Bournemouth University

Dementia Institute (BUDI)

Fire Safety Innovations for People Affected by Dementia

Report on Focus Group and Survey findings

November 2015

Dorset Fire & Rescue Service

inspired by 2012

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ACKNOWLEDGEMENTS

We would like to thank everyone who participated in this project. Thank you to the people with dementia and their carers and the professionals for taking part in the focus groups, the organisations and individuals who helped us to find them, and the Fire and Rescue Services that took part in the survey. We would also like to thank anyone else who engaged with this project, we appreciate your time and honesty when sharing your experiences with us.

Thanks to Linzi Holt and Sarah Moore from Dorset Fire & Rescue Service for their support and input into this project, with particular thanks to Sarah for researching suitable assistive technology and fire safety resources for people affected by dementia. Thank you to Dorset Fire and Rescue Service for commissioning us to undertake this research and to Dorset County Council for funding it through the Inspired by 2012: Health and Wellbeing Legacy fund.

EXECUTIVE SUMMARY

Introduction

The Fire Safety Innovation for People Affected by Dementia project was funded by Dorset County Council under the Inspired by 2012: Health and Wellbeing Legacy Fund. The aim was threefold, to:

- develop guidance that can be used nationally and internationally to help people affected by memory problems or dementia to be safer in their homes;
- enhance the quality of life of people affected by dementia by enabling them to live independently in their own homes for longer;
- create a training package that will ensure Fire and Rescue staff and volunteers, and other practitioners who visit people in their own homes, are better equipped to work with people affected by dementia to ensure they are as safe as possible from fire risk.

Bournemouth University Dementia Institute (BUDI) were commissioned by Dorset Fire and Rescue Service (DFRS), as part of Fire Safety Innovation for People Affected by Dementia project, to undertake focus groups and a survey to explore fire risks and safety strategies in the homes of people with dementia. In this report we detail the findings from these focus groups and the survey, alongside the methods, analysis, findings and recommendations that were drawn from this part of the project.

Methods of data collection

Four focus groups were held: one with fire service professionals; one with other professionals that work with people with dementia; and two with people with dementia and their family carers. A survey was created in Survey Monkey and a link was emailed to the Head of the Prevention Team (or their equivalent) at all FRSs in the United Kingdom (UK) (n=55).

Data analysis

The survey analysis was undertaken in Survey Monkey using the package's analysis

tools, and included descriptive analysis of the frequency of responses to each question. The transcripts of the focus groups were analysed thematically and were managed using NVivo.10 software. The analysis was inductive, in that themes were allowed to emerge from the transcripts as the analysis progressed, rather than imposing a theoretical framework to the data. However, to ensure the analysis directly addressed the aims and objectives of the project, an overall framework that drew on the topics set out in the focus group topic guide was also used. These were: fire risks in the homes of people with dementia; fire risk reduction strategies in the homes of people with dementia; and suggestions for guidance documents, resources and training packages.

Ethics

Ethical approval for the focus groups was obtained from the Social Science and Humanities Ethics Committee, at Bournemouth University. Principles of informed consent, voluntary participation, the right to withdraw, confidentiality and anonymity were adhered to. All participants were able to give informed consent.

Focus group findings

A total of 32 people took part in the focus groups, equating to eight people with dementia, eight carers or family members, two support groups facilitators/volunteers, 10 fire and rescue service professionals and four other professionals.

Fire risks in the homes of people with dementia

- There were four types of fire risk identified by fire service participants and professionals working with people with dementia: those related to a person's past role or actions; using appliances inappropriately; related to memory impairment and the person's home environment.
- Participants who were not professionals or employed by the fire service (i.e. people with dementia and family carers) tended to focus on non-fire related safety risks, however, with probing, some participants identified fire hazards, including sitting too close to or falling into open or electric fires, using metal containers in microwaves, candles, forgetting to put cigarettes out, leaving the cooker or gas on or putting an electric kettle on a gas hob.

Fire risk reduction strategies in the homes of people with dementia

- Fire service participants and professionals working with people with dementia identified four risk reduction strategies: a person-centred approach; partnerships to identify vulnerable households; assistive technology in the home environment; and dementia aware prevention strategies.
- People with dementia and family carers identified decluttering, avoiding trip hazards, installing smoke and carbon monoxide detectors and relying on observant neighbours as ways of staying safe at home.
- Challenges to fire risk reduction strategies included working with people who have not accepted their dementia diagnosis and therefore refuse specific supports, people who had not received a diagnosis and therefore were not 'in the system' and lack of knowledge held by people with dementia and family carers of available fire risk reduction technologies.
- A key challenge is to ensure the installation of technology in a person's home does not have a catastrophic unintended consequence of causing them harm.

Suggestions for guidance documents, resources and training packages

- There is a clear need for awareness raising for fire service personnel, people with dementia and family carers.
- Fire service personnel want clear referral processes, particularly for those at risk who do not fall into their safeguarding remit.
- Fire service personnel want better knowledge of what technology is available and who is responsible for funding and installing it.
- Family carers want information that is accessible in face to face or leaflet form.
- Information for people with dementia may be more easily digested in laminate form, Plain English, accessible font and including illustrations.

Survey findings

- The amount of fires occurring in the homes of people with dementia is unknown, as the current system used by FRSs to record incidents does not allow them to record whether someone has memory loss or dementia.

- People with memory loss or dementia are likely to be involved in accidental dwelling fire confined to one room or more than one room, and fire fatalities amongst this group are often linked to smoking and cooking.
- FRSs provide a range of fire safety guidance to older people, including: leaflets, talks to groups, signposting to other organisations and large print booklets. Fire safety messages are written in plain English and promote electrical safety, good housekeeping, cooking safety, as well as advice on bedtime routines.
- Whilst some FRSs provide fire safety guidance to people with dementia and/or their carers (examples included a checklist fridge magnet to keep safe at night, leaflet with less words and more pictures), other FRSs do not offer this group any specific resources or key messages; instead using the resources designed for older people in general.
- FRSs were less likely to offer professionals working with people with dementia and/or their carers dementia-specific fire safety guidance.
- None of the respondents answered the question about whether anyone else (i.e. partner organisation) offers fire safety advice to vulnerable groups on their behalf, or if they were planning on doing so in the next 12 months.
- FRSs stated that if they received fire safety guidance for people affected by dementia, they would be likely to use it to develop resources (including fire safety leaflets for people affected by dementia) and summarise it and circulate it to colleagues in a staff briefing note.
- FRSs would find it useful to know more about:
  - Communicating with people affected by dementia;
  - Signposting people affected by dementia to appropriate information and support;
  - Best practice and legal aspects of assisting/assessing people with dementia;
  - Using visual reminders/signs/diagrams for fire safety.

Conclusions

This project demonstrates that understanding the person and their individual situation is vital in determining the risks within their home environment. Risk assessments must therefore be undertaken using a person-centred approach and to ensure that risk reduction strategies are effective for that person. Risk reduction

strategies however may be time limited as the condition progresses and behaviours change, therefore regular risk assessments should be undertaken. Assistive technology (such as telecare) should be introduced as early as possible. Professionals who work with people with dementia, including Fire and Rescue Services, need to understand more about the condition, as well as have an awareness of person-centred approaches. There is a need for a range of resources that reflect individual needs.

1. BACKGROUND

Dementia is caused when the brain is damaged by diseases (such as Alzheimer's disease or Strokes) (Alzheimer's Society, 2015a). Dementia is an umbrella term that describes a set of symptoms such as memory loss, and difficulties with thinking, problem-solving or language (Alzheimer's Society, 2015a). This may mean people have problems recalling recent events, following a conversation or finding the right word, keeping track of where they are (resulting in becoming lost), making decisions or cooking a meal, and judging distances or seeing three dimensional objects (Alzheimer's Society, 2015a). Some people with dementia may also experience changes in their mood or behaviour (for example become frustrated or irritable, withdrawn, anxious, easily upset or unusually sad), whilst other may have visual hallucinations or delusions (Alzheimer's Society, 2015a). The symptoms of dementia will gradually get worse over time (meaning it is a progressive condition); however no two people with the condition will experience it in the same way (Alzheimer's Society, 2015a). People with dementia value being supported to live well with their condition and how others respond to them can have a positive or negative impact on them (Alzheimer's Society, 2015a). It is important to talk to the person to explore their individual needs rather than focusing on aspects of the condition, as well as drawing on the 'expertise' of people affected by dementia by asking them about their experiences (Holley-Moore and Scrutton, 2015).

There were an estimated 44.4 million people living with dementia worldwide in 2013 (Alzheimer's Disease International, 2014). This is estimated to increase to 75.6 million in 2030, and 135.5 million by 2050 (Alzheimer's Disease International, 2014). There are currently 820,000 people living with dementia in the United Kingdom (UK), projected to rise to 1,000,000 people by 2021 (Alzheimer Society, 2015b). In Dorset the number of people aged 65 or over living with dementia will increase from 7,796 in 2010 to 11,734 by 2025 (Dorset Health Scrutiny Committee, 2010). This rapid increase in the number of people who will be living with dementia in the next few

years has resulted in significant public and political commitment to drive improvement and change for those affected by dementia in the UK (Alzheimer Society, 2013). Dementia is a National Health Priority in the United Kingdom (UK). The UK Prime Minister launched a specific Dementia Challenge in 2012, aiming to improve the lives of people with dementia and their families through three areas of action: driving improvements in health and care, creating dementia-friendly communities and improving dementia research (Department of Health, 2012). In Dorset, the Health and Well Being Board have outlined working with people affected by dementia as a priority. Two thirds of people with dementia live in the community, rather than in care homes (Alzheimer's Society, 2015b). People with dementia and their families value being able to remain in their own homes for as long as possible, and this also reduces the cost of care for the state (Holley-Moore and Scrutton, 2015). One of the main reasons that older people go into care homes is due to concerns over home safety (Bowers et al., 2009). Therefore there is a key role for prevention and early intervention that enables people to remain active and safely living in their own homes, for as long as possible (HM Government, 2012: 26).

The Fire and Rescue Services Act 2004 places a statutory duty on all UK Fire and Rescue Services (FRSs) to promote community safety, with the intention of preventing deaths and injuries in the home (The National Archives, 2004). Since the introduction of this duty there has been a downward trend in the number of fire fatalities in the home, with the exception of fatalities in people aged sixty and over which has remained constant (with a slight increase amongst people aged 80 and over) (Department for Communities and Local Government, 2012: 22). There is evidence from the US to suggest that people aged sixty and over who live alone are at higher risk of injury or death from fire in the home; and that impairment, disability and dementia are substantial factors in increasing the risk of injury or death from fire in the home (US Fire Administration, 2006). The likelihood of developing dementia increases dramatically with age, doubling for every five year age group after the age of 65 (Alzheimer's Society, 2015b). Given the predicted increase in the UK of people aged 60 and over (Office of National Statistics, 2013: 1) and of people with dementia (Alzheimer's Society, 2013), it can be assumed that the number of fires in the homes of people with dementia will increase, unless dementia-specific fire prevention

guidance is developed. However, the extent to which dementia increases the risk of injury or death from fire is not yet known, as there are currently no available statistics that report on the number of people with dementia injured or dying in fires in the home in the UK.

FRSs provide fire safety resources that they adapt to meet diverse needs, allowing the whole community to be fire safe. However the lack of local, national and international fire safety guidance for people affected by dementia means that the needs of this high risk group are currently not being met by all FRSs. The paucity of literature, empirical research and dementia-specific fire prevention guidance means that the fire risks associated with this group and the preventative measures that can be put in place to reduce such risks are unclear. This project develops critical understanding of fire risk and prevention strategies in the homes of people with dementia that will enable people with dementia and their families, practitioners (including Fire Service personal), policy makers, and other key stakeholders to better understand such risks and the approaches they might take to reducing them. The findings and recommendations focus on people with dementia living in their own homes (owner occupied, social rented or private rented) within the community; however some may also be applicable for care homes. This report should be read in conjunction with Holley-Moore and Scrutton's (2015) report which discusses dementia and electrical safety.

1.1 Aim and stages of the project

This aim of this project is threefold, to:

- develop guidance that can be used nationally and internationally to help people affected by memory problems or dementia to be safer in their homes;
- enhance the quality of life of people affected by dementia by enabling them to live independently in their own homes for longer;
- create a training package that will ensure Fire and Rescue staff and volunteers, and other practitioners who visit people in their own homes, are

better equipped to work with people affected by dementia to ensure they are as safe as possible from fire risk.

Dorset Fire and Rescue Service (DFRS) received funding from Dorset County Council under the Inspired by 2012: Health and wellbeing Legacy Fund for this 18-month project. DFRS commissioned Bournemouth University Dementia Institute (BUDI) to undertake some aspects of this project, as described in Table 1.

1.2 Focus of this report

This report details the findings of the focus groups and survey undertaken and analysed by BUDI.

Table 1: Outline of tasks undertaken during this project

Stage	Task	Undertaken by
1	Focus groups and survey to map fire risks and prevention strategies currently utilised in the homes of people with dementia.	BUDI
2	Research national and international resources and current assistive technology for fire related risk reduction	DFRS
3	Define optimised fire prevention strategies in the homes of people with dementia.	BUDI
4	Design suitable resources such as a leaflet.	DFRS
5	Develop and deliver training toolkit to DFS Champions to identify signs and best practice when working with people affected by dementia to make them fire safe.	BUDI
6	DFRS Champions cascade training to all operational frontline staff, volunteers and home safety advisors.	DFRS
7	Integrate training and resources in to DFRS procedures and training and advice through Chief Fire Officers Association to other FRSs nationally.	DFRS
8	Evaluation. The impact of this project will be assessed through data supplied to BUDI by DFRS.	BUDI

2. RESEARCH DESIGN

This section provides a description of how the focus groups and survey were undertaken and analysed, including a discussion of the ethical issues considered prior to and during the research.

2.1 Focus groups

Four focus groups were held in Dorset: one with fire service professionals; one with other professionals that work with people with dementia; and two with people with dementia and their family carers. Professionals responded to an open request for participants for a focus group sent by email to the Fire Service and their partner organisations (including Domiciliary Care Providers and signposting services for older people).The focus groups with people with dementia comprised of existing groups who met regularly and who allowed the researchers to attend some or all of their meeting to speak with those willing to share their views and experiences. Existing groups provided by Age UK, Alzheimer's Society and local Adult Social Care services were contacted to enquire about their ability and wish to take part in the research. Key gatekeepers within each organisation provided information about different groups and facilitated access for the project team.

All focus groups were conducting in the same way: two researchers attended (one to guide the discussion and the other to take detailed notes) and, following introductions, sharing round of fruit and biscuits and an explanation of the research, all participants were provided with an information sheet (Appendix 1 – Professionals and Appendix 2 – People with Dementia and carers) which they were invited to read and had summarised where necessary. Once everyone had read and understood the information sheet and had any questions answered, they were asked to sign a consent form (Appendix 3). A topic guide was used at all focus groups to guide the discussion, there were two versions of this, one for the professionals (Appendix 4) and another for the people affected by dementia (same questions but with a vignette

Appendix 5). All focus groups were audio-recorded with participants' consent and later transcribed.

2.2 Survey

The survey was created in Survey Monkey and a link was emailed to the Head of the Prevention Team (or their equivalent) at all FRSs in the United Kingdom (UK) (n=55). The email included information about the project: an explanation of the study (why it was being undertaken, what their participation involved, and that their participation was voluntary) and specified that consent was being given via their completion of the survey. Contact details of the researchers were also included in case people needed further clarification. Three reminders were sent following the initial email inviting FRSs to take part. Twenty FRSs responded giving a response rate of 36.4%.

2.3 Ethical considerations

Ethical approval for this project was obtained from the Social Science and Humanities Ethics Committee, at Bournemouth University (Bournemouth University, 2009). There are particular ethical considerations when working with people with dementia, notably that of ensuring informed consent. Focus groups were therefore designed on a premise of inclusion and informed consent. It is important to hear about experiences from people with dementia themselves, so as not to assume that proxy reports (from family members or professionals) actually reflect their experiences. The team followed specific and established process consent procedures developed for people with dementia (Dewing, 2008) to ensure that the project complied with the Mental Capacity Act (2005). All participants were able to give informed consent.

Throughout the focus groups the following ethical principles were adhered to:

- Information sheets (Appendix 1 – Professionals and Appendix 2 – People with Dementia and carers) about the project were developed. They explained why the focus groups were being undertaken, what participation would involve for

individuals and a description of issues of consent, voluntary participation, confidentiality and anonymity. Photographs of the researchers that would be facilitating the focus groups along with their contact details were also included in case people needed further clarification.

- The information sheets were circulated to potential participants by gatekeepers or attached to the email invitation letter sent to the Fire Service and their partner organisations.

- Prior to the start of each focus group, the facilitator distributed information sheets to the participants and talked through the content with them. Those who wished to participate were asked to complete and sign a consent form (Appendix 3).

- Participants were assured that participation was entirely voluntary and that they could leave the session at any time.

- Participants were asked for permission to audio-record the focus group conversations and were reassured that the data would only be used for this project, that any quotes used in the report to the funders or any publications would be anonymised and that no-one would be identifiable in any reports or publications.

- The audio recordings were transcribed by a university approved transcription service.

- Interview transcripts were anonymised prior to analysis and participants were assigned a code number in line with confidentiality and anonymity arrangements.

- To comply with the University's records management policy, all project files are stored on password protected network drives and data are not available to third parties.

- A lay summary of the findings will be sent to all the gatekeepers to circulate to the participants involved.

2.4 Data analysis

The survey analysis was undertaken in Survey Monkey using the package's analysis tools. This included descriptive analysis of the frequency of responses to each question. The transcripts of the focus groups were analysed thematically and were managed using NVivo.10 software (Joffe & Yardley, 2004). The analysis was inductive, in that themes were allowed to emerge from the transcripts as the analysis progressed, rather than imposing a theoretical framework to the data (Boyatzis, 1998). However, to ensure the analysis directly addressed the aims and objectives of the project, an overall framework that drew on the topics set out in the focus group topic guide was also used (Boyatzis, 1998). These were:

1. Fire risks in the homes of people with dementia
2. Fire risk reduction strategies in the homes of people with dementia
3. Suggestions for guidance documents, resources and training packages.

Meaningful phrases of varying lengths were coded and the coding was inclusive meaning that phrases could be coded to more than one code (Boyatzis, 1998). One researcher undertook the thematic analysis of all four focus group transcripts. To enhance the rigour of the analysis, a second researcher read through the transcripts noting down the emergent themes, and then scrutinised the themes and process used to arrive at these themes.

3. FOCUS GROUP FINDINGS

This section outlines the participant characteristics and the key themes that arose during the focus groups. Themes cutting across focus groups are considered the key themes as these are more representative of wider experiences. Linked to the topics on the focus group schedule, the themes can be divided into three distinct areas: fire risks in the homes of people with dementia; fire risk reduction strategies in the homes of people with dementia; and suggestions for guidance documents, resources and training packages. Each area is presented below, following a description of the participant characteristics.

3.1 Participant characteristics

A total of 32 people took part in the focus groups. This equated to eight people with dementia, eight carers or family members, two support groups facilitators/volunteers, 10 fire and rescue service professionals and four other professionals. Table 2 below provides details of the type and number of participants who took part in each focus group. All focus groups were lively with most participants eager to contribute their experiences and views. Their duration ranged from 35 to 120 minutes. The participant codes used in the findings section of this report are explained in Table 3.

Table 2: Type and number of participants involved in each focus group

Breakdown of participants						
Group number	**People with dementia**	**Family members/ carers**	**Support group facilitators/ volunteers**	**Fire and Rescue Service Professionals**	**Other professionals**	**Total participants**
Group 1	0	0	0	10	0	**10**
Group 2	0	0	0	0	4	**4**
Group 3	4	5	0	0	0	**9**
Group 4	4	3	2	0	0	**9**
Total	**8**	**8**	**2**	**10**	**4**	**32**

Table 3: Participant codes

Participant codes			
Group number	**Gender**	**Participant number**	**Participant type (where applicable)**
Group 1 - 4	F = Female; M = Male	Order spoke in the focus group	C=Family member/carer; D = person with dementia; O = Group facilitator/volunteer.
Examples: G1M1 = Group 1 (Professionals) first male to speak G3M1D = Group 3 (People affected by dementia) first male with dementia to speak			

3.2 Fire risks in the homes of people with dementia

There were four types of fire risk identified by fire service participants and professionals working with people with dementia: those related to a person's past role or actions; using appliances inappropriately; related to memory impairment and the person's home environment.

3.2.1 Related to a person's past role or actions

Examples of types of fire risk related to past roles or actions included someone with dementia who smoked in bed, a man who had been an electrical engineer attempting to fix electrical problems, and someone else who threw a burning chip pan out the window as this was what she had done in the past, as described by participants below:

> *… because whenever a light bulb blew, he would actually completely disconnect the light fittings and leave bare wires hanging from the ceilings. Anything electrical was a hazard because if it didn't work he would just*

dismantle it and leave it. And nothing that we told him was ever going to have any effect. (G1F1)

But she actually threw it (burning chip pan) out into the garden herself, instead of calling anyone out (G1F2)

3.2.2 Using appliances inappropriately

Examples related to using appliances inappropriately included putting an electric kettle or plastic tray on a lit gas hob, putting inappropriate items in the microwave or drying clothes on unsuitable heaters.

It was a chap that stuck his underpants in the microwave to dry, and a lady that set fire to her knickers on the radiator. (G1M3)

I think the worst one I ever saw was the electric kettle in the microwave with the microwave on as I arrived. (G2F1)

3.2.3 Related to memory impairment or stress

Examples related to cognitive impairment included forgetting to turn heaters off, forgetting about food cooking in the oven, not grasping there is a problem and taking appropriate action or not being able to respond to an alarm such as a smoke detector, as illustrated by these participants:

… the same lady, several times a week, for several weeks, same times of day as well, so she would put the dinner on, go in, sit in the living room, and completely forget about it, and dinner would be incinerated. But then, having automatic fire alarms, the fire service would turn up, I wasn't cooking anything. There's incinerated mushrooms in the bin. No, I wasn't cooking anything. (G1F1)

> *What happens when a fire happens and how does somebody with dementia understand? It's all right having a smoke alarm, but if you don't understand what that smoke alarm is and you think it's the ambulance going by or something (G2F2)*

Carer stress was raised by one participant as a possible contributor to a fire risk: specifically taking the battery out of the smoke detector:

> *My dad had Alzheimer's and he would get obsessed with things, so when the smoke alarm started bleeping, because my mother was nearly 80, was exhausted, he'd say, shut that up, shut that up, shut that up. So what does she do? Take the battery out. So that's the first thing she does, because she's had quite enough to cope with all day with him without hearing him say shut that up, shut that up… So things like that can happen quite easily when you've got two people in the home because people forget how stressful it is living with somebody with a dementia. (G2F1)*

3.2.4 Person's home environment and situation

More general fire risks related to the person's home environment, including over loaded plug sockets or extension cables and clutter, particularly near open fires, drying the washing in front of the fire, or sitting too close to a fire, as these participants described:

> *I've seen gentlemen with their trousers melted on their legs because they tend to sit too close to fires. (G2F2)*

> *They had clothes hanging up everywhere, they had extension lead, extension lead, extension lead, with just everything plugged into these extension leads, and they'd leave aerosol cans right near the fire (G1F5)*

The situation at home was different for each participant too: some people with dementia living were living alone, whilst others were living with a carer (usually spouse or partner, but could be siblings, sons or daughters). There were also examples of people with dementia, caring for their spouses or partners with dementia:

…her husband, he was caring for her, but it became quite obvious to us throughout the conversation that he had issues as well, his memory wasn't great, so you had somebody caring for somebody, who wasn't particularly caring, and he himself needed caring for. (G1M1)

3.2.5 Risks raised by people with dementia and their carers

When considering fire risk in different rooms of the house, participants who were not professionals or employed by the fire service (i.e. people with dementia and family carers in focus groups 3 and 4) tended to focus on other types of safety risk, for example slipping on wet bathroom floors, or ingesting bathroom clearing products by mistake, flooding, trip hazards and clutter. However, with probing, some participants identified fire hazards, including sitting too close to or falling into open or electric fires, using metal containers in microwaves, candles, forgetting to put cigarettes out, leaving the cooker or gas on or putting an electric kettle on a gas hob:

Because they could turn it (gas hob) on and not ignite it. Or forget to turn it off (G3F1C)

The microwave could be dangerous if you put some metal in it. (G3M1D)

The classic would be the electric kettle being put onto the gas hob. (G3M5C)

… forgetting to put cigarettes out or putting them in the wrong place. (G4F2C)

Well, even electric fires, too, if they fall. (G4M1D)

A neighbour of ours, her husband tended to sort of fiddle around with things all the time, be very restless, and she had to follow him round the house because he would turn on the gas taps and walk away. (G4F1C)

Summary points – fire risks in the homes of people with dementia

- There were four types of fire risk identified by fire service participants and professionals working with people with dementia: those related to a person's past role or actions; using appliances inappropriately; related to memory impairment and the person's home environment.
- Participants who were not professionals or employed by the fire service (i.e. people with dementia and family carers) tended to focus on non-fire related safety risks, however, with probing, some participants identified fire hazards, including sitting too close to or falling into open or electric fires, using metal containers in microwaves, candles, forgetting to put cigarettes out, leaving the cooker or gas on or putting an electric kettle on a gas hob.

3.3 Fire risk reduction strategies in the homes of people with dementia

Fire service participants and professionals working with people with dementia (groups 1 and 2) identified four risk reduction strategies: a person-centred approach; partnerships to identify vulnerable households; assistive technology in the home environment; and dementia aware prevention strategies. These are discussed in turn, along with the challenges of implementing such approaches. Strategies raised by people with dementia and their carers are also noted.

3.3.1 A person-centred approach

Participants suggested that there is no one size fits all approach when working with people with dementia:

> *…I don't think that there's a catch all solution for all this, but as far as management is concerned there may be one particular thing that you can do for one particular group of people, but they're probably going to be a*

> *very small group of people because everybody's dementia is so unique. So it would be lovely if we could say this is going to be the answer to everybody's problems, but it's completely unrealistic. (G2F3)*

Examples of using a person-centred approach when working with people with dementia included: training staff to spend time building a relationship and getting to know the person with dementia:

> *We tried with healthcare support workers, to try and teach and to explain and to spend some time with the person with dementia to be able to understand what the microwave is for….. So it varies, but it's allowing them some independence within their ability, and that can take some time to help them to understand and get used to your reasoning. (G2F2)*

Assessing risk on a case by case basis to ensure an individual approach:

> *…..you literally look at everybody on an individual basis. We look at person centred care anyway, so we're looking, and then risk assessing everything, and then from that see what you can make better and what you can't. And some of it…like hording…. the collecting thing. You can't do that to people, start taking their things. We wouldn't have it in our own homes would we? No one's coming in and picking up my post irrespective of what it is. (G2F1)*

And adapting the usual approach by repeating key information on several occasions:

> *… after I've done a Home Safety Check, I always highlight any main issues that I've found at the end. With somebody that's starting to behave as though they've possibly got dementia, I will repeat that regularly, all the way round, I will just re-iterate constantly. We'll talk about it one room, I'll repeat it before we leave that room. I'll repeat it again before we go to the next room. I'll repeat it again before we go upstairs. I'll say, just to recap on the ground floor, what you're looking at is…and then upstairs, like we*

> *found downstairs, blah, blah, blah…and then before leaving as well… just constantly repeating the same message and hoping that it sticks. (G1F1)*

3.3.2 Partnerships to identify vulnerable households

The benefit of being able to identify the houses where people with dementia live was discussed by Fire and Rescue Service participants, as it would enable them to target prevention activities such as Home Safety Checks and, in the event of an incident, mean that the crews are aware of the diagnosis before entering the property:

> *That would help our dynamic risk assessment, before we get there. So if I was told, these people have got dementia, we'll be looking for things slightly differently. (G1M5)*

However, the difficulty of keeping such information up to date was also discussed:

> *The problem we have is that if we collect data.., and we put on the system that they've got dementia, if they move or if they pass away, those bits of information aren't updated in any way, so you might go to that property in a year's time, and it still says on the details that that person's got dementia, well they moved and now it's a young family with two kids living there, and that's where we start breaching our Data Protection laws. (G1F4)*

Other professionals felt that there is a need to involve Fire Service professionals within multiagency teams (including social workers, domiciliary care providers, community mental health nurses etc.) that meet regularly to discuss care needs of individuals:

> *…. if you could make the fire service part of that multiagency team to meet annually about that person's care, more often if necessary…, to discuss that person's ongoing need. (G2F1)*

The Fire Service were referring vulnerable people to other service providers, primarily through the Safe and Independent Living (SAIL) referral scheme but also by personally contacting them by email or telephone. The converse was also the case: other professionals were aware of the Home Safety Check service provided by the Fire Service and were referring those who gave their consent to be referred.

> *When we see somebody that needs help from another agency we do need to have their consent or the carer's consent or the person who's got power of attorney to be able to signpost it to a certain service…. very straightforward process [signposting to the fire service]. (G2M1)*

For individuals that refuse or are unable to give their consent, service providers are able to consult each other if they believe it is in the 'best interests' of the individual or there is a risk to the safety of others. However, it was recognised that there was a need to develop a more joined up referral approach; one where all service providers are able to monitor and record the outcomes for individuals:

> *I do think that one of the little things I thought before was the better links between the fire service and us [domiciliary care providers], whoever's involved in the community, and how we do that better, because we make a referral and somebody will go out and we might link in but that might be the end of it then. It's sort of got a little bit lost. They'll advise on putting up this and doing that, and it might happen, but then what? G2F2.*

This was reiterated by Fire Service professionals who were unsure who they should contact about people with dementia they encountered who may need some support rather than safeguarding:

> *I think the problem we'll come across is, if we find somebody in the community who we feel have got issues, and they're not receptive, so they go, no nothing wrong with me, we contact social services, and they've never heard of them. Then where do we stand? Do social services go round there? (G1F3)*

> *No, but I think there's another element here that Health and Wellbeing or Partners in Health need to pick up, because… we've got a duty of care while we're there doing our job, and if it's a safeguarding issue, then we've got a process, and if someone is at risk of abuse then we do something about it. Actually, my ideal world would be that health would fund people… in a locality… that are picking up those types of things, they're not a safeguarding issue, they're not something that we have the expertise to deal with, but it is a signpost. Because [our signposting process] doesn't always capture that. It just signposts people… to the Memory Advisory Service. But there's a lot of low level issues linked to people with dementia that we've got nowhere to go with. (G1F4)*

3.3.3 Assistive technology in the home environment

In terms of assistive technology in the home environment, participants talked about various kinds including gas shut off valves, flood detectors and telecare (see Appendix 6 for further details). For the most vulnerable, there was also discussion of the usefulness of other equipment such as flame retardant bedding and spray. Reducing the risk of fire in the homes of people, where their dementia means they were no longer able to recognise or respond to smoke alarms, was discussed. Fitting a sprinkler system was considered the most effective approach, however the responsibility and cost of financing the installation and maintenance of such systems was problematic:

> *…..you've got to weigh up…., how much does it cost for a crew to be mobilised for a fire, and if it's a property fire, that's two whole time crews, the cost of that, and… if they've got carers and all the different technology, when actually for two grand, they've got sprinklers and you haven't got to worry about it again. (G1F3)*

Telecare linked smoke detection was discussed as an alternative; however the concerns about funding and process to acquire telecare remained:

> *I've managed to get three of four telecare [providers] for people, and social services, whether they fund it, they've always given me a few different answers on whether they can do it or not, someone has said, we haven't got the funding any more, other people have said, yes, I can do that straight away, and it's been put in place very quickly, so that's always been a bit of a grey area. (G1M4)*

The challenge reported by participants in regard to implementing assistive technology was who funded it and how it was funded:

> *In terms of funding, 'cause obviously anything like that costs money, what about funding, what funding's available? To me that would be the biggest issue? G1F3.*

Managing the loss of independence that people with dementia might feel if assistive technology is fitted into their homes, does requires particular attention by professionals who are advising or installing such equipment in people's homes, as this example shows:

> *Well there was a lady that I saw once, whose husband was very concerned because she had early onset of Alzheimer's. She recognised the gas fire in the living room but couldn't remember how to operate it. She knew she had to do something with that knob, but she couldn't remember what to do after that. So, in the end he wouldn't let her touch it. So it's that frustrating grey area, where she recognises the object, she knows what it does, she knows that she used to be able to operate it, but now she can't remember how to. But she's determined to keep trying. (G1F1)*

There is also a need to carefully consider how well the person is likely to adapt to the new equipment being fitted:

> *'Cause that was the problem with the lady at (name of place), eventually…there was no gas in the building at all, but eventually they disconnected the cooker, because she couldn't be trusted to use the hob, even with a kitchen timer thing. It would go off, and she just couldn't remember what it was set for. (G1F1)*

And:

> *That needs to be assessed quite carefully, because if someone's got a rough idea of how to use a hob, and obviously no idea how to use a microwave, it can be a double edged sword. (G1M4)*

3.3.4 Dementia aware prevention strategies

As the number of people affected by dementia will continue to grow well into the future, it is important that prevention strategies consider the needs of people with the condition. Early intervention with people affected by dementia was seen as important by professionals in order to enable people to plan for the future and implement their individual risk reduction strategies, as these participants discussed:

> *…..it's getting in there when they get diagnosed, whoever does the diagnosis, doctors, and you're getting all the new cases so to speak, and you can… (G1F3)*

> *And getting them to sign up to [telecare and linked smoke detection] and stuff, early on, 'cause you can explain the issues that, you know, it might be that this is how things will be in a few years' time, and if you want to stay at home, and if you don't want to worry your family, if you put this in place now, in five or ten years' time, it's going to make things far easier for you, when they can't get to grips and understand what's going on. (G1F2)*

Identified risks can change over time as an individual's dementia progresses, it was noted that risk assessment processes need to take this into consideration and be repeated regularly:

> *I think it also depends how quickly the disease progresses, because there was a lady that I did an initial visit for, had a few memory issues but was largely able to take it on board and was fine, less than six months later I had a phone call from a neighbour, saying, I really need you to come and have a look, she has deteriorated so rapidly, I am seriously concerned for her safety. There was nothing that I could do, because fire wise, she was as safe as she could be, but in every other aspect, she was…she should never have been living on her own. If it wasn't for the neighbour, she would have probably been in hospital, because she was falling over so much. (G1F1)*

Professionals talked about how patience and understanding were key traits when working with people with dementia:

> *Repetition, repetition, repetition. The same conversation. Before you've even left one room. That's the warning sign for me. It's not just the absence of memory, it's that, I'm going to tell you something in great detail, and then ten minutes later, I'm going to tell you something in great detail, and you just think, we've had this conversation…, but when you get that kind of conversation going on, it's like, right, all is not well…you've just got to go with the flow. (G1F1)*

It was suggested that risks from fire were not always considered by people with dementia and their carers, who often prioritised other risks:

> *I think it's just getting the risks out there, 'cause I think a lot of carers think that the main risk is them wandering off, and things like that. So, we hear stories of people being locked in their house. So they're locked in at tea time and then they're let out again in the morning. Well actually, that's a huge risk, from our point of view. (G1F2)*

Professionals felt that education is important for themselves as well as carers and people with dementia. There were some inconsistencies in who had received the training, for example in the Fire Service, dementia training had been provided to Home Safety Advisors and not Firefighters. There was also a process for signposting those at risk who do not fall into the safeguarding remit to Home Safety Advisors, however this was informal rather than being outlined in any policy:

> *They've [Firefighters] had safeguarding input, so they're confident that if they come across something that they're not happy with, or that this person's not safe, that they know the procedure, to go through the safeguarding…. if …it's not life risk.. and this person needs a bit more time, they know that they can come back and pass it on to a Home Safety Advisor, and then one of us can go out and spend a bit more time with them. G1F2.*

Professionals felt that contact with people following a diagnosis of dementia was important, and would help people to plan for the future:

> *…..it's the education to the people that are around the people that's diagnosed with dementia, early on, and maybe getting the person that's diagnosed with dementia, early on, to agree to some sort of package whilst they're still able to understand the risks that they might encounter in five years' time, or ten years' time, and getting all these things in place, early doors, so they get used to [telecare and linked smoke detection] and things like that, before they can't understand what the risks are any more. (G1F2)*

Dementia training would enable professionals who work with people with dementia to be informed about the condition and help them spot the early warning signs.

3.3.5 Challenges

Professionals also discussed the wider challenges in implementing these risk reduction strategies. Challenges for professionals offering support included

individuals and their families who had not accepted their diagnosis:

> *Well, the first thing is trying to get the family on board, which is often quite difficult because families don't want to accept that mum won't put that in the microwave. She'll realise it's not meant to be there, and you have those conversations. You can't remove the microwave. That's the hardest thing. You can't really remove anything from the home. So it's a management nightmare. (G2F1)*

Or even received a diagnosis even when struggling with memory difficulties:

> *Neither of them have been diagnosed now…., not officially …., And it took six months, and she's just been assessed, and they've said, oh yeah, we'll definitely get her to a consultant, and sorted. (G1F5)*

This was the same for family carers too:

> *I don't know. You get extremes don't you? Some people are risk averse and everything is really a worry to them, and others… It depends on what relationship you've had with some of the family, how much they want to be part of that… (G2F2)*

> *Yeah, sometimes they just won't even accept that somebody in their family's got dementia, and there's a whole heap of other problems if you can't get the family on board. (G2F3)*

There were some examples that illustrate unintended consequences of the best intended actions. Tragically, this included a gentleman who died of food poisoning after having a gas stove shut off fitted:

> *…a chap, he had a brain injury…. He basically was friends with the local hunts, and they had given him lots of meat, and he used to be quite fond of deer's hearts and things like that, and he'd stick them in the oven and just forget about them. And … he [had] a 30 minute timer on the [oven*

> *fitted] … cause he'd forget how to operate the oven, you'd get 30 minutes from there, that was it, and then it would knock off…. He died from food poisoning of raw chicken is the problem.* G1M4.

As well as a lady dying in a fire after not leaving her property due to a sign on the door informing her not to leave the house:

> *And she had the fire in the airing cupboard, and she walked past the fire, and went downstairs, and because she knew she shouldn't go out the front door, she went and sat in the front room. But all the doors were open, so she died from smoke inhalation.., there was a sign on the front door, that said, don't go out of the door. So, she didn't. (G1F4)*

This Fire Service personnel felt demonstrated the importance of assistive technology such as telecare linked smoke detectors:

> *….if she had [telecare], connected to smoke alarms, so it automatically went to a call centre, so she didn't even have to ring 999, the smoke alarm goes off, and the mobilise a pump immediately, that would have possibly saved her life. (G1F2).*

3.3.6 Strategies raised by people with dementia and their carers

People with dementia and their carers (groups 3 and 4) were asked to comment on how people with a similar condition could be safer in their home. Their responses included: decluttering or packing objects away in boxes; keeping floors tidy to avoid tripping; and avoiding rugs and cables on the floor and leaving drawers open. They felt that the most unsafe room of the house was the kitchen, and suggested that putting labels on cupboard doors may help some people with dementia to locate items more easily. However they suggested that these strategies were often time limited, and that eventually the risks would mean that most people with the condition were likely to need some help to complete everyday tasks for themselves. Dealing with this increasing dependency is difficult and some carers had their own ways of

managed this:

> *… I've got a check list – which sounds ridiculous – but one of the things on there is to make sure I've switched off all the gas hob [general agreement] and just make sure all the knobs are facing the right direction; because when you've got them turned low, like you say, with the sun coming in as well, you can't actually see they're on. (G4F4C)*

Support from neighbours was clear amongst the groups:

> *I've actually got reasonably new neighbours and this chap came and tapped on the door to introduce himself, and he said, I'm Mike, or something, and he said, you won't actually see my wife very much because she's got Alzheimer's – no, dementia he actually said – and I just went, snap; I just thought, oh, and he sort of stood back; I said, look, actually my husband has got it as well…. And his wife is a lot worse, but we have got something in common… So a bit of support for him. (G4F4C)*

And it was this support that professionals felt was valuable to support people living with the condition:

> *One thing about people with disability generally, is that when we turn up… I know straight away, if [we are outside] someone's house who's got dementia or they're in a wheelchair, the neighbour's normally out there…. and they'll say that [inaudible 22:20] in a wheelchair. Even in Home Safety, people come and knock, and say, is everything alright? And we say, yeah, we're just the Home Fire Safety, they'll say oh it's just because he's got dementia, so I think the public look after them quite well. (G1M1)*

In terms of fire safety, people with dementia and their carers had smoke detectors and carbon monoxide detectors in their homes although none were very informed about assistive technology or knew about telecare linked smoke detectors:

Interviewer: Does anyone have a smoke detector that's connected to Telecare or anything like that?

G3M3C: No.

G3M1D: Sorry what's Telecare?

Summary points – fire risk reduction strategies in the homes of people with dementia

- Fire service participants and professionals working with people with dementia identified four risk reduction strategies: a person-centred approach; partnerships to identify vulnerable households; assistive technology in the home environment; and dementia aware prevention strategies.
- People with dementia and family carers identified decluttering, avoiding trip hazards, installing smoke and carbon monoxide detectors and relying on observant neighbours as ways of staying safe at home.
- Challenges to fire risk reduction strategies included working with people who have not accepted their dementia diagnosis and therefore refuse specific supports, people who had not received a diagnosis and therefore were not ‘in the system’ and lack of knowledge held by people with dementia and family carers of available fire risk reduction technologies.
- A key challenge is to ensure the installation of technology in a person’s home does not have a catastrophic unintended consequence of causing them harm.

3.4 Suggestions for guidance documents, resources and training packages

A key starting point raised by fire service and professional participants was the need for fire risk awareness: fire service personnel need to know the potential consequences of fire safety strategies or advice and people with dementia and family carers need to know risks to safety of their actions (removing a battery from a bleeping fire alarm or unplugging a safety alarm):

> *And some people all their lives have been told to unplug everything at night. I still know people who do that, and they will unplug everything at night, including the things that could potentially save their lives. (G2F3)*

Fire service personnel raised the complexity of identifying and responding to someone who was potentially at risk but who did not fall in to their remit for taking action: safeguarding or risk of abuse category:

> *But there's a lot of low level issues linked to people with dementia that we've got nowhere to go with (G1F4).*

They wanted a clear process for supporting people with dementia they identify as at risk 'of low level issues' both in terms of knowing who to pass information on to (someone within the fire service or a health or social work professional) and in terms of knowing what safety interventions are available and how to get them installed.

Carers particularly valued receiving information face to face, and professionals felt this could be done as part of their own (or other organisation's) course or programme delivery. This was seen as a way of ensuring family carers were not overburdened with attending courses. Participants felt that information delivered to people with dementia might be more useful in written form, so that it could be read and re-read. Suggestions for the format of literature included keeping it in simple English, bold writing, black text on white, inclusion of pictures, a laminated leaflet *'so it doesn't matter if you spill your coffee over it' (G4M1D)* and that could be 'stuck on a wall' Carers also felt this type of information could also be available online as a PDF. It is also worth considering that actions taken to reduce risks in people's homes do not always need to be expensive, as found in another study, a simple sticker costing five

pence that was placed over a plug socket to warn the person with dementia not to touch it was effective in preventing tampering (Holley-Moore and Scrutton, 2015).

Summary points – suggestions for guidance

- There is a clear need for awareness raising for fire service personnel, people with dementia and family carers.
- Fire service personnel want clear referral processes, particularly for those at risk who do not fall into their safeguarding remit.
- Fire service personnel want better knowledge of what technology is available and who is responsible for funding and installing it.
- Family carers want information that is accessible in face to face or leaflet form.
- Information for people with dementia may be more easily digested in laminate form, Plain English, accessible font and including illustrations.

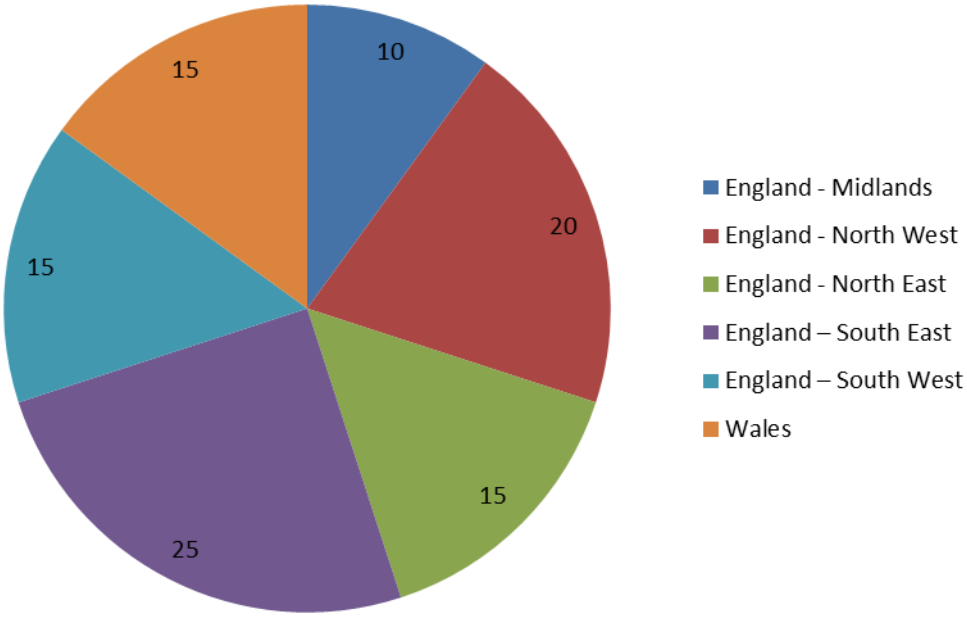
4. SURVEY FINDINGS

This section summarises the key findings of the survey. It was not possible for respondents to answer all of the questions asked as some of the information requested is not collected by FRSs through the Incident Recording System (IRS) nationally.

4.1 Respondents

Respondents were fairly evenly spilt across the UK, with the majority being located in South East England (25% or n=5), as shown in Chart 1. No responses were received from FRSs located in Northern Ireland or Scotland.

Chart 1: Chart to show the locality of FRSs that responded to the survey



4.2 Incidents involving people with dementia

Respondents were asked to determine the number of fire incidents they attend involving people with memory difficulty or dementia. 8 respondents answered this question and 12 skipped it. One respondent (12.5%) stated ‘yes’, whilst the other 7 (87.5%) stated ‘no’ and commented that this information is unknown as they do not record whether someone has memory loss or dementia following an incident. Respondents were asked to report how often they respond to a fire incident involving people with memory loss or dementia. 8 respondents answered this question and 12 skipped it. One respondent (12.5%) stated ‘several times per week’, whilst the other 7 (87.5%) stated ‘other’ and commented that this information is unknown as they do not record whether someone has memory loss or dementia following an incident:

> *This is something that cannot be accurately recorded. We cannot ask people direct if they have memory loss or dementia as some people have not even had a diagnosis. Also asking these questions would put the fire crews and staff in an uncomfortable position.*

> *This is not always apparent at the time so you cannot give any accurate figure per day/week. I believe it would be better to approximate 20% average across the incidents attended.*

Respondents were asked to determine the type of fire incidents that people with memory loss or dementia are most often involved in. 8 respondents answered this question and 12 skipped it. 3 respondents (37.5%) stated ‘accidental dwelling fire confined to one room’, 1 respondent (12.5%) stated ‘accidental dwelling fire of more than one room’, and the remaining 4 respondents (50%) stated ‘other’ and commented that this information is unknown as they do not record whether someone has memory loss or dementia following an incident. Respondents were asked to state the most common cause of fires where fatalities have been people with memory loss or dementia, 4 (57%) were unable to answer the question, whilst the remaining 3 (43%) answered:

> *Smoking, kitchen fire.*

> *Forgetting to switch off heat sources from cooking or warming rooms.*

> *Relatives say that they often forget the oven hob has been left on.*

4.3 Fire safety advice and guidance

Respondents were asked to state whether they offer fire safety advice to (i) older people, (ii) people with dementia and/or their carers, and (iii) professionals working with people with dementia and/or their carers. 9 respondents answered the question about older people, whilst 8 respondents answered the other two questions. All respondents stated that they 'frequently' or 'always' provide fire safety advice to older people and people with dementia and/or their carers, as shown in Table 4. Fire safety advice was less likely to be offered to professionals working with people with dementia and/or their carers, as 3 respondents (or 37.5%) stated they do this 'sometimes' and 5 respondents (or 62.5%) 'always'..

Table 4: How often Fire and Rescue Services provide fire safety advice to older people, people affected by dementia and professionals working with people affected by dementia

	Do you offer fire safety advice to:					
	Older people		People with dementia and/or their carers		Professionals working with people with dementia and/or their carers	
Never	0	0%	0	0%	0	0%
Infrequently	0	0%	0	0%	0	0%
Sometimes	0	0%	0	0%	3	37.5%
Frequently	2	22.2%	2	25%	0	0%
Always	7	77.8%	6	75%	5	62.5%
Total	**9**	**100%**	**8**	**100%**	**8**	**100%**

Respondents were asked to provide some examples of the types of fire safety advice (including resources and key messages) they provide for these groups. 7 respondents (35%) answered these questions. When asked what fire safety

advice they provide older people, 2 respondents did not comment and 5 respondents stated that they provide:

> *Leaflets with information about Home Safety Checks and telecare providers.*

> *Home fire safety visits where we provide fire safety guidance to groups / clubs for older people as requested. Escape plan, electrical safety, kitchen safety, smoking if applicable, trip hazards, and anything else that is relevant to them.*

> *Emergency heating/lighting/food provision to combat immediate hardship due to fuel poverty, with signposting to services to provide longer term solutions for fuel poverty and a raft of social care issues.*

> *Leaflets, signposting, [signposting to other organisations], deaf alerts, large print booklets, easy to understand safety messages. Home fire safety check conducted which includes a risk assessment, provision and fitting of free smoke alarms where necessary and advice given on electrical safety, good housekeeping, cooking safety, bedtime routine and advice around any risks identified during the visit/assessment.*

> *Night time check lists. Leaflets about electrical safety and general household fire safety. Leaflets about safety at Christmas. CDs for people with sight, hearing or mobility difficulties. Reminders to check smoke alarms regularly.*

When asked what fire safety advice they give to people with dementia and/or their carers, 1 respondent stated that the advice is the same as for older people, 3 stated that the advice is the same for older people except for:

> *..the message given the same as before however we do ask the carer to take note of any burn marks or obvious signs of small fires as these can be addressed.*

..see advice for elderly, plus exploring the use of assistive technology to support independent living.

..the advice is in line with the previous explanation for a Home fire safety check but may extend to any identified risk during the conversation but there is no standard information.

The remaining 3 stated that they provide:

…good handouts and leaflets, we provide a fridge magnet which is a safety checklist to prompt people living with dementia on how to keep safe at night. Our leaflets are now very pictorial as opposed to wordy and the colours used are of sufficient difference to be understood by somebody living with dementia.

..signposting, easy to read literature, in depth visit with HSA to include carer/family members

Reminder leaflets and papers which can be placed in prominent places as a visual reminder.

When asked what fire safety advice they provide professionals working with people with dementia and/or their carers, 3 respondents stated that the advice is the same as for older people, the remaining 4 stated that they provide:

… 30 min or an hour talk to all domiciliary care workers across [name of County]. Key messages around this are ensuring…fire resistant bedding is supplied, look for signs of new burn marks or damage to pots and pans used for cooking. Also how to refer the client [for Home Safety Check] if no care package is in place.

A bespoke training package on mental health has been developed and is currently being delivered internally to all operational staff. [Name of FRS] are currently in the process of developing a fire safety training package for carers.

Talks to professionals [at our education centre], seminars for domiciliary care workers.

Checklists which can be given out. The need to check smoke alarms and contact details if they need replacement alarms.

Respondents were asked if anyone else (i.e. partner organisation) offers fire safety advice to (i) older people, (ii) people with dementia and/or their carers, and (iii) professionals working with people with dementia and/or their carers, on their behalf, or if they were planning on doing so in the next 12 months. All 20 respondents skipped this question for all 3 groups.

Respondents were asked to comment on the following statements (see Table 5) in order to determine how they might use specific fire safety guidance designed for people affected by dementia. Respondents were also asked to comment on whether, if they received fire safety guidance for people affected by dementia, they would use it for any purpose other than those outlined in Table 5 below. Respondents felt that they may also use the information:

…depending on the quality of the fire safety guidance.

And if it….

… is relevant to other people living with mental disorders as well.

Table 5: How Fire and Rescue Services might use specific fire safety guidance designed people affected by dementia

If I received fire safety guidance for people affected by dementia:	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	Total
I would use it to develop resources including fire safety leaflets for people affected by dementia.	0.00% 0	0.00% 0	22.22% 2	33.33% 3	44.44% 4	**100% 9**
I would summarise it and circulate it to colleagues in a staff briefing note.	0.00% 0	0.00% 0	22.22% 2	22.22% 2	55.56% 5	**100% 9**
I would file it for later as we have no funding to currently use it.	55.56% 5	11.11% 1	33.33% 3	0.00% 0	0.00% 0	**100% 9**
I would not use it as it is not relevant to the population in this area.	77.78% 7	0.00% 0	22.22% 2	0.00% 0	0.00% 0	**100% 9**

Respondents were asked to comment on what information they would find useful in fire safety guidance for people affected by memory loss or dementia. Their responses included:

Easy read guidance.

Ensuring that carers / responsible adults are aware of an escape route in the event of fire. The promotion and use of signs / diagrams to assist in their escape route. Ensure that carers / responsible adults are aware of the information available related to assisted living technology.

Basic fire safety guidance - guidance for crews carrying out [Home Safety Checks] on how to best engage with target audience.

Maybe pictures rather than written guidance.

Legal situation, best practice in assisting/assessing individuals. Is there help available and if so, where?

How to best use visual reminders for fire safety.

Respondents were asked to make any further comments:

We understand the dangers of fire to people with dementia, we train our staff, issue guidance…, the main issue is knowing where they are and having a multi agency approach to the problem with the agencies and families that care for them.

[Name of FRS] takes dementia very seriously and we are in the process of making [Name of FRS] a dementia friendly service…, we have had an incident at a care home specialising in people living with dementia and other mental illnesses; the responding crews have all received their training which helped the residents cope with what is undoubtedly a very stressful event.

It is very hard to record the amount of people we deal with, with dementia or similar due to the nature of the illness and its acceptance with sufferers and carers.

Summary points – survey findings

- The amount of fires occurring in the homes of people with dementia is unknown, as the current system used by FRSs to record incidents does not allow them to record whether someone has memory loss or dementia.

- People with memory loss or dementia are likely to be involved in accidental dwelling fire confined to one room or more than one room, and fire fatalities amongst this group are often linked to smoking and cooking.

- FRSs provide a range of fire safety guidance to older people, including: leaflets, talks to groups, signposting to other organisations and large print booklets. Fire safety messages are written in plain English and promote electrical safety, good housekeeping, cooking safety, as well as advice on bedtime routines.

- Whilst some FRSs provide fire safety guidance to people with dementia and/or their carers (examples included a checklist fridge magnet to keep safe at night, leaflet with les words and more pictures), other FRSs do not offer this group any specific resources or key messages; instead using the resources designed for older people in general.

- FRSs were less likely to offer professionals working with people with dementia and/or their carers dementia-specific fire safety guidance.

- None of the respondents answered the question about whether anyone else (i.e. partner organisation) offers fire safety advice to vulnerable groups on their behalf, or if they were planning on doing so in the next 12 months.

- FRSs stated that if they received fire safety guidance for people affected by dementia, they would be likely to use it to develop resources (including fire safety leaflets for people affected by dementia) and summarise it and circulate it to colleagues in a staff briefing note.

- FRSs would find it useful to know more about:
  - Communicating with people affected by dementia;
  - Signposting people affected by dementia to appropriate information and support;
  - Best practice and legal aspects of assisting/assessing people with dementia;
  - Using visual reminders/signs/diagrams for fire safety.

5. DISCUSSION OF FINDINGS

This section provides a discussion of the findings. The fire risks and risk reduction strategies identified by people affected by dementia varied to those outlined by professionals. In general, people with dementia and carers described home safety risks, and after further probing some identified fire hazards, including sitting too close to or falling into open or electric fires, using metal containers in microwaves, candles, forgetting to put cigarettes out, leaving the cooker or gas on or putting an electric kettle on a gas hob. In another study, fire, water and electrical safety were identified as being the third most common concern for carers when leaving a person with dementia alone (Walker et al, 2005). Professionals however, reported four types of fire risk in the homes of people with dementia: related to a person's past role or actions; using appliances inappropriately; related to memory impairment and the person's home environment. People with dementia and carers identified decluttering, avoiding trip hazards, installing smoke and carbon monoxide detectors and relying on observant neighbours as ways of staying safe at home. Professionals identified four risk reduction strategies: a person-centred approach; partnerships to identify vulnerable households; assistive technology in the home environment; and dementia aware prevention strategies.

5.1 Understanding the person, their situation and risks

The focus group findings demonstrate the heterogeneity of dementia. Every person with dementia will have a different experience of the condition, which may include a range of symptoms and the rate of progression. In other studies it has been found that people with dementia may also fiddle with appliances (Holley-Moore and Scrutton, 2015), or leave them on for a long time due to memory difficulty and if they become sensitive to temperature (which can be a symptom of dementia) (Seitzer, 2009). The sensory challenges of dementia (sight, smell, taste, hearing and touch) are also worth noting (see Houston, 2008). For example, it has also been noted that people with dementia may experience visual hallucinations and that these could

include believing that objects, people or rooms are on fire when they are not (Byrne, 1996). Whilst others have reported that people with dementia may smell a chemical or burning smell that does not exist (Rubin et al., 1988).This combined with their individual lifestyle and situation means that risks and the resulting reduction strategies will vary from one person to the next. A person-centred approach to risk assessment is therefore recommended. Where possible involve all stakeholders in decision making (i.e. the person, their carer, family, professionals, etc.), however the decision should be made by the person themselves, unless they do not have mental capacity. As the survey findings demonstrate, the current recording and monitoring system used by FRSs nationally across the UK means that it is not possible to determine the amount of fires occurring in the homes of people with dementia. However, it has been determined that dementia is a substantial risk factor in terms of increasing risk of injury or death from fire in the home (US Fire Administration, 2006). Across the groups participants' experiences and understanding of dementia and fire risk did vary. Whilst some of the professionals had vast experiences of working with people with dementia, others had much less experience (for example asking for clarification of the symptoms of dementia). In the same way, some of the people with dementia and carers were more vocal about home and fire safety than others. This highlights some inconsistencies in knowledge and experience and therefore a need to understand more about dementia and how the condition might impact on home safety, including fire risk. To be able to effectively respond to the needs of a person with dementia and/or their carer requires an individual approach. One size will not fit all in this case and there is a need for tailored risk reduction strategies and resources that reflect individual needs. This approach will take time and for the most vulnerable cases requires specialist knowledge (i.e. telecare) and signposting to other agencies – this may be outside of the remit of Home Safety Advisors and therefore a role may need to be developed. Risk assessments must also be undertaken regularly as needs change.

5.2 The importance of early diagnosis, intervention and multi-agency approaches

The importance of early intervention with people affected by dementia has been documented (Prince et al., 2011). Early diagnosis and intervention provides people with dementia and their families an opportunity to understand what is happening to them and the ability to make choices about their future (Prince et al., 2011). Effective intervention also has the potential to prevent problems and crisis points that may occur in the future (Prince et al., 2011). In terms of reducing fire risks, early intervention will enable the introduction of risk reduction strategies (such as telecare linked smoke detectors) that will enable people with dementia to live independently in their own homes for longer and also reassure carers. Identifying where vulnerable people (including people with dementia) live is problematic. FRSs are able to provide people with dementia with information, support and signposting to other organisations and the same is true for other organisations who can signpost vulnerable people to the fire service for a Home Safety Check. Fire service personnel want clear referral processes, particularly for those at risk who do not fall into their safeguarding remit, as well as better knowledge of what technology is available and who is responsible for funding and installing it. That said, working directly with people affected by dementia is not without its challenges. The findings show that challenges to implementing fire risk reduction strategies include working with people who have not accepted their dementia diagnosis and therefore refuse specific supports, people who had not received a diagnosis and therefore were not 'in the system' and lack of knowledge held by people with dementia and family carers of available fire risk reduction technologies. As discussed in the findings chapter, Fire Service personnel discussed the importance of assistive technology such as telecare linked smoke detectors after reporting several examples of people not responded to their smoke detector as they would expect (i.e. staying inside the building rather than evacuating). A key challenge is to ensure the installation of technology or other risk reduction strategies in a person's home continue to be relevant for that person's needs, and that it does not have a catastrophic unintended consequence of causing them harm.

5.3 Raising awareness of fire risks associated with dementia

The survey findings show that FRSs provide a range of fire safety guidance to older people, including: leaflets, talks to groups, signposting to other organisations and large print booklets. Fire safety messages are written in plain English and promote electrical safety, good housekeeping, cooking safety, as well as advice on bedtime routines. However the same is not true for people affected by dementia, as some FRS s provide this group with specific fire safety guidance (examples included a checklist fridge magnet to keep safe at night, leaflet with les words and more pictures), whilst many do not, instead using the guidance designed for older people in general. Carers may instinctively check that they have turned off appliances such as the television and lock doors before going to bed for example, although providing a checklist has been advocated by Holley-Moore and Scrutton (2015) to help identify risks. As the findings demonstrate, there are fire risks that are specific to people with dementia who remain living in their own homes; this underlines the importance of fire safety guidance that is specific to this group. For example, the survey findings show that people with memory loss or dementia are likely to be involved in accidental dwelling fires rather than other incidents that FRSs attend. The cause of fire fatalities amongst this group are often linked to smoking and cooking. The focus groups demonstrate that family carers want information that is accessible in face to face or leaflet form, and that information for people with dementia may be more easily digested in laminate form, Plain English, accessible font and including illustrations. The survey findings show that FRSs are supportive of creating fire safety guidance for people affected by dementia, and so we hope that this document will prove useful in helping to develop this work, and in the longer term will mean that people with dementia are safer in their homes and improve their quality of life. We recommend the development of specific prevention messages and resources (such as a laminated leaflet) for people with dementia and/or their carers, alongside providing advice on individually tailored risk reduction strategies. As part of the wider project an internet search for existing resources was conduced (Appendix 7 contains a list of these resources). Not all FRSs offer professionals working with people with dementia and/or their carers fire safety awareness training and

this is something that we recommend is offered to organisations such as domiciliary care providers.

6. CONCLUSIONS

This project demonstrates that understanding the person and their individual situation is vital in determining the risks within their home environment. Risk assessments must therefore be undertaken using a person-centred approach and to ensure that risk reduction strategies are effective for that person. Risk reduction strategies however may be time limited as the condition progresses and behaviours change, therefore regular risk assessments should be undertaken. Assistive technology (such as telecare) should be introduced as early as possible. Professionals who work with people with dementia, including Fire and Rescue Services, need to understand more about the condition, as well as have an awareness of person-centred approaches. There is a need for a range of resources that reflect individual needs.

7. RECOMMENDATIONS

The project recommendations drawn from the findings are defined in Table 6.

Table 6: Recommendations drawn from the project findings

PROJECT RECOMMENDATIONS	
Recommendation	**Suggestions for addressing this**
Put the person first: sufficient time and co-ordinated support and information	• Throughout the dementia journey people need to be given time to talk, reflect and seek advice and information.
Assess risk regularly using a person-centred approach	• Understanding the person and their individual situation is vital to determining the risks within their home environment. • Risk reduction strategies however may be time limited as the condition progresses and behaviours change, should be undertaken. • Use an established person-centred approach (one example being the Person-Centred Risk Assessment and Management System (PRAMS) model (Titterton, 2005).
Ensure that assistive technology is fitted as early as possible	• To enable people with dementia and their carers and families to make informed decisions about future care and alleviate decision making once dementia has progressed to later stages.
Provide dementia training and support to Fire Service and other professionals working with people with dementia	• Dementia training needs to develop understanding of dementia as well as person-centred approaches. • Knowledge of assistive technology that is available and a clear referral process for funding and installing it. • Develop clear referral processes, particularly for those at risk that do not fall into safeguarding remits.

Develop multi-agency approaches and share information about where people with dementia live	• Develop Fire and Rescue Service's involvement in multi-agency teams that care for community-dwelling people with dementia by developing specialist Home Safety Advisors who have more specialist dementia knowledge and are given longer to work with vulnerable people and develop a network of key contacts in other agencies. • Develop local partnerships and data sharing agreements to identify where people with dementia live. • Outline process between Fire and Rescue Services and Adult Mental Health Teams to determine who funds, fits, maintains telecare and linked smoke detection.
Increase awareness and understanding of dementia and the associated fire risks	• A number of participants described a lack of basic knowledge about dementia and fire risks amongst family carers and paid carers in particular (i.e. leaving food to be heated in the microwave in metal trays). • There is still work to be done to increase awareness and understanding about dementia and the associated fire risks of professionals (including fire service personnel) and people affected by dementia.
Develop a range of accessible resources	• There is a need for a range of resources that reflect different needs. • Family carers want information that is accessible in face to face or leaflet form. • Information for people with dementia may be more easily digested in laminate form, Plain English, accessible font and including illustrations. • Fire and Rescue Service personnel would find it useful to know more about: - Communicating with people affected by dementia; - Signposting people affected by dementia to appropriate information and support; - Best practice and legal aspects of assisting/assessing people with dementia; - Using visual reminders/signs/diagrams for fire safety.

REFERENCES

Alzheimer's Disease International. (2014) 'Dementia Statistics', *http://www.alz.co.uk/research/statistics. Accessed* 1st May 2014.

Alzheimer's Society. (2015a) 'What is dementia?' *http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=106.* Accessed 28th September 2015.

Alzheimer's Society (2015b) 'Statistics', *http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=341.* Accessed 28th September 2015.

Alzheimer's Society. (2013) 'Building dementia friendly communities: A priority for everyone', *http://www.alzheimers.org.uk/dementiafriendlycommunities.* Accessed 6th May 2014.

Bournemouth University (2009) *Research Ethics Code of Practice*, Bournemouth University, University Research Ethics Committee.

Bowers, H., Clark, A., Crosby, G., Easterbrook, L., Macadam, A., MacDonald, R., Macfarlane, A., Maclean, M., Patel, M., Runnicles, D., Oshinaike., T., and Smith, C. (2009) 'Older people's vision for long-term care' *http://www.cpa.org.uk/ltc/older-people-vision-for-care-full.pdf*. Accessed 30th September 2015.

Boyatzis, R. (1998) *Transforming Qualitative Information: Thematic Analysis and Code Development.* Thousand Oaks: Sage Publications.

Bryne, E. (1996) 'Noncognitive symptoms in Lewy Body Dementia', in C. Ballard, K. Lowery, R. Harrison, and I. McKeith (Eds.) *Dementia with Lewy Bodies: Clinical, pathological and treatment issues.* Cambridge: Cambridge University Press.

Department for Communities and Local Government. (2012) 'Fire statistics: Great Britain, 2011 to 2012', *https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/36467/FSGB_2011_to_12.pdf.* Accessed 24th February 2014.

Department of Health. (2012). *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015.* London: DH Publications.

Dewing, J. (2008) 'Participatory research: A method for process consent with persons who have dementia'. *Dementia* February 2007 6: 11-25, doi: 10.1177/1471301207075625.

Dorset Health Scrutiny Committee, Scrutiny Review Panel. (2010) 'Dementia Services Dorset: Improving the quality of life for people in Dorset, now and for the future', *http://www.dorsethealthcare.nhs.uk/WS-DorsethealthCare/Downloads/About%20The%20Trust%20and%20Membership/Trust%20Board/Board%20Minutes%20and%20Agendas/201010-Board-Agenda.pdf.* Accessed 20th April 2014.

Holley-Moore, G., and Scrutton, J. (2015) 'A Shock to the System: Electrical Safety in an Ageing Society', *http://www.electricalsafetyfirst.org.uk/mediafile/100304187/A-Shock-to-the-System.pdf*. Accessed 28th September 2015.

Houston, A. (2008) 'Dementia and Sensory Challenges', *http://www.sdwg.org.uk/wp-content/uploads/2008/05/Sensory-Leaflet.pdf.* Accessed 27th October 2015.

HM Government. (2012) *Caring for our future: reforming care and support*. London: The Stationery Office Limited.

Joffe, H., and Yardley, L. (2004) 'Content and Thematic Analysis', in D. Marks and L. Yardley (2004) (Eds.) *Research Methods for Clinical and Health Psychology*. London: Sage Publications Limited.

Mental Capacity Act. (2005) 'Mental Capacity Act 2005', *http://www.legislation.gov.uk/ukpga/2005/9/contents*. Accessed 5th November 2013.

Office for National Statistics. (2013) 'National Population Projections, 2012 - based Statistical Bulletin', *http://www.ons.gov.uk/ons/dcp171778_334975.pdf*. Accessed 25th February 2014.

Prince, M., Bryce, R., Ferri, C. (2011) 'World Alzheimer Report 2011: The benefits of early diagnosis and intervention', *https://www.alz.co.uk/research/WorldAlzheimerReport2011.pdf.* Accessed 28th September 2015.

Rubin, E., Drevets, W., Burke, W. (1988) The Nature of Psychotic Symptoms in Senile Dementia of the Alzheimer Type, *Journal of Geriatric Psychiatry Neurology* vol. 1 no. 1 16-20.

Seitzer, M. (2009). 'Home Safe Home: Creating a Dementia-Friendly Environment', *Aging Well.* 2(5).

The National Archives. (2004) 'Fire and Rescue Services Act 2004', *http://www.legislation.gov.uk/ukpga/2004/21/contents.* Accessed 21st February 2014.

Titterton, M. (2005) *Risk and Risk Taking in Health and Social Welfare*. London: Jessica Kingsley Publishers.

U.S. Fire Administration. (2006) 'Fire and the Older Adult', *http://www.usfa.fema.gov/downloads/pdf/publications/fa-300.pdf.* Accessed 10th November 2013.

Walker, A., Livingston, G., Cooper, C., Katona, C., and Kitchen, G. (2005) 'Caregivers experience of risk in dementia: the LASER-AD study', *Aging & Mental Health*, 10(5): 532-538.

APPENDICES

Appendix 1: Information sheet – Professionals

Bournemouth University

Bournemouth University Dementia Institute (BUDI)

INFORMATION SHEET

To be discussed prior to group discussion

Group discussion to discuss fire risks and safety strategies in the homes of people affected by memory problems or dementia

We would like to invite you to take part in this study, which is funded by the Dorset Olympic Legacy Fund 'Inspired by 2012 Health and Wellbeing Legacy Fund'. Before you decide, we would like to explain why the study is being done and what it involves for you. One of the study team will go through this information sheet with you and answer any questions you may have. This will probably take about five minutes.

What is this research for?
We are seeking people's views on potential fire risks and safety strategies in the homes of people affected by memory problems and dementia. This will be used to help develop local guidance for Dorset Fire and Rescue Search to help reduce the number of fires occurring in the homes of people affected by memory problems or dementia. We hope that this guidance will also be used nationally and internationally by other Fire and Rescue Services for the same purpose.

What is my involvement in the research?
You are a professional who visits people with dementia in their own homes or works for the fire service. You have been invited to take part in a discussion about what you think could be potential fire risks and safety strategies in the homes of people affected by memory problems and dementia, To find out your thoughts and/or experiences, we would like to talk with you in a small group. Your participation is voluntary: you can choose whether or not to take part. You are also free to withdraw from the study up to the point where it is not possible to establish your identity from the data (the point of anonymisation during data analysis). If you are living with dementia you may also take part in the study without your family member if you prefer.

What will happen to the information I give?
We would like to audio -record the group discussion. If you are not comfortable with this, but would still like to give us your views on the study, let us know and we can

write your comments down. Audio recordings will be kept until they have been transcribed, and then deleted. Transcripts from the group meeting will be kept for five years and then deleted (this is in line with University and data protection requirements).

All the information we collect during the group discussion will be treated in confidence, and accessed only by the study team.

We will write a report and other publications on our findings and may like to quote you to illustrate the points we make. We will ensure that no-one will be identified by using anonymised quotes in any reports or publications – this means we will write something like 'one person said….', rather than name you specifically.

Will the study benefit me?
We cannot promise that the study will benefit you directly, but hope our findings will help people with memory problems or dementia to avoid them being involved in fires in their homes.

Further information
Should you wish to discuss the study further before making a decision the you can contact us by e-mail or telephone:

Dr Michelle Heward	Dr Fiona Kelly
	
Email: mheward@bournemouth.ac.uk Telephone: 01202 962538 or 07809 225207	Email: fkelly@bournemouth.ac.uk Telephone: 07834 788150

Thank you for taking the time to read this information sheet. If you are happy to take part in this study we will ask you to sign a consent form.

Michelle Heward and Fiona Kelly

Complaints
If at any time you wish to make a complaint, you may do so by contacting Professor Anthea Innes, Director of Bournemouth University Dementia Institute:
E-mail: ainnes@bournemouth.ac.uk Telephone: 01202 961632.

Appendix 2: Information sheet – People with dementia and cares

Bournemouth University

Bournemouth University Dementia Institute (BUDI)

INFORMATION SHEET

To be discussed prior to group discussion

Group discussion to discuss home safety strategies in the homes of people affected by memory problems or dementia

We would like to invite you to take part in this study, which is funded by the Dorset Olympic Legacy Fund 'Inspired by 2012 Health and Wellbeing Legacy Fund'. Before you decide, we would like to explain why the study is being done and what it involves for you. One of the study team will go through this information sheet with you and answer any questions you may have. This will probably take about five minutes.

What is this research for?
We are seeking your views on home safety strategies based on your experiences and also in response to a short scenario which we have created. This will be used to help develop local guidance for Dorset Fire and Rescue Service to help people affected by memory problems or dementia to be safer in their homes. We hope that this guidance will also be used nationally and internationally by other Fire and Rescue Services for the same purpose.

What is my involvement in the research?
You have been invited to take part because you are either living with dementia or are a family member of someone with dementia. To find out your experiences, we would like to talk with you in a small group. Your participation is voluntary: you can choose whether or not to take part. You are also free to withdraw from the study at any time. You may also take part in the study without your family member if you prefer.

What will happen to the information I give?
We would like to audio -record the group discussion. If you are not comfortable with this, but would still like to give us your views on the study, let us know and we can write your comments down. Audio recordings will be kept until they have been transcribed, and then deleted. Transcripts from the group meeting will be kept for five years and then deleted (this is in line with University and data protection requirements).

All the information we collect during the group discussion will be treated in confidence, and accessed only by the study team.

We will write a report and other publications on our findings and may like to quote you to illustrate the points we make. We will ensure that no-one will be identified by

using anonymised quotes in any reports or publications – this means we will write something like 'one person said….', rather than name you specifically.

Will the study benefit me?
We cannot promise that the study will benefit you directly, but hope our findings will help people with memory problems or dementia to avoid them being involved in fires in their homes.

Further information
Should you wish to discuss the study further before making a decision the you can contact us by e-mail or telephone:

Dr Michelle Heward	Dr Fiona Kelly
	
Email: mheward@bournemouth.ac.uk Telephone: 01202 962538 or 07809 225207	Email: fkelly@bournemouth.ac.uk Telephone: 07834 788150

Thank you for taking the time to read this information sheet. If you are happy to take part in this study we will ask you to sign a consent form.

Michelle Heward and Fiona Kelly

Complaints
If at any time you wish to make a complaint, you may do so by contacting Professor Anthea Innes, Director of Bournemouth University Dementia Institute:
E-mail: ainnes@bournemouth.ac.uk Telephone: 01202 961632.

Appendix 3: Participant Consent Form

Bournemouth University

Bournemouth University Dementia Institute (BUDI)

Participant number:

CONSENT FORM

Group meeting to discuss home safety strategies in the homes of people affected by memory problems and dementia

Please initial boxes

1. I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw up to the point where it is not possible to establish my identity from the data (the point of anonymisation during data analysis).	
3. I understand that all information will be kept confidential and stored securely.	
4. I agree that the information can be used on condition that it will not be possible to establish my identity from it.	
5. I understand that all information will only be accessed by members of the study team. Audio recordings will be kept until they have been transcribed, and then deleted. Transcripts from the group meeting will be kept for five years and then deleted (this is in line with University and data protection requirements).	
6. I give my permission for the group discussion to be audio-recorded.	
7. I agree to take part in the above study.	

Participant's name	Signature	Date
Researcher's name	Signature	Date

Appendix 4: Focus group topic guide - Professionals

Fire Safety Innovations for People Affected by Dementia

Focus group topic guide – Fire Service Staff and Professionals

1. **Fire risks exercise**
    a. Participants will be asked to identify fire risks specific to people affected by memory loss and dementia in each room of a house (i.e. kitchen, lounge, bedroom, bathroom etc.). Where possible participants will be asked to clarify the experience behind this (i.e. put an electric kettle onto a gas stove).
    b. These will be written on post it notes and stuck on the picture of each room and will be used as an aide memoir throughout the discussion.

2. **Fire safety strategies**
    a. Are there specific messages or personal strategies/actions/activities you do that could help people affected by memory loss and dementia to avoid the fire risks identified? (I.e. replace the electric kettle with a whistle kettle).
    b. Do you know of any technology that might help people affected by memory loss and dementia to avoid the fire risks identified? Can you describe any technology that could help to avoid these fire risks?
    c. Do you know of any services or interventions that might help people affected by memory loss and dementia to avoid the fire risks identified? Can you describe any services or interventions that could help to avoid these fire risks?

3. **Suggestions for guidance**
    a. Have you ever seen any fire safety guidance for people affected by memory loss/dementia?
        - Where did you get it from/who gave it to you?
        - What are the good points?
        - What are the bad points?
        - Areas for improvement
    b. What format would guidance be useful in?

Appendix 5: Focus group topic guide - People with dementia and carers

Fire Safety Innovations for People Affected by Dementia

Focus group topic guide – People with Dementia and their Carers

1. **Vignette** (this will also be printed for the participants to read and refer back to throughout the discussion)

Joe and Mary live together in a two bedroom house in Dorchester. Joe and Mary have been married for 40 years and they have a daughter called Kate. Mary has been diagnosed with Alzheimer's Disease.

a. Can you think of things that might be unsafe in the living room (show the picture of the living room)?
b. Can you think of things that might be unsafe in the kitchen (show the picture of the kitchen)?
c. Can you think of things that might be unsafe in the bedroom (show the picture of the bedroom)?
d. Can you think of things that might be unsafe in the bathroom (show the picture of the bathroom)?
e. How could Joe and Mary be supported to make them safer in their home?

These will be written on post it notes and stuck on the picture of each room and will be used as an aide memoir throughout the discussion.

2. **Now think about yourselves:**
   a. What home safety service would be useful for you/ would information would you need?
   b. Are there specific messages or personal strategies/actions/activities you do that could help other people?

3. **Suggestions for guidance**
   c. Have you ever seen any home safety guidance for people affected by memory loss/dementia?
      - Where did you get it from/who gave it to you?
      - What are the good points?
      - What are the bad points?
      - Areas for improvement
   d. What format would guidance be useful in?

Appendix 6: Examples of assistive technology

Name	Description	Source	Cost (£)
Telecare linked smoke detector	Telecare smoke alarms automatically sound an alarm in the home when they detect smoke. They also send an alarm to the monitoring centre at the same time—and this is how they differ from the standard smoke alarms fitted in the home. When an alarm is received, your call centre operator may talk to you about the cause before calling for the fire brigade—if a toaster has burnt the toast or a pan has boiled dry and the smoke has triggered the alarm it will not be necessary to call the emergency services. This procedure will be discussed with you and your carer in full before any response procedures are agreed. A telecare smoke detector may be recommended with a temperature extremes sensor.	http://www.telecare.org.uk/consumer-services/telecare-and-telehealth#Fire	Varies depending on service provider however can be free of charge if certain criteria are met, including dementia and other similar conditions
Assistive Technology	Once a telecare has been installed in a home, numerous additions can be made. These can include flood alarms, intruder alarms, medical alerts, seizure alerts, movement detectors etc.	www.easylink.co.uk	On a needs basis, costs vary
Innohome Stoveguard System	Innohome Stove Guard prevents cooker fires effectively and intelligently, without interfering with cooking. It identifies a dangerously high temperature and steep temperature rise and responds to the sounds of various alarms, always turning the cooker off in a risk situation.	https://www.innohome.com/stove-guard-sgk500	

Canary	Canary is a discreet, easy to install monitoring and notification system that provides round the clock reassurance to family members whilst allowing the older or vulnerable person to stay in the home they love. Canary respects the privacy of people who need care and support so does not use cameras so no-one can be seen or heard.	https://www.canarycare.co.uk	As of November 2015 £270 + a monthly cost of £15 for the monitoring service. Also available to rent from £36 a month.
Just Checking	Just Checking is an easy-to-use online activity monitoring system that helps people who are becoming forgetful stay independent in their own home. The system is easy to install, simple to use, and creates a clear chart of daily living activity that you can view securely online. You'll find no snooping cameras or microphones here, just discreet wireless motion sensors and a plug-in controller. Just Checking is the easiest way to care when you physically can't be there.	http://www.justchecking.co.uk	Available on request.
Live!y	Lively gives family members insight when a loved one may need their help. And with Lively's new stylish and easy-to-use safety watch, 24/7 emergency response is just a single button push away. With its simple design, anyone can use it — and stay safer from falls and emergencies.	http://www.mylively.com	Available on request.

Source: Information collected by Dorset Fire and Rescue Service as part of the wider project.

Appendix 7: Existing fire safety and dementia resources

Name	Type	Description	Developed by	Weblink
Safety in the home	Booklet	This factsheet presents some sensible precautions that those close to someone with dementia can take to help minimise risk in the home environment.	Alzheimer's Society	http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1793
Dementia Awareness Guide for Norfolk Fire and Rescue Service Staff	Booklet	Dementia Awareness Guide for Norfolk Fire and Rescue Service Staff	Norfolk County Council	
Home Safety for People with Alzheimer's Disease	Booklet	This booklet is for those who provide in-home care for people with Alzheimer's disease or related disorders. Our goal is to improve home safety by identifying potential problems in the home and offering possible solutions to help prevent accidents.	Alzheimer's Disease Education and Referral (ADEAR) Centre	http://www.nia.nih.gov/sites/default/files/home_safety_for_people_with_alzheimers_disease_2.pdf
Analysis of Preventable Fire Fatalities of Older People and People with Disabilities: Risk reduction advice for the Community Care Sector	Document	Australian Report analysing fires and risk reduction relating to older people	Worcester Polytechnic Institute	https://www.wpi.edu/Pubs/E-project/Available/E-project-050211-
Warning Bells	A4 leaflet	Warning signs on what to spot for a host of different issues from fire, security, health issues.	Used at Staffordshire Fire and Rescue Service	
Is it Dementia?	Online Training and Information	A selection of training clips and resources	Alzheimer's Australia and Australian Government	http://isitdementia.com.au/fire.html#5

Source: Information collected by Dorset Fire and Rescue Service as part of the wider project.

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