them.

Although people were asked about what was important to them and the list of items included in the picture card exercise was extensive there was always the risk that an important indicator of quality of life could have been omitted, not adequately represented, or misinterpreted. This potentially was particularly the case for people with more severe dementia and participants from black and minority ethnic groups and where interpreters were used. On occasions it did appear that there was some confusion as to whether the person was rating according to what they believed to be important or what they perceived to be important in the circumstances they were living in.

The presence of family members, interpreters, or other participants in the focus groups may have inhibited participants' answers.