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Improving hospital environments for People with dementia: Listening Event Report

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Improving Hospital Environments for People with Dementia

Listening event report

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ABSTRACT

Aim: This report provides feedback on a Listening Event held on September 11th 2011 that explored issues in relation to dementia and the built hospital environment.

Background: In the last decade especially, there has been a growing interest in enhancing health and social care delivery environments including hospitals, nursing and residential care homes. This is partly in response to recognition that the environment in which care is delivered can have a significant effect on patient and staff experience, patient wellbeing and ultimately recovery or appropriate end of life care. In the UK, there has been rapid growth in development of new-build care environments as well as adaptations of existing care facilities with varying success at meeting the needs of people with dementia and those who care for them.

The research evidence base in support of developments in the built environment for dementia care is growing, yet remains patchy and incomplete. Other valuable evidence in the form of views of people with dementia, their families and those in an informal or paid care role, have not always been taken into account when designing health care related buildings. Whilst there is much accepted good design practice evident, there remain challenges, tensions and unmet needs of people with dementia, in relation to the built environment, that the Listening Event sought to explore.

Approach: The Listening Event brought together a wide range of people with an interest or direct experience of dementia. These included people with dementia, their family members, informal carers, paid care workers, representatives of organisations that work with people with dementia and academic staff with an interest and expertise in dementia care including nurses, architects and social workers. In a workshop environment, participant's views were uncovered using a range of techniques including discussion of photographs of accepted good practice in dementia care environments and facilitated discussion groups on a choice of topics of importance to participants. Issues of interest and concern were prioritised. Good practice was highlighted and aspects of dementia care environments in need of improvement were discussed. Solutions were suggested by participants and future research opportunities identified. All workshop activities were audio-recorded and extensive notes

made to enable thorough feedback to be given to participants and others with an interest in the process and outcomes of the event. Whilst not a research activity itself, the event has been a valuable community engagement activity aimed at identifying future research and innovation topics and priorities, and creating the beginnings of an ongoing relationship with willing participants to take ideas forward.

Discussion: Examination of discussion content revealed 7 core themes of importance to participants. The first 4 of these resonate with the current and relevant research literature. The latter 3 themes indicate something less reported on and in need of further exploration. The 7 themes are:

- Fabric of the environment
- Ambience of the environment
- Psychological impact of the environment
- Sociological impact of the environment

Plus,

- Functional activities and safety
- Information and communication
- Approaches to care

Within these themes, several conflicting issues were apparent that are also reported on. These conflicting issues illustrate some of the challenges in creating the best possible built environments for dementia care and the realities in delivering dementia care within them. The event uncovered valuable feedback about the preferences for future research into dementia care and the built health care environment.

Conclusions: Clear messages from participants indicated a need for further and more focused research into the impact of the built hospital and health related care environment on the care and experience of people with dementia. Participants welcomed the multi-stakeholder approach to exploring issues of shared concern and being given an opportunity to voice their views and importantly have those views listened to with the expectation of them being acted upon. This report goes some way in sharing the learning from this important topic area and catalysing future action to make design of dementia care buildings are fit for purpose.

FOREWORD

The foreword in this report is represents multiple perspectives from leaders within academic, professional and political arenas. The common thread amongst these viewpoints relates to how dementia has impacted directly or indirectly in their lives.

Academic View

To move good ideas from theory to practice takes more than just having the idea and publishing research on it. Successful implementation requires an informed public to adopt it. There is no better way to achieve buy-in than listening to people and incorporating their interests, experience, and wishes into decisions that affect their lives. The first step is identifying who to include in the listening circle. The group assembled for this report comprised people living with dementia, their families, health and social care staff, architects, designers and academics. Each has relevant experiences and information useful to others. Everyone listens to everyone else and collective learning is great.

At least two important dimensions of this report deserve particular attention.

First, it is becoming increasingly clear that the number of people with dementia is growing and that pharmaceutical treatment research is banging up against a brick wall—at least for the present. It is becoming increasingly clear as well, as this report reflects, that the best thing to do for people living with dementia at present is to improve their lives with non-pharmacological—ecopsychosocial—interventions. The most basic of these is a physical environment adapted to the needs of all its users, in this case including persons with dementia and the people who love and care for them.

Second, and this might be even more important, is that this listening exercise was aimed at better understanding the experience and needs of persons living with dementia in hospitals—in a building type primarily used by others without dementia. It would not have been remarkable, had the group been studying questions of evidence-based design applied to a dedicated care home or a memory care clinic because those operate only for this group of users. But they did not.

As this report exemplifies, to achieve true "universal design" of our public spaces and public buildings—such as hospitals—we must carry out research on and include the needs and wishes of people with dementia and their care partners to make effective evidence-based design decisions in such settings.

Professor **John Zeisel**
President and co-founder of Hearthstone Alzheimer Care, Ltd.
Author of I'm Still Here: A New Philosophy of Alzheimer's Care, 2009, Piatkus

Professional View

There can be few people that are not aware of the impact of dementia. However, it has been and still is, to some degree, something that is pushed behind a curtain.

My current experience is that I have two male friends in their early 60s who are affected by dementia to different degrees. Both extremely successful businessmen, one is now completely incapable of any form of independent living and the other has lost the ability to make decisions and organise his activities. The care of both is the responsibility of their respective wives who, living in different parts of England, have been able to access very different levels of clinical and social care for their partners and negligible support for themselves as carers.

I find that my experience is mirrored when I raise the issue with my friends around the country and even more so when I talk to my older relatives and friends who all have a legion of stories about the impact of the condition on the people they know, or have known, and the intolerable burden on the carers.

Looking back to my role as a hospital manager and duty director responsible for an NHS hospital in the 1990s I am haunted by the comments of the clinical staff on the elective surgical wards that raised annoyance caused by confused older patients who disrupted the routine of the ward and the work of the clinical staff. I also recognise that in directing the design of new hospital environments at that time we focussed on meeting the needs of other groups in society, particularly people with visual, mobility and hearing difficulties, but not on the needs of people with dementia. There was and remains ignorance of the environment, physical and emotional, that is needed to ensure the best possible care of people with dementia.

David Cameron, the Prime Minister and the leaders of NHS and Social Care have recognised that change is needed. Decisions will have to be made on what should change to balance the needs of individual patients and their carers together with the requirement to deliver hospital and social care in safe, value for money ways that necessarily mean using innovative new processes and procedures. The changes that will be introduced should be based on sound well-researched information and understanding. It is an area that is under researched, where it is estimated that 60% of people with dementia are undiagnosed, and many people suppress open acknowledgement of the condition.

We must all commit to the challenge, the scope of which is still emerging, to improve the lives of people with dementia, the carers and the professional staff who support them. We must undertake investigations and research that recognise the complex and competing demands to produce evidence on which to base decisions that are needed to improve the quality of the lives of people with dementia.

This report "Improving Hospital Environments for People with Dementia" gives valuable insights into the further work that is needed.

Rob Smith

Visiting Professor, SOBE—School of the Built Environment, Salford University
Retired Dir. Estates and Facilities of NHS in England and President for the HEFMA

Political View

I am delighted to have been asked to write the foreword to the University of Salford's important "Improving Hospital Environments for People with Dementia" report. Dementia is an issue that touches the lives of every family in Britain and is rightly a major concern not just for the NHS, but for public services as a whole. Like most people I got involved because someone I love has dementia – my Mum – and over the past five years I have seen and experienced the impact on her and my Dad who, at the age of 85, is still her full-time carer.

Caring for those with dementia is a massive challenge for us all, and pressure from the public and academics has helped to focus the minds of politicians and practitioners on what can and should be done to support those with dementia, their families and their carers.

Re-examining the way that we care for people with dementia is so important because of the scale and the cost. The 2009 National Dementia Strategy put the total cost of dementia to the UK economy at £17 billion per year – with an ageing population this is estimated to triple over the next 30 years.

This report is an important examination of the way that we deal with dementia, with a focus on how the experience and well-being of hospital patients who have dementia can be improved. I was particularly interested by the methodology used in the production of this report; instead of focusing on scientific data, this report was produced after a listening exercise was conducted, and uses the experiences of people with dementia and their carers to provide an assessment of the direct impact that healthcare settings can have.

By looking at a wide range of variables from clinical aspects such as health, hygiene and infection control, to environmental factors such as acoustics, colour and clutter, the report provides a comprehensive understanding of the different ways that a hospital environment can be improved to support people living with dementia.

Crucially this report acknowledges the need for an integration of physical and mental health services instead of having them as distinct and separate. This is an important step towards creating a comprehensive care package for people with dementia and planning a built environment that is specifically designed for their needs. It shows that there is a greater understanding of the unique circumstances that people with dementia face.

As dementia gains a greater national profile it is important that all possible avenues of treatment and ways to improve the quality of life of those with dementia are explored. I'm therefore delighted that the University of Salford has produced this innovative report, and I look forward to continuing my close work with the University and working in Parliament to ensure that dementia care is given the important attention it deserves.

Rt Hon **Hazel Blears**: M.P.
Vice Chair of the All-Party Parliamentary Group on Dementia (APPG)

ACKNOWLEDGEMENTS

CONTENTS

1   INTRODUCTION

In September 2011, we undertook an innovative community engagement activity known as a 'Listening Event' to explore views about hospital design in relation to people with dementia. In this report we share what we heard when we listened to those who are directly and indirectly impacted by dementia. We account for the issues that were raised in relation to the adequacy of hospital environments for people with dementia and their formal and informal carers. To provide the background and an overview about design for dementia, this report is structured as follows.

Section two presents a general overview in terms of trends related to the UK population and dementia. It also briefly discusses what dementia is and the academic research that has been done to investigate how the built environment can impact positively and negatively on dementia care and experience. Section three describes the listening event approach and the method used to collect and analyse information from participants. Section four presents the findings of the event, including potential problems and possible solutions, as well as some conflicting issues that emerged, It also includes the priority issues for future exploration, from the perspective of those who attended the event. Finally, section five presents the conclusions and recommendations for improvement.

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2   DEMENTIA: OVERVIEW

2.1   Understanding Dementia

"*Dementia is one of the most important issues we face as the population ages*" (Department of Health, 2010). It is believed that there are approximately 800, 000 people in the UK living with Dementia (Alzheimer's Society, 2012), only less than half of these, around 40%, have been diagnosed (All Party Parliamentary Group, 2011). "*The number of people living with dementia is projected to increase by over 70% in England between 2010 and 2030*" (Verne *et al*, 2011).

Dementia is the result of different diseases and conditions that cause a loss of brain function that can result in memory loss, mood changes, problems with communication and reasoning and a decrease in the ability and skill in carrying out daily activities e.g. washing, dressing, cooking and caring for self (Alzheimer's Society, 2012 and Dementia UK, 2012).

Improving the care environment to ensure that it is suitable for people living with dementia can help improve outcomes for individuals and reduce the risk of avoidable deterioration in abilities and associated costs (APPG, 2011). In this respect, evidence shows that the physical environment can directly impact on a person's functional ability and independence. There is potential for improvements to both the well-being of those living with dementia and to the cost effectiveness of care through careful planning and design of the environment (APPG, 2011). This is the subject addressed in this report.

2.2   Dementia and the Physical Environment

Since the 1980s there has been a steady increase in the professional and academic literature linking design of the physical environment and dementia and dementia care (Day, 2000). The adaptation of the environment can make the life of a person living with dementia easier; not doing so can result in unnecessary distress and reduced quality of life (Parsons, 2001).

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Adaptation of the environment for those with dementia is still a relatively new exercise, specifically in the case of the acute care sector (Dementia Services Development Centre, 2012).

Progress is being made to raise awareness of the impact of the environment on those living with dementia, such as the commitment to the care of people with dementia in general hospitals by the Royal College of Nursing (RCN, 2012). Resources such as the Dementia Supportive Environment Audit Tools developed by the Dementia Services Development Centre (DSDC, 2012) and the King's Fund project Enhancing the Healing Environment (King's Fund, 2012) have been introduced to help planners, architects and hospital staff with the design of the acute care setting.

2.2.1 Background

The need to consider the impact of the hospital environment on the experience, health and well-being of patients who have dementia is an important consideration for architects, nurses, designers and hospital managers, amongst others. Having an optimum design can result in better care, with a more positive experience for patients and staff; whilst also contributing to savings in costs (DSDC, 2012). It is estimated that at any given time 25-40% of the patients in the acute hospital ward and accident and emergency settings have dementia (DSDC, 2012). More than 90% of people with dementia are known to experience behavioural and psychological symptoms which can cause stress for the individual, their family and staff caring for them (Robert *et al*, 2005). Some of these symptoms such as disorientation, confusion, memory loss rigidity, loss of movement, hallucinations (both visual and audio), can affect how a person with dementia is able to undertake day-to-day activities and is able to react and get around the physical environment (Parsons, 2001). These symptoms are often exacerbated during times of stress with a key trigger of stress being attendance at hospital. This can ultimately result in damaging short and long term impacts upon the physical and psychological health of the person with dementia (NHS Confederation, 2010). It can also often lead to a longer stay in hospital which increases costs for the NHS (DSDC, 2012).

2.2.2   Physical Environment and Dementia

When considering the impact of the environment on the well-being of patients who have dementia it is important to consider the interrelationship between the personal competence of an individual with dementia and the environmental demands they experience (Goodall, 2006). This interrelationship is also addressed by Zeisel *et al* (2003) who suggest that "a balanced combination of pharmacologic, behavioural and environmental approaches" is most likely to be effective in improving the well-being of people with dementia.

Much of the evidence on the physical environment and people with dementia relates to residential care settings and not hospitals. However, these settings are very different. Hospitals are clinical settings where the aim is to treat patients for healthcare issues and to have as short a patient stay as possible. Whereas residential settings often provide care on a long-term basis, with an emphasis on providing social care and perhaps some health care for residents. There are potentially conflicting issues when caring for a person with dementia in an acute setting that do not exist within a residential setting. For example familiarity is important to a person with dementia yet this is difficult in an acute setting where stays are intended to be short (DSDC, 2012).

The integration of different aspects of dementia care, which includes attention to and use of the therapeutic environment are summarised by the RCN and the DH (2011) who have issued five principles as part of a commitment to the care of people with dementia in hospitals. The principle that focuses on the environment includes recommendations that address the use of:

- Appropriate lighting
- Floor coverings
- Aids to support orientation and visual stimulation
- Personalising of the bed area and adequate space
- Resources to support activity and stimulation

A resource that suggests the features of the hospital environment that impact on the well-being of people with dementia is the recently published environment assessment tool kit (King's Fund, 2012) developed as part of the Enhancing the Healing Environment

programme. The assessment tool addresses how the environment promotes seven features of the patient's experience:

- Meaningful interaction between patients, their families and staff
- Well-being
- Eating and drinking
- Mobility
- Continence and independence
- Orientation
- Calmness and security

Disorientation and therefore stress for a person with dementia may be relieved through design solutions, which do not need to be expensive or complicated. Some of these solutions include social areas, easy to read information and clearer way-finding and signage (NHS Confederation, 2010). Way-finding can be made easier to understand through the use of pictorial signs or colour codes. Incontinence coupled with disorientation can make the life of a person with dementia stressful. An example of a design solution to this situation is to colour the toilet doors differently to other doors so that they are easily found and distinct from the walls and other doors (Design Council, 2011).

In a recent report published by the Dementia Services Development Centre (DSDC, 2012), Sterling University identifies 16 'key design features', 6 'key features of specific rooms' and 3 'outside' features that should be considered in the design, planning and building of a hospital. These are very similar to those which have been previously identified as recommendations and/or considerations for people with dementia in residential care settings. They are:

- Key design
  - Floors
  - Clocks and calendars
  - Lighting
  - Sound
  - Furniture
  - Mirrors
  - Enabling relatives and friends to remain with the patient
  - Storage

- Nurse call system
- Nurses' stations
- Essential notices and leaflet racks
- Key features of specific rooms
  - Waiting rooms
  - Physiotherapy and occupational rooms
  - Toilets
  - Bathrooms/shower rooms
  - Bedroom areas
  - Day rooms
- Outside
  - Looking outside
  - Getting outside
  - Being outside

2.2.3   Considering Evidence from Residential Care Settings:

In the National Institute for Clinical Excellence guidance on supporting people with dementia and their carers in health and social care (NICE, 2011) it is reported that people with dementia and formal and informal carers of people with dementia prefer and interact better in a non-institutional setting. This presents a design challenge for hospitals to be designed and function appropriately as less institutionalised settings. Another challenge is that this approach is difficult to realise due to the official systems and regulations that are already in place within the hospital environment (Moor *et al.*, 2000). Research findings related to single rooms and the creation of 'homeliness' may not be transferable to the hospital setting as unlike in residential care the single room could be the only room in which the person with dementia may spend their time. In long-term care settings, day rooms and dining rooms would also be accessible yet these types of rooms are less prevalent in modern hospitals (Fleming & Purantare, 2010). The goal of homeliness for the whole of a hospital environment, which has a primarily clinical function, may also be inappropriate. However, the inclusion of homelike, personal belongings in a patient's immediate personal environment could be a realistic compromise.

From a practical viewpoint, Utton (2006; 2009) and Kerr (2007) provide examples of environments and how they enable and disable people with dementia. Both authors describe the functionalities and constraints related to the space designed for people with dementia as well as ideas that support the well-being of people with dementia. Kerr (2007)

goes further and describes 5 design principles that support people with dementia: calm and stress-free; predictable and make sense; familiar; suitably stimulating and safe.

The term 'built environment' encompasses the surroundings or conditions, created and built through human intervention, where a person, animal or plant lives or operate (Codinhoto *et al,* 2008). A review of research studies that explore the impact of the built environment for the design of long-term environments for people with dementia concluded that designers may confidently use environmental design features to enhance the well-being of people with dementia (Fleming & Purantare, 2010). These include unobtrusive safety measures; variation in ambience; size and shape of spaces; provision of single rooms; maximisation of visual access; and controlled levels of stimulation. In the long-term care setting they found that there is less agreement on the usefulness of signage; homeliness; provision for engagement in ordinary activities; small size of outside spaces and the lack of its provision.

Day *et al* (2000) undertook a review of empirical research on guidelines on physical design of residential settings for people with dementia. They found that design recommendations were grouped into four main areas: planning principles; general attributes; design organisation and specific rooms and activity spaces. In terms of planning principles, planning should appropriately accommodate the whole spectrum of illnesses and care needed when developing a dementia care facility. The arrangement of spaces within the care facility should support individual's sense of orientation. The design of particular rooms such as bathrooms should preserve resident's dignity and privacy.

In addition, Zeisel *et al* (2003) found that certain environmental attributes in residential care settings resulted in decreased levels of anxiety, depression, social withdrawal and aggression amongst people with dementia. Environments that had a positive effect on the well-being of people with dementia provided a sense of privacy and personalisation, provided controlled sensory input, accessibility to different types of rooms and used restrictions on exit that were covert rather than overt.

When considering the impact of the physical environment upon mental health and well-being, four specific features should be taken into account: the fabric of the environment; the ambience of the environment; the psychological impact and the sociological impact of the

environment (Cooper *et al*, 2008). This framework was generated by these authors through a systematic compilation of more than 300 pieces of evidence from different types of environments.

In this respect, the fabric of the environment includes the design and construction of buildings (e.g. floors, walls, doors, ceilings, windows) and the spaces between buildings (gardens). Consideration should be given to the use of colour (e.g. red, blue, yellow); texture (e.g. rough, smooth, silky); pattern (e.g. checked, stripes, flecks); material (e.g. wood, metal, rubber) and structure (e.g. hard, soft, firm).

The ambience of the environment pertains to the surrounding character and atmosphere of the environment. This includes noise (background, white-noise, silent, loud, constant); lighting (harsh, stark, mellow, bright, dim); temperature (cold, hot, mild); colour (warm, cool, cheerful, natural, subdued); air quality and ventilation (clear, polluted, dirty, fresh); humidity (damp, dry) and views of nature (natural sunlight).

The psychological impacts of the environment are the perceptions of the physical environment and its impact upon individuals such as density (e.g. crowding, desolate); sense of safety or fear; way-finding (e.g. easy, hard, confusing); accessibility (e.g. difficult, direct, easy, off putting) and identity (e.g. homely, clinical, institutional, traditional or modern).

The sociological impact of the environment is the social significance of buildings and their environments in relation to symbolic values and meanings, for example grouping (e.g. young/old, political/religious, staff/patient, male/female, unisex space/single sex space, public, private and communal spaces for socialising, care, work, leisure, reflection) amongst others.

The outside space is also of great importance in the area of care and well-being for a person with dementia. With more and more evidence claiming that outdoor exercise is beneficial both physically and mentally (Sustainable Development Commission, 2008; Mind, 2007; Fukukawa *et al,* 2004; Abbott *et al,* 2004; Ulrich, 2004; and Larson *et al,* 2006), designers are placing just as much importance on the location and outdoor space for people with dementia as the buildings themselves.

2.2.4   Environmental Psychology - Theoretical Ideas

There are many theories explaining how the built environment affects human life and behaviour. The intention of this report is not to cover all of them but rather to give a brief account to explain the different elements that are believed to explain the relationship between the built environment and health related outcomes. Sundstrom *et al,* (1996) suggest that six theories have been more influential than others in recent research developments within the environmental psychology field. These are described below:

- Arousal theory predicts optimum performance and satisfaction under conditions of moderate arousal when triggered by environmental features such as sound, temperature and light (Thayer, 1989; Biner *et al*, 1989; Anderson, 1989; Bell, 1992).

- Environmental load theory predicts that humans have a finite capacity for processing stimuli and information and that we cope with sensory or information overload through selective attention of high-priority inputs and ignoring low-priority inputs. Veitch (1990), Smith (1991) and Loewen and Suedfeld (1992) are examples of researchers who have tested the environmental load theory.

- Stress and adaptation theory explains that environmental extremes such as temperature, sound, and other variables trigger physiological and psychological stress, as well as the development of coping and adaptive behaviours that mitigate stress. Examples of researchers testing this hypothesis include Hedge (1989), Baum *et al* (1990), Hobfoll (1991), Rubonis and Bickman (1991) and Baum and Fleming (1993).

- Privacy-regulation theory relates privacy, spatial behaviour (i.e. how an individual or group react to the immediate built environment and its occupants), crowding, and territoriality with a human tendency to seek optimum social interaction, partly through use of the physical environment (Altman, 1993). It also suggests that the cause of stress also triggers the mitigation of it. Research in this area includes that by Block and Garnett (1989), Haggard and Werner (1990) and Brown (1992).

- The ecological psychology and behaviour setting theory views environments in terms of behaviour settings which are defined as "*small scale social systems composed of people and physical objects configured in such a way as to carry out a 'routinised' program of activities with specifiable time and place boundaries*" (Wicker, 1992). This hypothesis is

investigated in the work developed by Schoggen (1989), Sommer and Wicker (1991), Wicker (1992) and Wicker and August (1995).

- Transactional approach is related to privacy regulation theory (Sundstrom *et al,* 1996). According to Brown *et al*, (1992), Werner *et al,*(1992) and Altman (1993) the physical environment provides context for social interaction that can support, constrain, symbolise, and confer meaning upon various aspects of social relationships.

- Proxemics theory relates peoples' use of their perceptual apparatus in different emotional states during different activities, in different relationships, built environment settings, and contexts (Hall, 1968; Cook, 1970; Raybeck, 1991).

- The language of space theory predicts that the built environment has signs and specific characteristics that can be 'read' by its users, therefore influencing human behaviour (Lawson, 2001). Lawson (2001) recognises that the language of space model is simplistic, and it does not include all types of behaviour such as those triggered by social phenomena as described by Proshansky *et al* (1976) in Lawson (2001).

Additionally, research about the design and use of healthcare facilities for people with mental health needs (e.g. Lawton, 2001) has been conducted by specialist healthcare designers, health professionals and the NHS Estates (e.g. NHS Estates, 1996). These reviews aim to clarify a broad set of issues related to mental illness and its connection with the physical environment. They address, for instance, the lack of consensus amongst candidate theories and how knowledge can be gained from research studies.

To summarise, the phenomena under investigation, i.e. changes in humans' reactions due to the stimulus caused by characteristics or different configurations of the built environment, can be explained in different ways according to the observed outcome. From the presented theories it can be said that:

- The built and social environment cannot be considered as separate environments
- The built environment is perceived through the use of our senses, which stimulate our cognition in the first place
- Cognition can be stimulated when the 'natural' environmental balance is disturbed, through the 'readability' of the features of the built environment or through humans'

priorities. However, the parameters which establish balance, readability, and priorities and whether they vary from person to person were not identified in the literature

- The psychological impacts caused by the built environment may lead to subsequent physical or physiological consequences

- Features of the built environment triggering negative effects also cause the development of coping mechanisms

2.3   Discussion

There is the need for research to be undertaken that investigates the impact of the hospital environment on the experience and well-being of patients who have dementia. In the absence of a significant body of research evidence that specifically focuses on the design and use of the hospital environment for people with dementia, it is necessary to draw upon research evidence that investigates the impact of the residential care environment on people who have dementia. The same issues such as confusion, wandering, disorientation and agitation may affect a person with dementia and the way they navigate and respond to the environment in both residential and acute care settings. Some of the solutions that are used in residential care settings are transferable to acute care settings, for example the use of different floor colours to highlight the transition from one area to another (Gutman, 2005).

Evidence based practice requires the integration of the best available research findings, the patients' experience and the practitioners' expertise (Sackett, 2000). It may be necessary to integrate research evidence from studies of the residential care environment with evidence from patients' (and their family) and practitioners to generate the evidence base for the design of hospital environments until a wider body of hospital focused research findings are available. The use of 'listening events' attended by people who have dementia, their families, and informal carers, health and social care workers, architects and designers amongst other stakeholders, is an approach that can capture the experience and expertise of patients and practitioners alike. The evidence collated from such events, can then be used to inform judgements about the transferability of research evidence between care settings. The remainder of this report details the undertaking and findings from such a listening event as a means of sharing insights and informing future research and action in the field of dementia care within the built healthcare environment.

3   THE LISTENING EVENT APPROACH

The one-day event comprised a range of techniques to engage participants in informal, facilitated activities to prompt discussion on topics of importance to them and the event facilitators. Whilst not research, the event did allow us to gather a range of information, feedback, personal experiences and insights from participants. In total, seventy seven people took part in the event including the facilitators and note takers.

For the purposes of organising the day, all participants were categorised as representing four core stakeholder groups: people with dementia, carers of people with dementia, health and social care professionals and designers. In reality, these categories were overlapping as many participants spanned more than one e.g. designers and health and social care professionals were also carers of people with dementia. Grouping participants in this way simply enabled us to be confident that a range of different perspectives would be gained and that no one grouping was under-represented or 'given less of a voice'. Views were gained from the 77 people that attended the listening event as described below.

- 4 people living with dementia
- 10 informal carers of people with dementia (e.g. family members)
- 40 health and social care professionals involved in delivering care services for people with dementia
- 3 people involved in designing spaces for those living with dementia
- 20 academics investigating some aspect of dementia care (7 participated as note takers, 7 as facilitators, 1 as event Chair and 5 participated in the debate).

Group discussions were organised into three consecutive sessions. Each table had a facilitator who had been prepared for the role in advance, and who ensured that each participant had a chance to contribute if they wished. All tables were equipped with a digital audio-recorder, four colours of post-it notes, flip-charts pads and pens. An individual was also present who had been prepared prior to the event to act as a note taker, with

instruction to be as detailed as possible to enable clarity of meaning to be grasped after the event. Summary notes of this kind can often lack meaning after an event and so each discussion was also audio-recorded with permission of those present, simply to enable more accurate reporting.

Prior to discussions, as a warm-up exercise, participants were given a 20 minutes overview of the purpose of the day and its format. Each discussion session is further described below.

3.1   Discussion Session One

In the first discussion group participants were presented with a printed set of 10 photographs depicting different areas of hospital environments. The photographs were of traditional hospital settings as well as modern, award winning designs. Pictures were shown to stimulate discussion and gauge participant reactions about what factors they felt worked well and less well in those environments for people with dementia, from their different perspectives.

Participants were allocated a coloured, adhesive-backed dot to represent the stakeholder group they belonged to and directed to a table formed by a mix of different stakeholders. They were asked to consider whether the photographs depicted settings that they believed would help or hinder people with dementia. They were also asked to discuss and share issues with others about their experiences of care environments. Participants were asked to individually write their positive experiences on green post-it notes and negative ones on pink ones.

Additional experiences and issues raised that were not directly related to the photographs were captured on blue post-it notes and placed onto a sheet of flip chart paper at the end of the discussion session.

Each group identified the two most important issues that they wished to share with the main audience, which was done by writing these on further post-it notes and displaying them collectively on one wall of the room.

Due to the visual nature of this activity, discussions were video-taped as well as audio-taped for accurate reporting.

One of the event leads then themed these priority issues into eight key pairs that were then distributed to participants to focus on in the next set of discussions. The topics that emerged in the first session that were considered as a priority and discussed in Session 2 were:

1. How do I find my way?
2. Staff and personal engagement (includes care related issues as opposed to Built Environment)
3. How can I feel safe?
4. Health/ hygiene/ infection control
5. Room with a view
6. It's too noisy
7. Using colour
8. Too much clutter
9. Other priorities - combined services (include mental health), carer involvement in care, cost effectiveness

3.2 Discussion Session Two

In this session, participants could choose where they sat and so perspectives were mixed. Participants selected which of the topics derived from Discussion Session 1, that they wished to discuss in greater depth. Participants were also asked how hospital environments could be improved for people who have dementia. The focus of each discussion was on identifying what could be done to provide *solutions or improvements* to the issues identified in Discussion Session 1.

To prompt discussion, a further set of only award winning hospital environment photographs was given to each group. Participants were prompted to consider whether the hospital environments depicted in the photographs would help or hinder people with dementia.

There was further discussion about their own and anecdotal experiences of care environments. Participants jotted their positive experiences on green post-it notes and negative ones on pink ones. Solutions or improvements that were proposed but not related to the photographs were captured on blue post-it notes and attached to a sheet of flip chart paper.

Each group was asked to agree amongst them, their two most important discussion points. These were again collated from all tables so that all participants could look at these when displayed on a single wall in the room. A verbal summary was given by the event Chair at the end of the session.

Key issues and problems identified in Discussion Session 1, as well as key solutions identified in Discussion Session 2, were displayed on flip-charts and participants asked to identify the 3 most relevant ones. For this purpose, an arbitrary means of identifying which issues were of most concern was undertaken whereby participants placed their allocation of 5 coloured self-adhesive dots against the issue of their choice. They could put one or all of their stickers on an issue. This was followed by a simple counting exercise to see where participants had placed their 5 stickers. The colour coding also enabled the spread of concerns of different stakeholder groups to be identified.

3.3   Discussion Session Three

This discussion session followed a similar process to the other two sessions and focused on identifying what could be learnt from the home environment and non-hospital environments. Three themes were introduced by the event facilitators to focus discussion: a) independent living at home; b) the outdoor environment; and c) assistive technology. Participants were asked to join a table topic that they felt best able to contribute to or had a personal interest in. Participants discussed the issues, problems and solutions of the home environment, according to these three themes and how they could be used/adapted in hospital environments. Participants were again encouraged to share their own experiences and insights. Participant's individual positive experiences were jotted onto green post-it notes and negative ones on pink ones. Each group was asked to agree the two most

important issues and/or solutions that they had discussed. These were then shared with the main audience at the end of the session.

3.4   Analysis Approach

A multi-disciplinary team comprising two academics from the School of Nursing, Midwifery and Social Work and two academics and a researcher from the School of the Built Environment at the University of Salford undertook analysis of event discussions. The analysis was carried out with a focus on capturing the content of what people told us and establishing the participants' sense of priority.

The analysis began by listing the identified issues, problems and solutions identified by participants. In this respect, analysis used an adapted version of the 'impacts of the physical environment on mental well-being' framework as devised by Cooper *et al,* (2008). This framework is described in the literature review section of this report. In addition to the four themes identified by Cooper *et al* (2008), three new themes emerged from the listening event.

Themes identified by Cooper *et al* (2008):

- Fabric of the Environment
- Ambience of the Environment
- Psychological Impact of the Environment
- Sociological Impact of the Environment

New additional themes identified from listening event:

- Functional Activities and Safety
- Information and Communication
- Approaches to Care

Here is an overview of the composition of the three new themes:

Information and Communication: This theme was about giving and receiving information, signage, assessment, visual cueing. The target audience of information and communication

may be for patients, visitors or staff. Information and communication may be about purpose of rooms, space, instructions for care, personal preferences, health and safety, directions. Information and communication may be visual, written or aural. The nature of information and communication may be confidential or open access and required by all users of hospital environments.

Functional Activities and Safety: This theme was about the day-to-day activities of people who have dementia: eating, drinking, using toilets, hygiene, walking and recreational activities. Functional activity of people who have dementia may be reduced by visual, hearing, muscular-skeletal and neurological impairments. The theme includes related arrangements and activities that minimise risk of harm to patients, staff and visitors. It includes the accepted level of risk stated in health and social care policy, law or agreed by consensus of staff. It includes arrangements and activities that maintain the physical, emotional, psychological and sociological well-being of patients.

Approaches to Care: This theme explores a range of issues pertinent to the provision of care including strategies, care interventions, assistive technology, nurse education, dignity, privacy and confidentiality with regards to care of patients who have dementia.

From the discussion data, the team populated the 7 overarching themes previously identified within the literature and from their own deliberations. Interpretations were compared and contrasted from a built environment and health care perspective. These are themes are presented in Section 4.

During analysis a number of conflicting issues were identified between the requirements of a person with dementia and what was deemed as suitable for an acute care setting. For instance a person with dementia may want independence and freedom however in an acute care setting this can pose dangers and so this raises risk and safety issues. A list and description of these conflicting issues can be found in Section 4.9.

4   SUMMARY OF FINDINGS

This section presents a summary of the issues that arose during discussion Sessions 1 and 2. Conflicting issues are also presented towards the end of each section where relevant.

4.1   Fabric of the Environment

In regards to the fabric of the environment, several issues were raised including the use of outdoor spaces, the use of adequate colour schemes, patterns of walls and flooring, wayfinding, accessibility, individual preference and occupation.

The discussions related to outdoor space (mostly about gardens) indicated that this is perceived as having therapeutic qualities. In this respect, having access to the outdoors and a pleasant view is very important for a person with dementia as a source of relaxation. Despite its perceived positive impact, there are issues related to access in terms of whether or not access needs to be monitored, thus revealing conflicting safety and independence requirements.

Colour was an issue mentioned many times throughout this exercise. The 'wrong' use of colour is perceived as a cause for confusion, falls and disorientation. The 'correct' use can help with wayfinding and emotions. There was consensus that the use of increased 'contrast' seems to provide support to people with dementia. Related to colour, patterns were in the main seen as a negative feature for a person with dementia, whether they are on the floor, curtains or ceiling. Participants who had dementia commented that colour and pattern that they considered to be like that found in 'nature' were preferable to what they considered as being 'artificial'.

Furthermore, wayfinding was mentioned as one key contributor to stress. Participants have declared that wayfinding needs to be clear and simple - not too much information, at the right level (eye sight) and not too many colours. In this exercise, it was not possible to gather

a meaningful measure for the right amount of information, level or the number of colours. In this respect, participants' opinion was divided as to whether colour coding was a positive or a negative feature for people with dementia.

Additional issues were also discussed in relation to accessibility and preference. Accessibility to facilities within the hospital such as the toilet and outdoor space needs to be easy, according to participants. Easy access for participants was related to wayfinding and proper signage, but also to authorisation of access. For instance, some participants mentioned that some care facilities offer gardens for staff but not patients. This subject triggered discussions regarding individual preferences. The discussion brought to light that the design of healthcare facilities needs to ensure they are functional, clinical, safe and acknowledge that it is not possible to cater to certain individual preferences (e.g. comfort, style), as "one size does not fit all". The counter argument was that not attending to people's preferences may lead to accidents, such as falling caused by the 'incorrect' use of colour, material, pattern and lighting which can in turn lead to more serious health problems.

A conflicting issue that emerged during discussions was related to requirements for a more aesthetically pleasing environment *versus* an environment that supports easy infection control. On the one hand, patients and carers felt that a more relaxing environment is one that resembles the home environment. On the other hand, clinical staff argued that an environment that is cluttered with personal things in pursuit of creating 'homeliness', can be hazardous and make it difficult to implement infection control measures.

4.2   Ambience of the Environment

In relation to the ambience of the environment, similar issues emerged during the discussion sessions. Clutter, for instance, which can be in a toilet, on a bedside table, in a corridor, on a floor or in a garden, was perceived as adding to the confusion of a person with dementia, which can lead to falls and stress.

Lighting was another characteristic mentioned amongst participants. It was discussed that lighting needs to be at the right level for a person with dementia as either extreme (too much or too little) can cause disorientation, which again can lead to falls. Glare, in particular

was mentioned as a trigger of negative effects. Natural lighting should also be considered in the design of healthcare facilities. Well-lit corridors and bedrooms were considered important in stimulating people with dementia to walk and engage in physical and social activity.

Noise was a characteristic that emerged as relevant for people with dementia. Loud noise, continual noise or just general 'hustle and bustle' was suggested as being a source of great agitation to a person with dementia. Some solutions suggested to reduce noise levels, related to the design of furniture and devices and use of fabric in a way to absorb noise.

Colour was an issue in both this theme and in Fabric of the Environment. In the current theme, use of it relates to its incorrect use, leading to falls and disorientation. This discussion focused upon the impact of colour on emotions and how they can aggravate or soothe. It was further perceived that clinical areas can be 'warmed' by colour, without compromising health and safety. Natural colours were favoured over artificial colours. There was a view that hospitals need to make greater use of current research evidence on the therapeutic use of colour.

Outdoor space is known for its therapeutic qualities. It was again raised that having access to a view is very important for a person with dementia. Emphasis was placed on feeling and smelling the content and surroundings in outdoor spaces.

Another feature of the built environment that was discussed is art. Art was viewed as having positive therapeutic effects on people. In this respect, only a narrower concept of art was considered and mostly related to having artwork (pictures, sculptures, music) as complementing the ambience. However, art was also (co) related to individual preferences rather collective ones. In respect to access to gardens, the use of digital images was suggested where there are limitations regarding access to real ones.

Conflicting issues arising from the discussions were the same as in the previous section. Issues around aesthetic composition of the environment (highlighted by people with dementia and their carers) seemed contradictory to functionality issues raised by clinical staff. Also, issues related to balancing respect for the independence of individuals and safety measures to protect them.

4.3   Psychological Impact of the Environment

The need for different types of space was discussed many times during the discussion sessions. Emphasis was given to the need for both a quiet space and a space for socialising. In respect of the psychological impact of the environment, spaces for socialising were seen as essential to people with dementia. However, throughout social interactions the person with dementia may need quiet space to 'debrief' or relax if the social interaction has caused some level of anxiety or another negative feeling.

Moreover, it was discussed that some design features of the built environment may lead to people feeling imprisoned. It was reported that certain characteristics, such as the (in general, dark) colour and lighting, as well as bars on windows can trigger feelings of imprisonment. Living independently, it emerged, contributes to high self-esteem pushing away the self-awareness of living with a condition (i.e. dementia). In this respect, we interpreted that a subtle stigma exists that is related to having dementia and depending on others to perform daily domestic tasks (risking learned helplessness).

Lastly, the issue related to homeliness was considered within the psychological impacts of the built environment. There was consensus around the fact that people with dementia demonstrate less stress if they feel like they are 'at home'. This debate triggered discussions around how to increase the homeliness of healthcare facilities when they comprise unfamiliar surroundings filled with strangers.

4.4   Sociological Impact of the Environment

 The main issues within this theme were around personalisation and familiarity with the environment. Personalisation and familiarity of the person with dementia's space (e.g. through using photos and personal possessions) was highlighted as important in the alleviation of agitation. Despite its positive impacts, the discussions turned to the difficulties of having inpatients bring personal items to a hospital environment. Issues raised were focused on the limit of items that could be brought in different hospital environments, clutter and the security of such items.

As highlighted previously, quiet as well as communal spaces were also viewed as necessary features. Patients, whether they have dementia or not, were expected to require both a quiet space where they can get away from the noise and busyness of the hospital, as well as space where they can socialise and interact with others. Both spaces were considered equally important. This debate raised a few issues about staff practices (unnecessary talking/chattering) rather than just the buildings themselves, and the need for inter-professional collaboration amongst health care staff and designers plus public and patient involvement. This was so, services and building design decisions were informed by those who use hospitals rather than a reliance on post inpatient evaluation.

4.5   Functional Activity and Safety

The discussions on what aspects of the hospital work well for people with dementia and which aspects could be enhanced, identified the need for an 'enabling' environment. This related to both the immediate environment around bed space for in-patients and wider environment of hospital wards, departments, corridors and communal spaces, internal and external environments.

Several aspects of the immediate bed space surrounding a patient were highlighted. It was suggested that attention by designers and health care staff should focus on ensuring the inclusion of enabling features of this environment that promote and support functional activities such as eating, drinking, walking, engaging views and the ability to return to the correct bed space.

In the wider ward are specific reference was made to the design and environmental features of toilets, including the importance of having doors that clearly indicate purpose of room and of toilet flush handles needing to look like flush handles rather than being of an ultra-modern non touch design. The benefit of non touch design of flush handles from an infection control perspective are acknowledged but the need to promote the independence of people with dementia in day-to-day living must also be taken into consideration.

This raises the challenge in many of the issues discussed, of the need to balance one important aspect of patient care with equally important but opposing duties of care. For

example, the need to balance patients need for freedom of movement with the promotion of safety.

Infection control is an important aspect of care and simple methods such as hand washing by staff and patients are key to promoting this aspect of safety and well-being. If taps used for hand washing are of a modern design, that do not bear a resemblance to traditional taps, this may be a barrier to people with dementia being able to maintain good hygiene practices such as hand washing.

Many issues identified as relating to safety, also related to functional activity. Issues raised related to how the environment was viewed to contribute to the safety of people with dementia, highlighting the balance that is required between risk taking, freedom, independence and duty of care. One dimension frequently highlighted was the activity of walking around the immediate environment, the risk of falling, the risk of getting lost and the promotion of independence.

Suggestions for addressing concerns in relation to walking included:

'Managing risk of falling and getting lost' and 'Promotion of walking and independence'
Disguise doors that patients would not need to use e.g. to clinical areas or sluice, by painting the same colour as the surrounding wall
Use of hand rails and lean rails in all hospital wards and corridors, to facilitate safe walking
Use of display cabinet by each bed to hold personally significant items that would assist with identification by a person with dementia of their personal bed space
Use of colour coded walls to distinguish between different areas of wards and different areas of the hospital
Clear and helpful signage (as discussed in the 'Information and Communication' section of report)

Features that are found in dementia specialist units need to be included in general and other specialist wards and departments e.g. lean rails, appropriate flooring, coloured doors

The balance between functional activity and safety also appears to impact on the psychological safety of patients with dementia and repeated reference was made to the 'prison like features' of hospital environments. An example of such features was a first floor hospital ward which had windows that provided a pleasant outdoor view yet were obscured by bars that promoted safety.

Psychological well-being was often discussed as being positively influenced by the quality of the view available to the person with dementia e.g. from the bed space. Where views of the outside, nature, gardens and people were available this was suggested as being preferable to views of walls and corridors.

The issue of balancing the safety needs of people with dementia and the need to have equipment for the provision of care was highlighted in discussions of equipment that might be dangerous if incorrectly or inappropriately used e.g. emergency trolleys, wheel chairs, intravenous infusion pumps. Such equipment could also contribute to a cluttered environment which may be confusing to a person with dementia.

Access to outdoor space for people with dementia was raised as a positive feature of hospital environments, although use of such space may require relevant support by carers or staff. Safe, enclosed therapeutic gardens were suggested as the ideal outdoor space to be accessed. Some hospitals, such as Wythenshawe Hospital in Manchester, have a specific 'green' organisation identity that is evident in the creation of many garden spaces. It was felt that some of these spaces could be further developed to be dementia friendly, by considering which features could be enhanced to promote the safe use of these spaces by people with dementia.

Although discrete information strategies such as the Butterfly Scheme have been designed to promote appropriate care and safety of people with dementia (by use of a butterfly sticker to identify patients who have dementia), such approaches risk breaching confidentiality of people with dementia. Participants were not aware of any other patient group that has a publically viewable symbol or label identifying their illness on view. It was argued that professional communication that maintains confidentiality is appropriate for all patients. The needs of people with dementia who also have a sensory deficit were

highlighted for consideration. In addition to the issues identified, further thought was indicated regarding how the environment could be enhanced to be enabling for patients who also have visual and hearing impairments.

4.6   Information and Communication

In terms of information *about* people with dementia, participants spoke about the importance of communicating those people's needs and the use of symbols such as the aforementioned Butterfly Scheme. This raised questions as to how care service providers currently share information about patients and whether this could be done in a more dignified and private way.

Generally there was a shared view that a combination of words and pictures/images was the ideal approach in providing environmental information *for* people with dementia. These were in terms of day-to-day navigation to reach facilities such as toilets, dining spaces and exits. Too much text and visual information was considered likely to 'bombard' a person with dementia. Any visually presented material needed to be visible to a person with dementia who may have visual impairment. There was some discussion about whether signage needed to be different for people who did or did not have dementia, yet no agreement was reached. There was also a belief that many people with dementia look down a lot and may not notice signs above a certain height. It was questioned whether clearly presented written and visual information would be comprehended by a person with dementia. These issues suggest that the evidence base on visual impairment and people with dementia may be worth examining further. Related to these issues was the appropriateness of some objects and whether they were easily identifiable by a person with dementia e.g. non-touch taps which are triggered by a hand sensor. Whilst use of colour was also considered in relation to zoning of buildings or the function of areas, it was quickly countered with the difficulty of explaining the meaning of the different colours to people e.g. flooring, doors, and zones. It was acknowledged that lighting needed to be sufficient for people to be able to see signage and visual cues clearly.

Participants were less in agreement as to whether artefacts representing a person with dementia's previous home or their actual personal belongings should be used to foster a

sense of familiarity that may help orientate them e.g. a kettle. Participants were very aware that styles of household goods and fixtures varied dramatically across people's life course and modern day telephones for example may be hard to identify as being such a device. A range of strategies were advocated such as use of 'memory boxes', wallpaper with a bookshelf mural on it to discourage congregating in doorways or disguise the doors themselves, prompt cards stating "you are in hospital - your family knows where you are", and a version of the Alzheimer's Society 'get to know me' system whereby a card records individual's preferences such as name, food, pastimes and so on.

At times participants recognised that information is wanted directly *from* people with dementia such as when they want assistance. In various care settings this may involve noisy call systems or flashing lights. The availability and evidence base for systems and devices to manage auditory and visual nuisance/assistance and nurse call/alarm systems and so on, was considered in need of further exploration. The advantages and disadvantages of technologies that inform monitoring personnel about the status and well-being of people with dementia, such as door alarms and movement sensors were discussed. The need for balancing privacy and safety was again raised with regards to these.

Whilst mentioned previously, an important message to be communicated was where people were physically located. A consistent view about some modern healthcare environments was that people with dementia would struggle to identify where they were, as many such places did not look like traditional hospitals of past decades. This view was reinforced by several participants who explained how people with dementia may draw heavily on long term rather than short term memory in making sense of their surroundings.

4.7 Approaches to Care

A range of insights was shared about the care approaches that health care staff adopted in relation to people with experience of dementia. A particular challenge concerned the use of the term 'people with dementia' as it risked bunching people together as a group with loss of their individual identities. This prompted further discussion about the fact that acute health care settings in particular are used by large numbers of people who have dementia. There were mixed views based on perceived advantages and disadvantages about whether

people with dementia related needs should be cared for in dedicated settings or in settings for the general adult hospital population. For example, a preference for integration of people with dementia across care settings was countered by a need for such things as rest amongst patients in a cardiac care setting who may be disturbed by someone who was agitated due to dementia. Healthcare environments were commonly perceived by participants as less than sympathetic to the needs of people with dementia.

Many suggestions were made by participants as to the suitability of standard hospital equipment illustrated in photographs they were shown. Many items of equipment such as bed pedals were viewed as likely to attract attention of somebody who was confused or restless who may then fidget with them. This raised some discussion about how to best occupy people with dementia to settle them. Several comments showed how different care settings were known to have responded by having equipment fitted to aid people who may be keen to walk e.g. lengthy and chunky hand rails to walk along. Other areas had seemingly given little thought to this and there was a lack of such aids and adaptations.

There was a general consensus that 'one size won't fit all' and that people with dementia should not have their needs overlooked in a sea of other patients. Finding a middle ground was seen as a major challenge. Some positive approaches were identified including shared bedrooms for some people who may be less lonely when cared for that way, whereas others may prefer a single room. The importance of suitable staff interaction with a person with dementia was stressed as well as the environment in which they are cared for. The two were viewed as inseparable. There was a general plea for staff to be specifically trained in dementia care and for assessments of new admissions to hospital to be made by staff who are dementia aware also. As well as adequate staffing numbers there was concern about calibre of available staff. Therefore, training provision for all staff groups about dementia care was highlighted by many participants.

There was recognition of some practices viewed as positive in the care of people with dementia especially. For example the provision of a therapy space for aromatherapy or 'quiet time' was raised several times, as was the need for private consultation space for discussions with health care staff. The provision of hearing-looped rooms to help those with hearing impairment was advocated as standard practice. Avoidance of some practices was

highlighted such as the carrying of 'jangly' ward keys. Again technologies such as door alarms were also raised as a means of assisting the staff to care for large numbers of people but not at the cost of care quality. Less intrusive technology such as those to locate patients who had 'wandered' away were favoured by some participants although they recognised they would need safeguards in place to protect privacy and so on.

One approach viewed as particularly effective was where general hospital care environments have easy access to input from mental health nurses to support the care of people with dementia. A key message was that quality of care was far more important than the physical environment it was delivered in. Participants also reminded each other that dementia affected people across a wide age range including considerable numbers of people in their forties and fifties.

Whilst personalised care was mentioned frequently, there was also recognition that the needs of informal carers of people with dementia such as family members, are important to meet too. The preference for some informal carers to be involved in care activities such as eating at mealtimes were considered important. In addition to mealtimes, other social gathering opportunities were highlighted as valuable, such as gardening and even having a singing session whilst gardening had been found to be beneficial.

4.8   Conflicting issues ('trade offs')

This section sets out the conflicting issues, contradictions and 'trade-offs' identified during discussions at the listening event. These further highlight some of the gaps and inconsistencies in the evidence base concerning the needs and preferences of people with dementia, and what is currently believed or accepted good practice in health related care settings.

- **Infection control** *versus* **shared spaces** (personal preference)

  - Single rooms not ideal (but may be a personal choice) and needed at times for infection control

- **Safety** *versus* **freedom** (independence issues)

- Balance of benefit of moving and free will *versus* risk of falling, getting lost
- Right to access outside but safety implications
- Sense of safety and calm *versus* risk of harm and actual injury

- **Lighting for clinical staff *versus* lighting for person with dementia**

- **Privacy** (confidentiality) *versus* **duty of care**. Labelling of patients (symbols denoting dementia diagnosis) - breach of confidentiality

- **Appliances familiar to patients *versus* modern technologies**

- **Majority preference** (customisation) *versus* **personal preference** (individual requirements)

- **Aesthetics *versus* practicalities/functionality/infection control**

  - Some building designs may look aesthetically pleasing e.g. high ceilings but these are not necessarily the best choice for people with dementia care needs
  - Person with dementia *versus* design for others without a dementia diagnosis

- **Personalisation *versus* infection control**

- **Avoidance of clutter** whilst using creative ways of accommodating personal touches

- **Infection control *versus* social integration**

  - Systems and environment should be adaptive to the patient's needs
  - Social provision in a clinical setting

- **Staff well-being *versus* person with dementia's well-being**

- **Too much information *versus* not enough**

  - Double signage favoured, the use of different methods of communicating the same message (e.g. a toilet symbol and word 'toilet'). Too much information looks cluttered and can cause confusion

- **Segregation *versus* integration**

  - Person with dementia cared for on specialist units or on general care wards?
  - Restlessness of person with dementia may detract from well-being of other patients
  - Hospital environment that is suitable for a person with dementia may also be suitable for those without dementia

- **Enough stimulation *versus* too much stimulation**

- **Prison analogy**, result of intention to keep physically safe but may be psychologically and socially detrimental

- **Space to rest** *versus* **space to socialise**

  - Quiet space where people can get away from noise and busyness of the hospital as well as communal space to socialise and interact with others

- **Dignity, confidentiality** issues, restricted by physical resources/layout of wards and time available

- **Colour coding** of key aspects of environment yet this does not reflect people's home environments

- Challenges of need to **call for assistance** contributing to ward noise

- **Technology** as a help or hindrance

- **Specialist roles** in dementia care and general training for all staff; regarding care given in the environment

4.9   Coloured Dots Exercise

Thirty-four participants remained for the optional afternoon session where they undertook the 'prioritising of issues' exercise using self-adhesive stickers. This coloured dot exercise utilised a different colour to represent each stakeholder group. The number of stickers each stakeholder group had with which to vote for their priority issues was proportionate to their attendance figures at the listening event.

Prioritisation by the participants of some of the issues suggested as being significant in the hospital environment highlighted that the use of the environment is an important consideration. 'How do I find my way' reflects the importance of independence as a result of wayfinding, signage and communication.

Table 1 shows that a large number of participants gave priority for wayfinding issues, the staff and personal engagement that occurred in the environment and feelings of safety. Figure 1 shows the breakdown of cast votes per participants' category. It is evident that the priority issues identified by the participants are concentrated around way finding, engagement between staff and patient and issues related to maintaining the safety of the person with dementia. Figure 2 shows a proportional view considering the number of participants per group category. From the graph, it can be seen that there is agreement

related to the importance of way-finding, but less so in relation to staff and patient engagement. In this respect, the design group gave priority to issues for each they can intervene such as providing a room with a view.

Table 1 – Coloured dot exercise results

| Issue	% PWD or Carer votes	% Practitioners' votes (NHS)	% Practitioners' votes (Non-NHS)	% Designers votes	% Weighted vote
How do I find my way	20	17.8	36.7	23.1	25
Staff and personal engagement	25.7	25.5	20.0	7.7	20
How can I feel safe	17.1	17.8	10.0	15.4	15
Health/ hygiene/ infection control	2.9	7.8	13.3	15.4	10
Room with a view	2.9	6.7	6.7	23.1	10
It's too noisy	5.7	3.3	0.0	15.4	6
Using colour	5.7	2.2	10.0	0.0	5
Too much clutter	0	5.6	0.0	0.0	1
Other priorities	20	3.3	3.3	0.0	8
Total	100%	100%	100%	100%	100%

PWD – Person with Dementia
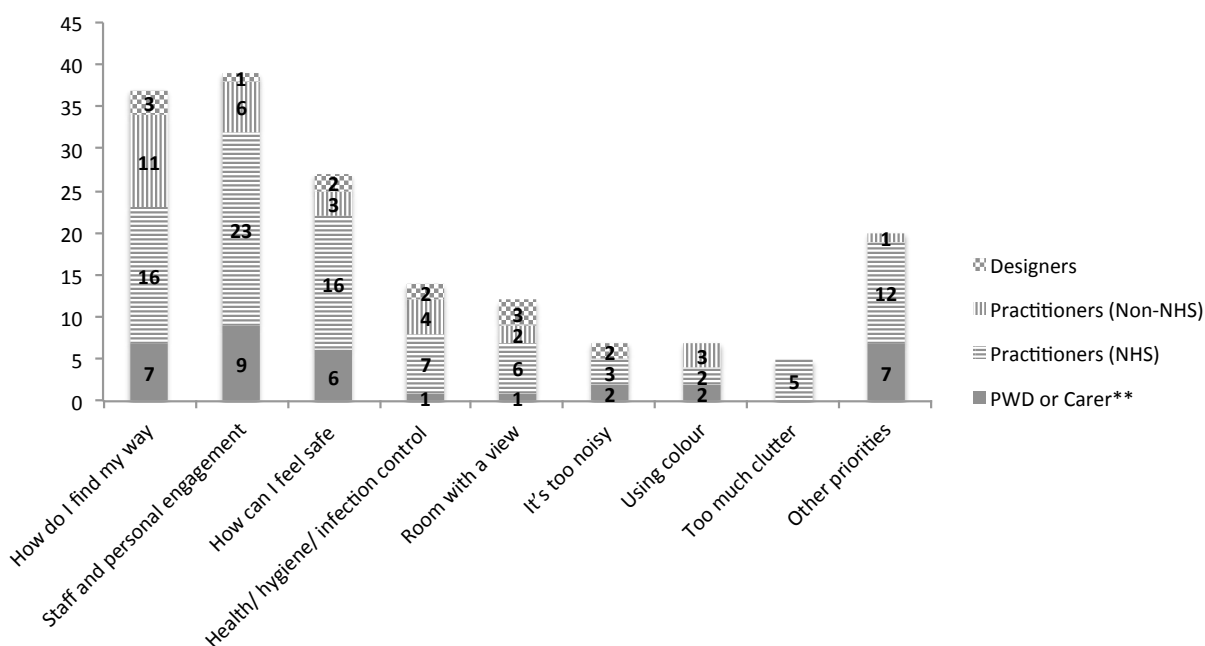
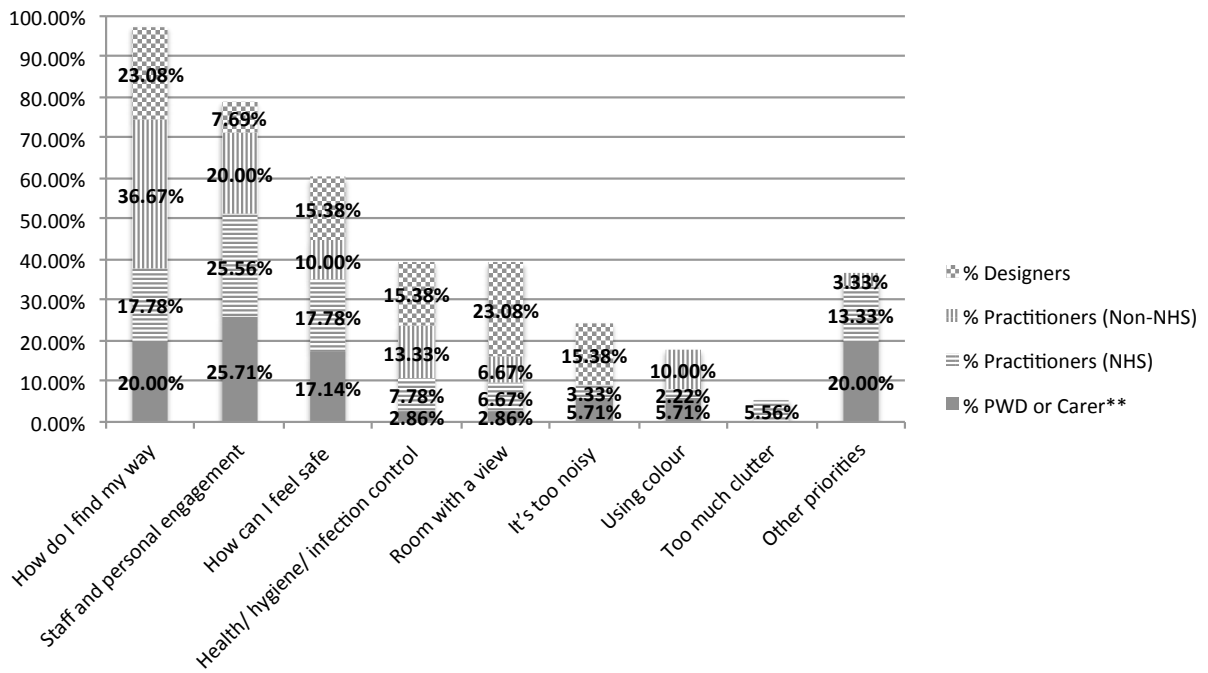Figure 1 – Coloured dot exercise: raw figures

Figure 2 – Coloured dot exercise: proportional view

4.10 Discussion

Discussions held between the listening event facilitators after the event led them identify a set of characteristics within the built environment that were distinctly possible triggers of positive and negative outcomes in people with dementia. We argue that the feelings that are triggered by experiencing the built environment are related to the well-being of the person with dementia. We understand that the communication 'channel' that is used by people with dementia and their carers is not related to measures of health, such as stress, blood pressure or any other physiological health outcomes. Rather, those feelings of security and familiarity seem to be what reduces the use of adaptive behaviour and may contribute to alleviation of stress, depression and behavioural challenges.

Below (Figure 3), we present an open map where the established characteristics of the built environment are in parallel with the feelings that have been expressed in the listening event. It seems that some characteristics are linked more to one or other feeling than others. Without a solid basis of evidence, we cannot confirm those links that remain in need of further exploration. The texture in the middle of the image represents our lack of knowledge regarding cause-effect mechanisms.

Built Environment

Social Environment

Flexibility
(Personal stuff/ adjustable)

Organisation
(Layout / Clutter)

Adequate Load
(Noise/ visuals/ temperature)

Barriers
(bars / doors / windows)

Zoning
(social / leisure / individual)

Contrast

Service
(Experience)

Familiarity

Safety

Privacy

Independency

Imprisonment

Calmness

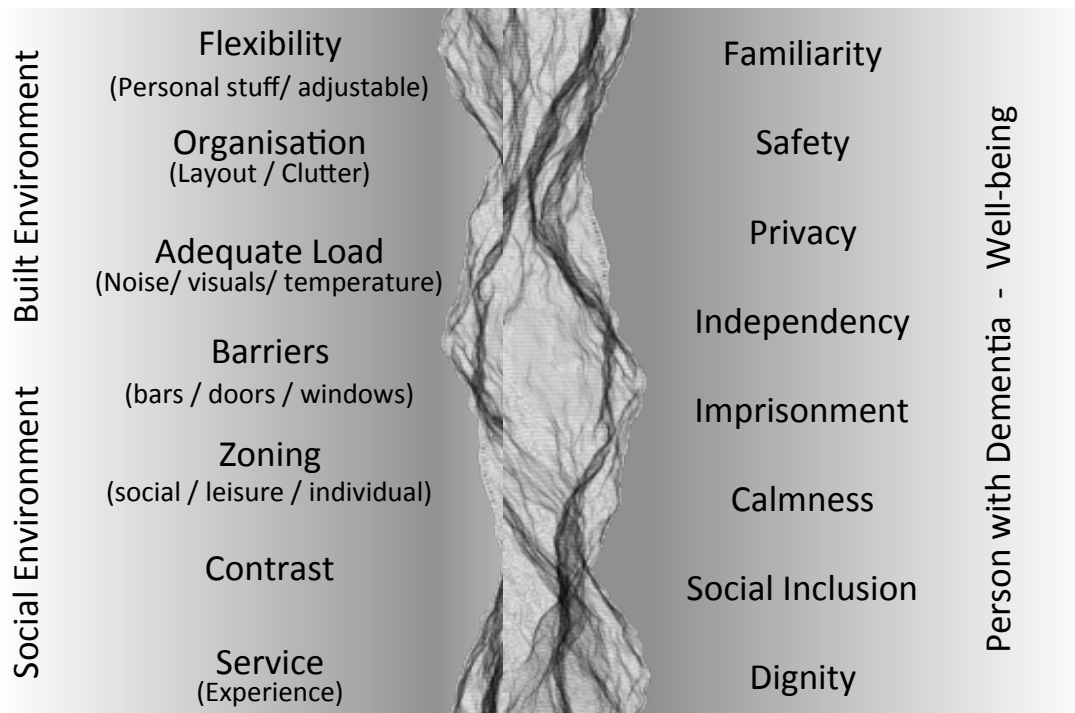Social Inclusion

Dignity

Person with Dementia - Well-being

Figure 3 – Built Environment/Feelings Map

5 CONCLUSION

Dementia is a condition that affects a large and increasing number of people in the UK. Certain aspects of the built environment can enhance or detract from the well-being of people with dementia.

Originally, a multi-perspective understanding of the issues around the environment and its impact on people with dementia and their carers was sought. For this purpose, a listening event was organised in September 2011 at the University of Salford that brought together people with dementia, their carers, health and social care staff and academics. This event was not designed to be a research study; rather it was used as an instrument to stimulate discussions and elicit the testimony of those living with dementia or supporting those living with dementia.

Preparation for 'listening' involved the conduction of a literature review about the known impacts of the built environment on people with dementia and the examination of an existing framework containing features that links people with dementia and their environments. These features were the fabric, the ambience, the psychological environment and the sociological environment. Functional activity and safety, information and communication and approaches to care were added to the framework. This adapted framework has in our view been strengthened by the comments and opinions of the 77 participants of the listening event and is offered to readers to critically consider and help us develop further as a 'rudder' for exploring dementia and the healthcare built environment further.

'Staff and personal engagement' was the focus of several of the group discussions, which is a useful reminder of how the built environment needs to optimise patient and staff interaction. Additional issues were suggested as being of importance including the benefit of integrating physical and mental health services rather than separating them and the importance of involving carers in the care decisions and care provision. The inclusion of

these issues reinforces the need for inclusive design involving architects, people with dementia and their carers and staff in the planning of the built environment.

As hospitals can be an alien environment, this issue of the impact of the built environment on 'how can I feel safe' reinforces the psychosocial aspects of the patient experience. Such needs as these were captured in the preference for a 'room with a view'. Clinical issues of promoting 'health, hygiene, and infection control' are a reminder of the focus of the service provided in the built environment and the need for the environment to support these aspects of the care provided. The issue of the acoustics of the hospital environment highlight the role that the built environment can play in modifying the impact of the sound generated through the unavoidable activities that occur in a hospital. Awareness of the use of colour and the presence of clutter were also highlighted as being issues for consideration when enhancing the hospital environment to improve the experience of people who have dementia.

The achieved outcomes of this initiative go beyond academic findings. To listen to those living with dementia or caring for people with dementia has given us a broader perspective on dementia design and well-being. It brought a different dimension of interpretation to the results found in scientific reports. We have identified through this exercise that many healthcare settings, as currently configured, trigger negative feelings such as stress in those with dementia. This same negativity is addressed in scientific reports that contribute research evidence about the environment and its impacts on people living with dementia. Overall, we suggest areas in need of further research as being:

- The issues of functional activity and safety highlighted in the listening event demonstrate the need for inter-professional collaboration on design; occupational therapists, architects, nurses, furniture and equipment designers, acoustic designers, lighting designers, paint and colour experts, physiotherapists and so on, as well as substantive public involvement
- Decisions about the design and use of hospital environments need to balance the needs of all those who use the space. Design and care decisions need to promote the independence of people with dementia and promote their safety. The challenge is to

provide hospital environments and care that can meet these at times of conflicting demands

- The evidence base for what communication approaches work for people with dementia as well as others, in terms of inter-personal communication practices by staff, technologies and care environments is in need of review and development. This may be underpinned or complemented by a systematically undertaken review of techniques and practices and the theories underpinning communication approaches and their application in health care related settings. This is especially the case for settings that will accommodate people with dementia

- That the needs of people with dementia and communication impairment such as visual and hearing difficulties be further explored

- That standards of education and preparation of health care related staff to work with people with dementia and their families, be explored

- That the evidence base for specialist or integrated care facilities for people with dementia and impact on care outcomes (for those with and without dementia), including patient and carer reported outcomes, is developed

- That 'occupation' (how time is spent day-to-day) of people with dementia is further examined

- That the impact of people with dementia experiencing confusion is considered in relation to care staff, patients and the person with dementia

- That means of promoting exercise such as safe walking as a means of helping people with dementia to live actively, be explored

- That people with dementia are facilitated and supported to have more of a say in the development of technologies aimed at enhancing their care and management

In addition to the described outcomes, an extended network of people and organisations has been formed as a result of this initiative. Within Salford and the surrounding area, it brought together 32 academics. Nationally, it reached established groups and organisations willing to share their experience and knowledge around such an emerging topic. Finally, it has helped to set a better-informed direction for a collaborative research agenda.

Despite its positive results, we acknowledge the limitations of our approach. This report should not be considered (and it was not intended to be) as a research report. The method used was not scientifically designed and as such it does not provide scientific evidence, but rather testimony. We also understand, that there was an imbalance related to the number and experience of our participants. For this reason we are taking the work forward in a number of ways including the launch of this report at a University of Salford led dementia conference in September 2012. At this same event we will be formally announcing our imminent plans to set up an international dementia design network.

For those willing to follow the same approach, much more can be shared that has not been reported here. Mostly in relation to the capture of information, that in this case was designed in a complex way. Much was learnt that could support the preparation of scientific research and we welcome further joint working drawing on our specific expertise around built environment, dementia care, inclusive design and public and community engagement and involvement.

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7 APPENDICES

Appendix 1: Breakdown of casted votes in the coloured dots exercise

Additional information: Coloured dots exercise

- Yellow= Person with dementia or informal carer = 35 dots
- Blue= practitioner (NHS)= 90 dots
- Red= practitioner (non NHS)= 30 dots
- Green= Designer= 13 dots

Each heading total in table 1 = weighted vote (total= 393) = % of weighted vote (total = 100 %). Results: frequency (as percentage of each colour= weighted vote)

The breakdown of votes for each category is presented below. The numbers in brackets represent the weighted percentage for each stakeholder group. Figure 1 shows the results with the full number of cast votes.

- How do I find my way = 94 (weighted vote) = 23.92 % weighted vote

  - 3d signage-simplicity of signage-combination of triggers: 6 (20) red/ 2 (15) green/ 5 (14) yellow/ 12 (13) blue **=58**
  - Friendly assistance: 1 (1) blue**=1**
  - Signage pictures-eye levels- ability to personalise e.g toilets: 3 red (10)/ 1 (8) green / 2 (6) yellow / 1 (1) blue **=26**
  - Signage- too much text, wrong height (for staff and person with dementia), more use of symbols, colour code: 2 (7)red/ 2 (2) blue **=9**

- Staff and personal engagement = 81(weighted vote) - (note 79points for care related issue not built environment) = 20.61 % weighted vote

  - Improved communication-personal care plan as bed side guide, training of staff: 23 (26) blue/ 1 (8) green/8 (24) yellow/6 (20) red **=78**
  - Privacy- wrong lay out-little space- claustrophobic: 1 (3) yellow **= 3**

- How can I feel safe = 61 (weighted vote)= 15.52 % weighted vote

  - Assistive technology- avoid fall hazards, wandering about (sensors): 2 (6) yellow **=6**
  - People with knowledge of dementia consulted on design, operations and risk assessment: 16 (18) blue/4 (12) yellow/ 3 (10) red/ 2 (15) green **=55**
  - Design to decrease perceived safety (visual impairment, physical limitations) e.g glass rails on 1st floor level- need to be opaque

- Health/ hygiene/ infection control = 39 (weighted vote) =9.92 % weighted vote

  - Patient experience or infection control targets: 1(3) red/1 (8) green/ 1 (1)blue **=12**
  - Sharing knowledge between practitioners: 1 (3)yellow **=3**
  - Freedom- acute hospitals could learn from mental health (in your bed or beside your bed): 3 (10) red: 4 (4) blue **=14**
  - Health, hygiene and safety versus freedom of control: 1 (8) green/ 2 (2) blue **=10**

- Room with a view = 38(weighted vote) = 9.67 % weighted vote

- Indoor spaces for art/murals/interactive gadgets: 1 (3) red/ 1 (1) blue **=4**
- Virtual green spaces on brick walls (through windows or indoors) 4 (4) blue/3 (23) green/ 1 (3) yellow **=30**
- Real world garden-views-watching world go by: 1 (1) blue/1 (3) red **=4**

- It's too noisy = 25 (weighted vote) =6.36 % weighted vote

  - Noise- there is a need to eliminate surrounding noise- acoustic planning: 3 blue (4) / 2 (15) green/2 (6) yellow **=25**
  - Use of fabric/space design to minimise echoes and address acoustic related issues
- Unnecessary noise- call buzzers-just use lights or electronic means e.g. pages

- Using colour = 18 (weighted vote) = 4.58 % weighted vote

  - Natural palate for background colours rather than artificial colours e.g. yellow good choice (except where is a specific door or leading to an important walkway): 3 (10) red/ 2 (6) yellow **=16**
  - Pattern- ok –up to level found in natural materials rather than heightened artificial pattern
  - Signage and colour codes all well and good but often signs are high up. Coloured paths are distracting and people not able to learn/remember routes, so need to design out the need to remember: 2 (2) blue **=2**
- Colour of doors all the same- too much sameness – don't know where they are

- Too much clutter = 6 (weighted vote) =1.53 % weighted vote

  - Lack of clutter to avoid accidents of patients moving from one position to another: 5 (6) blue **=6**
  - Context of care- some clutter is vital to mainstream ward but in specialist care clutter has to be managed

- Other priorities = 31 (weighted vote) = 7.89 % weighted vote

  - Co-location of medical and mental health; 4 (12) yellow/ 1 (1) blue **=13**
  - Measuring the cost of solutions against resources currently available: 2 (2) blue **=2**
  - Inclusion of carers at least in planning and also in carrying out of care plan. Facilities to enable this- larger bed space, private rooms, extra chair/bed: 2 blue (2) / 1 (3) red/ 2 (6) yellow **=11**
  - Life story work: 5 (6) blue/ 1 (3) yellow **=3**
  - Make it look like what it is- a hospital: 2 (2) blue**=2**

The image on the front cover is a piece of art work developed by graphic designer John Rooney. His starting point was a scanned image of the blood flow through the brain of a person with dementia. The concave fold in the acrylic glass represents the two hemispheres of the brain and the holes represent the dementia related changes in the brain. The tilted acrylic glass sheet represents the need to consider the altered perceptions and experience that may result from dementia and the view of the sky represents the importance of maintaining a positive and appreciative view of the life experience of people living with dementia. The image created by John Rooney is now the logo for the International Dementia Design group hosted by the University of Salford.