

## ***Risk Communication in Dementia Care***

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### ***FINAL REPORT***

#### ***Abstract***

##### ***Why did we start?***

Supporting people with dementia in line with community care policies requires increasing attention to assessing, communicating and managing risks for people living in their own home. There is a challenge in supporting client choices that include risk-taking whilst demonstrating professional accountability. Risk communication is increasingly important as we seek to engage clients and families in shared decision making. This presents particular challenges in dementia services.

##### ***What did we do?***

We conducted:

- a rigorous review of research on risk concepts and risk communication in dementia;
- a qualitative study with people with mild-moderate dementia;
- analysis of this data involving people with mild-moderate dementia;
- a qualitative study with family carers of a person with dementia;
- a qualitative study with professionals in community dementia services; and
- a survey of professionals in community dementia services.

##### ***What did we find?***

- Risk is often conceptualised as seriousness of possible harm rather than as likelihood.
- Background and emotion may influence the conceptualisation and communication of risk.
- Family carers are often involved in managing complex risks.
- Common risks were identified, and have been codified into a framework to aid understanding.
- Health and social care professionals make extensive use of numeric information in practice, although they more often communicate risk information with words.
- Professionals frequently overestimate how often risks with severe outcomes occur.
- Verbal descriptors for numeric likelihoods of possible harm are widely interpreted.
- There was strong interest in the possibilities for visual modes of communicating risk.

##### ***What do these findings mean for practice?***

- Professionals need to be aware of the life and work history, personality and experiences of the person with dementia in order to implement person-centred approaches to managing risk.
- Clear communication of risks and benefits of care options should include likelihood information.
- People with dementia and family carers should be supported to share feelings about risks, and encouraged to ask questions.
- There is need for development of a more robust knowledge base of likelihoods of possible harmful outcomes to inform professional and public decision making.
- Learning resources (for example training and information) are needed for people with dementia and family carers on positive risk taking and on communicating about risks.
- Practitioners should translate important professional concepts such as 'positive risk taking' and 'proportionality' into meaningful terms for service users and families.

##### ***What should be done now?***

- The public leaflet being produced with the PHA and HSC Board should be widely distributed.
- The leaflet for professionals hosted on the University website should be widely advertised.
- Models of co-research should continue to be developed.
- The materials on domains of risk and risk communication should be included in appropriate training resources and similar guidance material for staff.
- A database of risk factors should be developed to support staff in managing risks.
- Visual methods of communicating risk should be studied for their potential application.

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## **2. List of abbreviations**

ABC = Adaptive Behaviour and Cognition Research Group, Max Planck Institute for Human Development, Berlin  
AP = Atlantic Philanthropies  
AS = Alzheimer's Society  
BNT = Berlin Numeracy Test  
CI = Chief Investigator  
DARES = *Decision, Assessment, Risk and Evidence Studies* research cluster at Ulster University  
DH = Department of Health (Belfast)  
EMA = European Medicines Agency  
GP = General (Medical) Practitioner  
HSC = Health and Social Care  
MPIB = Max-Planck Institut für Bildungsforschung (Max Planck Institute for Human Development), Berlin  
NISCC = Northern Ireland Social Care Council  
PHA = Public Health Agency  
PI = Principal Investigator  
PPI = Personal and Public Involvement  
PWD = People with Dementia  
RA = Research Assistant  
SCIE = Social Care Institute for Excellence  
SEU = Subjective Expected Utility (model of human judgement)  
SLT = Speech and Language Therapist  
SURP Service User Review Panel (Alzheimer's Society)  
SW = Social Worker

### 3. Main body of report

This Part of the report considers in turn the Background (Section 4A), Aims and Objectives (Section 4B), Methods (Section 4C) and Findings (Section 4D) of the study. The findings are then discussed (Section 4E) in terms of their implications, and Conclusions (Section 4F) are then drawn.

The Background Section (4A) has been structured as:

- i) *Background context of dementia care*
- ii) *Background to risk communication in health and social care*
- iii) *Background to numeric, verbal and visual risk communication*
- iv) *Background to risk concepts and risk communication in dementia*
- v) *Background to involving people with dementia in risk communication*
- vi) *Background to risk communication with family carers of a person with dementia*
- vii) *Background to risk communication by professionals in community dementia services*
- viii) *Background to literature searching*
- ix) *Background to engaging people with dementia in data analysis.*

This project comprised seven distinct stages, each of which has led to preparation of a journal article, six of which have been accepted for publication. For ease of reading, the Methods, Findings and Discussion Sections in this Part have been subdivided into sub-sections relating to each of these seven stages:

- i) *Literature searching*
- ii) *Literature review*
- iii) *Qualitative study of people with dementia*
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- vii) *Survey of professionals in community dementia services.*

Please note that varied terminology including 'service user', 'client', 'consumer', 'patient' is used in this Report both because this report is compiled from seven journal articles each with a slightly different audience, and also because individuals take on different role names when they access different services. Thus an individual may be a 'patient' when in hospital but a 'client' when meeting with a social worker, solicitor or aromatherapist.

- **4 A Background**

(Based on: Stevenson et al., 2016; Stevenson, McDowell et al., in press; Stevenson, Savage et al., in press; Stevenson & Taylor, in press, a; Stevenson & Taylor, 2016; Stevenson & Taylor, in press, b; Taylor et al., submitted)

- i. Background context of dementia care*

Globally there are an estimated 46 million people living with dementia with this figure projected to increase to 131.5 million by 2050 (Prince et al., 2015). Global population ageing and the associated increase in prevalence of dementia (Sosa-Ortiz, Acosta-Castillo, & Prince, 2012) present a major international health and policy issue (Wortmann, 2012) with global economic and societal impacts (Wimo, Winblad, & Jönsson, 2010; Wimo et al., 2013; Prince et al., 2015). Determining appropriate health and social care for people with dementia is therefore paramount for future health policy initiatives. Understanding how the risks experienced by people living with dementia are conceptualised and communicated by individuals, family members and professionals will be integral in informing such initiatives.

Dementia is an umbrella term referring to a group of diseases and conditions that may affect a range of cognitive and emotional functions. These can include memory, orientation, comprehension, calculation and judgement as well as changes in mood, emotional control or behaviour, and challenges with activities of daily living (Alzheimer's Society, 2014; World Health Organisation, 1993; 2015). Importantly, these changes can make an individual more susceptible to risks of daily life, such as falls (Kröpelin, Neyens, Halfens, Kempen, & Hamers, 2013; Muir, Gopaul, & Odasso, 2012); risks associated with driving (Adler, Rottunda, & Dysken, 2005; Flanagan, 2011) or walking about (often referred to as 'wandering') (Cipriani, Lucetti, Nuti, & Danti, 2014; Douglas, Letts, & Richardson, 2011); mismanagement of medication (Douglas et al., 2011; While, Duane, Beanland, & Koch, 2013); increased vulnerability to abuse (Compton, Flanagan, & Gregg, 1997; Selwood & Cooper, 2009) as well as psychological risks such as loneliness (Holmen, Ericsson, & Winblad, 1999; Moyle, Kellett, Ballantyne, & Gracia, 2011) and loss of identity (Caddell & Clare, 2010).

As the progression of dementia is highly unique, these risks will vary according to individual circumstances and availability of support systems. Decisions relating to health and social care in dementia often involve dealing with risks, making good communication and an understanding of the meaning of risk to different stakeholders of core importance. While studies relating to more general aspects of understanding and improving communication between healthcare providers and people with dementia are of relevance (Adams & Gardiner, 2005; Österholm & Hydén, 2014), research specifically focused on the communication of risk information between professionals, people with dementia and family carers is necessary to inform this particular area of health and social care.

- ii. Background to risk communication in health and social care*

Risk communication in health and social care is defined as the open, multi-way sharing of evidence based information and opinions about risks and benefits, to improve understanding and facilitate better decisions. (Ahmed, Naik, Willoughby, & Edwards, 2012; Taylor, 2013). Effective communication about risks between service users, professionals and family carers is fundamental to support informed, shared decision making processes (Paling, 2003; Thornton, 2003; Godolphin, 2009). Developing effective practices of communicating information about risks to people with dementia to promote optimal comprehension of risks and benefits and sharing of perspectives and values is imperative to ensure that individuals with dementia are not excluded from decisions relating to their daily life and care.

While there exists a substantial and evolving body of literature on risk communication for purposes of medical decision making, a systematic literature search up to Feb 2016 (Stevenson, Taylor, & Knox, 2016; Stevenson, McDowell, & Taylor, 2016) sourced no research papers with a primary focus on risk communication in dementia care, although there were a number on conceptualisations of risk. Understanding how risks are conceptualised by groups affected by

dementia and current practices in communicating about these risks is a critical starting point in developing a body of literature specific to this domain.

Communication and choice in community care is increasingly recognised (McCaffrey et al., 2015). The challenges in communicating about risks is less clearly articulated, but is essential if individuals and families are to be educated and empowered to make good care decisions. Professionals, family members and those who are the focus of our care may conceptualise risks in different ways (Nay et al. 2015). Policies seeking to prevent people being admitted to hospital or long-term care unnecessarily (Twaites et al., 2017) may be supported by a greater focus on 'managing risk' at home.

The challenge in community dementia care is to take "proportionate, measured and enabling approaches to risk" (Department of Health, 2010, p.6) to enable independent living (Heward, Innes, Cutler & Hambidge, 2017). Effective risk management requires clear communication between individuals with dementia, family carers and professionals. Shared decision making – often within the context of 'assessment' (Taylor, 2012) - presents challenges in terms of managing risk (Department of Health, 2007; Stevenson & Taylor, in press, a). The concept of 'enablement' includes some sense of balancing potential benefits from taking risks against possible harm (Taylor, 2008). This presents challenges with the increasing attention given to risk management within clinical and social care governance (Taylor & Campbell, 2011) and respect for client choice. Good risk communication is essential for effective risk management.

### *iii. Background to numeric, verbal and visual risk communication*

Interpersonal risk communication involves exchange of information about risks, increasingly viewed in terms of both potential benefits as well as possible harms (EMA, 2011; Taylor, 2017). 'Risk literacy' (Cokeley et al., 2012) is increasingly recognised as integral to health literacy and shared decision making (SDM) in health and social care (Ahmed, Naik, Willoughby & Edwards, 2012; Elwyn et al., 2004; Lewiecki, 2010; Zipkin et al., 2014). Including people with dementia in decision making contributes to quality of life (Menne, Judge, & Whitlatch, 2009), personhood (Fetherstonhaugh, Tarzia & Nay, 2013) and autonomy (Samsi & Manthorpe, 2013). However involvement remains limited (Taghizadeh et al., 2014; Miller, Whitlatch & Lyons, 2016) and there are challenges in communicating about risks (Sinclair, Oyebode & Owens, 2016).

Effective risk communication requires an understanding of how risks are conceptualised (Moreland, Raup-Krieger, Hecht & Miller-Day, 2013), which may vary across contexts. Individuals with dementia and family carers may conceptualise risk more as an action or consequence than as likelihood (Stevenson, Savage et al., in press; Stevenson & Taylor 2016). Professionals in community health and social care deal with uncertainties where outcomes (for example getting lost) may be better known than their probabilities of occurrence (Mousavi & Gigerenzer, 2014; Stevenson & Taylor, in press, b). Despite the lack of quantified data, dementia care routinely involves communicating about 'risks' between clients, families and professionals.

Different formats for communicating likelihood of harm - including verbal (e.g. likely/rare or high/medium/low), numeric (percentages, frequencies and probabilities) and visual (graphs, tables and pictorial representations) – vary in effectiveness. Practitioners seem to prefer verbal descriptors, such as ordinal scales (low, medium, high) or terms such as 'small increased risk of', rather than numeric likelihoods (Stevenson & Taylor, in press, b). Verbal expressions of likelihood are widely used in everyday discourse (Renooij & Witteman, 1999) but may be more ambiguous (Bocklisch, Bocklisch & Krems, 2012; Brun and Teigen, 1988; Lipkus et al., 2007), particularly in the correspondence between numeric values and verbal expressions (Theil, 2002; Visschers, Meertens, Passchier & De Vries, 2009). Use of verbal descriptors to present side effects of medications may lead to overestimating risks (Knapp, Raynor & Berry, 2004; Büchter, Fechtelpeter, Knelangen, Ehrlich, & Waltering, 2014; Peters, Hart, Tusler & Fraenkel, 2014). Inaccurate communication of risk may lead to less than optimal management of care risks.

Numeric formats are more precise than verbal and allow for calculations (Renooij & Witteman, 1999; Akl et al., 2011) although individuals with low numeracy skills may have comprehension difficulties (Peters et al., 2006; Ciampa, Osborn, Peterson & Rothman, 2010; Bodemer, Meder & Gigerenzer, 2014). Low numeracy has been associated with reduced understanding of health risks (Rothman, Montori, Cherrington & Pignone, 2008; Reyna, Nelson, Han & Dieckmann, 2009);

increased susceptibility to framing effects (LaVallie, Wolf, Jacobsen, Sprague & Buchwald, 2012); and avoiding involvement in shared decision making (Galesic & Garcia-Retamero, 2011). Optimal risk communication methods may therefore depend on numeracy skills (Fagerlin, Ubel, Smith & Zikmund-Fisher, 2007). Frequency formats have shown robust effects in improving understanding (Brase 2008; Galesic, Gigerenzer & Straubinger, 2009; Knapp et al., 2009; Akl et al., 2011), although individuals with cognitive impairments such as dementia may experience difficulties with numeric risk data (Martini, Domahs, Benke & Delazer, 2003; Pertl et al., 2014).

Visual displays of risk information include graphs, charts, and icon arrays, and these seem to enhance understanding of probabilistic information (Edwards, Elwyn & Mulley, 2002; Galesic, Garcia-Retamero & Gigerenzer, 2009; Garcia-Retamero, Okan, Garcia-Retamero, Galesic & Cokely, 2012), although the format has also been found to influence risk perception (Schapira, Nattinger & McAuliffe, 2006; Hawley et al., 2008; Tait, Voepel-Lewis, Zikmund-Fisher & Fagerlin, 2010). Individual differences in numeracy (Brown et al., 2011) and graph literacy influence effectiveness of specific visual aids (Galesic & Garcia-Retamero, 2011; Gaissmaier et al., 2012; Okan et al., 2012). Professionals in dementia care see potential in visual forms of risk communication (Stevenson & Taylor, in press, b) but there is no consistent preference regarding type.

Reasonably accurate estimations of likelihoods are important to ensure proportionate responses to risk. Inflated estimates of how often highly adverse outcomes occur could potentially lead to unnecessarily risk averse approaches to care. Dread risks – regarded as low probability, high consequence events, associated with fear and avoidant behaviours (cf. Gigerenzer, 2004) – are prone to overestimation bias (Lerner, Gonzalez, Small & Fischhoff, 2003; Slovic & Peters, 2006). ‘Dread risks’ in dementia might potentially include serious outcomes such as causing a fire in the home or being involved in a road traffic collision. Lower numeracy is associated with greater estimation error and an overestimation of risk (Davids, Schapira, McAuliffe & Nattinger, 2004; Gurmankin, Baron & Armstrong, 2004; Låg, Bauger, Lindberg & Friborg, 2014). Individuals with low numeracy may be more susceptible to factors that may bias their interpretations of quantitative data such as emotions and presentation formats (Peters, 2008; Reyna et al., 2009).

#### *iv. Background to risk concepts and risk communication in dementia*

The range of potential physical and psychological risks faced by people with dementia means that these individuals and their families are often faced with care decisions involving risks. For example, the decision whether or not to use assistive technology or to take a particular medication. Clear and transparent communication of information about risks is an important condition for such decision making, particularly given an increased focus on autonomy and informed decision making not only in dementia care (Alzheimer Europe, 2009; Fetherstonhaugh, Tarzia, & Nay, 2013) but in healthcare more generally (Stacey et al., 2014). For the purposes of this review, risk communication is defined as the exchange of information between individuals receiving services, family members and professionals about possible harm and potential benefits in client situations and care options, so as to inform decision making about care (cf. Taylor, 2013). The practice of good risk communication should be a shared process involving the patient and carer, and should aim to facilitate informed choice (Bodemer & Gaissmaier, 2012, p625; Edwards & Elwyn, 2001). Of core importance to this process are person-centred approaches built on a relationship and dialogue between the individual and health professional (Alaszewski, 2005). While there exists a substantial and expanding body of literature on risk communication in health care, research on risk communication in dementia care is less developed. To address this gap, the current paper aims to synthesis work on risk communication in dementia care to better inform practice in this field.

A related issue integral to effective risk communication is an understanding of what constitutes a risk to different stakeholders. This matter is even more crucial in the context of dementia care owing to the many different stakeholders involved in decisions involving risks (e.g., family carers, professionals, and the individuals with dementia themselves). For instance, in order to communicate risks, individuals must first develop ideas about risks including identifying which scenarios they define as risky; which risks they find to be most concerning; and deciding on preferred approaches to the risks based on these concepts. Similarly the manner in which information about risks is communicated may also shape conceptualisations by enabling

individuals to understand risk outcomes more accurately, including likelihood of risks, and by facilitating understanding of alternative perspectives. There is no standard definition of 'risk' in relation to dementia care. One approach to understand the multiple meanings of risk for different stakeholders across situations (Clarke, Wilkinson, Keady, & Gibb (2011a)), is to analyse how risk is discussed in the literature.

Risk is often understood as a numeric concept representing a quantification of the probability of an event (Lupton, 1999, p7) and is frequently associated in contemporary society with negative terms such as hazard, harm and loss (Lupton, 1999, p8). However, quantifying risks experienced by individuals with dementia is challenging given that many risk outcomes (e.g., minor home accidents, or getting lost) are unlikely to be documented or are difficult to recognise and record (e.g., psychological risks). Further, depending on the perspective, risks can be conceived as both negative and positive, and risk-taking can enable many beneficial outcomes (Manthorpe & Moriarty, 2010; Morgan, 2004; Morgan & Williamson, 2014). The lack of a clear definition of risk, the multiplicity of perspectives, and an absence of a quantifiable knowledge base from which to extrapolate likelihood for many risks makes risk communication in this domain problematic. Exploration of these multiple meanings and perspectives of risk from the literature and understanding how these risks are constructed may therefore better inform the risk communication process. An examination of underlying concepts and approaches towards dealing with risk can facilitate our understanding of how stakeholders manage risks and the processes that inform these approaches.

Risk concepts have been investigated in prior work on dementia care, however, the focus of this work has centred on the assessment and management of risk (Thom & Blair, 1998) and on understanding risk and resilience in dementia (Bailey et al., 2013). Thom and Blair (1998) synthesised findings from 19 publications (including journal articles, research papers, books and publications from voluntary organisations) and identified contrasting approaches towards risks across different professional groups. Both risk-averse attitudes that focused primarily on the carer's perspective and more comprehensive, balanced approaches factoring into account the rights and views of the individual with dementia were found to be evident. The authors established that there was a paucity of research on self-assessment and management of risk from the perspective of people with dementia. Although the authors attempted to gather statistical evidence on the prevalence of various risks, the data was found to be limited and inconclusive. As the current paper focused on risk communication and risk concepts more broadly, no papers included in the review by Thom and Blair (1998) were retrieved in the current search, although one additional paper was extracted from the reference list. Further, since their publication, a substantial body of literature exploring the experiences and perspectives of people with dementia, carers, and professionals has developed.

More recently, Bailey et al. (2013) reviewed literature on risk, resilience and dementia and included findings from UK Government documents and reports in addition to peer-reviewed publications. Four key dimensions of risk and resilience were identified: risk and resilience across the lifespan; risky and resilient life with dementia; multiple narratives; and the significance of people and place. The review established the significance of local community in managing risks to people with dementia, owing to the enduring knowledge of the individual and a willingness to support them. Although the theme of resilience was less relevant to the current synthesis, seven of the papers included in Bailey et al. (2013) were identified through the current search, and one additional paper was sourced from the reference list of that previous review.

#### *v. Background to involving people with dementia in risk communication*

The increasing prevalence of dementia presents substantial challenges for health and social care services (Department of Health, Social Services & Public Safety (DHSSPS), 2011; Department of Health (DH), 2013; Alzheimer's Society, 2014b; Prince et al., 2015) and for families providing care (Brodsky & Donkin, 2008; Prince et al., 2015). A consistent challenge in dementia care relates to dealing with the increased levels of risk that the person with dementia may face across domains of daily living for example risks relating to driving, using electrical appliances or leaving the home unsupervised.

Concepts and perceptions of risk in health and social care domains have important implications for innovation in service development, resource allocation and practice (Brown, 2010; MacDonald & MacDonald, 2010; Kearney, 2013; Taylor, 2013). Developing an understanding of the concepts that underpin approaches to risk in dementia care is critical if we are to understand the implications of this, although research on the topic is limited (Stevenson, Taylor, & Knox, 2016; Stevenson, McDowell, & Taylor, 2016). A nuanced understanding of what 'risk' means in practice involves the perspectives of three core groups – individuals with dementia, family carers and professionals. Previous research has demonstrated variability in perceptions of and approaches towards risk between and within these central groups (Thom & Blair, 1998; Clarke et al., 2009, 2010, 2011; Manthorpe & Moriarty, 2010; Bailey et al., 2013; Stevenson, McDowell, & Taylor, 2016). Developing shared understandings of risk between stakeholders (Manthorpe & Moriarty, 2010) is necessary to facilitate meaningful communication of risk.

An emerging body of primary research involving individuals with dementia as participants has enabled enhanced insight into the experiences and perspectives of this group towards risk (Gilmour, Gibson, & Campbell, 2003; Beattie, Daker-White, Gilliard, & Means, 2004; Harris, 2006; Robinson et al., 2007; Clarke et al., 2010; Cott & Tierney, 2013; Sandberg, Rosenberg, Sandman, & Borell 2015). These qualitative studies, primarily involving individuals with mild to moderate dementia, have found evidence of measured and careful approaches towards risk taking (Morgan, 2009; Sandberg et al., 2015), as amongst older people more generally (Taylor, Killick, O'Brien, Begley, & Carter-Anand, 2014). Risks were more likely to be tolerated when tangible personal benefits were perceived, for example, maintaining a sense of purpose and exercising a level of autonomy over decisions (Clarke et al., 2010). In addition, individuals were in some cases more concerned with maintaining independence rather than focusing on risks (Beattie et al., 2004; Harris, 2006). Alternately, apprehensions regarding safety and feelings of vulnerability precipitated risk-avoiding behaviours (Harris, 2006; Clarke et al., 2010, Sandberg et al., 2015). While these studies have explored attitudes towards risk and how people with dementia approach risk in daily life, a more detailed understanding of what risk means to these individuals is necessary to guide person-centred practice.

Involving individuals with dementia in decisions about their everyday life and care is central to preserving autonomy, quality of life and personhood (Horton-Deutsch, Twigg, & Evans, 2007; Samsi & Manthorpe, 2013; Fetherstonhaugh, Tarzia, & Nay, 2013; Fetherstonhaugh, Rayner, & Tarzia, 2016). This will of necessity include making informed choices about risks and benefits when there is capacity so to do (DH, 2007; DHSSPS, 2011). A recent review found that individuals with dementia reported that they wanted to participate in decisions about their care, although their actual level of involvement was limited and declined considerably as dementia progressed beyond the mild stages (Miller, Whitlach, & Lyons, 2016). In particular, persons with dementia are more likely to be excluded or overridden in decision making when risks are concerned (Sampson & Clark 2015; Fetherstonhaugh et al., 2016) and when making decisions about their medical treatment (Smebye, Kirkevold, & Engedal, 2012, Miller et al., 2016), highlighting the focus of the present study.

#### *vi. Background to risk communication with family carers*

The cognitive, physical and behavioural changes associated with dementia often result in vulnerability of individuals to increased risk in daily life. Living with risk is an inevitable feature of dementia that will present challenges not just for the individual affected, but also family members and professionals involved in care. Globally there are an estimated 46 million people living with dementia (Prince et al. 2015) with the number of family members involved in provision of care for these individuals likely to be in considerable excess of this figure. A reported 670,000 people are thought to be providing informal dementia care in the UK with costs of unpaid care estimated to be around £11.6 billion (Prince et al. 2014).

The subject of risk in dementia care has received increasing attention in the literature recently (Stevenson, Taylor and Knox 2015; Stevenson, McDowell and Taylor 2016). Research has included topics of assessment and management of risk in professional practice (Clarke et al. 2009, 2011; McDonald 2010) and identification of risk factors for specific issues of concern such as abuse (Cooney and Howard 1995; Wigglesworth et al. 2010; Taylor et al. 2014), falls (Pellfolk et al.

2009; Kröpelin et al. 2013), medication non-adherence (Thiruchselvam et al. 2012) and suicide risk (Nicholson 2013; Sabodash et al. 2013).

A growing body of studies have explored perspectives of risk held by the various key stakeholder groups examining concerns, attitudes and approaches towards risk. These studies have involved professionals working in dementia care (Clarke 2000; Gilmour, Gibson, and Campbell 2003; Robinson et al. 2007; Clarke et al. 2011), family carers (Clarke 2000; Gilmour, Gibson, and Campbell 2003; Walker et al. 2006; Robinson et al. 2007; Cott and Tierney 2013) and individuals with dementia (Beattie et al. 2004; Harris 2006; Robinson et al. 2007; Morgan 2009; Clarke et al. 2010; Cott and Tierney 2013). There is also a relevant broader literature relating to risk and its assessment relating to older people more generally (Taylor and Donnelly 2006a, 2006b; Taylor 2012).

One of the primary challenges identified in the literature regarding risk in dementia care is the differing and at times conflicting perspectives of family carers, people with dementia and professionals (Clarke 2000; Robinson et al. 2007; Clarke et al. 2009; Waugh 2009; Cott and Tierney 2013). Such conflicts in perspectives will logically lead to different ideas about how risk situations should be managed. Communicating and developing a shared understanding of diverse perspectives of risk is recommended both in the general literature on risk communication and decision making in health care (Edwards and Elwyn 2001; Bodemer and Gaissmaier 2012) and in literature specifically relating to risk in dementia care (Manthorpe and Moriarty 2010; Morgan and Williamson 2014).

Understanding the attitudes of family carers towards risk is of key importance as these individuals often take an active role in care decisions involving people with dementia. Mixed findings have reported family carers to be both more tolerant of risks than professionals (Clarke 2000; Robinson et al. 2007) or conversely to be more risk-averse (Clarke et al. 2009). More accommodating approaches to risk have been suggested to be underpinned by personal knowledge of the individual (Clarke 2000; Gilmour, Gibson, and Campbell 2003). Risks reported as presenting concern to families have generally been found to relate to matters of physical safety such as burns (Oyebode, Bradley, and Allen 2013), driving (Cott and Tierney 2013), falls (Buri and Dawson 2000; Gilmour, Gibson and Campbell 2003; Walker et al. 2006; Cott and Tierney 2013); medication management (Cott and Tierney 2013) and getting lost (Gilmour, Gibson, and Campbell 2003; Walker et al. 2006; Robinson et al. 2007). However, recognition of the significance of risks to psychological wellbeing has also been reported (Clarke 2000; Cott and Tierney 2013). Knowledge and skills of caregivers to prevent harm or injury to the care recipient have been recognised as a primary risk modification factor (Horvath et al. 2005). Evidence from the literature demonstrates that carers often take measures to manage risks such as supervision (Lach et al. 1995; Buri and Dawson 2000; Walker et al. 2006; Cott and Tierney 2013), environmental adaptations (Lach et al. 1995; Walker et al. 2006) or restriction of activities (Bond et al. 2002). Carers were in some circumstances found to experience a dilemma with respect to balancing their desire to protect the care recipient from harm versus maintenance of the well-being of the individual (Robinson et al. 2007; Cott and Tierney 2013).

As capacity of the person with dementia declines, family members often become increasingly involved in decisions including those relating to health and social care of the individual (Samsi and Manthorpe 2013; Miller, Whitlatch, and Lyons 2014). Such decisions often involve cognisance not only of the benefits inherent in specific treatments, interventions or supports, but also the risks involved (Saleh et al. 2014). Risk communication thus has a key role in the process of informed decision making in the domain of health and social care (Coulter and Collins 2011; NICE-SCIE 2012). Recommendations from the literature advise that effective risk communication should enable comprehension of relevant information (including probabilistic data) about risks in order to facilitate informed choice and should be a shared process involving the patient and their families (Edwards and Elwyn 2001; Godolphin 2003; Ruland 2004; Bodemer and Gaissmaier 2012).

#### *vii. Background to risk communication by professionals in community dementia services*

Health and social care staff providing support and treatment in dementia care are routinely involved in decisions concerning judgement of risks. Communicating effectively about these risks

to service users with dementia, family members and other professionals is essential to support informed choices about care (Taylor, 2012a). Presently there is limited conceptualisation of 'risk' for the purposes of planning community services within assessment tools for the health and social care of older people (Taylor, 2012b).

Developing an understanding of how risk is conceptualised in the domain of dementia care is fundamental to inform processes of risk communication. In a wider context including disciplines as diverse as finance, environment and medicine, risk has been defined in multiple different ways across the literature. Aven (2012) in a review of definitions of the concept of risk, identifies nine core definition categories. These definitions include varying classifications comprised of one or more elements including expected value, probability, objective uncertainty, uncertainty, potential, event, consequences (and severity of these) and loss. Hansson (2010) more broadly distinguishes between two fundamental categorisations of risk – definitions that are objective (fact-based) and those that are subjective (value-based). While these viewpoints have often been presented as conflicting in the literature, Hansson argues that the complexity of risk necessitates a dual understanding of the term as both objective and value laden. He postulates that conceptualising an event as undesirable will always involve subjectivity, while subjective probabilities involving 'degrees of belief' will in some form converge towards objective real world frequencies. More specific to dementia, Clarke *et al.* (2011, p11) describe risk in this domain as having 'multiple meanings for multiple people in multiple situations'. Cott and Tierney (2013, p412) similarly conclude that risk (as defined by family carers and professionals working in dementia care) is not objective and measurable but rather 'fluid and context-dependent'. Such descriptions imply that meanings of risk in dementia are fundamentally subjective. Previous literature reviews have noted variability in these subjective perceptions of risk in dementia care between and within different professional groups, individuals with dementia and family carers (Thom and Blair, 1998; Manthorpe and Moriarty, 2010; Bailey *et al.*, 2013; Stevenson *et al.*, 2016a). Developing a more in-depth understanding of how risk is conceptualised by professionals working in dementia care is important as this will shape policy and practice in critical areas of concern (Kemshall, 2010).

'*Risk Communication*' has been defined as the 'open two way exchange of information and opinion about harms and benefits' (Ahmed *et al.*, 2012, p1). Risk communication is integral to the process of informed, shared decision making in health and social care; in order to make informed decisions about treatments, supports or interventions, individuals need to be cognisant not only of the benefits inherent in these options, but also the risks involved (Taylor, 2013). Although communication about risk is integral to dementia care practice, there is a paucity of evidence-based guidance on effective risk communication in this domain. While general guidance on risk communication (Gigerenzer and Edwards, 2003; Paling, 2003; Bodemer and Gaissmaier, 2012) may have some applicability to dementia care, professionals would benefit from recommendations that are tailored more specifically to this context. A comprehensive search across twelve bibliographic databases and one online search engine up to December 2013 (updated 23<sup>rd</sup> February 2016), sourced no existing peer reviewed literature with an explicit focus on risk communication in dementia care (Stevenson *et al.*, 2016a,b)

Research in the broad field of risk communication generally involves exploration of the most effective ways of communicating probabilistic data about the likelihood of harm so as to optimise understanding of this information. Probabilistic information about risks may be presented in various formats including verbal expressions (for example, 'common' or 'rare'), numeric representations (percentages, probabilities and frequencies) and visual expressions (graphs or icon arrays). Different formats present advantages and limitations depending on the user. For example, while some individuals may report feeling more comfortable using and receiving verbal descriptors in comparison to numeric (Renooij and Witteman, 1999), such terms are often imprecise (Lipkus, 2007), subject to ambiguous interpretations (Brun and Teigen, 1988) and may result in overestimation of risks (Knapp *et al.*, 2004; Büchter *et al.*, 2014; Peters *et al.*, 2014). While numeric formats are more precise than verbal and allow for calculations (Renooij and Witteman, 1999), individuals with low numeracy skills may have difficulties comprehending such data (Peters *et al.*, 2007; Bodemer *et al.*, 2014). Visual aids have been found to enhance understanding of probabilistic information (Galesic *et al.*, 2009a; Garcia-Retamero *et al.*, 2012). However, studies have demonstrated that individual differences in graph literacy influence effectiveness of visual

aids for facilitating comprehension (Galesic and Garcia-Retamero, 2011; Gaissmaier *et al.*, 2012; Okan *et al.*, 2012). Different groups might therefore be expected to benefit from different modes of risk communication.

Discussion about risks in health and care situations often involves providing clients with information about the probability of specific outcomes, for example incidence of side effects from a particular medication or effectiveness of a treatment. Closer to dementia care are studies that have demonstrated difficulties in comprehending numeric health information (such as medicinal dosage instructions) for participants with cognitive impairment (Delazer *et al.*, 2013; Pertl *et al.*, 2014). An issue particularly relevant to dementia care is that professionals are often dealing with uncertainties, where probabilities of outcomes are not known (Mousavi and Gigerenzer, 2014).

### *viii. Background to literature searching*

The importance of using a robust evidence base to inform practice and service development in dementia care is well accepted. Systematic reviews of literature can support the development of practice and services by identifying, appraising and summarising relevant research findings (National Institute for Health Research, 2010; SCIE, 2005). Pertaining to the social science of risk in dementia care, accessing and synthesising relevant literature from the vast bodies of research on both dementia and risk can help inform the processes of risk assessment, management and communication. Searching the literature can also enhance understanding of the perspectives and attitudes towards risks of key stakeholders including individuals with dementia, familial carers and professionals working in dementia care. Retrieving relevant literature on topics relating to risk can be challenging given the ever expanding volume of research on this subject across a wide range of domains. Ambiguity in interpretations (Slovic, 2001) and thus applications of the term may also present challenges when searching for relevant data.

Developing an effective search strategy starting with a specific research topic, appropriate search terms, selection of suitable data sources and a well-defined selection criteria will facilitate retrieval of pertinent literature while also minimising time spent trawling through irrelevant data. Most work on aspects of systematic literature reviewing focuses on questions of the effectiveness of interventions, and therefore focuses on identifying experimental and quasi-experimental research. However, identifying the knowledge base at various stages of the process of developing effective interventions (Medical Research Council, 2008) may require retrieval of research using a variety of methods such as for questions about processes and experiences of delivering services. For this study the focus is on the challenges faced by health and social care professionals in managing risks and communicating risk information effectively to patients and clients (Taylor and Campbell, 2011). This developing aspect of the professional role would benefit from a more robust knowledge base (Taylor, 2006; Taylor and Donnelly 2006a, 2006b; Taylor, Killick, O'Brien, Begley and Carter-Anand, 2014) and presents some different challenges in identifying relevant research than in the case of a review of effectiveness of an intervention.

The systematic literature review is widely regarded as a rigorous method of identifying, appraising and synthesising literature relating to a specific topic or question. The review process is treated as a scientific process in its own right (Petticrew, 2006) that is methodical, explicit, replicable and challengeable (Fink, 2010; Mulrow, 1994; Petticrew and Roberts, 2006). The purpose of a systematic literature review is to collate a body of information relating to a specific topic or question in order to improve understanding of the subject area (Booth, Papaioannou and Sutton, 2012; Kamienski, Carman, Wolf, Henderson and Manton, 2013); to synthesise a large body of information (Mulrow, 1994); and to identify gaps in research (Booth *et al.*, 2012). The review may be used to inform practice in health and social care (Leonardelli, 2013; McFadden, Taylor, Campbell and McQuilkin, 2012); to support decision making (Gilbody and Petticrew, 1999; Mulrow, 1994; Petticrew, 2001); and to inform the development of innovative research projects (Mulrow, 1994) to improve services.

There is a growing body of publications providing recommendations on how to conduct effectively a systematic literature search including advice on how to formulate a search strategy (Booth *et al.*, 2012; Kamienski *et al.*, 2013; Petticrew, 2001; Taylor, 2003); appraisal of search techniques such as database searching and hand searching (Armstrong, Jackson, Doyle, Waters and Howes, 2005; Papaioannou, Sutton, Carroll, Booth and Wong, 2010); and usefulness of

databases in terms of retrieval of studies relevant to specific topics (Best, Taylor, Manktelow and McQuilkin, 2014; McFadden et al., 2012; Taylor, Wylie, Dempster and Donnelly, 2007). In addition, the explicit methodologies set out in peer reviewed papers where systematic literature searches have been undertaken can also serve as useful, adaptable guides for future systematic searches.

Our systematic literature search aimed to apply a strategic and replicable search methodology to facilitate retrieval of all relevant information on the topic.

#### *ix. Background to engaging people with dementia in data analysis*

Patient and Public Involvement (PPI) in research is extensively accepted as good practice and increasingly becoming a requirement of funders (Gillard, Simons, Turner, Lucock, & Edwards, 2012; INVOLVE, 2012; Littlechild, Tanner, & Hall, 2015) and publishers (Richards, Snow, & Schroter, 2015). PPI in research involves relevant groups and individuals, for example service users or carers, as partners rather than as participants (HSC Public Health Agency, 2014; Trivedi & Wykes, 2002; Taylor, Killick, O'Brien, Begley, Carter-Anand, 2014). Involving those who are directly affected by the topic that is being researched ensures relevance and improves quality by adding an expert perspective (INVOLVE, 2012; Brett et al., 2014b; Needleman, 2014; NIHR, 2014). Good practice guidance recommends that PPI should be incorporated into all stages of the research cycle (INVOLVE, 2012; National Institute for Health Research [NIHR], 2014) from identifying and prioritising topics, developing proposals, designing data collection materials, preparing participant information sheets, collecting data, analysing data and disseminating research findings. However, a recent scoping study and survey in the United Kingdom (Mathie et al., 2014) reported low levels of user involvement in some activities including data collection, report writing and data analysis.

PPI is actively endorsed across dementia research networks (Alzheimer's Research UK, n.d; Alzheimer's Society, n.d). Involving people with dementia as partners is recognised as not only improving quality of the research, but also providing benefits for the individual with dementia for example feeling valued, involved and informed (Dementia Action Alliance, 2010; Scottish Dementia Working Group, 2014) as well as developing skills and forming networks (Littlechild et al., 2015). More generally, service user involvement can reduce power imbalances between researcher and those being researched (Godfrey, 2004), enhance appropriateness of research (Brett et al., 2014a) and build confidence and self-worth of service users (Brett et al., 2014b). Although such participation is widely accepted as beneficial and ultimately necessary, research papers describing the involvement of people with dementia as co-researchers are lacking. In particular papers involving this group as collaborators in the analysis process are scarce. Development of literature in this domain is needed to guide and inform researchers.

While PPI is endorsed at all stages of the research cycle, involvement of service users in analysis in general has not been well documented (Cashman et al., 2008; Nind, 2011). A developing body of papers describing involvement in analysis has emerged in research involving children and young people (Coad & Evans, 2008; Lundy, McEvoy, & Byrne, 2011), learning difficulties (Richardson, 2002; Tuffrey-Wijne & Butler, 2010), Down Syndrome (Stevenson, 2014) mental health (Gillard et al., 2012) and older people (Tanner, 2012). Publications detailing co-research with older people with dementia (Tanner, 2012; Littlechild et al., 2015) make a valuable contribution to the development of collaborative research approaches. However these papers are limited in that they do not provide substantial detail on how this group were involved in analysis. The value of involving service users in qualitative data analysis is clear if we consider that this phase of the research cycle is central to knowledge construction and consequent impact (Nind, 2011). Involving users in analysis enhances validity (Tuffrey-Wijne & Butler, 2010; Nind, 2011), credibility (Dobbs & Moore, 2002), provides a wider, more relevant viewpoint (Brett et al., 2014a) and can also enable researchers to identify themes and topics for exploration in succeeding interviews (Miller et al., 2006; Littlechild et al., 2015).

However, as with any form of involvement in research, involving users as partners presents ethical and practical challenges of which researchers must be aware (Littlechild et al, 2015). While the ethos of PPI is generally accepted as positive, there have been criticisms around the practice of user involvement in research and queries pertaining to its actual impact. Ethical issues raised often relate to tokenistic practice (Snape et al., 2014; Ocloo & Matthews, 2016) and lack of

diversity of representation in user groups (Beresford, 2007; Brett et al., 2014b). Criticisms have also been levied around service user participation as a covert form of controlling and exploiting users to advance underlying political or institutional agendas (Cowden & Singh, 2007; Carey, 2009; Carey, 2011). Moreover concerns have been raised about the limited robust evidence base demonstrating the actual impact of PPI (Haywood et al., 2015) with issues such as poor reporting and lack of systematic evaluation noted (Staniszewska et al., 2011; Staniszewska & Denegri, 2013; Mathie et al., 2014). On a more practical level, matters including recruitment, associated financial costs, training, and time required for planning and delivery (Brett et al., 2014b; Mathie et al., 2014) can present barriers to effective practice in PPI. Papers reporting the methodology of involving users with dementia as co-researchers in different stages of the research cycle, discussing potential challenges to be considered and demonstrating the impact of this involvement are therefore needed.

- **4 B Aims & objectives**

- i. *Literature searching*

This systematic literature search aimed to apply a strategic and replicable search methodology to facilitate retrieval of all available peer reviewed journal articles on the topics of risk communication or risk concepts in dementia care. The aim was to produce a robust search that retrieved a high proportion of relevant articles while reducing the likelihood of retrieving irrelevant papers.

- ii. *Literature review*

The aim of the literature review was to synthesise findings of studies on risk concepts in dementia care (including differing perceptions and approaches) with a particular focus on the issues and challenges in risk communication.

- iii. *Qualitative study of people with dementia*

This phase of the study aimed to explore concepts of risk and experiences from the perspectives of individuals with dementia, in particular how risks were communicated between these individuals with families and health and social care providers.

- iv. *Engagement of people with dementia in data analysis*

The aim of this exercise was to involve individuals with dementia as co-researchers in analysis of research findings to enhance validity through a process of applying multiple perspectives to data analysis.

- v. *Qualitative study of family carers of a person with dementia*

This phase of the study aimed to explore experiences and concepts of risk from the perspective of family carers while also addressing topics relating to risk communication.

- vi. *Qualitative study of professionals in community dementia services*

This study explores how risk and uncertainty are conceptualised and communicated in community dementia care from the perspective of professionals in the field.

- vii. *Survey of professionals in community dementia services*

The survey of professionals in community dementia services aimed to:

- 1) describe the use of numeric data and numeracy levels in dementia care;
- 2) explore variability in understanding and use of verbal and numeric expressions of risk likelihoods;
- 3) establish a rudimentary estimate of the frequency of sixteen major risks in community dementia care teams;
- 4) measure accuracy of perception of frequency of risks having severe outcomes against recorded data;
- 5) model and explore experience, concern and numeracy as predictors of accuracy of perception of frequency of risks having severe outcomes;
- 6) investigate views on visual aids for communicating risk likelihoods; and
- 7) identify practice issues in risk communication relating to people with dementia living in the community.

- **4 C Methods**

This project comprised seven parts:

- i. *Literature searching*
- ii. *Literature appraisal and synthesis*
- iii. *Qualitative study of people with dementia*
- iv. *Engagement of people with dementia in data analysis*
- v. *Qualitative study of family carers of a person with dementia*
- vi. *Qualitative study of professionals in community dementia services*
- vii. *Quantitative study of professionals in community dementia services*

The engagement of people with mild-moderate dementia in data analysis (iv) was an additional feature beyond the scope outlined in our funding bid. The other parts listed above were planned to follow sequentially as listed, each part informing subsequent parts. The literature review (i and ii) informed all later stages. Due to challenges in recruitment, the qualitative study of people with mild-moderate dementia (iii) was not complete before stages (v) and (vi) were commenced. The qualitative study of family members (v) was informed by the early findings of the study of people with dementia (iii). The qualitative study of professionals in community dementia services was informed by the interim findings of the study of people with dementia (iii) and by the findings of the study of family members (v). The survey of professionals in community dementia services (vii) was informed by all earlier stages of the project. This was particularly important so as to ensure that the questions and scenarios in the questionnaire took account of relevant concepts, language, scales and anchors so as to be meaningful to respondents and so that the survey produced results with external validity. The method for each of the seven parts is outlined below, drawing on the journal article prepared on each part.

Ethical approval for the study (including the involvement of peer-researchers) was granted by the Office for Research Ethics Committees Northern Ireland (Ref 15NI0008).

- i. Methods: Literature searching** (based on: Stevenson et al., 2016)

The specific aim of the literature search was to identify all available peer reviewed journal articles published on the topics of risk communication or risk concepts in dementia care. We report on an appraisal of the effectiveness of a range of health and social science databases and one online search engine in retrieving peer reviewed journal articles published on the topics of empirical research on risk communication and risk concepts in dementia care. The essence of the method was to measure the ability of each database to retrieve relevant papers (and avoid retrieving irrelevant papers) when applying a consistent search strategy across the databases. Reference lists of identified literature reviews were also searched and relevant items included.

#### *Framing the search*

The search topic selected was '*risk concepts and risk communication in dementia care.*' This breadth of focus was selected as being appropriate on the basis of background reading and a preliminary scoping exercise which indicated a low volume of studies on this topic (Leonardelli, 2013; Matthews et al., 1999; Taylor et al., 2007). The breadth is broader than a question about the effectiveness of an intervention, and identifying relevant studies on this topic illustrates the challenges in identifying studies on research questions for which a range of research methods may be appropriate. All journal articles retrieved were assessed against pre-defined inclusion criteria to evaluate whether they were eligible to be included, as outlined below. The searches were all run within one week in May 2014, and all relevant articles published up to the end of December 2013 were included.

#### *Topic and defining concept groups*

Included studies had to relate to either risk communication or risk concepts in dementia care. Thus studies on risks associated with living with dementia (such as risks relating to personal safety or wellbeing) were included while papers relating to likelihood (risk) of developing dementia were excluded. Studies relating to risks associated with caring for a person with dementia such as stress of family carers were not included.

The search question was divided into two concept groups for purposes of the literature search: 'dementia' and 'risk' (relating to both risk communication and risk concepts). Consideration was given as to whether to include 'care' as a third concept group as risks related to living with dementia might be described as 'dementia care'. However preliminary experimentation revealed that while this may have reduced the number of irrelevant articles (such as articles on the risks of developing dementia) being retrieved, and thus aided efficiency, it would have resulted in several relevant articles being eliminated. In addition, 'care' proved to be a very diffuse concept encompassing such topics as location of care, types of carer, range of professionals involved in care, specific care services, quality of care, service policy and practice issues. For these reasons a 'care' concept was not included in the search.

### *Refining the search terms*

The next stage of the process involved selecting terms for each of the two concept groups to refine the search. Cochrane reviews on dementia and risk were examined to identify terms used within the search strategies, in addition to using the thesaurus function of each database to identify appropriate terminology. The same search concepts were applied across all databases, using appropriate index (thesaurus) terms as available.

Regarding terminology for *dementia*, the Alzheimer's Society estimates there are over 100 different types of dementia. Preliminary experimentation revealed that text searching distinct types of dementia would result in a very high volume of irrelevant articles. It was concluded that studies on risk communication and risk concepts were likely to be indexed against 'dementia' and 'Alzheimer's', rather than against less common forms of dementia. For databases without an index option both '*dementia*' and '*Alzheimer's*' were searched using text term searching.

Regarding the second concept group, it was recognised that '*risk*' is a very broad term relating to a diverse range of fields of knowledge (Matthews et al., 1999) such as finance, public health and construction. Therefore general terms such as '*risk*' and '*safety*' could not usefully be included in the search without retrieving an impossibly large number of hits of limited use. Thus work was undertaken to identify more specific terms relating to risk on this topic area. Background reading on risk communication and risk concepts identified some preliminary terms which were then further refined following completion of scoping exercises on a range of databases. One of the key challenges for this search was to reduce the number of articles being retrieved relating to the '*risks of developing dementia*' as this was not the focus of the review. While it was acknowledged that both '*risk assessment*' and '*risk management*' are fairly broad subject groups, these were both retained in the search as these are of central significance in terms of the focus of the search topic. Terms selected for the risk concept group included *risk communication*, *risk management*, *risk assessment*, *risk perception*, *risk concepts*, *attitudes to risk*, *ideas about risk*, *risk taking* and *risk enablement*.

### *Inclusion criteria*

Clearly-defined inclusion criteria are essential to ensure consistency of judgement by the reviewers in selecting relevant articles from the hits retrieved by the searches. The following inclusion criteria were used by the two reviewers independently who then met to resolve any differences the criteria.

The focus was exclusively on empirical research. Both qualitative and quantitative studies were included as eligible, including papers reporting experiments, surveys, focus group studies, interviews, action research and case studies. Literature reviews were also included and given particular attention to ensure that the review of which this search formed part was not duplicative. Reference lists of these literature reviews were then searched for relevant articles. Policy papers, case law, book reviews and purely theoretical or ideological papers were excluded.

All studies deemed as relevant had to present the results of research about people with dementia, family members of people with dementia or health and social care professionals working with people with dementia. The focus of the review was primarily on concepts of risk or risk communication relating to individuals with dementia in the mild to moderate stages living at home. However studies within care homes and supported living arrangements were included if the study content was transferrable to risks related to living at home.

Only articles published in peer-reviewed journals were included to ensure that a measure of quality appraisal had been conducted (Taylor et al., 2007). Some searchers emphasise the importance of including grey literature in reviews, primarily as a means to avoid publication bias in the review process (Booth et al., 2012), however publication bias seemed a low risk issue on this topic, and given the difficulties in developing a robust methodology for the purpose, grey literature was omitted.

#### *Databases, search engine and their facilities*

Previous studies have indicated that a comprehensive literature search requires use of a range of databases (McFadden et al., 2012; Stevinson and Lawler, 2004) particularly if the topic straddles a variety of disciplines as databases are often subject specific (Papaioannou et al., 2010) and will vary in their journal coverage (Brettell and Long, 2001). Twelve academic-professional bibliographic databases and one online search engine were selected with a view to appraising the ability of each database to retrieve articles relevant to the search question while limiting the number of irrelevant articles retrieved. The databases selected covered health, social care and social sciences and represent a broad range of disciplines: Applied Social Sciences Index and Abstracts (ASSIA), Campbell Collaboration, Cumulative Index to Nursing and Allied Health (CINAHL), Cochrane Library, Communication Abstracts by EBSCO, Medline, PsycINFO, Scopus, Social Care Online, Social Science Citation Index (SSCI), Social Services Abstracts and TRIP. These databases are generally available to academic staff and students at universities.

*Google Scholar* was included in the present case study as some previous papers on literature searching have concluded that this search engine has reasonable sensitivity (Gehanno, Rollin and Darmoni, 2013) and precision (McGinn, Taylor, McColgan and McQuilkin, in press), and may retrieve unique articles not retrieved on databases (McFadden et al., 2012).

Advanced search options were utilised when available in order to increase the precision of the search. Databases varied in terms of search functions, filters and index terms (thesauri) available. If the database provided the option of using an index or thesaurus function for any of the key terms, then this was used to increase the sensitivity and precision of the search, and text term searching was not then deemed necessary. Text term searching was utilized only when a key term did not exist as an index term on the database. Proximity searching was used when available to find terms within a particular number of words from each other, for example to retrieve all documents in which the words '*risk*' and '*perception*' were separated by three or less words. When proximity searching applications were available on a database then simple text searching was not utilised. Truncation searching was applied if available in order to retrieve variations of the same word. The majority of the databases provided the option of using Boolean operators (AND, OR, NOT and brackets) where algebraic principles are applied to combine sets of search terms in order to broaden or narrow the search (Taylor, 2003). The 'NOT' function was used when available during scoping exercises to inform decision about whether or not to include particular index terms in the search, but was not used in the final search formulae.

Searching using web search engines presents particular challenges as the commercial algorithm used is not available to the user. *Google Scholar* was included in this exercise so as to be able to judge one search web search engine against bibliographic databases. The advanced search function on *Google Scholar* was employed, allowing for a search combination of 'with all of the words' and 'with at least one of the words.' The advanced function thus allowed for the combination of these two concept groups. However it was noted that at the time of this search only one of these groups could contain more than one search term. This was suitable for the purposes of this search as only two sets were used and the dementia set could be limited to one term ('dementia'). However this highlighted a limitation of *Google Scholar*, application of the advanced search function may be of less benefit if more than two concept groups were being used or if both

of the two concept groups contained more than one search term. Scoping exercises on Google Scholar (not using the advanced function) found that the order of terms combined using 'OR' did not affect the number of articles retrieved or the relevancy order of the search results. However the order of terms combined by 'AND' did affect the order of relevancy for searches. For example, A AND (B OR C OR D) = A AND (C OR D OR B) however A AND (B OR C OR D) ≠ (B OR C OR D) AND A. It is not necessary to insert 'AND' on *Google Scholar* as search terms are automatically combined using AND unless another operator has been used. However this point about the deviation from Boolean logic is clarified here for guidance with future searches.

#### *Search filters*

Several of the databases provided an option of filtering results according to factors including publication type, language and date. Search filters were applied where available to reflect inclusion criteria, in particular publication type. No language limits were set for the database searching. In the event of an article being retrieved that was not available full text in English, the article would be translated using *Google Translate*. This would then be appraised for meaningfulness and coherence, and would be included only if the translation seemed adequate for the purpose. Search strategies as applied to each database are detailed in the Appendix.

#### *Measures used*

Of primary significance in appraising the value of each database was its ability to identify as many relevant articles as possible whilst limiting the number of irrelevant articles retrieved (Best et al., 2014; McFadden et al., 2012).

The *sensitivity* of a search refers to its effectiveness in retrieving a high proportion of the total number of publications relating to the specific research question (McFadden et al., 2012; Taylor, 2003; Taylor et al., 2007). Sensitivity of a database search is measured by dividing the number of relevant articles identified on a particular database by the total number of relevant publications available on the topic (Petticrew, 2006). For the purposes of this study, sensitivity of each database was measured by dividing the number of relevant articles retrieved by each specific database by the total number of relevant articles retrieved through the search on all databases, the web search engine and the reference list search of relevant literature reviews retrieved.

A search may be highly sensitive but may retrieve such a large volume of irrelevant articles that the search becomes so overly laborious as to be impractical (Best et al., 2014). Thus an efficient search strategy is required that limits the number of irrelevant articles retrieved. The ability of a search to identify relevant articles without retrieving irrelevant articles is measured through the concept of *precision* (Best et al., 2014; Taylor et al., 2003, 2007). Precision was measured by dividing the number of relevant articles found by each database by the total number of articles retrieved through the search on that specific database.

The number of *unique articles retrieved* on each database was recorded as a means of measuring the number of articles that would not have been sourced if that particular database had not been included in the process. The ability of a database to retrieve unique articles is thus an important measure of the value of the database relevant to a search on the topic.

When the option to *sort results by relevancy* was available, this was applied and a measure was taken of the proportion of relevant articles retrieved via that particular database in the first 25%, 50% and 75% of the overall number of articles sourced by the database. In relation to Google Scholar, only the first 300 articles (out of a total of 18100 results) were included in the search results after being sorted by relevancy. Relevancy sorting can potentially aid searchers to save time by locating the most relevant information more quickly (Hariri, 2011) but some evaluation of the quality of the algorithm is required, leading to its inclusion amongst the measures used in this study.

## **ii. Methods: Literature appraisal and synthesis** (based on: Stevenson, McDowell et al., in press)

For the literature review, all studies published up until and including December, 2013 were examined. Reference lists of relevant literature reviews retrieved via the database search were also inspected. The database search was later updated to include papers published up to 23 February 2016. Papers identified by subsequent contact with experts were also then added to the review.

To be included in the review studies had to be: empirical studies; focus on risk communication or risk concepts in dementia; be published in a peer-reviewed journal; and be available full text in English. Policy, case law, theoretical and ideological papers were excluded. Papers were included if they addressed topics of risk communication or risk concepts in dementia care, and examined either individuals with dementia, carers or family members of people with dementia, or health and social care professionals. Studies examining risks of developing dementia or exploring risks associated with caring for an individual with dementia were excluded.

Of the 3608 papers retrieved from the initial search, 209 were considered potentially relevant after removing duplicates and scanning abstracts. Twenty-nine articles met the inclusion criteria. Two additional articles were identified from the reference lists. Following the updated database search and contact with experts, five additional papers were added resulting in a total of 36 papers included in the review. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2009 checklist was used as a tool to inform data extraction.

The quality criterion for inclusion was that the study had been through a masked (blind) peer-review process and was published in a journal. The Quality Appraisal Tools (QAT) suite of quality appraisal tools (Taylor et al., 2015) was used to inform data extraction.

**iii. Methods: Qualitative study of people with dementia** (based on: Stevenson, Savage et al., in press)

*Design*

This qualitative study of the perceptions of people with dementia used elements of Grounded Theory, and used interviews for data gathering.

*Recruitment*

Seventeen interviews were completed with participants across the five Health and Social Care Trusts that deliver public services in Northern Ireland. Individuals with mild to moderate dementia, of any type, who had recently been involved in making a decision regarding their daily life activities or care (medical or social) that required them to weigh up information about risks were invited to participate in the study. Participants were purposively recruited by health and social care professionals practicing in community dementia care.

*Ethics and Consent*

Ethical approval for the study and all supporting documentation was obtained through the Office of Research Ethics Committee Northern Ireland (OREC NI). Protocols for dealing with distress and with disclosures were put in place. The health and social care professional involved in recruiting the participant was in the first instance responsible for making a judgement on whether that individual had capacity to consent, based on their professional knowledge and experience. It was recognised that capacity may fluctuate or there may have been decline in abilities affecting capacity between time of selection by professional and the time at which the interview took place. Consent was therefore obtained on the day of the interview, informed by guidance from Dewing (2002), Alzheimer Europe (2012), Higgins (2013) and Alzheimer's Society (2014a). Research staff conducting the interview paid careful attention to any signs that the individual did not have capacity to give informed consent at that stage such as signs of confusion or distress.

*Data collection*

Interviews were completed by the project research assistant and a co-researcher who was an Engagement and Participation Officer employed by Alzheimer's Society. Data collection was completed between 6<sup>th</sup> November 2015 and 1<sup>st</sup> November 2016. Prior to data collection, the

research team met with an individual with dementia who provided advice on interviewing including communication tips; building a respectful rapport; and practical guidance for dealing with scenarios that may arise during the process, for example if the interviewee became upset. The interview process was further guided by recommendations on communicating effectively with a person with dementia (Alzheimer's Society, 2012; Sedgewick, 2014) and guidance on interviewing a person with dementia (McKillop & Wilkinson, 2004).

Each interview was conducted in the participant's own home to facilitate a relaxed and familiar environment. The option was provided to have a family member present during the interview if the participant felt more comfortable with this. Participants chose the time of interview as it was recognised that there might be fluctuations in ability during the day, and particular times when the individual would feel more confident completing an interview. Interviews were audio recorded, with consent from participants.

A topic guide was prepared to facilitate discussion across three core domains; ideas about risk; approaches to risk; and risk communication. As well as the service-user comments in the design stage, the detailed prompts for wider exploration, the language and the sequencing of questions were reviewed and revised throughout the data collection phase as part of a reflective, iterative process in accordance with grounded theory principles.

Socio-demographic data was collected after interview including gender, living arrangements and location (urban/rural). Details of age group and type of dementia were recorded only when voluntarily specified by the participant.

### *Analysis*

Data was analysed using a constant comparison approach to allow for generation of knowledge in this understudied domain. Analysis was undertaken by the chief investigator, project research assistant, the collaborator from Alzheimer's Society (who was involved in data collection) and four individuals with dementia (who had not participated in the interviews). Interviews were transcribed by the project research assistant. **Analysis was undertaken between data gathering, and this was used to inform subsequent data gathering in accord with grounded theory tenets of theoretical sampling.**

Analysis involved both initial and focused coding (Charmaz, 2014) and continual revisiting and reconceptualisation of data. Initial coding of transcripts allowed for generation of broad and varied themes and concepts. Focused coding involved refining concepts and categories, and selecting the most significant themes for analysis. NVivo software was used for data management to assist in identifying, categorising and connecting emerging themes.

Mid-way through the data collection process an analysis session was organised involving individuals with dementia as co-researchers in preliminary analysis of the data, so as to incorporate interpretation of meaning from a user-perspective. These co-researchers were recruited through an Alzheimer's Society Service User Review Panel (SURP) and had not participated in the research study. Co-researchers were presented with anonymised extracts of data relating to meanings of risk and communication of risks with families and professionals. The session involved a presentation on the research project and clarification of 'co-research', followed by three interactive twenty-minute exercises – one analysing concepts of risk and two on risk communication. A combination of role play (between the facilitators) and hand-outs were used to present the anonymised quotes and extracts to co-researchers. Highlighters and pens were provided to the group to highlight any salient words or phrases and to make notes (see also, Stevenson, 2014). Ideas and comments were written up on a flipchart, forming a visual reminder for the group (Tanner, 2012). Meanings of risk based on the data, contextualisation of the findings and decisions on good practice in risk communication were formed during the session. Topics for further investigation in succeeding interviews were also identified. [The co-researcher element of this study is reported in further detail **below and** in Stevenson & Taylor, 2017a]

#### **iv. Methods: Engagement of people with dementia in data analysis (based on: Stevenson & Taylor, in press, a)**

The aim of the exercise was to involve individuals with dementia as co-researchers in analysis of research findings to enhance validity through a process of applying multiple perspectives to data analysis. The session centred on generation of ideas and themes from the perspective of individuals with dementia rather than verification of interpretations of the core research team. The analysis formed part of a wider grounded theory approach whereby the identification of salient themes or sub themes and points of interest raised by the group allowed for further exploration of these topics in subsequent interviews.

#### *The co-research team*

Four individuals with dementia were involved as co-researchers in analysis of findings (male (2), female (2); Under 65 (2), 70-74 (1), 75-79 (1)). Co-researchers were recruited through one of the recently formed Alzheimer's Society Service User Review Panels (SURPs) in Northern Ireland. SURPS are small groups of people with dementia who convene with a remit to discuss and review a diverse range of topics relevant to Alzheimer's Society and external organisations. Topics may include for example review of organisational strategies or critiquing information materials. The SURP was therefore seen as an appropriate forum for the analysis, fitting with the group remit as well as the interests and abilities of members. A request application form was submitted prior to attending the SURP, in accordance with Alzheimer's Society protocol. This afforded the group opportunity to make an informed, non-pressurised decision about whether they would like to be part of the analysis process. Ethical approval for the overall study, including this PPI exercise, was granted by the Office of Research Ethics Committee Northern Ireland (OREC NI). Individuals with dementia who had previously participated in interviews had signed consent forms allowing their anonymised data to be used in the analysis sessions.

#### *Data analysis session*

The session was informed by elements from previous research papers reporting involvement of service users in analysis of data, as referenced below. General guidance on communicating with people with dementia was followed (McKillop & Wilkinson, 2004; Alzheimer's Society, 2012; Scottish Dementia Working Group, 2014; Sedgewick, 2014) as well as reflections from previous interviews with people with dementia during the data collection phase. Facilitation skills were guided by Richardson (2002) taking a non-directive approach and recognising the importance of listening, reflecting back to the participants what they had said in their own words, acceptance and positive regard for opinions. Creation of a relaxed and non-judgmental environment to foster conversation and freedom of expression was paramount (Tanner, 2012; Tuffrey-Wijne & Butler, 2010). Reflective experience from the previous interviews had been that participants would tend to generally agree with the interviewer whenever the researcher attempted to summarize what the participant had meant by their response. For this reason during the interviews particular attention was given to paraphrasing using the participant's own words (rather than the interviewer's words) and to avoid making suggestions as to what the individual might have meant by a particular response. Based on this experience, it was considered more meaningful to involve the group in identifying themes rather than verifying the interpretations of the research team.

The data analysis session lasted two hours and was also attended by the facilitators of the SURP. The session commenced with a presentation on the research project and clarification of what co-research is, followed by three interactive twenty minute exercises – one analysing definitions of risk and two on risk communication. A short coffee and chat break was taken mid-session. Exercises involved group discussion guided by a series of pre-prepared prompts (*Figure 1*). A combination of role play (between the facilitators) and hand-outs were used to present the anonymised quotes and extracts to co-researchers for analysis. Highlighters and pens were provided to the group to highlight any salient words or phrases and to make notes (Stevenson, 2014). Ideas and comments were written up on a flipchart, constituting a visual reminder for the group (Tanner, 2012). It was emphasised repeatedly to the group that their involvement was not as participants in the research study but in making sense of the interview data as members of the research team.

#### *Group exercise – risk concepts*

Participants with dementia who had taken part in the interviews had been asked what the word risk made them think of. The SURP group were presented with anonymised responses from participants which included one word answers and short quotes. All responses to the question 'what does risk mean to you' from completed interviews were included. Only material for which interviewees had signed consent forms allowing their quotes to be used in these sessions was presented. The facilitator read through the responses and provided hand-outs to the group along with highlighters and pens for note taking. A series of prompts were presented to elicit views on what the group interpreted risk as meaning to a person with dementia (based on the participant responses), what they felt was interesting and how the responses connected together. The exercise aimed to allow the group to derive their own meanings from the data, rather than verifying the interpretations of the core research team. Following oral and written presentation of the participant responses, the group were given some time to reflect on these and converse amongst themselves about the responses, in particular anything they felt was interesting or relevant (Tuffrey-Wijne & Butler, 2010; Stevenson, 2014). Meanings of risk, based on the participant responses, were then discussed among the group for example the idea of risk as defined by a situation. Connections were also made between responses, for example that risk was a 'fear' of 'danger.'

#### *Group exercise – risk communication*

Participants in the primary research interviews had also been asked who they talked to about risks. Due to time constraints, it was decided by the research team to focus discussion on one health-based risk and one social care-based risk. Driving and medications were two of the risks that these individuals most often discussed with others such as their General Practitioner (GP), Pharmacist and family. Extracts were selected to include both male and female participants discussing different experiences of these risks. Excerpts included discussions with both professionals and family carers. The anonymised extracts from transcripts referencing these discussions were presented to the group via a role play (involving facilitators) and paper copies of the anonymised transcripts. Discussion was aided by prompts to explore what the group thought was interesting about these discussions, to identify and connect themes and any notable differences between communications with families and professionals. The group were encouraged to bear in mind the definition of risk communication as sharing information about risks and sharing ideas and opinions about risks (this definition was presented in bold print in hand-outs).

**Figure 1.** Sample prompts.

- Based on these responses, what you think risk means to a person with dementia?
- Are there any words or sentences you would group together?
- Is there anything that stands out to you when reading these quotes?
- Is there anything you find interesting?
- What do you think is important?
- Can you identify any themes from these responses?
- Can you see any ways in which these themes connect?
- How are (e.g. theme A) or (e.g. theme B) different from each other? OR Do you think (e.g. theme A) or (e.g. theme B) are the same?
- Is there anything we should ask more questions about the next time we do an interview?
- Can you see any differences in discussions with family and discussions with the GP?

This session required detailed preparatory work based on initial study findings, and took place during the latter part of the overall analysis process. The results of this analysis exercise then fed back into the ongoing analysis of this data by the research team.

**v. Methods: Qualitative study of family carers of a person with dementia**  
(based on: Stevenson & Taylor, 2016)

One focus group for family carers was held in the locality of each of the five Health and Social Care Trust areas which deliver publicly-funded health and social care services in Northern Ireland. Five groups were facilitated including 22 participants in total. Groups were conducted by a member of the core research team with support from the regular group facilitator from Alzheimer's Society. Participants were purposively recruited through the existing structure of Alzheimer's Society carer support groups on the premise that all carers of people with dementia will have had experiences of risk. Four key themes relating to concepts of risk and risk communication were explored through the groups: types of risks encountered and level of concern; approaches towards risk; sharing of information about risks with care recipient; and sharing of information about risks with professionals working in dementia care. A series of pre-prepared prompts were used to guide discussion (Figure 2). Interesting sub themes that emerged during the discourses were also explored. Discussions were audio recorded and transcribed by the group facilitator from the research team, with consent from participants. Ethical approval was granted by the Office for Research Ethics Committee (Northern Ireland). Groups were provided with Participant Information Sheets, including statements of confidentiality and limitations to confidentiality, one month prior to the sessions to allow time for informed consent. Processes for dealing with distress and disclosures were put in place.

Principles from grounded theory were used to inform data gathering and analysis of data, which used a constant comparative approach (Charmaz 2014). NVivo software was utilised to facilitate this analysis through coding of data transcripts to identify and connect themes. Data analysis was conducted by the group facilitator from within the core research team and verified by the Chief Investigator.

**Figure 2.** Sample prompts from topic guide.

What do you think of when you hear the word 'risk'?

I am interested in whether there are any particular risks you either encourage or discourage the person you care for to take.

When do you choose to encourage the person you care for to take risks?

When do you try to discourage them from taking risks?

Do you discuss your concerns about risk with your family member with dementia?

Do they discuss their concerns with you?

Do you tend to share similar concerns?

Have you been involved in making any decisions about the care or treatment of your family member that involved thinking about risks and benefits?

Can you give examples of these types of decisions?

What types of professionals discussed these risks and benefits with you?

How do you think professionals can best support families to understand and make decisions about risks?

**vi. Methods: Qualitative study of professionals in community dementia services** (based on: Stevenson & Taylor, in press, b)

*Recruitment and participants*

Participants were purposively recruited through the five Health and Social Care (HSC) Trusts in Northern Ireland, one focus group being held in each Trust area. Selection criteria included professionals, from any health and social care discipline, practising in community dementia services. Inclusion criteria was premised on the assumption that all practitioners in dementia care will have a level of experience of both managing risks and communicating about risks. Recruitment

was coordinated by senior dementia managers in the five HSC Trusts in Northern Ireland, who were collaborators in the multistage research study. Staff meeting inclusion criteria, were provided with Participant Information Sheets and Consent forms to enable an informed consent process. Details of professional backgrounds of participants were provided to the research team prior to focus groups. Ethical approval for the study and associated documentation was granted by the Office for Research Ethics Committee (Northern Ireland) and governance approval by each HSC Trust. Informed, written consent was obtained from all participants prior to data collection. Thirty-five professionals (thirty female and five male) participated in the focus groups. The range of professions included social work (12), nursing (13), occupational therapy (4), clinical psychology (1), trainees in nursing and psychology (2) and support staff (3). Five of these staff were team leaders. Number of years qualified ranged from those who were currently in training to participants who had been qualified in their profession for 34 years. Mean years qualified was 14.4 years. Length of time working in dementia care ranged from 0 to 32 years with mean of 10.8 years.

#### *Data collection*

An iterative, grounded theory approach was applied to data collection. A topic guide was prepared to facilitate discussion across four core domains: situations in which professionals are communicating information about risks to people with dementia and their families; language used by professionals to define and communicate risks; experience and views on different formats of communicating risk (including verbal, numeric and visual modes of presentation) and applicability in dementia care; sharing of good practice with respect to how risks are approached; and challenges in practice. Prompts from the topic guide were continually reviewed and revised as part of an iterative process to explore emerging themes in adequate depth and to ensure use of meaningful language.

To explore views of numeric modes of presentation, participants were presented with logically equivalent statements on side effects of a common dementia medication framed as percentage (11%), frequency (11 out of 100) and decimal likelihoods (0.11) for comparison. Statements were revised following the first two focus groups to include also the approximate value of 'about 1 in 10'. In relation to visual modes of risk communication, participants were presented with three different visual formats of communicating the same information comparing the number of people over 65 who fall each year both with and without dementia. Visuals presented included a bar chart, an icon array featuring oval icons and an icon array with people icons.

The core research team were satisfied that data saturation was achieved in relation to mapping domains of risk and exploration of concepts, communication of risks and practice issues. Further theoretical sampling was therefore not considered necessary.

#### *Method of analysis*

Focus groups were audio recorded and fully transcribed. A grounded theory method of constant comparison was used to analyse the data. Analysis was commenced in the early stages of data collection to allow for an iterative approach. Processes of initial and then focused coding were applied (Charmaz, 2014). Initial coding involved generation of a broad and varied range of emerging themes and concepts and was undertaken by the research assistant. Focused coding to decide on the most significant themes, their contribution to theory and to select and connect core categories for analysis was undertaken by the research assistant and chief investigator. NVIVO software was used to facilitate the coding process. Selection of original data in the form of quotations to accentuate key concepts was agreed following the focused coding stage of analysis.

#### **vii. Methods: Survey of professionals in community dementia services (based on: Taylor et al., submitted)**

An online survey was administered to all health and social care professionals in community dementia care in Northern Ireland using Qualtrics software. Selection of items, their terminology and scale anchors were informed by concepts of risk and practice issues identified in qualitative studies and a literature review (Stevenson, McDowell et al., *in press*; Stevenson, Savage et al., *in*

press; Stevenson & Taylor 2016; Stevenson & Taylor, *in press, b*). Where appropriate, questions were presented as practice scenarios to ensure relevance.

### *Measures and Procedure*

*Use of numerical data in practice.* Participants selected from a list of ten items which included clinical assessment tools, likelihoods of medication side effects and incident reports. Participants were invited to state any other forms of numeric data they used in practice.

*Numeracy.* The *Berlin Numeracy Test – Adaptive Version* (BNT) (Cokely, Galesic, Schulz, Ghazal & Garcia-Retamero, 2012) was used plus three items from Schwartz, Woloshin, Black & Welch (1997) added to increase discriminability of scores. The BNT is validated for prediction of risk literacy, defined as the ability to accurately interpret and use information about risks (Cokely et al., 2012). Scores were calculated as number of correct responses up to a maximum of seven.

*Numerical understanding of verbal probability expressions.* Participants were given verbal expressions of risk from the European Union guidance ((European Commission, 2009; European Medicines Agency, 2016) for the probability of medication risks: very rare, rare, uncommon, and very common. Participants were provided with two statements about the probability of medication side-effects (“nausea is a *common* side-effect of medication A; It is *rare* for people who take medication A to have a stroke”) and were asked to estimate how many out of 1,000 patients would experience the side-effect. To assess general concordance between participant’s estimates and the risk probabilities described in the EU guidance, participant’s numerical probability estimates were categorised according to the risk probabilities that accompany each verbal descriptor in the guidance.

*Verbal understanding of numerical probabilities.* Participants were asked how they would communicate to a patient using the five EU verbal descriptors regarding a medication side-effect that was estimated to occur in 21 out of 1,000 patients.

*Subjective judgements of probability.* Participants were provided with two case descriptions and were asked to make a judgement of level of risk. In one case, a participant was asked to judge the risk of a client falling (on a scale of low/medium/high) based on information including falls history, co-morbidities and an assessment score. In the other, respondents were asked describe a client’s risk of having an accident in the home (using a six item verbal scale from ‘very unlikely’ through to ‘very likely’) based on history of similar incidents.

*Use of transparent risk communication.* Participants were provided with a graphical presentation (line graph) of a patient’s verbally aggressive outbursts in xx weeks prior to and yy weeks following the trial of a new intervention. Participants selected from five alternatives for communicating this information to clients or colleagues: absolute risk reduction (‘reduced from twelve to six instances per week’); two relative risk reduction statements (the intervention ‘halved’ or ‘reduced aggressive instances by 50%’) and three verbal statements with no numeric references (‘reduced’, ‘moderately reduced’ and ‘substantially reduced’ the number of instances).

*Estimates of frequency and concern for dementia care risks.* Respondents were asked to estimate the frequency of occurrence (out of 100 patients coming to their team) of sixteen dementia risk factors identified in an earlier qualitative study (Stevenson & Taylor, *in press, b*) based on their working experience. Participants rated their levels of concern for each risk on an 11-point scale (0-10; zero = ‘not concerning at all’; ten = ‘extremely concerning’).

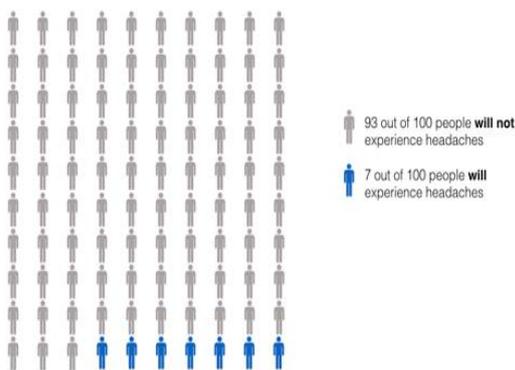
*Accuracy of perception of frequency of risks having severe outcomes.* Respondents were asked to estimate how many individuals with dementia (out of 1000) they would expect to experience four severe, low-probability risk outcomes within the next twelve months: (1) causing a home fire; (2) driving collision; (3) hospitalised after a fall; and (4) having a missing person’s report filed. Accuracy of professionals’ estimates was judged against data on frequency of risks having severe outcomes: (1) records on accidental dwelling fires (Northern Ireland Fire and Rescue Service, 2014); (2) driving collisions involving over 65s (Police Service of Northern Ireland 2014); (3) hospitalisation following over 60s population (Department of Health [Belfast], 2014); and (4) police missing person records in one United Kingdom policing area (Bantry-White & Montgomery, 2015). Prevalence of these incidents among the population of interest were based on an estimated dementia population of 19,765 in Northern Ireland (Alzheimer’s Society, 2014). Incidence of falls in the dementia population was assumed as twice that of over 65s without cognitive impairment

(Allan, Ballard, Rowan, & Kenny, 2009; Taylor, Lord, Delbaere, Mikolaizak & Close, 2012), at a rate of 21.3 per 1000. A ratio of 5:2 was assumed for driving collisions (Man-Son-Hing, Marshall, Molnar & Wilson, 2007). Prevalence rates regarding causing accidental fires were not available so the most conservative assumption was made i.e. that all recorded accidental fires for over 65s were caused by persons with dementia. As half of all accidental dwelling fires affect those over 65 (Department for Communities and Local Government, 2014), a rate of 22.7 out of 1000 was assumed. Incidence of having a missing person's report filed was estimated at 5 in 1000 (Bantry-White & Montgomery, 2015).

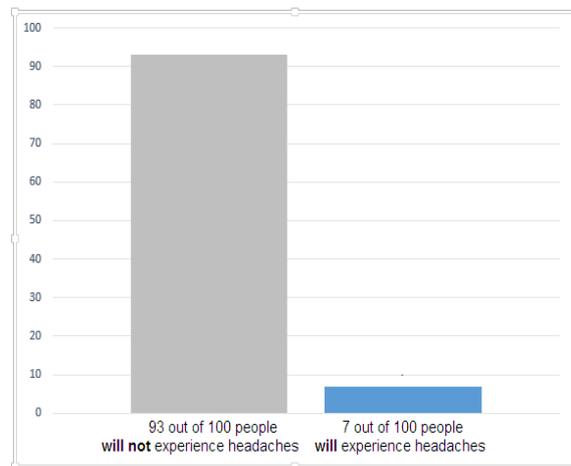
*Visual aids for communicating dementia risks.* Participants selected from three formats for communicating about side effects of medication with a client. The risk of headaches (x in 100) was displayed numerically accompanied by an icon array (100 figure icons presented in a 10x10 block with different colours for the number of people who did or did not experience the side effect); a bar chart; and in a simple frequency statement with no accompanying visual. Qualitative data was invited on the use of these visual aids.

**Figure 3.** Icon array, bar chart and verbal statement used in the survey

*Icon array*



*Bar chart*



*Verbal statement*

93 out of 100 people will not experience headaches. 7 out of 100 people will experience headaches.

*Challenges and practice issues.* Respondents were asked to rate (scale 0 to 10) challenges in risk communication based on issues identified in the earlier studies. Qualitative data was gathered to explore useful heuristics or 'rules of thumb' for addressing risk scenarios in dementia practice and ideas for enabling better risk communication.

Comments on the draft questionnaire were invited from the project Advisory Panel before piloting with two eldercare practitioners locally and four research staff at the Max Planck Institute of Human Development, Berlin. The Advisory Panel included the dementia services manager in each Health and Social Care Trust and 12 other individuals from various countries with expertise in dementia care, health communication, medicine, social work, nursing, risk communication, and speech and language therapy.

*Recruitment*

The dementia services manager in each of the five publicly-funded Health and Social Care Trusts in Northern Ireland invited all health and social care professionals (total 270 staff) in community dementia care to participate via email with accompanying electronic link to the survey. Data was

collected June to September 2016. Ethical approval was granted by the Office of Research Ethics Committees, Northern Ireland.

### *Analysis*

Statistical analysis used SPSS Version 22. A minimum sample size of 85 participants was required to detect an effect size of 0.15 for multiple linear regression. Bivariate correlational analysis using Pearson's R was conducted on the sixteen risk factors to correlate perceived frequency of risk and level of concern for that risk. The histograms indicated that the assumption of normality for correlational analysis was not met for fourteen of the sixteen risk factors. A bootstrapping method was therefore used with 95% confidence intervals. Correlational analyses were run for each of the theoretically-selected predictors against the outcome variable for preliminary examination. Four predictors were tested in the models including experience (years in dementia practice and experience of relevant risk factors within their team); level of concern associated with the risk; and numeracy. All predictors were scale variables. Qualitative analysis involved a thematic analysis responses being coded into general themes.

• **4 D Findings**

The findings of the seven parts of the project are outlined below in sequence.

- i. *Literature searching*
- ii. *Literature appraisal and synthesis*
- iii. *Qualitative study of people with dementia*
- iv. *Engagement of people with dementia in data analysis*
- v. *Qualitative study of family carers of a person with dementia*
- vi. *Qualitative study of professionals in community dementia services*
- vii. *Quantitative study of professionals in community dementia services*

The literature review (i and ii) informed all later stages. Due to challenges in recruitment, the qualitative study of people with mild-moderate dementia (iii) was not complete before stages v and vi were commenced. The qualitative study of family members (v) was informed by the early findings of the study of people with dementia (iii). The qualitative study of professionals in community dementia services was informed by the findings of the study of family members (v) and the interim findings of the study of people with dementia (iii). The survey of professionals in community dementia services (vii) was informed by all earlier stages of the project. This was particularly important so as to ensure that the questions and scenarios in the questionnaire took account of relevant concepts, language, scales and anchors so as to be meaningful to respondents and so that the survey produced results with external validity. The method for each of the seven parts is outlined below, drawing on the journal article prepared on each part.

**i. Findings: Literature searching** (based on: Stevenson et al., 2016)

The overall number of articles retrieved by each database was recorded together with the number of relevant articles retrieved by each database and the combined total number of relevant articles retrieved across all the databases, the web search engine and from the reference lists of reviews retrieved. From these figures sensitivity and precision percentages were calculated, and the number of unique articles retrieved by each database recorded.

**Table 1.** Results for sensitivity, precision and number of unique hits.

Database	Total articles retrieved by search	Relevant articles retrieved	Sensitivity* (%)	Precision* (%)	Unique relevant articles
ASSIA	26	5	16%	19%	0
Campbell	7	0	0%	0%	0
CINAHL	455	17	55%	4%	3
Cochrane Library	72	0	0%	0%	0
Cochrane Dementia & Cognitive Improvement Gp (all reviews)	113	0	0%	0%	0
Communication Abstracts (EBSCO)	0	0	0%	-	0

	300	10	32%	3%	1
<i>Google Scholar (300)**</i>					
<i>Medline</i>	1017	5	16%	0.5%	0
<i>PsycINFO</i>	188	15	48%	8%	1
<i>Scopus</i>	450	6	19%	1%	2
<i>Social Care Online (SCO)</i>	29	6	19%	21%	1
<i>Social Services Abstracts (SSA)</i>	8	2	6%	25%	0
<i>Social Sciences Citation Index(SSCI)</i>	207	9	29%	4%	1
<i>TRIP</i>	736	1	3%	0.1%	0
<i>Reference list search of retrieved literature reviews</i>	106	8	-	-	2

\*Sensitivity and precision figures rounded to nearest whole percentage

\*\* Results for first 300 articles retrieved by Google Scholar when sorted by relevancy

The total number of articles retrieved from the database and *Google Scholar* search (including duplicates and literature reviews) was 3608 (see Table 1). Following scanning of titles and abstracts, 209 of these papers (including two literature reviews and an article not in English as discussed below) were considered to be potentially relevant to the search. Following further examination 29 articles met the inclusion criteria for relevance (including the two literature reviews). One article (sourced through CINAHL, Google Scholar, Medline and Scopus) potentially met the inclusion criteria but was not available in English. The *Google Translate* function was applied, but we could not be confident that the translation was of a sufficient standard to allow for an accurate understanding and appraisal of this paper and it was therefore excluded. A further 106 papers were sourced from the reference lists of two literature reviews retrieved pertaining to the topic, resulting in 3714 papers in total (including duplicates). The reference lists of these reviews resulted in an additional two relevant papers not sourced through the database searches. Thirty-one papers were therefore retrieved in total including the two literature reviews.

#### *Sensitivity*

CINAHL and PsycINFO yielded the highest levels of sensitivity retrieving 55% and 48% of overall relevant articles respectively while Google Scholar and SSCI retrieved 32% and 29% of the overall relevant articles. Scopus and Social Care Online each recovered 19% while ASSIA and Medline recovered 16%. Social Services Abstracts and Trip generated relatively low sensitivity figures of 6% and 3% respectively. None of Campbell Library, Cochrane Library or Communication Abstracts (EBSCO) retrieved any papers that met the inclusion criteria.

#### *Precision*

Social Services Abstracts, Social Care Online and ASSIA had the highest levels of precision being 25%, 21% and 19% respectively. While CINAHL and PsycINFO yielded the highest degree of

sensitivity, their precision values were low at 4% and 8%. Precision rates for SSCI, Google Scholar (300), Scopus, Medline and Trip were also low at 4%, 3%, 1%, 0.5% and 0.1%.

*Relationship between number of articles retrieved by a database and sensitivity to precision ratio*

Table 2 demonstrates a direct correlation between the total number of articles retrieved by each of the databases and the sensitivity to precision ratios for these databases. As the number of total hits retrieved by a database increases, the sensitivity to precision ratio also increases in the same order.

**Table 2.** Total number of articles retrieved by a database and its sensitivity to precision ratio.

Database *	Total no of articles	Sensitivity % **	Precision % **	Sensitivity/Precision ***
<i>Medline</i>	1017	16%	0.5%	32.81
<i>Trip</i>	736	3%	0.1%	23.74
<i>CINAHL</i>	455	55%	4%	14.68
<i>Scopus</i>	450	19%	1%	14.52
<i>Google Scholar (300)****</i>	300	32%	3%	9.68
<i>SSCI</i>	207	29%	4%	6.68
<i>PsycInfo</i>	188	48%	8%	6.06
<i>SCO</i>	29	19%	21%	0.94
<i>ASSIA</i>	26	16%	19%	0.84
<i>SSA</i>	8	6%	25%	0.26

\* Databases sorted by number of articles retrieved, in descending order

\*\*Sensitivity and precision figures rounded to nearest whole percentage except for values less than 1%

\*\*\* Calculated using exact figures

\*\*\*\* Results for first 300 articles retrieved by Google Scholar when sorted by relevancy

Campbell Library, Cochrane Library and Communication Abstracts by EBSCO all had sensitivity and precision results of zero therefore were not included in Table 2.

*Unique articles retrieved*

CINAHL retrieved three unique articles that were not sourced through any of the other databases while Scopus retrieved two unique articles. Google Scholar, PsycINFO, Social Care Online and SSCI each retrieved one unique relevant paper. An additional two unique articles were identified from the reference lists of the literature reviews (one from each paper), which is to say that these papers were not otherwise retrieved by any search.

*Relevancy sorting*

Seven of the databases yielding relevant results provided the option of sorting these results in order of relevancy. Table 3 details the number of relevant articles found in the first 25%, 50% and 75% of results retrieved by each of these databases when this function was applied. None of these

databases retrieved all of their relevant articles within the first 25% of results when sorted by relevancy. Google Scholar (300) retrieved a markedly higher proportion of relevant articles in the top 25% of results than any of the other databases (70%). ASSIA was the only database where all of the relevant articles sourced were found in the top 50% of results when sorted by relevancy while Social Services Abstracts and Social Sciences Citation Index retrieved all of their relevant papers within the top 75% of results.

**Table 3.** Results sorted by database relevancy function.

Database	Total no of articles retrieved by database	Total no of relevant articles by database	No and % of articles in top 25% of results when sorted by relevancy	No and % of articles in top 50% of results when sorted by relevancy	No and % of articles in top 75% of results when sorted by relevancy
ASSIA	26	5	1 (20%)	5 (100%)	5 (100%)
CINAHL	455	17	3 (18%)	11 (65%)	13 (76%)
Google Scholar (300)*	300	10	7 (70%)	8 (80%)	8 (80%)
Scopus	450	6	2 (33%)	5 (83%)	5 (83%)
SCO	29	6	2 (33%)	4 (67%)	5 (83%)
SSA	8	2	1 (50%)	1 (50%)	2 (100%)
SSCI	207	9	4 (44%)	5 (56%)	9 (100%)

\* Results for first 300 articles retrieved by Google Scholar when sorted by relevancy

Neither Medline nor PsycINFO provided an option to sort by relevancy, and are therefore excluded from Table 3. Campbell Library, Cochrane Library and Communication Abstracts by EBSCO did provide the option of sorting by relevancy; however none of these databases yielded any results meeting inclusion criteria for the review in any case.

## **ii. Findings: Literature appraisal and synthesis** (based on: Stevenson, McDowell et al., in press)

This synthesis incorporated 25 papers not included in either of the previous reviews and analyses perceptions and constructions of risk, as well as approaches towards risk, with a focus on how these concepts may inform understanding of risk communication. The authors also set out to retrieve papers with a specific emphasis on risk communication in dementia care, a theme that was not explored in these previous reviews. The aim is to synthesise findings of studies on risk concepts in dementia care (including differing perceptions and approaches) with a particular focus on the issues and challenges in risk communication. Data extracted included country and year of publication, participant information (including demographic information, if available) method of data collection, method of analysis, types of risks identified, risk or protective factors specified and themes relating to risk concepts or risk communication. Data is summarised in the table in Appendix One.

### *Risk concepts*

Findings were categorised according to four recurring themes in the literature: (1) *types of risk* identified, and whether these risks extended beyond concepts of physical safety risks to acknowledge also psychosocial risks; (2) *perceptions and constructions of risk* including social constructions of risk, perceptions of risk (and protective) factors, congruence of risk perceptions with reality and the concept of care crises in risk; (3) *approaches to dealing with risk* including acceptable risk taking and risk tolerance versus risk aversion; and (4) *decision making involving risk* by individuals with dementia that tended to focus on experimental studies analysing whether cognitive processes and emotional responses impaired decision making behaviour of participants with dementia, specifically in the domain of risk. Potential implications for the process of risk communication across these four themes are suggested.

### *Types of risks*

Developing an understanding of the matters that are frequently conceptualised as 'risky' for people living with dementia is important in order to identify the types of situations that will involve communications about risks. Although psychosocial risks (risks to mental and emotional wellbeing) were mentioned in several papers, the predominant focus of the majority of papers was on physical safety risks (potential for accident or injury). Importantly, the concept of what constituted a risk varied across study groups. Themes that were referred to as risks or safety issues in the primary research element of the papers are included in [Appendix 1](#).

The most prominent risks identified in the literature could be categorised as risks to physical safety such as falls or medications management. Psychosocial risks were recognised in several papers in relation to themes including depression, family life, independence, institutionalisation, loneliness, personhood and self-esteem. Notably these psychosocial themes were referenced in five of the papers gathering data on individuals with dementia, two gathering data on family carers and two of the papers gathering data on professionals.

Consistent with the findings from previous reviews (Thom & Blair, 1998; Bailey et al., 2013), several of the papers drew attention to how groups conceptualised risk in different ways with respect to the situations or behaviours they perceived as risky. Gilmour, Gibson, and Campbell (2003) found that different professional groups tended to emphasise different risks with social workers most likely to identify risks similar to those of concern to family members. Robinson et al. (2007) discussed the concept of plural constructions of risk where the same risk, for example wandering, was conceptualised and managed in different ways. In some instances the activity was perceived as risky with an emphasis on prevention of harm while an activity might also be conceptualised as positive with respect to the benefits to health and wellbeing. Variability in the construction of risk from the perspective of people with dementia, caregivers and professionals was also reported in papers by Clarke (2000) and Clarke et al. (2009; 2010; 2011b).

### *Perceptions and constructions of risks*

Risk communication involves seeking a shared understanding of different perspectives of risk. Accordingly, how risks are perceived will undoubtedly affect attitudes and approaches towards these risks. When it came to how groups perceived and constructed risk, three main aspects were discussed. The section begins by first analysing social constructions of risk and by distinguishing risk factors that were identified in the literature as those interpreted to stem from the individual's dementia and those formed within the environment. The paper then looks at whether perceptions of risk factors are congruent with actual outcomes and whether there is a tendency to over or underestimate the risks perceived by different groups. Finally the concept of crises in risk is examined, as often approaches to risk are formed and decisions are made during this stage.

*Social construction of risk.* Concepts of risk were interpreted in several papers as being socially constructed via a variety of influences. In particular, a distinction was observed between perceptions of risk factors that could be interpreted as rooted within the individual's dementia experience and those that could be categorised as deriving from the environment. Social constructions of risk were influenced by:

- a) acquired knowledge, with professionals more likely to assess and manage risk based on their medical knowledge and prior experience in their field whereas family carers were influenced by their knowledge of the person (Clarke, 2000);
- b) discursive processes between professionals and family carers where risks were jointly constructed, assessed and managed through conversational exchanges (Adams, 2001);
- c) stereotyped or gendered constructions of risk behaviours held by professionals included the idea of males presenting as more aggressive in contrast to the “sweet old lady” with dementia (Beattie, Daker-White, Gilliard, & Means, 2005); and
- d) the construction of meaning within the social context of everyday experiences of people with dementia, including the benefits of various social behaviours or activities that justified engagement in potentially ‘risky’ activities (Clarke et al., 2010).

Stakeholders perceived various factors as increasing the likelihood of outcomes relating to either physical safety or psychosocial risks (Table 4; column five). Several of these risk factors could be conceptualised as stemming from the individual’s dementia, for example changing abilities, difficulty with recall and lack of insight or judgement (Bond, Corner, Lilley, & Ellwood, 2002; Clarke et al., 2009; Cott & Tierney, 2013; Johansson, Bachrach-Lindström, Struksnes, & Hedelin, 2009; Oyeboode, Bradley, & Allen, 2013; Sandberg, Rosenberg, Sandman, & Borell, 2015; Watts, Cassel, & Howell, 1989; Waugh, 2009). Alternatively risks were also perceived as relating to external risk or protective factors that could be located outside of the individual including the environmental (both hazards and supports), risks from strangers, levels of support (both formal and informal), caregiver skills and knowledge of dementia and safety matters, levels of supervision (including informal community surveillance), history of safety incidents and risks from society and systems (Buri & Dawson, 2000; Cott & Tierney, 2013; Gilmour et al., 2003; Harris, 2006; Horvath et al., 2005; Johansson et al., 2009; Lach, 1995; Morgan, 2009; Robinson et al., 2007; Sandberg et al., 2015; Tsunaka & Chung, 2012; Walker, Livingston, Cooper, Katona, & Kitchen, 2006; Watts, Cassel, & Howell, 1989; Waugh, 2009). Risks were also associated with continued engagement in everyday home or leisure activities for example running, socialising or domestic tasks (Bond et al., 2012; Clarke et al., 2009 & 2010; Tsunaka & Chung, 2012).

*Congruence of risk perceptions and reality.* Acknowledging the congruence between perceptions of risk and actual outcomes can have important implications for approaches to dealing with and communicating about risk. Overestimating risks may result in unnecessarily risk averse approaches while underestimations may result in individuals being placed at increased harm. Awareness of misperceptions is important to support communications that address these possible misinterpretations. A number of quantitative papers suggested that the congruence between judgements made by caregivers and professionals as to factors presumed to increase risk for people with dementia were not always significantly related to risk outcomes when measured. Further, people with dementia may even overestimate typical non-threatening situations. Accordingly, clarifying what an individual perceives to be a risk and determining how risky different behaviours actually are is important for the risk communication process.

A small number of quantitative studies examined associations between perceived risk factors and specific, measurable risk outcomes. Lach, Reed, Smith, and Carr (1995) explored caregiver safety concerns in relation to dementia severity and found that stage of dementia (categorised as either questionable/mild or moderate/severe) was not significantly associated with engagement in unsafe behaviours or number of reported accidents. Rather, unsafe behaviour was related to having had an accident in the previous year and further, none of these accidents resulted in more than minor injury or substantial damage to property, implying that these accidents were not serious. The study reported that carers were more likely to apply safety precautions for care recipients in the moderate to severe group which indicates greater levels of concern when caring for a person with more advanced dementia. However these preventative measures themselves may have led to reduction in risky behaviours and accidents, therefore acting as a moderating factor. Similarly to some of the findings above, in a qualitative study Gilmour et al. (2003) reported that no caregivers, professionals or people with dementia reported any major incidents of harm in respect to a group of ten people with dementia living alone. Notably these individuals were all known to services (nine received care packages) and had daily contact from either family, care

staff or neighbours. Another study measuring caregiver perception of risk, (Walker et al., 2006) found that family carers generally perceived it to be unsafe to leave a person with dementia (whether mild, moderate or severe) alone and 68.5% of these caregivers reported at least one incident that had considerably compromised the safety of their care recipient in the previous year. Findings showed that the greater the frequency of risk incidents, the greater the worry about leaving the care recipient alone. No significant relationship was however found between the number of hours the caregiver thought the care recipient should be left alone (a measure of perceived risk) and the number of incidents that had compromised the care recipient's safety over the previous year. Tuokko, MacCourt, and Heath (1999) in a study involving review of client records, found that while individuals living alone in the community were regarded by clinicians as being at increased risk in relation to some hazards in the home (nutrition, medication management, hygiene, fire and falls), they did not die earlier and were not placed within care facilities sooner than those living with a spouse. The findings suggest that these service users were not at markedly greater risk in the community. However, the authors did note that the sample involved only those who were accessing services and that the study did not report other outcomes including hospitalization or financial abuse from records. Together, these findings suggest that perceptions of risk factors by carers and professionals do not always correspond with actual quantified risks of adverse outcomes in the ways expected.

Perceptions of risk were in one study found to differ between individuals with varying stages of cognitive impairment and their peers without dementia. Henry et al. (2009) compared perceptions of threat by individuals with Mild Cognitive Impairment (MCI) and early stage dementia to age matched controls. Participants provided danger ratings for faces or situations considered to present low or high threat. Although all participants were able to differentiate appropriately between high and low threat facial expressions, people with dementia attributed greater levels of danger to typically non-threatening situations. The authors argue that for individuals with dementia such judgements may be rational given that low danger situations may present greater risk to these individuals than to the general population, and underestimating high threat situations would be of greater concern. Further, the results suggest that these differences were related to declines in cognitive functioning.

*Care crises and risk.* Communications and decisions about risks often take place during times of crisis. Risk was in some cases experienced as a critical life stage or event requiring a decision by carers. These decisions involved judgements regarding the tolerability of specific (and cumulative) risks and application of strategies to help balance the risks. Both cognitive and environmental changes were found to signal crises to carers. The concept of 'crisis' in risk was a distinct element in four of the papers reviewed (Buri & Dawson, 2000; Cott & Tierney, 2013; Ledgerd et al., 2015; Waugh, 2009). Buri and Dawson (2000) in their study on coping with falls risk refer to the idea of carers treading a precarious line between order and chaos while making attempts to either maintain or recreate order in their family life by applying various strategies to reduce the risk. Waugh (2009) refers to the idea of 'critical times' as identified by community care practitioners as placing the individual who lived alone as more at risk including decline in physical health and functional skills, withdrawal of support and diminishing community tolerance. It was recognised that the interaction between multiple crises often resulted in the individual being assessed as unsafe to live at home. This idea of cumulative risk factors is referenced also in the paper by Cott and Tierney (2013) who use a model of 'red flags' signalling behaviours or changes in behaviour that led relatives to question whether the risks could still be deemed as acceptable. The accumulation of 'red flags' led to levels of risk being viewed as unacceptable although they were previously tolerated. The application of risk-balancing strategies was in some instances found to return the level of risk to a level that was considered tolerable by carers.

Consistent with findings of different perceptions of risk between groups, a survey involving ranking of main precipitators of crises and of interventions to both prevent and manage crises, found that consumers (defined as people with dementia, family carers and voluntary agencies) differed from health and social care staff in their ratings of relevant risk factors in *some* domains. For example, physical and verbal aggression were rated as lesser risk factors by consumers than by professionals. However, there was also evidence of consistency of ranking in some areas,

certain risk factors including wandering, falls, infection and family carer burden were rated highly across all groups. Notably practitioners categorised as either physical or mental health were also found to differ from each other in their responses, demonstrating how different professional groups may interpret risks and crises in different ways.

#### *Approaches to dealing with risk*

A primary aim of risk communication is to reach a shared understanding of different ideas on how risks should be approached. There were no papers examining the role of risk communication in this process. However, a number of studies examined prevalent approaches toward dealing with risk that allow for insights into how different groups deal with risk and variations in preferred approaches.

*Acceptable and reasonable risk taking.* A small number of papers found that carer's concepts of acceptable or reasonable risk differed between carers and professionals. Different thresholds of acceptability were underpinned by different responsibilities; for example, professionals were bound by legal aspects of their roles, such as duty to protect from harm. Personal values such as the importance of maintaining quality of life also affected subjective judgements of acceptability. The concept of acceptable or reasonable risk was explicitly referred to in three papers (Clarke et al., 2009; Cott & Tierney, 2013; Robinson et al., 2007). Robinson et al. (2007) describe how concepts differed between family carers and professionals. Risks that were considered acceptable and tolerable to family members (e.g., wandering behaviour) were often unacceptable and potentially hazardous to professionals. The authors explain how these contrasting approaches stemmed from different perspectives and influences with professional approaches underpinned by fear of litigation while familial carers focused on quality of life for their family member. It should be noted that only three carers were involved in this study and ten professionals. Notably, individuals with mild dementia participating in this study did not refer to risks associated with wandering at all. In contrast, Clarke et al. (2009) in a survey of 46 professionals, found that participants believed family carers were more reluctant to accept *any* risk compared to professionals and that concepts of risk taking were closely associated with the need to maintain quality of life. Clarke et al. also acknowledged the dilemma in judging the threshold for when a particular risk reached an unacceptable level. Cott and Tierney (2013) found that concepts of acceptable risk held by 20 family carers were not static but were constantly being redefined in response to factors such as changes in abilities or behaviours. Further, familial carers defined the most unacceptable risks as risks to psychosocial wellbeing including loss of independence, reduced self-esteem and institutionalisation.

*Risk-tolerance, risk-aversion and risk-balancing.* There was some difference in approach to risk between the three core groups. People with dementia tended to be aware of risks but willing to tolerate them, although in some cases, apprehensions about risks led to these individuals avoiding certain situations. Professionals and family carers experienced challenges in respecting rights and needs while avoiding harm. Professionals tended to be slightly more risk-averse than family carers or people with dementia. Where evident, these protectionist approaches were grounded primarily in legal duties and fear of litigation, responsibilities that do not generally apply to service users.

Robinson et al. (2007) found that, in the context of a litigious society, fear of legal action among health professionals and nursing home staff, fostered approaches that minimized harm but were sometimes at odds with the rights of the person. Similarly, Clarke et al. (2011b) reported how fear of injury and consequent complaints or legal action led to risk-averse approaches in professional care. That is, risk-averse (or tolerant) approaches were steered by public and organisational culture and by personal attitudes to risk. Approaches were also influenced by legal frameworks when applicable. McDonald (2010) examined decision making of social workers in cases relating to entry to residential care following the recent implementation of the Mental Capacity Act (2005) in England and Wales (relating to decision making in the event of lack of capacity). It was found that 'risk-based' actuarial and legalistic approaches dominated practice in these cases compared to rights-based approaches. In particular, professionals experienced a

dilemma in relation to decisions they felt they *should* make and the practical decisions they actually *made*.

In general, professionals sought to balance rights against risks rather than avoiding risks (Clarke et al., 2009; Clarke et al., 2011b; Cott & Tierney, 2013; Johansson et al., 2009; Robinson et al., 2007; Waugh, 2009), a primary issue for both formal and informal dementia care. Rights of the individual included: civil liberties, societal rights, person centred care and personhood (Robinson et al., 2007); freedom of choice, maintenance of independence, quality of life and rights (Clarke et al., 2009); integrity and autonomy (Johansson et al., 2009); and independence and self-esteem (Cott & Tierney, 2013). These rights were weighted against factors including risks, potential harm and physical injuries (Robinson et al., 2007; Johansson et al., 2009; Waugh, 2009; Cott & Tierney, 2013). The act of balancing rights and risks was recognised as often presenting an ethical dilemma for professionals who aim to preserve autonomy while providing appropriate care (Johansson et al., 2009; Watts et al., 1989), creating tension for staff (Waugh, 2009) and leading staff to believe they sometimes failed to provide person centred care (Robinson et al., 2007). Additional challenges for balancing rights and risks occurred when professionals and family carers ascribed different weightings to risk (Clarke et al., 2009; Waugh 2009) and when tipping factors differed between professionals and family carers (Robinson et al., 2007). Watts et al. (1989) in a study involving the case of a widower with dementia living alone who had caused a fire in his home, concluded that health professionals should be sensitive to the needs and wishes of people with dementia and make efforts to preserve the autonomy of the individual. In this regard, professionals and carers who prioritise the needs of the individual tend to adopt risk-balancing approaches (Clarke et al., 2011b). The practice of balancing risks aligns with risk-tolerant as opposed to risk-averse approaches in professional dementia care.

In contrast to professionals, family carers were generally found to be more tolerant of risks. However, perspectives differed according to whose perspective was being sought: Clarke et al. (2009) reported that professionals described carers as being more risk-averse and protectionist than were professionals. Carers were perceived to more tolerant as a result of more detailed knowledge of the individual in contrast to the medical knowledge and field experience relied on by professionals. Clarke (2000) proposed that this prior personal knowledge meant that family caregivers were willing to tolerate behaviours and activities that they perceived to be 'normal' for the individual. Gilmour et al. (2003) even found that local knowledge of the individual with dementia in a small rural community served as a protective factor by providing informal surveillance and in some instances enabling individuals to continue behaviours that may have been viewed as problematic in other settings. When purely medical models were referenced in the literature, these were viewed as facilitating more risk-averse approaches. In one case described by Bond et al. (2002), concerns from both the spousal carer and professionals relating to lack of insight of the individual, resulted in the individual being restricted from running, a previously enjoyed and meaningful activity.

Individuals with dementia included in the studies reviewed tended to hold more risk-tolerant attitudes, supporting the idea that they should be permitted to take risks. However, risk avoidant behaviours were also evident in the literature, based on apprehensions relating to personal safety. Considered, balanced approaches to risk were apparent in some cases. Harris (2006) concluded that individuals with dementia were not only aware of the risks they faced in daily life but were willing to tolerate these risks. Rather, these 15 individuals (with early stage dementia or mild cognitive impairment) were more concerned with issues such as maintaining independence and being involved in decision making rather than focusing on the risks they encountered. Similarly 14 younger people with dementia participating in one study prioritised independence over risk and danger focused on by professionals (Beattie, Daker-White, Gilliard, & Means, 2004). A personal narrative written from the perspective of an individual with dementia (Morgan, 2009) acknowledged that people with dementia are surrounded by risk from the point of diagnosis but reflected that they should be supported to take risks in order to live a full life. Clarke et al. (2010), drawing on the experiences of four individuals with mild or moderate dementia, found that personal and beneficial experiences, such as purpose and maintaining a level of autonomy over decisions, justified engagement in activities that could otherwise be perceived as risky. Alternatively, in some instances people with dementia withdrew from social activities as they felt safer at home (Harris,

2006) and reported feeling “vulnerable” when going out alone (Clarke et al., 2010). Apprehensions regarding their safety therefore led to risk avoidant behaviours in some instances. A recent study by Sandberg et al. (2015) involving interviews with 12 individuals with mild to moderate dementia, found that experiences of risk as both unfamiliar and confusing (along with associated feelings of being out of control and worry), led to more effortful and careful approaches to risk in daily situations. Participants took active measures to deal with risks including making notes of when medications were taken, checking calculations several times, taking breaks or accepting assistance. These individuals reported weighing up potential benefits against negative consequences of taking risks. In some instances decisions were made not to expose selves to risk situations. Importantly participants recognised that in avoiding particular risks, they may be exposing themselves to other undesirable outcomes such as missing out on something they wanted to do.

#### *Decision making involving risk information*

Risk communication is integral to the process of informed decision making in health and social care. Understanding how individuals with dementia make decisions using risk information, as well as identifying challenges in this domain, is essential if effective modes of risk communication are to be developed. A small number of quantitative papers on decision making about risks in dementia suggest that people with dementia may appraise risk information differently from their peers without cognitive impairment. All of these studies involved computerised experiments in laboratory settings and therefore results may not generalise to judgements about actual physical safety or psychosocial risks in everyday life. However, these studies can provide insights into the potential impacts of cognitive decline on how people with dementia appraise risks.

Delazer, Sinz, Zamarian, and Benke (2007) found that participants with mild Dementia of Alzheimer’s Type (DAT) shifted more frequently between safe and risky alternatives and demonstrated less consistent response patterns than controls in a gambling task that examined risk estimations. The authors concluded that such responses indicated random decision making rather than the application of learning acquired through the task to establish an advantageous strategy. However, rather than making risky and impulsive choices, DAT participants and controls chose the most conservative response equally often, suggesting that participants did not make choices based on a lack of emotional control. Two related studies found that participants with mild DAT (Sinz, Zamarian, Benke, Wenning, & Delazer, 2008) and participants with Parkinson’s Disease Dementia (Delazer et al., 2009) tended to gamble more frequently in low winning probability conditions, indicative of more risky behaviour than controls. Sinz et al. also found that DAT participants gambled less frequently under high winning conditions than controls. Associations were found between less advantageous decision making and measures of cognitive functioning. Predecisional information sampling (PIS) was also found to be affected in a group of participants with mild DAT (Zamarian, Benke, Brand, Djamshidian, & Delazer, 2015). PIS refers to the process of gathering and evaluating information prior to making a decision. The study found that the participants with mild DAT gathered significantly less information than controls in the Information Sampling Task experiment, tolerated significantly higher degrees of uncertainty and were less sensitive to reward characteristics of the task.

Alternatively, Ha et al. (2012) assessed framing effects on risk taking and risk aversion behaviours for people with Alzheimer’s disease (AD). The authors found that, contrary to the control group, AD participants chose more risky options under positive frames (rewards highlighted) compared to negative frames (punishments emphasised). Further, AD participants made more risky choices across both frames, indicating greater sensitivity to framing effects in decision making.

#### *Risk communication*

Despite an extensive and systematic search no papers were found with an explicit focus on risk communication in dementia care. Two papers were sourced following consultation with experts relating to comprehension of numerical health information by people with cognitive impairment (but not dementia). Delazer, Kemmler, and Benke (2013) and Pertl et al. (2014) demonstrated that participants with cognitive impairment (but no dementia) and those with mild cognitive impairment

differed from control groups in tasks involving numerical health information, such as converting percentages or understanding dosage instructions. Lower levels of cognitive functioning were found to be associated with low health numeracy in both studies. The absence of research papers on the topic of risk communication in dementia care establishes a clear gap in the research knowledge and need for studies in this domain.

iii. **Findings: Qualitative study of people with dementia** (based on: Stevenson, Savage et al., in press)

Socio-demographic data on respondents is summarised in Table 4. Seven participants completed the interview on their own while ten chose to have a family member present. Findings are reported under three thematic headings – *defining risk*, *constructing risk* and *risk communication in decision making processes*.

**Table 4:** Study respondent characteristics

<i>Gender</i>	Male (9), Female (8)
<i>Age group</i>	Under 65 yrs (3), 65-69 yrs (1), 70-74 yrs (2), 75-79 yrs (2), 80-84 yrs (1), Over 85 yrs (3), Not specified (5)
<i>Type of dementia</i>	Alzheimer's (8), Vascular Dementia (1), Dementia with Lewy Bodies (1), Not specified (7)
<i>Location</i>	Urban (8), Rural (9)
<i>Living arrangements</i>	Living alone (2), Supported living accommodation (4), Living with a relative (11)

*Defining risk*

Negative conceptualisations of risk were apparent. Risk was associated with danger and vulnerability for some participants and held emotional connotations for several for example feelings of fear, being scared or worried. However, often 'risk' was simply not a preoccupation of the persons interviewed:

'I don't really think about it (risk) at all.'

Importantly 'risk' was not a word used with regularity by participants. This implies that 'risk' is not a term that is dominant in the discourse of individuals with dementia.

Risk was not conceptualised as a frequency or probability of an outcome by participants. However concepts were not completely divorced from quantifiable aspects of risk such as magnitude or likelihood. For example, one individual inferred a tiered concept of risk by describing herself as not having a very high risk level while another participant described risk as 'taking a chance' implying an unknown possibility element of risk. Importantly this individual felt that it could be worthwhile to take such chances:

'If you don't take a chance you get nowhere.'

Notions of risks were often intertwined with safety and being careful. In this respect, risk was defined by its related concepts:

'It is really important that you can be independent but safe.'

Risk was in some cases described as an action for example going out alone or not switching off the oven hob. In other instances risk was viewed as a situation, for example a stranger coming to the door. Risks were also understood as consequences pertaining to both self and others.

'You are going to hurt somebody or do something that will hurt yourself.'

'It means to me risk about, about (my wife)... that I might harm her or something with the dementia.'

Table 5 outlines the different situations (including actions) that presented risks, perceived consequences (both anticipated or actualities) and responses to these situations, particularly regarding communicating risk and decisions made.

**Table 5.** Risks of concern and adaptive strategies.

Situation or action	Consequence – actually occurred* and anticipated would occur**	Decision about adaptive strategy	PIN
<i>Daily activities</i>			
Leaving the home (for example walking or going to the shops)	<ul style="list-style-type: none"> <li>• Getting lost*</li> <li>• Falling*</li> <li>• Becoming disorientated in a shopping centre or other public place*</li> <li>• Feeling scared/panic*</li> <li>• Going missing**</li> <li>• Having an incontinence accident – embarrassment*</li> </ul>	<ul style="list-style-type: none"> <li>• Carry a mobile phone (including a mobile with an emergency call button)</li> <li>• Wear a tracking device</li> <li>• Go out with others e.g. when walking or socialising</li> <li>• Only walk where known by other people</li> <li>• Walk on familiar routes</li> <li>• Ask passers-by for directions</li> <li>• Take the dog when walking – dog familiar with route</li> <li>• Become more careful</li> <li>• Carry a change of incontinence pads</li> </ul>	B1, B3, N1, N2, SE1, SE2, SE4, SE5, S1, S2, W1, W2, N3
Using the oven/cooking	<ul style="list-style-type: none"> <li>• Burning food and utensils*</li> <li>• Causing a fire**</li> <li>• Becoming frustrated*</li> <li>• Setting off smoke alarm in residential building**</li> <li>• Not being permitted to assist staff with cooking tasks in supported living facility – missing out on something they enjoyed*</li> </ul>	<ul style="list-style-type: none"> <li>• Check the oven/hob more often</li> <li>• Ask another person in the house to also keep check of the oven/hob</li> <li>• Stop using oven/hob</li> <li>• Family prepare meals for them</li> <li>• Become more careful</li> <li>• Raise concerns with social worker/staff</li> </ul>	B1, N1, SE5, W1, N3, B5
Lighting the fire	<ul style="list-style-type: none"> <li>• Burning the carpet**</li> <li>• Causing a house fire**</li> </ul>	<ul style="list-style-type: none"> <li>• Stop lighting fire</li> </ul>	SE5
Lighting religious candles	<ul style="list-style-type: none"> <li>• Setting off smoke alarm in residential building**</li> </ul>	<ul style="list-style-type: none"> <li>• Stop lighting candles</li> </ul>	B1
Driving	<ul style="list-style-type: none"> <li>• Harming someone else**</li> <li>• Causing a fatality**</li> <li>• Having a minor accident*</li> <li>• Would be blamed if involved in an accident**</li> <li>• Not being adequately covered by insurance**</li> <li>• Getting annoyed with other drivers*</li> <li>• Feeling increasingly nervous*</li> <li>• Getting lost*</li> </ul>	<ul style="list-style-type: none"> <li>• Give up gradually e.g. night driving first</li> <li>• Drive only in local, familiar areas</li> <li>• Give up completely                             <ul style="list-style-type: none"> <li>– Decision made for them – GP, DVLA, family carer</li> <li>– Decided by self to stop driving</li> </ul> </li> </ul>	B1, N2, SE2, SE3, SE4, SE5, S1, S2, W1, W2
<i>Hobbies, occupation &amp;</i>			

<i>socialising</i>			
Activities/hobbies including gardening and woodwork	<ul style="list-style-type: none"> <li>• Falling off ladder*</li> <li>• Falling over*</li> <li>• Injury from using electrical equipment (woodwork)**</li> <li>• Injury from heavy lifting**</li> </ul>	<ul style="list-style-type: none"> <li>• Continue with hobby/gardening</li> <li>• Stop hobby – no longer able to drive to location of hobby</li> <li>• Become more cautious/careful</li> <li>• Have someone around if using ladders</li> </ul>	S1, N2, S2, W1
Going out for a drink	<ul style="list-style-type: none"> <li>• Worried might forget to take medications after drinking**</li> <li>• Drinking too much – incident where ended up in hospital after a binge*</li> </ul>	<ul style="list-style-type: none"> <li>• Continue to go out once a week for a couple of pints with friends</li> <li>• Drink in moderation</li> </ul>	B1, W2
Going on a holiday	<ul style="list-style-type: none"> <li>• Fear of flying*</li> <li>• Being in an unfamiliar environment*</li> <li>• Navigating the airport*</li> </ul>	<ul style="list-style-type: none"> <li>• Take the risk (flying) to visit family</li> <li>• Support from family with orientation e.g. when going for a walk</li> </ul>	B2, N1, S1
Giving up an occupation/paid employment	<ul style="list-style-type: none"> <li>• Loss of confidence*</li> <li>• Felt no longer safe*</li> <li>• Financial worries*</li> </ul>	<ul style="list-style-type: none"> <li>• Give up occupation</li> </ul>	W1, W2, S1
<i>Risks to others</i>			
Looking after grandchildren	<ul style="list-style-type: none"> <li>• Worrying about their road safety – running across the road or running off**</li> </ul>	<ul style="list-style-type: none"> <li>• Keep looking after grandchildren alone</li> <li>• Stop looking after grandchildren alone</li> <li>• Ensure someone else is around when looking after grandchildren</li> </ul>	B2, N1, SE3, W2
Risks to others (public)	<ul style="list-style-type: none"> <li>• Felt others might be afraid of her**</li> <li>•</li> </ul>	<ul style="list-style-type: none"> <li>• Continue to go out</li> </ul>	B3
Fear of what might happen in the future	<ul style="list-style-type: none"> <li>• Fear of becoming violent towards wife in the future – saw this depicted on TV**</li> </ul>	<ul style="list-style-type: none"> <li>• Statement of wishes - asked wife to put him into a care home if ever becomes violent</li> </ul>	W1
Concern for wife	<ul style="list-style-type: none"> <li>• Wife needing a break*</li> </ul>	<ul style="list-style-type: none"> <li>• Volunteered to enter respite care</li> <li>• Accept care worker in the home</li> </ul>	W1
Nightmares	<ul style="list-style-type: none"> <li>• Hitting out in sleep*</li> </ul>	<ul style="list-style-type: none"> <li>• Place pillow between self and spouse in bed as a buffer</li> </ul>	W1
<i>Risks from others</i>			
Strangers	<ul style="list-style-type: none"> <li>• Feeling frightened and vulnerable when a stranger came to the door*</li> <li>• Fear of strangers dating back to an incident from</li> </ul>	<ul style="list-style-type: none"> <li>• Decide to move to supported living</li> <li>• Did not think an incident was likely to happen – not a concern</li> <li>• Not answering the telephone</li> </ul>	B4, SE1, N1, B2

	<p>childhood*</p> <ul style="list-style-type: none"> <li>• Answering phone calls (cold callers)</li> </ul>		
Attending a day centre where other residents are at a more advanced stage	<ul style="list-style-type: none"> <li>• Concerned that being around people at a more advanced stage of dementia would make them progress more quickly</li> </ul>	<ul style="list-style-type: none"> <li>• Talk to social worker</li> </ul>	B1, SE2
<i>Medications and mental health</i>			
Medication side effects	<ul style="list-style-type: none"> <li>• Experienced some unpleasant side effects*</li> <li>• Thinking that medication is not effective*</li> </ul>	<ul style="list-style-type: none"> <li>• Talk openly to GP</li> <li>• Ask questions</li> <li>• Read up on side effects</li> </ul>	B1, N3
Independently administering own medications	<ul style="list-style-type: none"> <li>• Associated being medicated by others with ending up in a care home**</li> </ul>	<ul style="list-style-type: none"> <li>• Manage own medications using checklists and some supervision from family</li> </ul>	B1
Feeling suicidal	<ul style="list-style-type: none"> <li>• Risk of suicide**</li> </ul>	<ul style="list-style-type: none"> <li>• Talk openly to SW and GP</li> <li>• Contact telephone counselling lines</li> </ul>	B1

Risks situations referenced most frequently included *going out alone* (with associated consequences including falls, getting lost and panic), *driving* (being involved in an accident or harming others) and risks relating to *causing a fire* including using the oven, lighting the fire and lighting candles. Risks relating to *hobbies and occupations* for example social drinking, gardening, woodwork and former employment were also repeatedly mentioned. Clearly participants were experiencing a broad range of risks in daily life, around which they would make decisions.

### *Constructing risk*

Construction of risk was an ongoing process informed by life history, media representations of dementia, psychological processes (including personality and emotions) and continually shaped by experiences and situations encountered.

Life history, more specifically previous occupation, appeared to shape conceptualisations for some participants. For example, an individual who worked in the shipyards associated risk with health and safety; a former police officer held notions of risk connected to national security; while a retired probation officer referred to terms associated with risk assessment processes for example levels of risk and reducing risk. Previous occupation in these cases ultimately formed the context within which risk was now perceived:

‘I would never have thought about risk, maybe it’s because of the way I worked.’

Constructions were also formed through experiences and emotional responses to such. In particular incidents that had caused considerable anxiety or panic such as getting lost; falling; experiencing a health scare (resulting in a visit to accident & emergency services) following an all-day drinking session; almost causing a road traffic accident; and a stranger coming to the door appeared to be more salient. In other cases risks represented fears or worries about what might happen. Table 6 categorises consequences as either anticipated or actual. Notably outcomes that might be considered most severe including going missing, causing a fire, causing a fatality on the roads, becoming violent or being injured fell into the latter (anticipated but not experienced) category.

Media representations were particularly influential for one individual with respect to the risks that caused concern, what he anticipated might happen in the future and consequent decisions made. This individual feared that he may become violent towards his wife in the future: ‘because I [had] seen it on the TV with people with dementia’, leading to the decision that if such ever happened he would like to be placed within a care home. The same individual also decided to wear an electronic

tracking device when out walking, a decision partly influenced by a news report of a local man with dementia who had gone missing when out walking.

Finally psychological aspects of self, including personality and emotions, were found to shape attitudes towards risk. Attitudes to risk in some cases simply reflected the nature or personality of participants. For example, one individual reported that she was 'naturally not a worrier' and 'had always been careful'. Another participant similarly reported 'my attitude was always to be careful.' Constructs of risk were also often interconnected with emotions such as fear or worry, as previously described. Concepts of risk were essentially constructed within a unique context for each participant.

#### *Risk communication in decision making processes*

Individuals with dementia were making decisions involving risks across a wide range of domains from decisions relating to everyday activities to those concerning their health or social care. Decisions concerned whether to go out walking alone; managing medications independently; driving; using a cooker; looking after grandchildren alone; keeping up a hobby such as gardening or woodwork; attending a day centre; going into respite care; moving to a supported living facility; using an electronic tracker; travelling when afraid of flying; and alcohol intake. Such choices were rarely made in isolation. Participants reported discussing these issues with family members and a range of professionals including General Practitioners (GPs), Social Workers, Occupational Therapists, Physiotherapists, Community Pharmacists and voluntary agencies.

Risk communication involved discussion of concerns and wishes and was, in some cases, formative in decision making processes. Both active and passive models of decision making were evident. In active models the person with dementia was meaningfully involved in the decision making process, often initiating communications. In passive models, communications were initiated by professionals or family members and decision making essentially involved following the advice or wishes of the other individual rather than being actively included in the decision. Both acceptance and dissent were apparent in models. These different modes of decision making were illustrated in communications around driving, medications, social care and general everyday decisions.

*Driving.* Decision making around driving tended to be emotionally laden, and was in some cases a longer-term process involving shock, anger, deliberation and acceptance. Some participants reported voluntarily giving up driving for considered reasons including reduced confidence, fear, experience of minor road incidents or 'near misses', for insurance purposes or due to the possibility of harming others. Others choose to modify their driving habits for example driving in local areas only or gradually giving up this task, for example cessation of night time driving. One participant reported directly informing her GP of her own decision to stop driving. While the GP advised her that she did not have to give up driving at that particular stage, he did inform her that eventually she would need to do so and that if concerned about the issue, this decision was for the best.

'I decided that the best thing to do was to get rid of the car and then I wouldn't be tempted to be driving all the time...then if this got worse I wouldn't have an accident and hurt somebody else.'

The same individual advised that if she had been told to give up driving 'I might have felt it was maybe a bit heavy handed.' In other cases individuals described being told that they could no longer drive either by a medical practitioner, family member or via a letter from the driver and vehicle licencing agency. Mixed responses were apparent with evidence of both agreement and dissent. Several participants vividly recalled the shock or anger at being informed they would need to complete a driving test in order to continue driving.

'It was like a bombshell...terrible at the time.'

'I think they done the right thing in taking the licence off me, although I was angry at the time.'

Another lady reported being very upset at having her licence suspended by the police service. Acceptance was for these individuals a gradual, adaptive process. All three participants ultimately decided not to apply to have their licences renewed (which would have involved completing and passing a driving examination). For one individual, this was following a frank discussion with his

daughter where she had asked her father how he would feel if he caused an accident resulting in a fatality. Rather than expecting an immediate response, she requested that her father take some time to think about the issue. Other participants appeared content to accept the wishes of a Doctor or carer that they should no longer drive. One individual reported accepting his Doctor's advice that he should no longer drive because the Doctor had thought about the issue and it made sense to him. Such implies an implicit trust in professional judgement. Another participant, while he felt confident that he could still drive, reported that he did not continue driving as this would upset his wife: 'I don't need to upset her [his wife] if I can help it.'

*Medications.* Similarly with medications, there was evidence of both active decision making and passive trust in medics and family members. One participant would actively discuss concerns about side effects of his medications with his GP or Social Worker. This individual also held firm views about his medicines including his wishes to manage his own medication (with use of checklists and a level of supervision from family) and decision to remain on medications taking into consideration adverse side effects experienced. Another participant reported that she would proactively ask her GP at appointments if she could be taken off any medications. This individual also reported taking the initiative of reading up on the side effects of any medications she was on: 'If I am put on something, I always look it up.'

Other persons reported that they were happy for family members to manage their medicines or were content to trust their GP's judgement.

'If [GP] thinks I need it, then I would need it.'

'If I am told to do anything, I will do it.'

When asked, participants would report that medications had been explained well to them. However, they did not elaborate on what information was provided or how this information had been shared. Insight into how options around medical care were presented and decision making facilitated, was therefore limited.

*Social care.* Risk communication in social care importantly involved the person with dementia expressing with professionals their concerns and wishes about risk. However there was also evidence of some participants feeling disempowered in such decisions. Decisions related to day-care, residential care, respite options and moving to supported housing schemes (i.e. independent living in sheltered accommodation, integrated with care and support services).

Communications in some cases involved the person with dementia sharing their perspective on risk with practitioners. Two younger participants with dementia (both under 65 years old) viewed attendance at day care as a risk to their wellbeing and choose not to access this service on the basis of this concern. It was perceived by these participants that other individuals at the group were at a more advanced stage and that this would subsequently lead to the individuals themselves progressing more quickly. Importantly their views were listened to and respected with the option of day care left open for the future.

'It [going to the daycentre] made me feel worse because most of the people [are at a] further stage on than I am and that to me [was] making me go quicker on.'

Decision making around risk also involved making wishes known for the future. One participant was adamant that if at any stage he became violent towards his wife that he wanted to be placed within a residential care home.

'That's my own decision... I have spoken to (wife) about it and told (wife)...She doesn't want me to go into a home.'

This same individual also actively approached his social worker requesting to enter into respite care in order to give his wife a break. Decisions made by this particular person were fundamentally driven by consideration of his wife's needs.

In relation to supported living facilities, different experiences of involvement and autonomy in decision making were apparent. One participant reported that while she had talked through her wishes to move to a supportive living facility with family and her GP, that the decision was ultimately her own. 'It would have been awful if they had said you are going and that's it.' The decision itself was made in response to a risk experience involving a stranger coming to her home and was motivated by a need to feel safe. The same individual made note that she had brought up

a family, had a brain and wanted to be respected for those things. Alternatively, another participant described herself as being 'forced' into supportive living, after a relative was no longer able to look after her. A further participant residing in supported living accommodation expressed upset that she was not permitted to assist staff with cooking in the facility, despite offering to do so. This particular participant viewed the 'attitudes' of others as a risk. On further discussion it emerged that the family had spoken to their social worker and the situation was at that time being reviewed within the setting. The participant who had made the decision to move to supported living was observed to be much more content in her environment than the participants who did not indicate such autonomy over that decision.

*Everyday decisions.* Everyday decision making often involved adapting to changing levels of risk experienced and choosing strategies and supports to manage these. There was recurrent evidence of participants becoming more careful as they adapted to risk in daily life. Individuals talked about being 'sensible', 'cautious' and 'careful', for example checking the cooker more often; walking in familiar areas where they were known; carrying a mobile phone when away from the home; using pedestrian crossings; or not using ladders unless someone else was about. Participants also often used aids and supports to enable them to continue with activities for example tracking devices, checklists for managing medications or mobility supports. Support from family and friends reduced worry around many of the risks that participants experienced, for example relating to sorting of medications, accompaniment to social activities or providing transport.

Time was critical to good communications and decision making. This included time to process information, make choices and adapt to changes.

'Sometimes it takes a while for it to sink in you know.'

'You see I am trying to make a decision but there's millions of things going through my head too.'

Continuation of actions or hobbies that involved risks, for example walking alone or using machinery, tended to be motivated by the well-being (benefit) gained from the activity. Several participants reported that going walking improved their mood ('makes me in good form'), stimulated the mind ('keeps my mind going') and improved clarity ('makes my head go clear'). Occupation was also viewed in itself as important ('I have to keep my mind active as much as I can').

#### **iv. Findings: Engagement of people with dementia in data analysis (based on: Stevenson & Taylor, in press, a)**

##### *Group interpretations and impact of user involvement*

Involving users with dementia in analysis impacted on the overall quality of the study by allowing for inclusion of multiple perspectives in interpretation of findings and generating new insights to be explored in further interviews. Importantly group comments assisted the research team in identifying information considered to be of practical significance to users, consequently producing ideas for lay dissemination. The analysis also allowed for important critical reflections on some of the challenges and good practice in such sessions.

A primary benefit of involving individuals with dementia in analysis was in enhancing the core research team's understanding of the data from a user perspective. Reflections of the group provided the research team with a richer understanding of the wider context within which risks are experienced by the person with dementia. For example individuals offered their own personal reflections on risk, including that: risk is individual and depends on the stage the person is at; risks are often of more concern to the family than the person with dementia; and distinguishing between the importance of making someone aware of risks and making them worry about risks. Interpretations of the group importantly allowed researchers to identify the conceptualisations of risk (developed through the primary study) that were most meaningful to this group of individuals.

Co-researchers were particularly interested in responses that resonated most with their own experiences, particularly that they did not usually think about risk in daily life. It was noted that individuals do not tend to think about risk until they are in a particular situation, linking back to the

definition of risk as situation. Relative to communication of risks, the group again connected these responses to their own experiences enabling the researchers to understand the significance and authenticity of these responses from the perspective of the person with dementia (Littlechild et al., 2015). For example the group did not feel that the trust apparent in the doctor-patient relationship, as evidenced in the transcripts was reflective of their own experiences. Co-researchers were able to advise that they tended to ask about side effects if and when they occurred rather than when first taking the medications. These experiences again enabled researchers to develop better insight into the context in which communications about risk were taking place. Concerning discussions around driving one of the SURP members was able to share that they had a similar experience to that reported in one of the participant transcripts. Such connections with the data naturally opened up discussions and fostered a more authentic discourse. Both male participants identified strongly with the 'shock' reported around being informed that they would need to take a driving test following their diagnosis. The group added their perceptions of the differences between communications with family members and those with professionals, primarily being that those with family were more personal and allowed for 'total honesty.'

The analysis in turn generated additional sub-topics for exploration in subsequent interviews, for example how it makes the person with dementia feel if they are not included in discussions about their medications. The session also importantly led to development of ideas for dissemination of findings. Members commented on what was 'good' and effective about styles of risk communication (i.e. making the individual think by presenting a scenario, rather than telling them what to do) which supported the research team in development of recommendations that would be of practical benefit when reporting and disseminating findings. The need for a list of useful questions to ask clinicians about medications was also raised providing further ideas for structure of dissemination materials. Finally some general advice on good practice for interviewing was suggested to researchers. The need to 'dig deeper' to find out what the risks are when interviewing a person with dementia was emphasised by one of the co-researchers.

### *Evaluation*

Importantly the impact of involvement for service users was reported to be positive. The session was evaluated used open ended questions in a paper format, enquiring what participants enjoyed most and least about the session and what they felt were the benefits in being involved as co-researchers in the exercise. Evaluations from the group were overwhelmingly positive with no negative comments proffered. However due to the lack of a systematic evaluation methodology, such reports should be viewed with caution. Specific benefits perceived by the group included 'meeting other people with dementia who still have their wits about them – dementia usually focuses on people who are in the later stages' and 'a chance to think about situations and hear from other's their thoughts.' Positive comments were made relating to the usefulness of the role-play exercises as an opportunity to 'actually think about a situation that happened to someone else.' These responses indicate that the individuals benefitted from taking part in an activity that required them to reason, use their cognitive abilities, meet with others of similar ability, and hear the opinions of other people with dementia. While evaluation forms were anonymous they were identifiable which may have impacted on responses. Factors such as politeness or wanting to please the researcher were also possible influences.

## **v. Findings: Qualitative study of family carers of a person with dementia (based on: Stevenson & Taylor, 2016)**

Sixteen female carers and six male carers took part. All were family members. Five of the participants were former carers and one provided care for two people with dementia. Former carers (who continued to attend Alzheimer's Society carer support groups) were included in the groups as their reflections and experiences were still seen as relevant and valid to the discussions. To exclude such carers from the focus groups may also have caused unnecessary distress. Sixteen were spousal carers while the remainder cared for a parent (or parents) with dementia. Breakdown of type of dementia of care recipient is as follows: Alzheimer's Disease (13), Vascular

Dementia (4), Dementia with Lewy Bodies (1), Frontotemporal Dementia (1), Early onset Alzheimer's (1) and Not Specified (2). Living arrangements of care recipient included those who resided with a carer (17), resident in nursing home (2), living alone (1), living with another person with dementia (1) and not specified (1). Age groups of carers ranged from 31 to 40 years up to 81 to 90 years. The modal age group was 71 to 80 years old.

The main themes emerging from the data related to: concepts of risk; perceived risk factors; approaches towards risk; discussion about risk with care recipients; and discussion about risk with care professionals. These are discussed in turn.

### *Concepts of risk*

Participants associated risk with negative terms such as danger, harm, vulnerability and accidents. When later probed in discussions on approaches towards risk several carers did agree that risk taking could also be beneficial, as discussed below. Their comments focused on consequences rather than probabilities of risk. Notably none of the participants made reference to the likelihood of the adverse outcomes they discussed.

'It's like everything's a risk, everything's a danger.' FG1

As anticipated, a broad range of risks were identified by family carers as causing concern in daily life. Risks specified included bathing accidents, burns, cooking accidents, driving, falls, financial mismanagement and mistreatment, getting lost, leaving the home unsupervised, losing mail, medications mismanagement, misuse of alcohol, night-waking, pedestrian road safety and misuse of electrical appliances (primarily relating to cooking). The risks most frequently reported as causing concern to family carers were driving, falls, financial risks, getting lost and using electrical appliances. Generally impact on psychological well-being was not described as a risk by participants. However, being treated as a child was identified as damaging by participants in one group with consequent harm to self-esteem and independence recognised. Carers were also concerned about risks to others from relatively minor issues like being locked out of the home or mail going missing to more concerning matters including risks to grandchildren when in care of the person with dementia and physical attacks on the carer.

'She left it (*her handbag*) in the restaurant, the café ... (*Grandson*) had realised that Nanny has no bag ... he ran back from the train station across the two main roads to go to the café to get her handbag.' FG1

'I was absolutely black and blue every day and cuts and everything because he wouldn't have known what his strength was ... but I'm so thankful for the way he is now ... whereas before he was so angry.' FG2

### *Perceived risk factors*

While carers were not specifically asked to identify factors viewed as increasing the likelihood of risk outcomes, causes were frequently referred to in discussions. Factors included those related to the dementia trajectory and environmental elements, both from the physical setting and other persons.

Progression and stage of dementia were perceived as influencing the degree of risk. In some cases, increasing levels of impairment were found to amplify potential for harm. In other instances this was reported to be an inverse relationship with certain risks viewed as being reduced as dementia progressed. Impaired judgement caused by dementia was regarded by some as a concern increasing vulnerability to harm. An association between mobility and risk was also referenced with declining mobility viewed as increasing the chance of falls. However one carer reported that her husband's lack of mobility removed the option of walking off and getting lost. The same impairment was therefore perceived by different participants as increasing some risks while reducing others.

'I don't have a problem now because he's not on his feet, but in the beginning now I would have worried about that as well, him wandering out onto the road.' FG3

Co-morbidity and aspects of general health were also thought to affect risks experienced. In one case, a carer described how her husband at times experienced light headedness and dizzy spells, leading to concerns that he would fall. It was later established in the group that this individual had a co-morbid diagnosis of diabetes. Another carer attributed her husband's disorientation to tiredness.

One carer suggested that risks were affected by gender elaborating that females may for example be more subject to risks associated with cooking. Following further discussion amongst the group it was concluded that personal history of the individual was the more influential factor. A participant described how her mother never particularly enjoyed cooking or driving therefore giving up these activities and consequently avoiding the risks involved was not an issue. Activities that continued to be enjoyed by individuals - such as gardening, walking, swimming, bowling, cooking, volunteering and driving - presented differing risks. Carers did not generally wish to restrict participation in these activities, with the exception of using electrical appliances for cooking and in some instances driving, as discussed below.

The physical setting, both within the home and out and about in the community were viewed as presenting risks, with falls on stairs, bathing facilities, carpets, electrical equipment, steps, curbs and manholes identified as potential hazards. Environmental hazards also incorporated threats from other people. Risks from third parties were stated on several occasions, specifically in relation to potential financial mistreatment. Such risks were reportedly experienced both in person and via telephone contact.

'I think there's a risk from third parties, people who aren't friends or family. These people who just think that it is ok to go up and rap on somebody's door to ask them for money or to ask them to sign things or to ask for access to the house.' FG4

'Somebody rang her and said she'd won a holiday and they needed her credit card details.' FG5

Essentially risk factors were contextual with elements including progression of dementia, environmental conditions and co-morbidities being identified as determinants of risks experienced.

#### *Approaches towards risk*

Generally family carers took measures to manage risks rather than trying to 'eliminate' them. Benefits of taking risks were recognised by some carers. Details of informal processes for dealing with risks emerged through the focus groups.

'I've always the belief, risk is not to be avoided. It is to be managed.' FG1

Participants often reported intervening to moderate the risks faced by the person they cared for and employed a range of strategies to reduce potential for harm. In some cases, carers took over activities such as driving and cooking with little reported resistance by the care recipient. In other instances it was felt necessary to block these activities completely for example by turning off cooking appliances at the mains. An alternative approach was to accompany the individual on an activity, for example walking or to arrange for another individual such as a volunteer to provide aide.

'I don't stop (*husband*) going for a walk, I now go with him.' FG3

'He would go out to volunteer...I just still let him do that, because there is another person with him.' FG2

Carers also described modification of the home environment as a means of risk reduction. In several cases, professionals and voluntary agencies provided support with assessment of hazards in the home and subsequent adaptations including implementation of rails, handles, raised toilet frames, hoists, ramps, stair lifts and bathing stools. In these cases, practical support from services enabled carers to manage risks in the home more effectively.

Carers found themselves becoming more vigilant to risks when out and about for instance looking out for manhole covers that were raised or increasing surveillance of the care recipient.

'I'm watching her all the time. I'm always watching to see where she is... if I'm at a till or something paying for something and I turn around and she's not within my eye shot, I'm panicking then.' FG5

One carer reported responding to risks as they materialised, for example removal of loose carpet following a fall in the home.

'You can't plan for it, it comes along and that's a risk ... you've been living as you say 40, 50 years together. Why would you think there is a risk of them walking out the door or putting a kettle on? You don't until it materialises.' FG2

When probed, several participants agreed that people with dementia should be permitted to take risks in some instances.

'Well I let him have a risk every day. I just think, ok, you know, he shouldn't be doing this, but I let him do it and if anything happens, the worst can happen is the police will bring him home or he is going to get hurt. Sometimes I just think, he has to be allowed to.' FG2

Participants recognised that taking risks could be worthwhile for the person with dementia for example going swimming, shopping, volunteering or flying abroad to visit relatives. Benefits such as getting out of the house, stimulation and enjoyment of the activity were noted.

'I think the worst thing is to wrap somebody in cotton wool ... I think they should be out doing whatever, anything. If you think it stimulates them in any way whatsoever I would do it.' FG4

One carer proposed that restricting freedom of the care recipient could create other problems and resistance.

'You've got to give them as much freedom as you can because if you don't you'll find a problem. They will rebel against it.' FG2

When questioned about risk taking that would be discouraged both cooking and going out alone were mentioned, although not in great depth.

The importance of supervision was frequently referred to in discussions. One carer specified that if her mother was with another person, then she was willing to tolerate her parent partaking in most activities. Mobile phones were also used as means of supervision by proxy. Several carers mentioned use of phones as a method of checking up on the care recipient when they were in the home alone. Mobiles were also used to assist tracking of the individual with dementia, for example if the person had gone out to run an errand. A problem with this approach was that care recipients may not answer the phone, or might have difficulty using it.

'The doctor told (*husband*) to have his mobile on every time he's out but sure every time I phone he never answers it. He either doesn't hear it or whatever.' FG3

'I got another mobile for him but he can't use it.' FG3

'The other thing I would worry about is, he forgets his phone all the time.' FG1

Enabling risk taking in some circumstances caused stress and worry for family carers, in particular in relation to driving. While participants did not prohibit their spouses from driving, they did often express concerns regarding this particular activity.

'He can't think ahead, that's an awful dangerous thing that he's driving.' FG1

'Scares the life out of you.' FG1

'He still drives up the road you know in around where he knows, but I'm a bit worried, I don't know whether he should or not.' FG2

Carers were also probed regarding approaches of the care recipient towards risk. Several attendants felt that the individual cared for lacked awareness of danger. In other cases, there was evidence of care recipients practicing increased caution in certain domains, for example by driving more slowly or appearing to be more nervous about falling. Such elevated levels of caution would imply some level of awareness of risks. People with dementia were in some cases described as content for the carer to take over activities such as driving and may even have voluntarily relinquished this task. In other instances individuals chose to complete mandatory assessments in order to continue driving and found suggestion that they should give up this action upsetting. Personal history was found to influence attitudes towards risk with one carer describing her husband as risk averse, but adding that he had always been so. There was no reference to any major dissent between carers and care recipients in their attitudes and approaches towards risk taking. However, there was also no meaningful reference to agreement in approaches.

Just as risk factors were contextual, risk modification strategies could also be perceived as dependent on context. As described above, elements such as support from external agencies and knowledge of the individual's history and interests were found to influence the strategies applied. In addition, risk taking or risk avoidant attitudes of carers could be conceived as a factor affecting approaches towards risk and therefore outcomes.

#### *Discussion of risks with care recipient*

Carers reported talking about various issues including driving, falls, money and walking risks with their family member. Discussions primarily involved bringing the risk to the awareness of the care

recipient, for example reminding the individual that they may fall. Some carers would prompt their family member to take actions to reduce some of these hazards such as to use walking aids or lock the door at night. One carer would try to illustrate to her husband the seriousness of his poor money management by using language to inform him of the possible consequence, in this instance that he could be robbed.

Other carers reported a reluctance to discuss risk issues as it was felt this may create anxiety for the care recipient.

'I wouldn't put my wife in the situation to bring up "don't do this, don't do that" because I don't think she would retain it but also I wouldn't even want to go there because it's maybe creating something within their mind situation that they're going to worry about it.' FG4

'I think you don't want to say anything that would plant any wee seed that might turn into a worry.' FG4

Willingness to discuss risks was also dependent on the ability of the individual to comprehend the issues discussed, which was noted to vary across time.

'Sometimes depending on how well mum is or not, I would say more things to her than others, that could change from minute to minute, day to day or whatever.' FG4

'Sometimes he gets it and sometimes he doesn't.' FG3

Driving was noted by some carers as being a particularly sensitive subject with individuals reportedly being 'annoyed' or 'touchy' regarding this matter. One carer interjected in discussion around driving to highlight the importance of early diagnosis 'Because you can still talk to them then.'

People with dementia did in some cases voluntarily discuss concerns with family members which may have included apprehensions about certain risk issues, for example concerns relating to theft of property (which the carer established had not been an actuality). Several participants felt that the people they cared for lacked awareness of risk or danger.

While several carers reported discussing risks with their family member with dementia, findings would suggest that these conversations did not appear to be central to how carers dealt with risk in the home and community.

### *Discussion of risks with professionals*

Caregivers discussed risks with a variety of health and social care professionals including General Practitioners (GPs), Psychiatrists, Occupational Therapists (OTs), Social Workers (SWs), Speech and Language Therapists (SLTs) and Nurses. Risk issues were also discussed with staff within the voluntary sector including employees from befriending services and home safety schemes. Communication related to a range of risk situations including activities, driving, falls, side effects of medications, medical procedures and swallowing.

In cases where professionals initiated discussions about risks with carers, these included risks to the individual with dementia and those to others, including staff, family and service users. Driving appeared to be an issue that was more frequently addressed by professionals. Conversations involved informing people with dementia of their legal requirement to contact the driving and vehicle licencing agency and their car insurance companies. In other cases professionals broached the issue with patients that they should no longer continue driving.

Discussion of risks in several instances related to matters of health and safety for example risks to staff when moving and handling. Families and professionals were sometimes found to differ in their perspectives of these issues. In one instance a carer described how his wife was not provided with a stair lift he had requested due to the associated safety issues related to using this appliance, a decision he reported disagreeing with at the time. One family member informed the focus group of a situation where her mother was keen to go swimming along with a volunteer befriender, with this choice supported by both volunteer and family carer. The carer described how the volunteer's manager was reluctant to allow this due to the safety issues inherent in the activity.

'He was so careful and so cautious ... he was saying but she would have to go into the changing room, she would have to get changed into her costume, she would have to walk at the side of the pool, there would be water, she could drown. Well yeah! I didn't see that as a risk at all and R (*volunteer*) was more than happy to do it as well.' FG4

Professionals also focused on potential risks to carers inherent in situations discussed such as burn out or risks to their own physical health.

Risks to other service users were also reportedly raised with one family whose parent attended a day centre facility delivered in a local care home. The carer described a stage during which the family were frequently receiving phone calls relating to their mother's behaviour at the centre, advising of some challenging behaviours and consequent upset to other residents. The solution initially proposed by the centre was to medicate the individual. Following direct contact with management at the facility, the issue was resolved by improving communication with the family and learning more about the client. By communicating with the family, staff were able to identify early signs of distress, methods of calming the individual when agitated and about interests of the person. In this instance staff were able to manage the risk of challenging behaviour by liaising directly with the family and learning personal information about the individual.

'It's just the complete difference, night and day, and that was just having a bit of direct contact with the management of the home.' FG4

Treatment for a suspected tumour (which was later established to be a benign growth) was also discussed with one carer by the GP. It was reported that the GP recommended not commencing treatment, focusing on the stresses the treatment may cause to the individual with dementia rather than an potential benefits. In this instance the carer was in agreement with the GP, although reported that his daughter had wanted more information on the condition.

Carers were willing to broach concerns about risks with professionals. One carer raised the issue of side effects of her husband's medication with both the GP and psychiatrist.

'Well I think with medication they should you know tell you more about the side effects.'

FG3

The participant reported that discussions took place following occurrence of side effects rather than prior to commencing the medication. The same carer would actively read up on the side effects of any medications that her husband was on. It was reported that following this discussion, the person with dementia was taken off the particular treatment he was experiencing adverse side effects from. This outcome implied that the GP had listened to the carer's concerns and made a decision based on this information.

Carers communicated the seriousness of concerns by providing examples of incidents that occurred, such as a relative falling down the stairs, or advising of concerns relating to anticipated outcomes, such as fears that a parent will harm themselves in the kitchen. In one instance a carer referred to her husband's SLT as being 'very well aware,' of the seriousness of her concern, in this case relating to her spouse's swallow, indicating an implicit understanding of the risk issue by the professional.

In a couple of circumstances, carers felt that their concerns about risks present in some procedures or practices were not listened to. For example the risk of person with dementia becoming anxious during administration of an injection or regarding swallowing issues.

The value of general good communication was raised several times including being respectful, listening and taking time. The importance of using appropriate 'layman's language' was also highlighted by one carer who emphasised that professionals should not use words that the carer does not understand. One spousal carer mentioned use of a diary as a general communication tool between families and care workers coming into the home. Following further discussion with the group it was suggested that information about risks could also be recorded in such a diary.

Communication regarding risks ultimately fed into the overall process of managing these risks and decisions relating to care.

## **vi. Findings: Qualitative study of professionals in community dementia services** (based on: Stevenson & Taylor, in press, b)

### *Domains of risk in community dementia care*

A broad range of situations or events involving risks were encountered in practice. Domains of risk identified included those categorised as relating to:

- *health* including medications mismanagement, malnutrition and neglect of personal hygiene;
- *emotional well-being* for example loneliness, social isolation, deprivation of liberty and lack of meaningful activity;
- *abuse*, with financial abuse and general abuse being referenced;
- risks relating to *safety in the home or community* including accidents from using cooking appliances, falls, alcohol misuse, smoking, driving and leaving the home unsupervised (colloquially referred to as 'wandering'); and
- risks to *other persons* including manual handling risks.

Importantly risks encountered often related to the decisions or actions of the individual with dementia, including the activities that they chose to engage in and supports they accepted (or chose not to accept). Notably for some professionals, not accepting equipment in the home that an individual was assessed as needing was considered a risk. The associated risk consequences experienced ranged from relatively minor accidents such as burning pots and pans, through to highly severe (fatality as a result of fire). Importantly, both positive and negative outcomes relating to wellbeing were considered.

Risks were understood as continuously evolving for individuals during the course of their dementia and changing circumstances. Physical needs for example mobility, incontinence and manual handling risks were noted to become more prominent in the later stages. Conversely in other areas, risks were perceived to lessen as dementia progressed, for example risks of agitation, falling, 'wandering' or driving. It was also noted that individuals were sometimes more accepting of supports in later stages. Levels of risk presented were seen as conditional on family support and living arrangements:

'If they have family maybe the risks are a bit lower because of that input from the family but if somebody is living on their own and isolated...the risks are higher as the illness progresses.'

Participants recognised that risks needed to be viewed within the context of the individual's history and that perceived risky behaviours may have been a continuation of something clients had been doing for many years preceding their diagnosis rather than a change in behaviour as a result of their dementia:

'We might go into a house and think 'gosh that's wild risky' [*but*] they might have been doing it all of their life.'

### *Concepts of risk*

Risks were primarily conceptualised as consequences (both negative and positive) relating to the wide range of categories outlined above. Importantly it was recognised that outcomes of risk taking were not necessarily negative; rather a culture of positive risk-taking was generally evident. Staff referred to 'supporting people to live with the risks' and 'enabling' individuals to continue potentially risky activities such as smoking or cooking:

'I think the focus has been on taking positive risks, whereas before when you did risk assessments it was all 'oh we have to stop this, we have to stop that', but now I think it's all about how do we enable people to do this and keep it as safe as possible.'

Perceptions of risk were integral to the process of dealing with risk in practice. Risk was not referred to as an objective, quantifiable concept but rather as an entity that could potentially be judged as acceptable or not:

'I suppose every service has their own, perception of risk and their own sort of take on what's an acceptable risk for them.'

'We can't be playing big brother and dictating to people what's an acceptable risk and what's not, if they retain the capacity to weigh that up for themselves.'

Concepts of risk were inextricably linked to the risk management culture in which professionals operated including risk assessment mechanisms used. Participants referred to assessment tools that were 'strength based' while a previous tool was referred to in one group as 'very negatively based'. More general professional concepts relating to risk management practice were also referenced, for example 'proportionality,' 'best interests' and 'liberty'.

Several participants did refer to the concept of likelihood with respect to risk, for example the likelihood of falling or risk as 'the likelihood of (event) happening and (it's) consequences':

'I suppose, we all have to remember, I mean, risk is about likelihood.'

While the language of probability was used in discourses, it appeared to be used as an expression of uncertainty or as a means to access services (by emphasising high risk situations), rather than as a translation of some quantified value. Primarily risk was conceptualised as consequences and their severity rather than likelihoods, but importantly, consequences were recognised also as being potentially positive.

#### *Using numeric data in practice*

Participants reported routinely using and receiving quantitative information in practice, for example scores from assessments of cognitive abilities, functional skills or pain scales; likelihoods of side effects of medications; and reports of frequency of incidents such as falls or challenging behaviours. While these professionals regularly received or used such quantitative information in the course of practice, staff reported that they did not typically use numeric expressions in their communications. Multiple reasons were given for not using numeric representations including that clients generally did not ask for numbers and that other staff did not feel comfortable using numbers. It was noted also that communications often took place under stressful conditions. In such circumstances citing figures was not viewed as appropriate. Verbal expressions of likelihood were preferred in practice to numeric, as described in subsequent sections.

#### *Verbal expressions of risk likelihood*

While an aversion to using numeric expressions in communications was apparent, verbal expressions of likelihood were widely used. Likelihoods of risk were broadly understood in verbal terms, corresponding to the three tier language of 'high, medium or low' as used in the standard risk assessment tool familiar to all these professionals (DHSSPS, 2012). A tiered approach was also evident in communications with clients and families. Participants in one group referred to the use of different levels of language consistent with the perceived level of risk. Initially terms such as 'comfort, safety and independence' were used in communications with clients and families, progressing though to 'concern and worry' and then to words such as 'risk or danger'.

'If something has happened that has made the likelihood more real, you sort of up your language a bit.'

Interestingly, participants involved in communication of side effects of medications to people with dementia also expressed a preference for verbal descriptors such as 'low', 'most common' or 'small increased risk of', rather than communicating using numeric information provided with the medicines.

In their communications with other professionals, participants reported using verbal probability expressions. Words and phrases such as 'potential', 'probable', 'high probability' or 'increased likelihood' were noted to be used in reports as a means of emphasising risks and needs for services. Essentially staff were using probability expressions to communicate uncertainties rather than conveying quantified likelihoods, but with some sense of matching words to increased danger or urgency.

#### *Numeric communication of risk*

An overall preference for frequency formats was found both with respect to how participants would prefer to receive information and the mode in which it was judged service users and families would prefer to receive such information. There was some disagreement with respect to favoured denominator, for example whether to express the likelihood of harm as 'out of ten' or 'out of a hundred'. Generally using a denominator of ten was preferred to the denominator of 100, even though the latter was the exact quantity and the former an approximation (albeit a close one in the example presented). It was proposed that smaller numbers, in this case a smaller denominator, were easier to understand. However, one group expressed a preference for the larger denominator as it was judged that this made the risk appear smaller and would therefore be more appropriate if trying to persuade a client to take a medication:

'A group of ten people is smaller than a group of one hundred; you could hide in that group of one hundred.'

Probability formats expressed as decimals were also perceived as smaller:

'If you want to persuade, you would [say] the people who take Aricept have 0.11 chance.'

Format preference therefore appeared to be influenced by the goal of the communication and whether this was to persuade or inform.

#### *Visual forms of risk communication*

Although visual forms of general communication were widely used in practice, visuals were not being used to communicate information about risks. Some professionals saw potential for using such modes for communicating risks. There was a lack of consensus on the most appropriate format of visual presentation. Generally participants preferred bar charts as these were perceived as less busy, easier to understand, more familiar (to both staff and families) and easier to compare at a glance. Some focus group attendees preferred the icon arrays using people, while the icon array using ovals was generally not favoured. People icons were viewed by some as personalising the risk and it was also noted that these arrays were more engaging and encouraged the user to study the visual more closely.

Several practitioners were open to the potential of using visual forms of risk communication, under the right circumstances. One participant noted such charts representing falls risk would be useful if wanting to persuade an individual to accept equipment in the home. Others felt that these charts depersonalised risks as the person was then seen as 'part of a bigger category of people rather than an individual'. It was suggested that visuals might be more appropriate if personalised to the client, for example to represent changes in their individual scores in a specific domain.

#### *Challenges to communicating risk*

Professionals faced an array of challenges with respect to managing risks and communications. A core challenge in communicating with individuals, family members and other professionals was the variation in perceptions of acceptable risk:

'I think when somebody has a diagnosis of dementia, everything is heightened and everything becomes a bigger thing.'

Primary challenges when communicating with clients with dementia included lack of insight of the person of the risk, difficulties for the client in recalling the discussions and not wishing to cause distress. Risk of breakdown of the professional client relationship was also a constant consideration.

In relation to communication with other professionals, services that were not dementia specific such as in the acute sector were perceived as being more risk averse in their recommendations, at times leading to disagreements in practice:

'I actually find that the biggest challenge, in relation to managing risk within my role is perceptions of other professionals.'

Conflicts with families were noted to be more prominent when moving into best interest decisions, in the event of lack of capacity of the person with dementia. It was noted that relatives did not always grasp the benefits of decisions made by professionals. Unrealistic expectations of services, for example, to remove all risks or for professionals to take all responsibility for the person with dementia's safety were also problematic, as was navigating family dynamics and maintaining professional-client relationships. Finally practicing within a blame culture was found to at times to create apprehension for staff and led to being more careful, sometimes at the expense of being less precise, in their communications with families.

#### *Good practice in communicating risk*

Communicating with clients and families about risks was a very skilled area of practice involving creative and person centred approaches. Staff consciously supported the client with dementia to become aware of risks and to 'reason out the risk for themselves' rather than blatantly pointing out risks and instructing clients on what they should do:

'I think a lot of the time actually, what I find is that they highlight their own risks for themselves, through the conversation.'

Participants reported trying to gauge the client's insight into, and perspective on, the risk in the first instance, for example asking the person to tell them about their medication or how they were managing with a particular matter. If it became clear though the conversation that the individual did not perceive a problem, then staff recognised the need to be sensitive and take a different approach. Professionals would attempt to bring the risk to the attention of the client in subtle ways, for example asking them if they thought they might slip on a matt or if something was a worry to them. Staff also focused on solutions rather than problems such as suggesting alternatives 'I think rather than maybe raise the risks you are sort of trying to look at solutions'. Participants further highlighted the importance of choosing the appropriate time to discuss the risk with the individual. Shared decision making in practice was seen as imperative based on the understanding that risks could be perceived in different ways:

'I think it's important when we are making risk assessments or judgements that we don't make it in isolation, because what one person could deem severe, another or others may deem it as different.'

With respect to communications with families, acknowledging where the family were coming from with respect to their fears, feelings and belief systems was noted. Building a good relationship with clients and families was considered inherently important to ensure that communications were not simply one directional. For example, families with whom good relationships were cultivated were more likely to make contact with services to express concerns before reaching crisis point. Explaining risk decisions and the process through which they were arrived at to families was recommended.

**vii. Findings: Survey of professionals in community dementia services (based on: Taylor et al., submitted)**

Seventy complete and fifty-five partial responses (125 total) gave a response rates of 26% (completed) and 46% (partial) (see Table 6) from the community dementia services professionals. The appropriate denominator is used for analysis.

**Table 6.** Demographics of sample completing the full questionnaire (n=70).

<i>Gender</i>	Female	54 (77%)
	Male	16 (23%)
<i>Age</i>	21–30 yrs	6 (9%)
	31-40 yrs	21 (30%)
	41-50 yrs	17 (24%)
	51-60 yrs	25 (36%)
	>61yrs	1 (1%)
<i>Profession</i>	Nursing	32 (46%)
	Social Work	13 (19%)
	Occupational Therapy	11 (16%)
	Support Staff	7 (10%)
	Medicine	4 (6%)
	Speech & Language Therapy	1 (1%)
	Psychology	1 (1%)
	Other	1 (1%)
<i>Years in health and social care</i>	Mean 17 yrs, newly qualified to 44 years in practice	
<i>Years in dementia care</i>	Mean 11 yrs, newly qualified to 35 years in practice	
<i>Percent of current role in dementia</i>	Mean 84 per cent	

<i>Post-qualifying training</i>	Specialist training in dementia (7), Approved Social Worker (5), Mental Health Nursing (3), Specialist Practitioner (Older People) (3), Adult Safeguarding (2), Initial Professional Development (2), NVQ Assessor (1), Research Methods (1), Practice Teaching (1).
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*Using numbers in practice*

Average numeracy using BNT plus Schwartz items was low-moderate. Mean numeracy score (n=71) was 2.79 out of 7 (SD 1.6; 95% CI [2.42, 3.16]). Scores for the four BNT items alone were low. 43.7% of respondents scored no correct answers on the BNT, 45.1% scored one correct, 5.6% (two correct), 4.2% (three correct) and 0.8% (four correct). Most respondents (86%) reported using numbers in practice (Table 7), primarily from assessment scores, likelihoods of side effects of medicines, reports, calculations for care packages and data from team databases.

**Table 7.** Use of numeric data in practice (n=125).

<i>Numeric data source</i>	
Mini Mental State Exam	69%
Abbey Pain Scale	42%
Addenbrookes Cognitive Assessment	42%
Reports on how often client incidents have occurred	42%
Braden Pain Scale	42%
Geriatric Depression Scale	36%
Malnutrition Universal Screening Tool	28%
Hospital Anxiety and Depression Scale	14%
Likelihood of side effects of medications or treatment	13%
Montreal Cognitive Assessment	12%
Other	10%
<ul style="list-style-type: none"> <li>- Other assessment tools</li> <li>- 4AT (cognitive impairment and delirium)</li> <li>- Abbreviated Mental Test (AMT)</li> <li>- Calculating care packages</li> <li>- Challenging Behavior Scale (Moniz-Cook, 2001)</li> <li>- Clifton Assessment Procedures for the Elderly (CAPE)</li> <li>- Cohen-Mansfield Agitation Inventory (CMAI)</li> <li>- Cornell Depression Scale (CDS)</li> <li>- EASY-Care (physical, mental, social and environmental assessment)</li> <li>- Falls risk checklist</li> <li>- Neuropsychiatric Inventory (NI)</li> <li>- Pool Activity Level (PAL) assessment</li> <li>- SAD suicide assessment</li> <li>- St Andrews Sexual Behaviour assessment scale (SASBA)</li> <li>- Data from team database e.g. length of waiting times or average length of episode.</li> </ul>	
Do not use numeric information in work	14%

*Numbers corresponding with verbal descriptors of risk*

Participants' responses were variable on numeric estimates of verbal terms for risk likelihoods (of medication side effects). Few participants provided responses that were concordant with those used in the EU guidance. The median estimate for a side-effect risk described as 'common' was 200 out of 1000 (IQR 400), an estimate more aligned with an EU definition of 'uncommon'. The median estimate of 'rare' was 20 out of 1000 (IQR 69), more aligned with the EU definition of

'common' (European Commission, 2009). No respondents provided a numeric estimate of 'rare' that aligned with the EU description of this term while only 15% of respondents estimated a value of 'common' that fell within that EU range (Table 8).

**Table 8.** Categorisation by EU categories of respondents' numeric understanding of the terms 'rare' and 'common' in relation to side effects of medicines (n = 83).

<i>EU Verbal descriptor</i>	<i>Numeric understanding of 'Rare' in the range:</i>	<i>Numeric understanding of 'Common' in the range:</i>
<i>Very rare (&lt;1 in 10000)</i>	3.6%	1.2%
<i>Rare (<math>\geq 1</math> in 10,000 to &lt; 1 in 1,000)</i>	0%	0%
<i>Uncommon (<math>\geq 1</math> in 1,000 to &lt; 1 in 100)</i>	21.7%	2.4%
<i>Common (<math>\geq 1</math> in 100 to &lt; 1 in 10)</i>	51.8%	14.5%
<i>Very common (<math>\geq 1</math> in 10)</i>	22.9%	81.9%

#### *Verbal understanding of numerical probabilities*

When asked to select a verbal descriptor that corresponded to a risk of 21 out of 1000 from five given descriptors (very rare, rare, uncommon, common and very common), most participants selected either rare (38.6%) or uncommon (44.6%) as the verbal statement they would use to communicate this value to a client. According to EU guidelines this value would be within the 'common' range (which 7.2% of respondents selected).

#### *Variability in understanding and use of verbal descriptors of risk*

For the scenario in which respondents were asked to assess risk as high, medium or low, 25.3% of respondents selected low, 41% opted for medium and 33.7% chose high to describe the patient (client) risk level. To rate how likely it was that a client would experience a specific accident over six months, 55.4% choose 'somewhat likely' while 13.3% selected 'very likely', 12% likely, 14.5% somewhat likely, 3.6% unlikely and 1.2% very unlikely.

When selecting a verbal statement to describe graphic information to colleagues (n=81), 49% of respondents selected a relative risk statement ('reduced by 50%' or 'halved') to explain reduction in risk incidents. The absolute statement ('reduced from twelve incidents per week to six per week') was preferred by 28.4% while remaining respondents selected a verbal descriptor: reduced (8.6%), moderately reduced (6.2%) or substantially reduced (7.4%).

#### *Visual risk communication tools*

A visual form of communication was preferred by 80.5% (95% CI [71.5, 89.5]) respondents [n = 82], with icon arrays (51.2%) being preferred to bar charts (29.3%). Explanations for preferred communication method generally related to perceived ease of understanding for the client. Icon arrays were noted as being clear, simple, providing a good illustration of proportions and being easier to relate to than graphs or words. Bar charts were favoured by some respondents due to their familiarity. Similarly to icon arrays, respondents noted that bar charts aided comparisons between those who developed the risk outcome in that population compared to those who did not. Participants who favoured verbal statements felt that such statements were more direct while graphs could lead to confusion or information overload.

#### *Risks encountered in practice and levels of concern*

Table 9 ranks the risk factors perceived as occurring most frequently (estimates out of 100, averaged across participants) and levels of concern associated with these (ranked out of 10). Based on n=89 sample, correlational analysis was powered (0.80) to detect a minimum effect size of 0.29. Findings provide a rudimentary estimate of the perceived frequency of these general risk factors in community dementia care teams, the three risks perceived as occurring most often being falls, depression and poor personal hygiene. Risks of most concern were abuse from others, falls

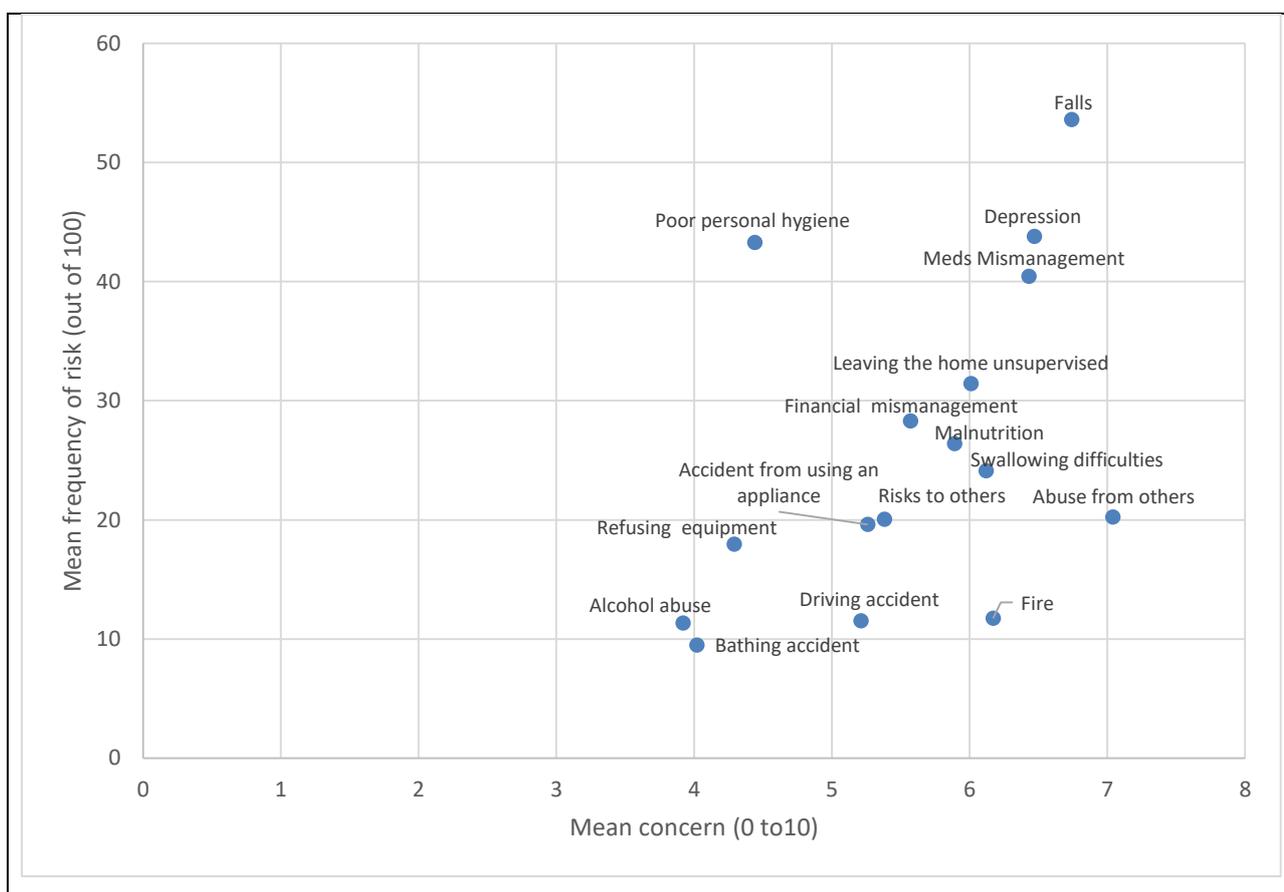
and depression. Results demonstrate low to moderate positive correlations for nine of the sixteen risks presented (Figure 4). For risk of fire and abuse from others levels of concern were high despite perceived frequency being low.

**Table 9.** Perceived frequency of risk factors amongst dementia team clients and levels of concern.

Risk	Frequency (n=99)		Concern (n=89)		Correlation with bootstrapping [95% CI]
	Mean	Median	Mean	Median	
Falls	53.6 (SD 24.2)	50	6.7 (SD 2.7)	7	r=0.45, p<0.001* [0.26, 0.62]
Depression	43.8 (SD 24.7)	48	6.5 (SD 2.5)	7	r=0.41, p<0.001* [0.23, 0.57]
Poor personal hygiene	43.3 (SD 25.1)	41	4.4 (SD 2.6)	4	r=0.26, p=0.013* [0.03, 0.50]
Medications mismanagement	40.5 (SD 26.7)	35	6.4 (SD 3.2)	7	r=0.27, p=0.011* [0.06, 0.44]
Leaving home unsupervised	31.4 (SD 24.8)	25	6.0 (SD 3.3)	6	r=-0.03, p=0.753 [-0.21, 0.25]
Financial mismanagement	28.3 (SD 27.2)	20	5.6 (SD 3.2)	6	r=0.35, p=0.001* [0.17, 0.51]
Malnutrition	26.4 (SD 24.5)	17	5.9 (SD 3.3)	6	r=0.21, p=0.044* [-0.004, 0.10]
Swallowing diffs	24.1 (SD 24.9)	13	6.1 (SD 3.3)	7	r=0.18, p=0.09 [0.002, 0.35]
Abuse from others	20.2 (SD 25.1)	10	7.0 (SD 3.0)	8	r=0.09, p=0.394 [-0.07, 0.24]
Risks to others	20.0 (SD 21.5)	12	5.4 (SD 3.3)	6	r=0.22, p=0.041* [0.03, 0.41]
Accident from using appliance	19.6 (SD 22.9)	10	5.3 (SD 3.4)	6	r=0.26, p=0.015* [0.08, 0.45]
Refusing equipment	17.9 (SD 20.5)	10	4.3 (SD 2.9)	5	r=0.26, p=0.014* [0.06, 0.44]
Fire	11.7 (SD 19.8)	4	6.2 (SD 3.9)	8	r=0.05, p=0.627 [-0.12, 0.22]
Driving accident	11.5 (SD 18.6)	5	5.2 (SD 3.8)	5	r=0.12, p=0.276 [-0.01, 0.25]
Alcohol abuse	11.3 (SD 11.4)	10	3.9 (SD 2.8)	3	r=0.18, p=0.087 [0.02, 0.34]
Bathing accident	9.5 (SD 15.1)	3	4.0 (SD 3.3)	4	r=0.16, p=0.133 [0.01, 0.31]

\*significant at 0.05 level (2 tailed)

**Figure 4.** Relationships between risk frequency and risk concern.



*Accuracy in estimations of severe risk outcomes*

Professionals overestimated how often risks with severe outcomes occurred (comparing median estimates to recorded data, Table 10). Median estimates relating to going missing or having a serious fall were ten times greater than the conservatively-estimated reality. Responses were variable with wide interquartile ranges, in particular regarding serious falls.

**Table 10.** Perception of likelihood for dread risks compared to estimated actual data (n=83).

Severe risk outcome (over the next 12 months)	Actual* (out of 1000)	Median estimate (out of 1000)	% Accurate (-50% to +100% of actual)
Be involved in a car accident	27	50 (IQR 133)	29.8%
Cause a fire in the home	22.7	50 (IQR 90)	19.3%
Have a missing person's report filed	5	50 (IQR 190)	21.7%
Have a serious fall resulting in hospitalisation	21.3	200 (IQR 440)	10.8%

\*Based on recorded data

Responses were classified as 'accurate' if the fell within the range of half to double the 'actual' estimate as a notional 'reasonable' professional knowledge base. Percentage of accurate responses for each severe risk outcome category ranged from 10.8% (serious fall) to 29.8% (car accident). Most practitioners (76%) made either none or one accurate estimate across all four scenarios whilst no respondents were accurate in their estimates across all four. The number of

accurate estimates per respondent was: 0 (46%); 1 (30%); 2 (20%); 3 (4%); and 4 (0%) of the total 83 accurate estimates.

### Predictors of accuracy

Diagnostics for multiple linear regression confirmed that assumptions of linearity, normality of residuals and homoscedasticity were violated for all models. A logistic regression model was used where accuracy was classified as a binary variable (accurate/inaccurate). However, the model was not adequately powered (0.80) to detect small effect sizes (Hsieh 1989; Chen, Cohen, & Chen, 2010). None of the logistic models could accommodate all four of the predictor variables when applying the 'one in ten rule' i.e. for every ten respondents in the smallest category, one predictor variable could be added to that model (Peduzzi, Concato, Kemper, Holford & Feinstein, 1996; Stoltzfus, 2011).

Correlational analysis with bootstrapping was used to explore relationships between accuracy (as a continuum from underestimations to overestimations) and the four theoretically-driven variables (Table 11). Numeracy and experience were not correlated with accuracy of estimation. Two variables (experience of the general risk factor and concern) were significantly correlated at  $p < 0.05$  with overestimation of risk, but were not consistently associated with significant levels of overestimation across all four severe risk outcome situations. Increased experience of the general risk factor within the team was significantly associated with moderate increased overestimation of the risk likelihood for two risk factors (experience of falls from minor to severe and experience of people with dementia 'wandering'). Increased concern relating to the general risk factor was significantly associated with low to moderate increased overestimation of the risk likelihood for three of the risk factors (experience of falls, driving accidents and fire). Confidence intervals are wide ranging from small effects through to moderate effects for those associations that were significant at  $p < 0.05$ .

**Table 11.** Correlation of accuracy with numeracy, experience and concern.

	Numeracy (n=71)*	Experience (years in dementia practice) (n=70)*	Experience (of general risk factor) (n=83)**	Concern (n=83)**
Serious fall	r=-0.029, p=0.811 95% CI [-0.235, 0.175]	r=-0.082, p=0.5 95% CI [-0.295, 0.140]	r=0.397*, p<0.001 95% CI [0.214, 0.565]	r=0.232*, p=0.035 95% CI [0.012, 0.438]
Cause fire	r=-0.071, p=0.556 95% CI [-0.304, 0.173]	r=0.102, p=0.399 95% CI [-0.069, 0.281]	r=0.089, p=0.425 95% CI [-0.057, 0.290]	r=0.258*, p=0.019 95% CI [0.078, 0.406]
Missing persons report	r=-0.059, p=0.624 95% CI [-0.267, 0.145]	r=-0.016, p=0.895 95% CI [-0.230, 0.199]	r=.300*, p=0.006 95% CI [0.107, 0.491]	r=0.134, p=0.226 95% CI [-0.079, 0.317]
Car accident	r=0.014, p=0.911 95% CI [-0.237, 0.189]	r=0.047, p=0.698 95% CI [-0.099, 0.268]	r=0.096, p=0.385 95% CI [-0.021, 0.286]	r=0.273*, p=0.012 95% CI [0.077, 0.444]

\*powered to detect minimum effect size of 0.33

\*\*powered to detect minimum effect size of 0.30

### Challenges for risk communication in practice

Table 13 ranks challenges relating to communicating risk from zero (not challenging at all) to ten (extremely challenging) in descending order. Conflicting ideas on clients best interests was rated as the greatest challenge, closely followed by the person with dementia lacking insight into the risk, whilst fear of complaint was regarded as least challenging of the issues presented.

**Table 13.** Perceived challenges in practice (n=71).

<i>Conflicting ideas on client's best interests</i>	6.9 (SD 2.2) 95% CI [6.4, 7.4]
<i>Person with dementia lacking insight into the risk</i>	6.3 (SD 2.6) 95% CI [5.7, 6.9]
<i>Unrealistic expectations of services</i>	6.0 (SD 2.8) 95% CI [5.3, 6.6]
<i>Risk of damage to professional/client relationship</i>	4.8 (SD 2.8) 95% CI [4.1, 5.5]
<i>Lack of data on likelihoods</i>	3.4 (SD 2.7) 95% CI [2.8, 4.1]
<i>Fear of complaint</i>	2.6 (SD 2.2) 95% CI [2.1, 3.1]

*General principles for communicating and managing risks*

Respondents outlined general principles they would apply to a case-based 'risk' scenario:

- gathering more information to place the risk behaviour in context;
- weighing the 'risk' against potential benefits;
- monitoring the situation;
- further assessment; and
- considering potential supports and strategies to reduce risk.

Suggestions to improve risk communication included: further training (including for staff who do not work within dementia services); availability of quality resources including information booklets offering practical guidance; access to a sound research base; availability of data on likelihoods of risks; and visual aids to explain risks.

- **4 E Discussion**

This discussion section considers the findings of each of the seven stages of the project, discussed as in the sequence below.

- i. *Literature searching*
- ii. *Literature appraisal and synthesis*
- iii. *Qualitative study of people with dementia*
- iv. *Engagement of people with dementia in data analysis*
- v. *Qualitative study of family carers of a person with dementia*
- vi. *Qualitative study of professionals in community dementia services*
- vii. *Quantitative study of professionals in community dementia services*

The final Conclusions section considers the theoretical and capacity-building advances through this project. The practice and policy implications are considered in Part 6 below.

- i. Discussion: Literature searching (based on: Stevenson et al., 2016)**

While efforts were taken to ensure that the search was as systematic and methodical as possible, it is impossible to eliminate some subjectivity in the selection of search terms to reflect the concept groups selected. One of the primary limitations to the effectiveness of the literature search was that supplementary search techniques such as hand searching of journals, author searches, reference list searches, citation searching and contacting experts (Armstrong, Jackson, Doyle, Waters and Howes, 2005; Greenhalgh and Peacock, 2005; Papaioannou et al., 2010; Stevenson and Lawler, 2004) were not applied. Inclusion of such methods might have increased the total number of relevant hits retrieved thus reducing the sensitivity figures reported here.

CINAHL and PsycInfo (both about 50%) were the most valuable databases in relation to retrieving a high volume of relevant articles (sensitivity), followed after a wide margin by Google Scholar and Social Sciences Citation Index (both around 30%). Social Services Abstracts had the highest precision rate, followed by Social Care Online and then ASSIA. This suggests that social work, and to some science, databases had better search terms for this topic. Five of the databases (CINAHL, Scopus, PsycInfo, Social Care Online and Social Sciences Citation Index) and Google Scholar retrieved unique articles not identified by any of other database. The ability to retrieve articles not sourced by another database could be regarded as an important feature justifying the inclusion of a particular database in a comprehensive search (Best et al., 2014).

None of the Campbell Library, Cochrane Library or Communication Abstracts databases resulted in retrieval of any relevant papers for the purposes of this search. In relation to the Communications Abstracts database, possibly the subject coverage was not as relevant to the topic of health communication as the database name might suggest. The Cochrane and Campbell Collaboration Libraries contain, of course, only systematic reviews of the effectiveness of interventions. In this context this could only possibly include experimental and quasi-experimental studies of ways to improve risk communication. The lack of studies on these databases suggests that the topic area has not yet been developed in sufficient depth for such studies to be viable (Medical Research Council, 2008).

Adding a third concept group might have increased the overall precision of the search as standard Boolean logic implies that combining three concept groups cannot yield more results than combining only two of the sets. However as previously discussed, our preliminary scoping indicated that using three concept groups would have compromised the sensitivity and feasibility of the search. Only four of the databases resulted in more than four hundred hits, therefore the time spent reading through irrelevant abstracts was not overly excessive. A low precision rate for a database becomes more of an inconvenience when that database has retrieved a very large volume of studies overall. If all of the databases had been retrieving very high volumes of articles then it may have been worth giving consideration to the introduction of the third concept group, although in this instance this was not deemed to be necessary.

When results were sorted by relevancy generally the reviewers would still have needed to read through all results, as opposed to the first 25%, 50% or 75%, in order to be certain that all relevant papers had been sourced. This may have been due to the search strategy employed where only two concept groups were combined. It is possible that use of three or more concept groups may have supported the databases in sorting results by relevancy in a manner more efficient to the search. This is an area for further research. Notably on Google Scholar 70% of the relevant articles included in the top three-hundred articles were found by reading the first 25% of the results, indicating that the relevancy-sorting feature of this search engine surpasses those on the databases. However caution needs to be applied when sorting by relevancy on Google; as noted in the methodology section above, the order in which searches are combined with the 'AND' function will affect the order of relevancy of results.

Generally the measure of sensitivity is considerably higher than the degree of precision for each database and that as sensitivity increases, precision decreases. The exceptions to this rule were those databases that retrieved a low overall volume of articles including ASSIA (twenty-six articles), Social Care Online (twenty-nine articles) and Social Services Abstracts (eight articles). In relation to these databases sensitivity and precision figures were roughly equivalent for ASSIA and Social Care Online and precision was more than four times higher than sensitivity for Social Services Abstracts. With regards to the relationship between sensitivity and precision, overall the results indicated that as the number of articles retrieved by a particular database increases the relative gap between precision and sensitivity widens (Table 2). It is noted that for Medline (the database retrieving the highest number of articles) that the measure of sensitivity is more than thirty-two times greater than the measure of precision and, interestingly, this figure continuously decreases for each database when ordered by number of overall articles retrieved.

Variations in indexing across the databases proved to be a challenge for the search with respect to ensuring consistency of the search strategy. It has been noted by Papaioannou et al. (2010) that use of standardized definitions and indexing has not been applied across the social sciences databases with the same rigour as within medical databases. Indeed it was noted during this search that the indexing of terms was not consistent across databases. While certain terms such as '*risk perception*' were indexed on some databases, they were not on others. Notably only one of the databases, ASSIA, included '*risk communication*' as an index term, but did not include a definition of the term in the scope notes. The absence of this term across database indexes may perhaps be explained given that '*risk communication*' is an emerging field in health and social care which is estimated by Leiss (1996) to have been first used in an academic publication in 1984. Variation in indexing of risk terms on databases and absence of some key terms from indices present challenges for literature searching on topics relating to health, risk and society. Searches pertaining to developing fields such as risk communication that are not included as key terms on a database, may benefit from use of more precise text terms and application of advanced search operators such as adjacency and truncation search functions.

For literature searching on health and social care aspects of risk and dementia, it is recommended that searches should incorporate a range of databases with relevant subject coverage. No one database performed outstandingly well compared to the others. The advanced search functions on databases are worth using to increase the precision of searching. Google Scholar was worth including in the search. The capability of other web search engines is yet to be appraised on this topic area. The search methodology procedures reported here will inform the thorough identification of relevant literature so as to build social science risk knowledge.

## **ii. Discussion: Literature review (based on: Stevenson, McDowell et al., in press)**

The absence of papers on risk communication in dementia care led to a focus on concepts of risks as underpinning communication. While conclusions from these papers can indirectly inform understanding of risk communication and lead to some recommendations for this domain, there is considerable scope for developing our understanding of risk communication in dementia care.

A systematic literature search sought to facilitate the retrieval of all relevant papers and to reduce bias in the review process. While efforts were taken to ensure the search was as methodical as possible, it is impossible to eliminate subjectivity and associated bias in the selection process. Supplementary search techniques such as hand searching of journals, author searches, reference list searches and citation searching were not applied. Grey literature, such as policy reports and local government documents on risk in dementia care, was excluded.

#### *Domains of risk*

While types of risks mentioned in the literature were tabulated to enable comparison between prevalence of physical and psychosocial risks, tallying different categories of risk was not the focus of the review and therefore the synthesis is limited in establishing those risks that were of most concern in dementia care settings. While papers on decision making involving risks were included where relevant, the authors cannot be confident that the search strategy retrieved all of the papers on such 'decision making' studies as this was not a search term. A further review may wish to search explicitly for these types of papers and synthesise the findings.

The majority of studies emphasised daily living and direct care risks. This could be attributed to the design of the research (e.g., some studies were designed to elicit views on a particular risk area such as falls) and to the framing of questions or tools that may have influenced risks identified. In fact, professionals recognised that they often prioritised physical rather than psychological needs, not because they viewed the latter as unimportant, but because the mechanisms for assessing and managing physical risks were more comprehensive than those relating to psychological needs (Clarke et al., 2011b). These findings support recommendations from Department of Health '*Nothing Ventured, Nothing Gained*' guidance proposing that approaches to risk assessment and management should extend beyond physical risks to incorporate also psychosocial aspects of risk (Manthorpe & Moriarty, 2010). There are occasional examples of assessment tools for older people incorporating psychosocial as well as physical risks (Taylor, 2012b) although this is generally more limited in relation to dementia specifically.

#### *Perceptions and constructions of risks*

*Social construction of risk.* In order to reach a shared understanding of risk, all groups affected by these risks must be involved in constructing their understanding (Clarke et al., 2011a). The current review demonstrates that there remains substantial variability in the construction and perception of risk in dementia care. According to social constructionism theories, risk concepts are generated within a sociocultural context shaped by prior knowledge and discourse of various groups or 'actors', and are therefore not purely objective or static (Lupton, 1999). Risks associated with living with dementia were constructed through conversational exchanges, personal experiences and individually acquired knowledge, highlighting the importance of involving multiple stakeholders in discussions about risk (Clarke et al., 2011a, p51). Notably all of the qualitative studies exploring perceptions and approaches towards risk in the dementia context were conducted in Western Societies (North America, Northern Europe and Australia/New Zealand). Further studies exploring perspectives in other cultures would be of interest.

Perceived risk (or protective) factors identified in the literature were categorised as risks from within the individual and their dementia and risks from external sources. The former category could be interpreted as corresponding to the medical model of disability where the cause of disablement is understood as stemming from a biological condition (Blood & Bamford, 2010; NICE-SCIE, 2007). Alternatively, the latter category could be viewed as aligning with to the social model where it is argued that it is society and the physical environment that causes individuals to experience disablement (Blood & Bamford, 2010; Gilliard, Means, Beattie, & Daker-White, 2005; NICE-SCIE, 2007). Overall external risk factors were identified in the literature more frequently than those stemming from the individual and their dementia suggesting that implementation of appropriate social or environmental supports may help reduce adverse outcomes while also enabling individual's with dementia to take risks when they chose to do so.

*Perceptions versus actual outcomes.* The research reviewed suggests a level of disconnect between perceptions of risk held by professionals and family carers and actual risk outcomes, often such that perceptions and actualities were not congruent. These findings contribute to

arguments that caregiver's and professional's perceptions of risk are independent of the mathematical probabilities of these risks (Bond et al., 2002) and that risk is not treated as objective and measurable but as fluid and context dependent (Cott & Tierney, 2013; Taylor, 2006). The incongruence between risk perceptions and the actual frequency of risk events has been reported across disciplines including in health and environment risks (e.g., natural hazards). One explanation for this phenomenon relates to work within the psychometric paradigm of risk perception where the general adult population are found to over- or underestimate risks according to different cognitive and affective characterisations of the risk event, such as when the risk event is associated with feelings of dread (Slovic, 1987). However, more recent work suggests that when an individual's environment is taken into consideration, people are quite accurate in judging the actual frequency of risk events and the events more likely to occur within their social environment (Benjamin, Dougan, & Buschena, 2001; Olivola & Sagara, 2009; Pachur, Hertwig, & Steinmann, 2012). For these reasons, judgements about risk events should not only take into consideration people's cognitive and affective assessments of risk, but also how relevant or frequent the risk event is likely to occur within an individual's environment.

To help challenge misperceptions, one objective of risk communication in dementia care could be to compare perceptions of risk against quantified evidence. However, a primary challenge for informing the development of risk communication tools in dementia is the difficulty in quantifying risks, in particular quantifying psychosocial risks. Accordingly, building a knowledge basis for the prevalence of different risk outcomes against which to measure perceptions is needed.

*Care crises and risk.* The need for decision making in relation to dementia care is often triggered by crisis or indication of impending crisis. Carers may face various options in relation to how they respond to these crises. Clear communication about the risks and benefits of different options by professionals is required to support carers facing these decisions as well as involving individuals with dementia in the process.

The concept of 'crisis' or critical stages in relation to dementia can have diverse meanings, as illustrated by the four papers in this review that explicitly referred to the concept. Crisis often implies a change of behaviour or situation, in this context commonly relating a decline in health or functional skills. However the concept of 'crisis' also embodies the concept of a difficulty or danger where an important or difficult decision must be made ("Crisis," 2010). A crisis is in essence a turning point and the decision required may be conceptualised as involving a threshold that has been crossed in some way, in common with themes arising in elder care more generally (Taylor & Donnelly, 2006) and in other domains of health and social care (e.g. Taylor & Killick, 2013). From the perspective of risk, the situation might be conceptualised in terms of signal detection theory (Taylor, 2012a) where the 'signal' of a critical point being reached must be detected amidst the 'noise' generated by apparently similar situations that are not in fact at the same level of crisis. For Buri and Dawson (2000) the threshold is between order and chaos in family life; the point at which family functioning ceases to be tolerable for at least one key family member providing care and nurture to one or more other, family members. The difficulty – perhaps impossibility – of measuring this crisis point on any simple scale is underlined by Waugh (2009). It is precisely in the complex dynamic interplay between risk factors that the no-longer-tolerable critical threshold is reached (MacNeil Vroomen, Bosmans, van Hout, & de Rooij., 2013) and a decision must be made. One noteworthy common feature in the papers is that the stress – and hence crisis - is often focused on the capacity of the family carer to continue to provide essential care, in accord with the main focus of the homeostatic model developed by MacNeil Vroomen et al. (2013) and as illustrated in the study by Cott and Tierney (2013).

#### *Approaches towards risk*

When it comes to approaches towards risk in dementia care, individuals have different views and tolerance levels. In the present review, balanced approaches were often discussed, where a certain degree of risk was considered to be acceptable. When risk-averse approaches were discussed, these tended to be underpinned by legal responsibilities and fear of litigation in professional practice, and purely medical constructions of dementia fostered more protectionist approaches. In contrast, risk-tolerant approaches were often grounded in person-centred, right's

based ideologies, and related to greater knowledge of the individual. In some instances, risk-taking was considered justified when personal benefits were to be experienced.

The concept of an acceptable risk relates to determining “how safe is safe enough” (Fischhoff, Slovic, Lichtenstein, Read, & Combs, 1978) and involves the trade-off between the risks and benefits associated with an activity. Möller (2012) adds that this is not a purely quantitative process but also necessitates consideration of ethical issues such as agency and rights. As reviewed, in dementia care the acceptability of risk was often determined through a person centred process of balancing rights and needs of the individual against risks and was a core theme identified in both formal and informal care. While this approach could be seen as aligning with an attitude towards positive risk taking in that the benefits of risk-taking were recognised (e.g., preserving rights and needs), the emphasis on balancing these benefits against the harms associated with taking the risk as opposed to harms in *not* taking the risk was evident. Establishing effective methods of communicating risks and benefits of different care options, applying the principles of positive risk taking (Manthorpe & Moriarty, 2010; Morgan, 2004; Morgan & Williamson, 2014), will support individuals to take more balanced approaches.

Risk communication ultimately plays a key role with respect to how decisions are made about risk in dementia care. Carson and Bain (2008) argue that approaches to risk taking should be judged not solely on the basis of outcomes, but on the quality of the decision-making process, including the risk communication element of this process. Further research on effective risk communication in dementia care is needed to inform this process.

#### *Decision making involving risk information*

There is an intrinsic link between risk and decision making in dementia care. Understanding the decision making abilities of individuals with dementia and the potential challenges experienced in this domain is of core importance if this group are to be adequately supported to make choices regarding their care. However, the focus of work on risks and decision-making in dementia primarily relate to the exploration of how cognitive impairments affect choices involving risks or probabilities in laboratory settings. While these studies suggest that people with dementia make more risky choices or have greater difficulty computing probabilities compared to people without dementia, there is a clear lack of studies evaluating how these differences translate to actual choices involving real risk situations. It is unclear whether these differences actually translate to poor decision-making in the real world or whether they may in fact lead to more adaptive decisions, particularly given that individuals with dementia are faced with a changing environment where normal (non-risky) behaviours can become risky. Further, risk taking in one domain does not necessarily transfer to others (Blais & Weber, 2006; Rolison, Hanoch, Wood, & Liu, 2013).

#### *Implications for risk communication*

Findings from research on decision making and risk in dementia support the importance of presenting information in a clear, transparent manner, developing more appropriate ways to present numeric probability information and being more conscious of framing effects. Supporting individuals in gathering and evaluating information at the predecisional stage is also imperative. Participants with cognitive impairment (but not dementia) were found to demonstrate lower health numeracy in two studies. We might expect this effect to be exacerbated for individuals with dementia. Low health numeracy has been associated with poorer comprehension of risks (Reyna, Nelson, Han, & Dieckmann, 2009) and avoidance of involvement in shared decision making (Galesic & Garcia-Retamero, 2011). Research into more effective means of presenting numeric health information to people with dementia should therefore be developed. These studies emphasise the importance of providing adequate support to enable individuals with dementia to understand health risk information (Pertl et al., 2014). However, the lack of studies evaluating risk communication or how people with dementia understand risks when communicated using different risk presentation strategies limits how work on risky choices can be used to inform people with dementia or to improve risk comprehension. Further research on how people with dementia understand health and social care risk information when presented in different formats is recommended.

iii. **Discussion: Qualitative study of people with dementia** (based on: Stevenson, Savage et al., in press)

The current study reports on experiences of individuals in the early to moderate stages of dementia who demonstrated insight into risks and the ability to articulate their opinions, wishes and concerns. It is recognised that risks experienced can fundamentally change as dementia progresses, and that experiences may be very different for those in the more advanced stages of dementia. The focus here was on individuals who had mild to moderate dementia, who recognised this and were recognised as such by professionals.

As with all qualitative research, there is a limit to the objectivity of the process. The involvement of three members of the research team in analysis of data helped to reduce an individual bias. The three members of the research team involved in data analysis had backgrounds in either social work or community dementia support services. This was counterbalanced by involving four people with mild to moderate dementia in data analysis. Our theoretical perspective was on the principles and processes of conceptualising, assessing, communicating and managing risk in the delivery of health and social care services as well as an understanding of professional judgement and decision processes about care. **People were recruited for this study through the Health and Social Care Trusts, and the criteria included them having recently experienced a decision about daily life activities or their care. This may have meant that the sample were more aware of risk issues than the general population.**

While socio-demographic was collated (Table 5), data on ethnicity of participants, stage of dementia and socio-economic background were not gathered. Consequently diversity of representation among participants was not fully captured. There is no reason to suppose that the respondent group was in any way atypical of those coming to the memory clinics and other public services for people with mild to moderate dementia provided by the Health and Social Care Trusts in Northern Ireland. Professionals were asked to refer to the study any of their clients who met the inclusion criteria and were willing to participate during the study recruitment period.

*Defining and conceptualising risk*

Positive approaches to risk in dementia practice emphasise the importance of reaching shared understandings of risk (Manthorpe & Moriarty, 2010). The present study on the perspectives of people with dementia provides a complement to studies of professional perspectives, which can be dominated by organisational, liability and blame aspects (Taylor & Donnelly, 2006; Taylor & Campbell, 2012). Risk was fundamentally perceived as negative by participants with conceptualisations often grounded in emotional experiences. Meanings of risk also related to situations (or actions) and consequences of the latter. Earlier qualitative phases of the study found that family carers similarly conceived of risk as a negative consequence (Stevenson & Taylor, 2016) while professional constructs more often encompass potential positive aspects of risk taking (Stevenson & Taylor, 2017b). Notably 'risk as likelihood' seems essentially absent from conceptualisations across all stakeholder groups. Absence of conceptualisation of likelihood aspects of risk might lead to disproportionate responses to risk in daily life and care (MacDonald & MacDonald, 2010). Supporting people with dementia and families to think about likelihoods would facilitate positive risk taking while potentially militating against unnecessarily risk averse approaches.

Importantly, individuals with dementia who were interviewed did not habitually use the word 'risk' in discussions, suggesting that the concept itself is not central to the everyday language of this group. Previous research on the social construction of risk by young people (Austen, 2009), also found that risk was simply not part of the discourse of that group. While health and social care professionals routinely utilise the discourse of risk in their communications, it is important to be aware that persons with dementia (and families) may not do so. Similarly the language of emotions used by study participants may reflect something of the language of 'crisis' used by professionals in a study of an earlier study of risk and decision making by older people in general (Taylor et al., 2014). In the case of several participants, risk was defined by related concepts including safety or being careful. Use of such positive terms may therefore be more meaningful and acceptable in

practitioner-client discussions. Practitioners must also be cognisant of the unique context in which constructs of risk are formed including the individual's personal experiences, former occupation and personality.

#### *Risk communication in decision making processes*

Risk communication for individuals with dementia typically involved discussion of concerns around risks and making decisions in response to these concerns. In general terms, decisions in the context of risk or uncertainty were made by balancing benefits against harms, even if this was not clearly articulated (Taylor, 2006). However this was far from a strict Expected Utility model (Taylor, 2016) with consideration of probabilities and values for each option. Rather it was more of a problem-solving approach, involving consideration of actions that might be taken in response to apparent risks. This seems to relate to the framing of the decision task (Huber, Huber, & Bär, 2014), and may vary considerably between individuals. These actions often involved communication with others about the risks involved.

Communication of risk was formative in decision making processes. Both active and passive styles were evident. Active models involved individuals with dementia approaching family or professionals to discuss their concerns and wishes for example in relation to driving or medications. Pro-active approaches were also evident in choices around day to day activities or hobbies, for example strategies or supports in order to continue activities such as walking alone or cooking. More passive approaches sometimes centred on trusting the wishes of family or professional judgement. A recent literature review (Joseph-Williams, Elwyn, & Edwards, 2014) of patient-reported barriers and facilitators to shared decision making, found that trusting relationships with medical doctors could in some instances lead to passive involvement, although for other patients greater trust enabled them to raise issues, share concerns and ask questions. There are parallels in the current study. Increased information about risks may improve understanding and increase a sense of competence in making decisions, but at the same time it may complicate established caring practices and relationships (Barnes, Henwood, & Smith, 2016).

Recent literature on shared decision making (SDM) in dementia has emphasised a broad spectrum of what this process essentially entails (Miller et al., 2016). Models of SDM relative to dementia remain to be developed to ensure that professionals can support such processes (Groen-van de Ven et al., 2016). More generically, SDM has been described as 'knowing and understanding the best available evidence on the risks and benefits of all available options while ensuring that the patient's values are taken into account' (Stacey et al., 2014). Clearly communication of risks is fundamental to SDM. While importantly there was evidence of the values and wishes of people with dementia being expressed and respected in DM, sharing of risk-benefit information across options was less apparent. This need for a greater emphasis on exploration of options in dementia care DM has been recognised (Wolfs et al., 2011).

Decision aids are interventions that facilitate active patient (and where appropriate carer) engagement in a shared decision-making process by clearly stating the decision to be considered; providing unbiased, comprehensible, evidence-based information about risks and benefits across available options; and incorporating the individual's values and preferences (Coulter & Collins, 2011). A recent Cochrane Review (Stacey et al., 2014) summarised the highest quality evidence on the effectiveness of decision aids, finding that they improve patient knowledge regarding options and reduce decisional conflict (feeling uninformed and unclear about personal values). The need for further research involving the systematic development and evaluation of such tools addressing the wide range of health and social care issues relevant to dementia has been recognised in a recent review (Carmody, Traynor, & Steele, 2015). In particular, there is a notable lack of aids specifically for use by people with dementia to ensure these individuals are not excluded from important decisions about their care. Development of tools should incorporate good practice guidance on effective risk communication. A recent qualitative study (Stevenson & Taylor, 2017b) found that health and social care practitioners in dementia saw potential in using visual methods of communicating risk likelihoods, for example icon arrays, in practice. Further research on optimal formats of risk communication tools in this domain are needed as well as development of appropriate content, with parallels in other domains of health and social care services (Taylor & McKeown, 2013).

**iv. Discussion: Engagement of people with dementia in data analysis**  
(based on: Stevenson & Taylor, in press, a)

The analysis essentially improved the quality of the research by allowing for a more contextual understanding of findings as well as identifying sub-topics for further investigation in succeeding interviews. Conducting this phase of the analysis mid-way through data collection also allowed for an iterative approach whereby further data collection and conceptualisation of data were shaped by the emerging themes, in keeping with grounded theory methodology. Importantly the experience of involvement for users was reported to be positive. Previous reports have similarly demonstrated positive impact of involvement for users with dementia including empowerment and providing a sense of purpose and value (Tanner, 2012; Di Lorito et al., 2016). While the intrinsic value (Snape et al., 2014) of PPI in research would seem to be apparent, more robust measures of evaluation are necessary to effectively assess impact of user involvement on this level.

Limitations included that Co-researchers were not presented with the complete series of manuscripts therefore were not involved in analysing the full body of data. This decision was grounded in practical considerations such as time constraints, resources and the onerous demands of reading through hundreds of pages of transcripts. However, selection of quotes and extracts by the core research team is recognised as introducing potential bias into the analysis procedure. Lack of training and inexperience in analysis skills (Nind, 2011) of the co-research group must be acknowledged as a potential barrier to meaningful involvement. Data analysis presents challenges for experienced, skilled researchers (Coad & Evans, 2008), therefore co-researchers would have benefited from a number of capacity building sessions (Lundy et al., 2011) or training exercises (Cotterell, 2008; Di Lorito et al., 2016) to develop their understanding of the wider research study, their distinct role as co-researchers and analysis skills. Indeed, developing the 'research literacy' (Ward et al., 2010) of users will fundamentally empower groups to engage more meaningfully and equally as research partners, as well as preserving academic rigour (Tuffrey-Wijne & Butler, 2010). Use of creative visual representations and closer attention to the physical space in which user involvement takes place (Bartlett, Hick, Houston, Gardiner, & Wallace, 2015) should also be considered when designing both capacity building and co-research sessions (Bartlett, Hick, Houston, Gardiner, & Wallace, 2015).

Ensuring that users with dementia are not misled about the nature of their role in the research process is imperative for ethical practice in PPI. The conceptual distinction between user involvement as partners and participant involvement to generate research data (Smith et al., 2008) is often not inherently grasped. Indeed misunderstandings around PPI and variance in interpretations have been found to be evident even within the research community (Mathie et al., 2014). The distinction between involvement in analysis as a partner, rather than as a participant generating new data, must be continually reinforced to ensure co-researchers clearly understand the meaning of their involvement. Core researchers should also ensure that reflections from co-analysis sessions are not presented as findings in reports.

Lack of diversity in user networks has been repeatedly raised as an issue in PPI (Beresford, 2007; Brett et al., 2014b) meaning only the voices of certain service users are effectively influencing research planning and delivery. Users involved in the current study represented broad age ranges (including younger people with dementia) with an equal gender split. Ethnicity, religion and socio-economic background were not gathered which may represent a limitation. While the specific stage of dementia of co-researchers was not established, it was speculated that members of the group were in the earlier stages of dementia while the study involved those with early to mid-stage dementia. The user group may therefore not have adequately represented those in the more moderate stages of dementia, who might be considered to experience risks differently from those in the earlier phases. Issues around involving those with more advanced dementia in PPI need to be addressed in wider discourses to ensure this voice is not excluded (Di Lorito et al., 2016). More generally academics should take active measures to ensure the diverse representation of the user voice in their research with respect to age, ethnicity, experience, gender and socio-economic background.

Finally while users with dementia were involved in other stages of the research process including advising on interviewing an individual with dementia and reviewing dissemination

materials, the overall study would have been strengthened by enhanced involvement of users. For example users could have been consulted on data collection materials, piloting interview questions, reviewing participant information sheets and consent forms or in data gathering. Establishing a PPI group involving individuals with dementia over the life span of a longer term project must take into account how the researchers will adapt to potential changing needs and abilities of the users. On a practical level, enhanced involvement of users must be adequately resourced and factored into planning of research activities.

**v. Discussion: Qualitative study of family carers of a person with dementia**  
(based on: Stevenson & Taylor, 2016)

*Concepts and perceptions of risks*

Concepts and perceptions of risk in the real world rarely seem to conform to an actuarial appraisal of measures of likelihoods and consequences of potentially harmful choices (Taylor 2006). The findings of this study start to provide a conceptualisation distinctly different from that which underpins the literature on risk communication regarding the side effects of medicines (Bahri and Harrison-Woolrych 2012). A person's conceptualisation will affect how risks are approached in dementia care situations, which will ultimately influence outcomes for the person with dementia. Carers in this study tended to associate risk with negative terms such as harm or loss and focused on consequences rather than probabilities of risks. Issues most regularly cited as causing concern to carers were driving, falls, financial risks, getting lost and using electrical appliances. Professional concepts such as potential 'abuse' were notably lacking (Killick et al. 2015; Taylor et al. 2014). Notably the issues identified involve (unquantifiable) uncertainty rather than risks for which there exists some quantified knowledge base, for example measures of frequency of side effects of a licenced medication. The literature tends to focus on communication of quantifiable likelihoods of harm (*risk*) rather than the messier real world of uncertainty (Renn, Klinke, and van Asselt 2011; Stalker 2003) where outcomes may be known, but not their probabilities (Mousavi and Gigerenzer 2014).

The absence of quantified evidence against which to measure perceptions of these risks may mean that dementia carers are over- or under- estimating certain risks and outcomes. Previous research has found that individuals in general do not necessarily perceive risks accurately, for example overestimation of rare risks and underestimation of more common risks (Moore et al. 2008). Overestimation of more rare risks may lead to greater risk-aversion than might otherwise be justifiable, at least from the perspective of professionals and organisations. Conversely, underestimation of more common risks, may lead to individuals being placed at increased harm. It may be that some of the risk outcomes presenting most concern to carers are actually rare in occurrence. For example, while a systematic review found that drivers with dementia demonstrated poorer driving skills, it was concluded that studies did not consistently establish higher collision rates (Man-Son-Hing et al, 2007). A recent study by Bantry White and Montgomery (2015) quantifying incidence of getting lost in the dementia population in Ireland using police missing-person records, estimated the incidence to be 0.5 per cent. This was noted to be lower than estimates drawn from previous carer reports. In addition, it was found that people with dementia rarely sustained harm while missing. These studies relating to some of the risks most often cited as causing concern to carers demonstrate that actual incidence of these risks were low. However the possible severity of the outcomes - for example death in two cases in the Bantry White and Montgomery study - was potentially very high. The current study found that carers primarily emphasised assumed severity of events with little attention to the actual probabilities of these events as has been demonstrated in other areas of healthcare decision making for example breast cancer (Holmberg et al. 2015). Developing a robust knowledge of incidence of specific risks of concern in dementia care would support professionals, families and people with dementia to understand and manage risks more effectively by focusing not just on outcomes, but also likelihoods.

There are obvious challenges in forming a database of community care risks in that many incidents, such as minor injury from falls or cooking, may never be known to agencies and

therefore not recorded. In addition, it would be expected that there might be considerable variance in outcomes in relation to extent of injury and any psychological consequences. While focus would still need to be on individual circumstances and these statistics would not necessarily be predictive for the individual with dementia, they could enable stakeholders to look at the issue from a different perspective and provide some additional information to take into account when making decisions about risk.

#### *Risk communication*

Carers were found to engage in discussions about risk with professionals and also in some circumstances with their family member with dementia. Consultations took place with medical professionals, allied health professionals, social workers and staff from within the voluntary sectors. Discussions related not only to medical treatments, but also to supports in the home and to health and safety issues. Evidence of different perspectives was presented, in some instances carers reported disagreeing with decisions made by professionals. Manthorpe and Moriarty (2010) propose that reaching a shared understanding of risk, as distinct from shared agreement, between stakeholders (Manthorpe and Moriarty 2010) is therefore of fundamental importance. The process of risk communication would appear to be as significant as the outcome for family members. Carers wanted their concerns and wishes to be listened to, to be respected and for communication to be devoid of jargon. There is a growing body of research on risk communication in health and recommendations for practitioners – particularly in relation to side effects of medicines. Risk communication in relation to social care and the more nebulous risks in providing health and social care at home is less developed (Taylor 2006, 2013). One cause of this is no doubt the greater difficulty in carrying out robust research where the likelihood of harm is harder to quantify, and where the language for conceptualising risk – as addressed by this study – is less well developed.

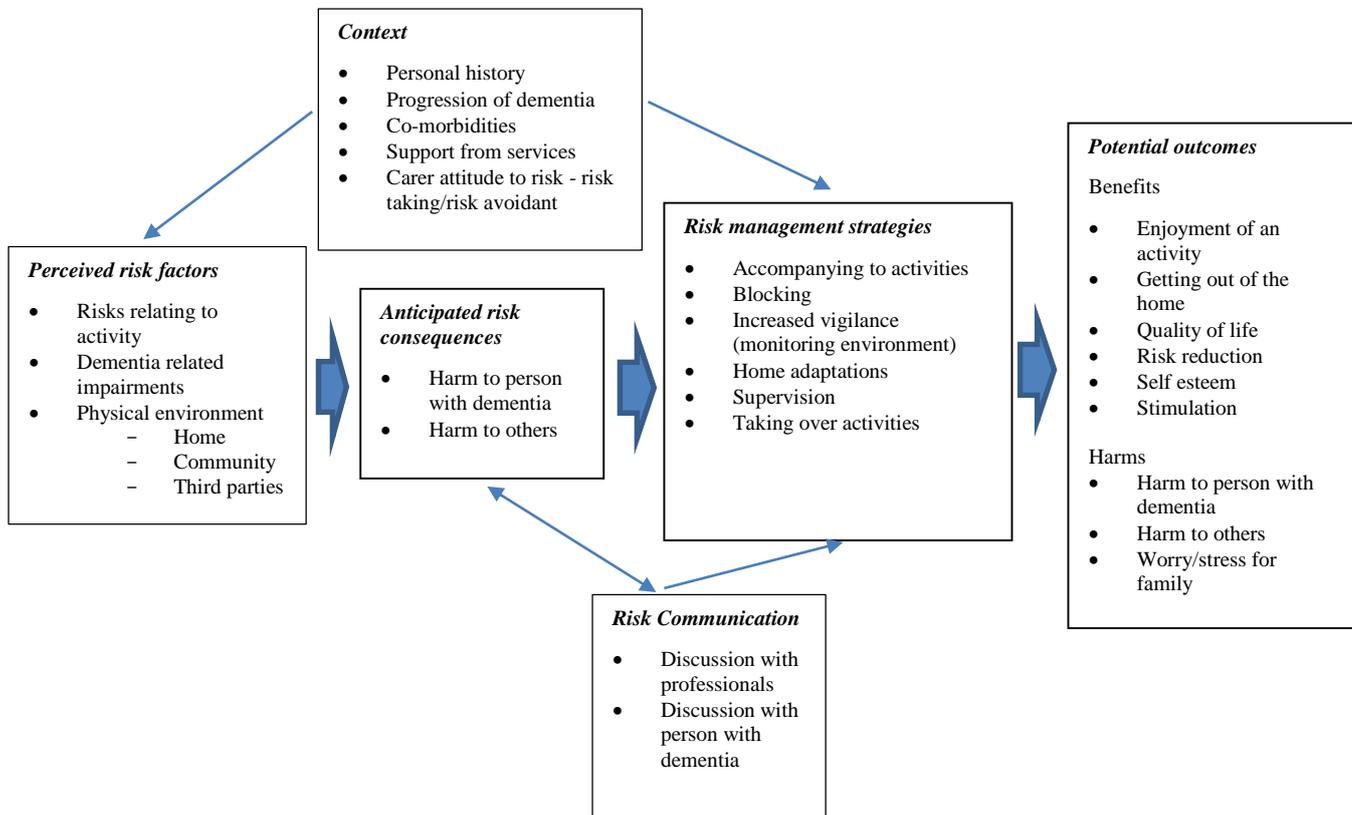
Discussions with care recipients tended to revolve around raising awareness of risks or prompting family members to take precautions to help minimize certain risks. Often participants chose not to discuss these issues with the person they cared for as they did not want to cause stress for the individual or it was felt that the individual would have difficulties comprehending the risk. While communicating with people with dementia in order to facilitate involvement in decision making is widely promoted in dementia care as a means of preserving autonomy, it may be that there is a reluctance to involve people with dementia for these reasons. Recent research exploring decision making processes of male carers of persons with dementia (Sampson and Clark 2015) found that while these carers generally involved care recipients in everyday choices that were predictable and task related such as household chores, decision making in relation to less controllable and more risky aspects of daily life - such as where injury, falls and challenging behaviours might be an issue - tended to be 'fear-driven' and to exclude the person with dementia. Supporting families to engage meaningfully with individuals with dementia in decisions concerning risks, while being aware of the anxiety this may cause to these carers, is therefore an important aspect of professional practice in dementia care.

#### *Informal risk management*

Communication about risks was found to have a role in how family carers managed everyday risks, with discussion about risk with health professionals and family members influencing approaches taken. Participants were in effect conducting informal processes of risk assessment and management for their family member with dementia living in the community involving identification of risk factors; anticipation of outcomes based on previous experience; and application of risk modification strategies. Input from health, social care and voluntary services in managing risks in turn influenced and supported this process (Taylor 2011, 2013). Informal practices of risk management undertaken by families are evident in the wider literature on risk and dementia. These processes have involved balancing rights and needs of the individual with dementia against risks (Robinson et al. 2007; Cott and Tierney 2013); making judgements on acceptability of specific risks (Cott and Tierney 2013); and applying measures to minimise harm (Lach et al. 1995; Buri and Dawson 2000; Gilmour, Gibson, and Campbell 2003; Walker et al. 2006). These informal processes of risk management have also been documented in other domains of care for example mental health (Ryan, 2002). Familial carers of people with dementia clearly take an active role in

dealing with risks in the community and may benefit from more directed education and support from services in this particular aspect of their caring role. From the study data a model to conceptualise risk communication in dementia care was developed (Figure 5) informed by model building in the domain of child abuse (Morrow and Smith 1995).

**Figure 5.** Risk communication within informal process of risk management by family carers



The model illustrates how family carers identified specific risk factors which they were concerned might lead to particular adverse consequences. These concerns then led carers to apply strategies to help minimise these risks. In some instances carers discussed risks with either professionals or the care recipient which in turn affected the approach taken. The overall process was mediated by the individual context with factors including personal history, progression of dementia, supports available and attitudes of family carers affecting both perception of risk factors and also approaches taken. While findings suggested that risk communication, in terms of discussion of risks with both professionals and care recipient, was not necessarily central to this process, the model illustrates how effective risk communication could support carers in managing risks in the community. Discourses about risk, with both care recipient and professionals, could both support carers in identifying appropriate solutions to risks while also in some instances, modifying concerns in relation to outcomes. Importantly the attitude of the carer to risk also forms part of the overall context, influencing perceptions of risk factors, approaches to risk and ultimately outcomes for the person with dementia. Both potential positive and negative outcomes of approaches to risk reported by carers are included in the model to reflect that consequences of any approach will always be uncertain.

**vi. Discussion: Qualitative study of professionals in community dementia services** (based on: Stevenson & Taylor, in press, b)

A limitation of this study was that initial coding was undertaken by only one member of the research team, potentially introducing researcher bias into the preliminary stages of analysis. This effect was substantially mitigated by involving two members of the research team in the selective, focused stage of coding where concepts and categories were refined and decisions made in relation to significance of data and contribution to knowledge.

Good practice in risk communication essentially involved multi-way communication processes that sensitively explored then integrated the perspectives and feelings of people with dementia and family members with professional expertise. Communications centred around both potential harms and potential benefits inherent in situations. Concepts underpinning these communications essentially defined risk as consequence with limited attention to the likelihood element of risk. Implications of these conceptualisations for practice are discussed below. Exploratory findings from this study suggest that presentation of risk information in numeric frequency and visual formats may enhance understanding of these risks by service users. These findings are corroborated in the more general research where natural frequency formats and icon arrays have been found to enhance understanding of likelihoods among older adults and those with low numeracy (Trevena *et al.*, 2006; Galesic *et al.*, 2009 a & b; Gigerenzer, 2011; Peters *et al.*, 2014). Further systematic research to establish optimal formats for communicating about risks to people with dementia is necessary to support service users and families to make informed decisions about their care.

Practitioners were dealing with a myriad of complex, inter-connected risks to which social workers and other professionals must attend in seeking to provide client-centred care (Taylor and Donnelly, 2006b; Taylor *et al.*, 2014). In addition to the complexity of inter-related domains of risk, professionals were also doing their best to manage a fluctuating landscape of dangers and possibilities as the individual changed in health, functional skills and behaviour; as there were changes in expectations and levels of support from family members; and as thresholds for acceptability of risks changed (Taylor and Donnelly, 2006a). This aspect of the findings highlighted the need for improved conceptualisation of risk within assessment tool design (Taylor, 2012b).

The recognition of disparate domains that must be considered, often simultaneously, in order to provide holistic care adds urgency to the need to bring together robust information on the risks in a format that best informs professionals 'on the ground' (Taylor *et al.*, 2015). For managers of social care (including social work) services, this need to provide sound, usable knowledge for their staff forms part of their responsibility for social care governance (Taylor and Campbell, 2011), the need being heightened by the inherently 'risky' nature of risk-taking decision making.

While previous research has established variations in perspectives of risk in dementia practice across different professions (Gilmour *et al.*, 2003; Clarke *et al.*, 2011), the fundamental differences in professional perspectives established in this study were situated in the team environment. Essentially approaches to risk were reported to differ primarily between those working as part of specialist dementia teams and those practicing in the more general acute sector. The multidisciplinary nature of dementia teams in Northern Ireland, integrating health and social care, may explain why differences between professions are less marked than in previously reported studies. As the focus groups did not involve participants from more general services, caution must be applied in drawing conclusions in relation to approaches in this sector.

Risk was primarily conceptualised as a consequence. Consequences were not only related to loss or undesirable events, but included also potentially positive outcomes. Subjective beliefs about acceptability were core to their conceptualisation. However concepts were not completely divorced from probability-based understandings of risk as such terms were used in staff discourse relating to the possibility of uncertain events (i.e. unknown probabilities of outcomes). When staff did use terms such as 'high probability', whether such terminology was rooted in any quantified data was unclear. Notably participants did not use the term 'uncertainty' in discourse. This may be reflective of a lack of understanding of the distinction between risk and uncertainty (Volz and Gigerenzer, 2012), as has been noted in social work by MacDonald and MacDonald (2010). The creation of more robust professional conceptualisations of risk, rather than simply defining risk as a catalogue of consequences, is necessary for the development of community dementia care practice. Likelihood aspects of risk must be assimilated into these conceptualisations to protect

against potential misallocation of resources (disproportionately driven by very low probability, high consequence events) and risk averse practice (MacDonald and MacDonald, 2010; Kearney, 2013).

The subjective element of risk concepts (perceptions of consequences and acceptability) can be understood by sociocultural theories of risk. These theories posit that understandings of risk are culturally embedded and constructed through societal processes, systems and discourses (Lupton, 1999). Perceptions of risk were in part a product of the risk assessment culture within which staff were operating including the 'risk-benefit assessment and management tool' used (Taylor and Moorhead, in press). For example concepts appeared to be shaped by the types of risks itemised in checklists, inclusion of 'benefits' in this tool, language used and verbal descriptions of likelihood (i.e. low, medium or high) within the standard tool (DHSSPS, 2012). This common conceptualisation into three domains strongly reflects the conceptualisation in the assessment tool introduced in that region within the past decade. This is a contrasting finding to data gathered a decade earlier when 'risk' was typically conceptualised into two domains: 'urgent' and 'non-urgent' (Taylor and Donnelly, 2006a) reflecting instead a legal concept of negligence where service providers in the UK are required to have some system for prioritising 'urgent' cases (Taylor, 2013). The profession is to be commended on the increased sophistication of the risk conceptualisation amongst practitioners.

If the professional conceptualisation has changed in parallel with the conceptualisation inherent in the regional risk assessment tool, that does not in itself tell us which is the cause and which the effect. However the widespread use of the tripartite conceptualisation across so many members of the focus groups suggests that the tool has influenced professionals, even if it is the leaders amongst those same professionals who have created the tool. This adds gravitas to the challenge of designing assessment tools. For example, if actuarial risk assessment involving calculations of possible outcomes drawing on available risk data (McDonald, 2010; Dixon and Robb, 2015) were incorporated into the risk assessment tool, would professionals be more encompassing of the likelihood aspect of risk?

Professional understandings also related to wider discourses on risk-taking in dementia (Manthorpe and Moriarty, 2010) and with older people more generally (Galesic *et al.*, 2009b). In particular, the concept of positive risk taking focuses on the benefits of taking risks, risk enablement and seeking shared understandings rather than on negative effects alone (Carr, 2010; Manthorpe and Moriarty, 2010; Morgan & Williamson, 2014). This highlights the possibility for developing a broader conceptual model of key elements in risk (and its communication) in dementia care. For example, by comparison with conventional 'static' approaches to calculating likelihoods in traditional decision research, it may be that multiple dimensions – such as legal and policy aspects, service delivery and prioritisation issues – will give a radically different and more 'dynamic' conceptualisation. Rather than the precision of subjective expected utility (with its calculation of values and likelihoods which are then multiplied) it may be that something along the lines of a 'fuzzy logic' is more useful (Brase, 2008; Taylor, 2012). For example, the conceptualisation developed by Paul Brearley (1982) of vulnerabilities, triggers and strengths (using different language) gives a rational structure to the process of weighing up risks but without the precise calculations. This may be regarded as a form of heuristic judgement that does not accord either with expected utility or with Aristotelian logic, but is none the less rational (Mousavi and Gigerenzer, 2014; Taylor, 2016).

As the profession continues to develop its evidence base for practice, it becomes ever more important that we have mechanisms to bring together evidence from research with practice wisdom. Information about professional processes of risk and decision making in dementia may inform, and be informed by, comparable processes in other domains of social work for example child protection or physical disability (Kearney, 2013; Taylor and McKeown, 2013).

**vii. Discussion: Survey of professionals in community dementia services**  
(based on: Taylor *et al.*, submitted)

The complete-questionnaire response rate was typical of busy professionals, but disappointing in that it was slightly below the desired number required for the power calculation for some questions.

From piloting, the whole questionnaire was estimated to take about 15 minutes to complete. The large number of partial completions is noteworthy. Our concern was that the numeracy question would be found daunting so this was put later in the questionnaire, although in fact participants dropped out incrementally from an early stage. It is speculated that respondents were prioritising their normal work, despite encouragement from managers for the study.

As community care increasingly involves considering possible harm, professionals need to develop risk communication knowledge and skills as part of their repertoire in order to manage diverse risks (Thwaites, Glasby, le Mesurier & Littlechild, 2017). The study of risk communication is bridging the gap between approaches to assessing and managing risk (Bantry-White & Montgomery, 2016) and understandings of professional judgement and decision making (Keller, Siegrist & Gutscher, 2006; Taylor, *in press*). However approaches to risk communication need to broaden beyond the better-established research area of numeric communication about the side effects of medicines (Bahri 2010) to encompass the diversity of risks, communication modes and contexts encountered in health and social care.

Numeracy scores were in the low-moderate range, consistent with studies demonstrating that even highly-educated samples have difficulty understanding numeric information (Reyna et al., 2009; Garcia-Retamero, Cokely, Wicki & Joeris, 2016). Numeracy scores have been found to be robust predictors of good judgement and decision making across financial, medical and strategic tasks (Ghazal, Cokely, & Garcia-Retamero, 2014). The BNT is validated for prediction of risk literacy, defined as the ability to accurately interpret and use information about risks (Cokely et al., 2012). While this study did not find a significant association between numeracy and accurate perceptions of risk likelihoods in practice-based scenarios, it did highlight the need to develop risk literacy among dementia care practitioners. This might include more explicit consideration of the issues explored in this study about how risks are conceptualised and communicated. Teaching about effective risk communication might also include an understanding of base rates for risk factors, and the use of natural frequencies rather than odds ratios and absolute rather than relative risks to communicate likelihoods (Gigerenzer, 2014; and see [www.ulster.ac.uk/dare](http://www.ulster.ac.uk/dare)).

Practitioners saw potential in using visual aids to communicate risk likelihoods, based on such as the ideas tested here (McDowell, 2016). Studies are required on types of icons (Arcia et al., 2016), adaptation to age (Finucane, 2008), and for patients and clients with impaired cognitive ability. Visual aids have been found to improve understanding of risks by increasing the amount of time less numerate individuals spend processing information and deliberating about risks (Garcia-Retamero et al., 2016). This is a novel and under-developed area of research. Ideas might be gleaned from such as the Harding Centre for Risk Literacy at the Max Planck Institute for Human Development in Berlin where *fact boxes* have been developed aimed at simple yet accurate communication about health care interventions and screening (Author's own 9 - McDowell, 2016). The potential in a field where patients and clients have impaired cognitive ability is apparent. Systematic development of visual aids and feasibility testing of such is needed.

Professionals generally over-estimated the frequency of occurrence of serious harmful events in the population. The 'actual' frequencies used were conservative estimates based on available data, so overestimation of risks was probably even higher than the figures presented here. There is diverse speculation on cognitive mechanisms underpinning judgements of risk frequencies (Harris & Corner, 2011; Hertwig, Pachur & Kurzenhäuser, 2005), in particular how these relate to decision processes (Meder, Mayrhofer, & Waldmann, 2014) and professional role (Taylor, 2017). People might become blasé when they experience (adverse) events frequently (Hertwig & Erev, 2009) although the present findings do not confirm that effect. Knowledgeable professionals should be able to distinguish between the 'seriousness' of the possible harm and its 'likelihood' even if their 'concern' relates more strongly to seriousness than to likelihoods (Stevenson & Taylor, *in press*, b). Further studies with larger sample sizes and increased power are needed to identify predictors of accuracy and related knowledge needs of staff. Robust data on base-rates for the risk domains commonly encountered is required to inform best practice.

There was variation in both verbal descriptors selected to describe numeric values and the numeric interpretation of words for probability of harm, reflecting the high levels of variability in the literature (Budescu, Por, & Broomell, 2012). As words rather than numbers are widely used (Stevenson & Taylor, *in press*, b) this is a particular area for research and development. Building

on the small scale studies on diverse topics (Mosteller & Youtz, 1990), now is the time for coherent work on developing standardised, evidence-based lexicons (where verbal terms used to communicate uncertainties are attached to specific numeric ranges) to improve risk communication in defined domains (Ho, Budescu, Dhami & Mandel, 2015). While guidance on the relationship between numbers and words for frequency is available for communicating side effects of medications ((European Commission, 2009), practitioner interpretations did not generally align with this EU guidance. This is perhaps reflected in that same Guidance indicating that both numbers and words should be used. The scaling of words against numbers for risks may be context specific (McDowell et al. 2016; Taylor in press). However the varied understanding of verbal expressions for probability information identified in this study raises questions about the need for greater consistency within specific contexts or domains of care provision. Research needs to focus on personal and contextual factors (Büchter et al., 2014) that influence the semantic logic. The development of guidance needs to involve clients, families and professionals involved in the domain (Taylor, 2017) as well as taking account of their diverse needs and expectations in relation to risk communication.

- **4 F Conclusions**

(Based on: Stevenson et al., 2016; Stevenson, McDowell et al., in press; Stevenson, Savage et al., in press; Stevenson & Taylor, in press, a; Stevenson & Taylor, 2016; Stevenson & Taylor, in press, b; Taylor et al., submitted)

This section focuses on achievements of this project in terms of the main theoretical and methodological advances; knowledge-building; and identified topics for future research. Part 6 below identifies the main practice and policy implications.

*Conclusions regarding literature searching*

The potential for rigorous literature searching is growing as computer technology advances. However the amount of published literature may be growing even faster! Searching for literature in social sciences is more challenging than in a discipline with a tightly defined terminology, such as medicine. As an example, consider the variations across history and geography for terms to describe intellectual disability (such as intellectual impairment, mental handicap, learning disability, mental disorder, etc.). Also, the concepts used in social work are shaped by judicial categories and terminology.

This study has added to the world-leading capacity of Ulster University in rigorous searching for research on social science topics. The paper published from this study builds on previous studies at the University (Best et al., 2014; Campbell et al., in press; McElhinney et al., 2016; McFadden et al., 2012; McGinn et al., in press) and leading to pioneering work in considering the place of web search engines in relation to literature searching (Bates et al., 2017). Such studies have created a knowledge base that is informing many other diverse studies through teaching materials (Taylor, 2003; Taylor et al., 2003; Taylor et al., 2015a) PhD classes both in the University and more widely (Taylor, 2004), conference presentations (Taylor, 2007; Taylor et al., 2015b) and contributions to reviewing articles for journals (Taylor, 2009).

*Conclusions regarding the literature review*

In the literature synthesis, findings were categorised according to four recurring themes in the literature: (1) *types of risk* identified, and whether these risks extended beyond concepts of physical safety risks to acknowledge also psychosocial risks; (2) *perceptions and constructions of risk* including social constructions of risk, perceptions of risk (and protective) factors, congruence of risk perceptions with reality and the concept of care crises in risk; (3) *approaches to dealing with risk* including acceptable risk taking and risk tolerance versus risk aversion; and (4) *decision making involving risk* by individuals with dementia that tended to focus on experimental studies analysing whether cognitive processes and emotional responses impaired decision making behaviour of participants with dementia, specifically in the domain of risk. In developing the methodology of systematic narrative reviews (reviews with a narrative synthesis but built on rigorous study identification) this provides a useful reflection. Building the themes from the literature itself reflects the approach of data analysis qualitative studies. In synthesis, alternative approaches include using a given policy or theoretical framework within which to locate studies. This study provides useful exemplar material for teaching PhD students and post-qualifying MSc classes.

Differences in concepts of and approaches towards risk both within and between groups were evident across the literature. These conceptualisations in turn are often formed through different experiences and perceptual bases. These variations in perspectives highlight the importance of communicating between all stakeholders when making care decisions involving risk. While different responses are not necessarily maladaptive, they do highlight the importance of communicating information about risks in a transparent and comprehensible way to support informed decision making. The absence of primary research papers on the topic of risk communication in dementia care warrants research in this field. Establishing a quantified knowledge base of risk outcomes in dementia care across a range of settings and risk categories would be beneficial to support the development of the most effective health and social care policies and practices.

### *Conclusions regarding people with dementia communicating risk*

Communications with a person with dementia regarding risk must take cognisance of what risk means to that individual and the language used to conceptualise it. Concepts of risk are often interconnected with emotional experiences. Risk was understood often as a situation, an action or an outcome rather than as a probability. The frame of reference for considering decisions in risk situations included elements of the context which might indicate or moderate the response to that risk. Involvement in risk-related decision making ranged from passive acceptance to pro-active approaches. Decision making was strongly connected with emotions. Encouragingly there was ample evidence of participants expressing their concerns and wishes around risks (both experienced and anticipated). However descriptions of how risk-benefit information was shared with participants were lacking.

Supporting people with dementia and families to consider and communicate about all aspects of risk is important to facilitate positive risk taking while avoiding disproportionately risk-averse approaches. Tools to support people with dementia to weigh up information on risks are needed to facilitate informed, shared decision making in practice. Visual formats of communicating risk (including interactive computer-assisted versions of these) could potentially improve understanding of the likelihood of harm, and perhaps also weightings of risks and benefits. Shared decision making in the context of risk will not be enabled by rhetoric alone, but requires rigorous research and development of appropriate aids for collaborative use by professionals, family members and the individual whose care is of concern.

### *Conclusions regarding family risk communication*

There is limited research on perceptions and communication of risk involving **family members**. In particular there is limited research specifically on family members of a person with dementia communicating risk, which this study starts to address. 'Risk' was generally connoted with terms such as danger, harm, vulnerability and accidents, and was conceptualised in terms of consequences rather than involving likelihoods. While risks of most concern to family members mainly related to matters of physical and personal safety, many family carers could also give examples of taking risks and did recognise the benefits of risk taking in relation to the wellbeing of the individual with dementia.

Family carers were often performing informal processes of risk assessment and risk management for their loved ones in the community. These processes involved identifying risk factors, judging potential outcomes of risks and applying strategies to manage these issues. Discussion of risks with professionals and (to a lesser extent) care recipients with dementia were frequent parts of the process, though often unrecognised for their value. A model of risk communication is developed illustrating how this plays a key role in informed, shared decision making where a family member has dementia, playing an important role in risk management processes in informal community dementia care. Through greater attention to their language and nuances of communication about risks professionals could help family carers to develop greater confidence and competence in their challenging task of managing risk in providing essential care at home for their family member with dementia.

### *Conclusions regarding professional risk communication*

Risk in health and social care dementia practice was conceptualised by professionals as a catalogue of consequences presenting both benefits and harms. A culture of positive risk taking was evident. The language of likelihood was used in risk discourses but in a subjective rather than numerate way. While staff routinely received numeric communications, they avoided using these themselves even when quantified data such as side effects of medication was available. Lack of confidence using numbers or not seeing such communications as necessary or appropriate were given as reasons. Preliminary findings on preferred formats for communicating and receiving risk information were inconclusive although they suggest that natural frequency and visual modes of communicating risks may enhance understandings of likelihoods for service users with dementia and practitioners.

Further research to inform practice should include the identification of frequency of risks (in particular those risks viewed as most problematic) in dementia care in order to develop a knowledge base against which likelihoods can be more accurately estimated; examination of how perceptions of risk frequency of health and social care professionals in this domain align with available data; a more refined analysis of how words, numbers and visual forms of quantified risk data are understood and communicated in practice; and investigation of the most appropriate formats for communicating risks with people with dementia to optimise understanding. A broad theoretical conceptualisation of risk communication in **health and** social care is also necessary. Finally promotion of statistical literacy amongst practitioners in dementia health and social care practice needs to be addressed. Such developments in dementia care need to be integrated with a broader conceptualisation of risk and its communication within social work more generally so that the profession can better serve clients and families.

Risk communication is at the conflux of interest between educating and empowering people regarding their own health and care, and in equipping health and social care professionals to reconceptualise their roles in a 'world of risk management'. These micro-skills represent a practice issue essential to community care policy. Health and social care professionals need to develop clarity of communication about risk and benefits, and thereby improve decision processes. This requires a knowledge base readily available in the workplace, as well as supportive mechanisms to enable connection to practice. Professional and employing bodies as well as individual professionals need to rise to the challenges – and possibilities – presented by the developing world of *risk literacy* in order to most effectively support patients, clients and families in making informed and reasoned decisions about their care in the face of risk and uncertainty.

This study concludes that:

- a) health and social care professionals make extensive use of numeric information although they more often communicate risk information with words;
- b) professionals frequently overestimate how often risks with severe outcomes occur; and
- c) verbal descriptors for numeric likelihoods of possible harm are widely interpreted.

#### *Conclusions regarding developing co-researcher methodology*

Involving individuals with dementia in the data analysis process improved quality of research by adding an expert perspective while also providing benefits for the person with dementia including opportunity to exercise skills and abilities. Care must be taken to avoid tokenism in such processes. In particular the exercise should meet the interests, abilities and skills of the co-research group. Further literature documenting involvement of people with dementia in data analysis is needed to provide guidance on this process to ensure that people with dementia can be involved in this specific domain of co-research in meaningful ways. Methods for effectively evaluating impact and capacity building are also necessary. More generally, evidence based models of good practice of PPI in dementia research are needed.

#### *Summary of main conclusions*

- *Database search methods*
  - The CINAHL, PsycInfo, and Social Science Citation Index bibliographic databases retrieved the highest number of relevant articles on the topic, with the Google Scholar web search engine also performing well.
  - The analysis of the 'sort by relevance' function was innovative as this is a developing feature of bibliographic databases.
  - The framing of the search question and the development of search terminology will prove useful for the methodology of future literature reviews on related topics.
- *Literature synthesis*
  - We were unable to identify any previous research specifically on risk communication in dementia care.
  - Findings were synthesised according to recurring themes in the literature:
    - types of risk;
    - perceptions and constructions of risk;

- approaches to dealing with risk; and
- decision making involving risk.
- *Empirical findings*
  - Individuals with dementia and family members communicated with a wide range of professionals regarding concerns about risks.
  - The identification of risk situations and adaptive strategies will be useful for information and discussion with individuals, families and practitioners, and to inform training.
  - The main focus of attention in terms of 'risk' was more about seriousness than likelihood of consequences.
  - Consideration of 'risk' was generally linked to decisions about what one could or should do in response to identified concerns.
  - Family members conceptualised their role more as managing risk than as trying to eliminate it, and a model of this has been developed.
  - Professionals were generally more likely to consider the benefits inherent in some risk-taking decisions than were individuals with dementia or family members.
  - Professionals regularly received numeric information about risks, but generally communicated about risks without numbers.
  - Professionals generally over-estimated the frequency of occurrence of serious harmful events.
  - Professionals saw potential benefit in the development of visual means of communicating risks in dementia care.
- *Other benefits*
  - A method of engaging people with mild-moderate dementia in analysis of qualitative research data has been developed and found useful.
  - A public information leaflet has been produced in collaboration with the appropriate departments of the Public Health Agency and the Health and Social Care Board.
  - Professionals in the field have been informed through summary material and presentations.
  - The collaborative work with the Health and Social Care Trusts, the Alzheimer's Society and the Max Planck Institute for Human Development in Berlin has helped to forge relationships that will support future research endeavours.

## 5. Personal and Public Involvement

People with dementia and family carers were involved in providing advice to the research team (on interviewing a person with dementia); in analysing qualitative data about the interviews with people with dementia; and in reviewing dissemination materials. User involvement was co-ordinated through the Alzheimer's Society (AS), the staff of which were key collaborators in the study.

### *Advice on interviewing a person with dementia*

Prior to data collection, the research team met with an individual with dementia recruited through AS who provided advice on interviewing including communication tips, building a respectful rapport and practical guidance for dealing with scenarios that may arise during the process, for example if the interviewee became upset.

### *Review of dissemination materials*

A public information leaflet was co-produced with people with dementia and family carers. Members of Alzheimer's Society Service User Review Panel, Belfast Group selected quotes for the publication, provided advice on the order in which 'practical tips' should be presented, and advice on language used. Family carers from Alzheimer's Society Antrim carer's support group then reviewed and commented on the revised draft. No major changes were suggested by family carers. This booklet will be published as part of the PHA Dementia Together NI series of leaflets. Refinement of this draft leaflet **continues** with staff from the Public Health Agency and the Health and Social Care Board.

### *Analysis of qualitative data*

Individuals with dementia were involved as co-researchers in analysis of qualitative data from the interviews with people with dementia. These co-researchers had not participated in these interviews. Co-researchers were involved in deriving meaning from the data, identifying and connecting themes. Co-researchers were recruited through one of the recently formed Alzheimer's Society Service User Review Panels (SURPs) in Northern Ireland. SURPs are small groups of people with dementia who convene with a remit to discuss and review a diverse range of topics relevant to Alzheimer's Society and external organisations. Topics may include for example review of organisational strategies or critiquing information materials. The SURP was therefore seen as an appropriate forum for the analysis, fitting with the group remit as well as the interests and abilities of members. A request application form was submitted prior to attending the SURP, in accordance with Alzheimer's Society protocol. This afforded the group opportunity to make an informed, non-pressurised decision about whether they would like to be part of the analysis process. Ethical approval for this additional part of the study was granted by the Office of Research Ethics Committee Northern Ireland (OREC NI) as an amendment to the original ethical approval. **These four individuals were described as co-researchers assisting the researchers in this analysis task as described above. They were not described as 'participants' in the way that the word might be used in relation to the respondents to the interview study.** Individuals with dementia who had previously participated in interviews had signed consent forms allowing their anonymised data to be used in the analysis sessions. Four individuals with dementia were involved as co-researchers in analysis of findings (male (2), female (2); Under 65 (2), 70-74 (1), 75-79 (1)). Further detail of the analysis process is described, reflections on the exercise provided and impact discussed in the main body of this report above.

## 6. Practice and policy implications

Below is the current draft text of the dissemination to professionals which will be hosted on the Ulster University website once finalised. This includes the main practice and policy implications in language suited to professionals in practice. The text was piloted with front line practitioners from social work, speech and language therapy, and nursing.



### Risk communication in dementia care practice

#### ***Why is risk communication important?***

Living with dementia can mean that some individuals are more likely to experience risks in daily life. These may include risks to physical safety or to emotional wellbeing. Risks experienced will be unique for each individual depending on factors including:

- the progression of their dementia
- co-morbidities
- supports in place
- their environment.

Health and social care practice in dementia care often involves making judgments involving risks or providing advice to people with dementia and families around risks. Risk communication in dementia care involves *sharing information* and *sharing ideas and preferences* about risks between people with dementia, family carers and health & social care practitioners. Risk communication should be central to shared decision making processes. In order to make informed decisions about their health and social care, people with dementia and their families need to be aware of the potential benefits and harms in the different options available to them.

This document summarises key findings from a research project at Ulster University on *Risk Communication in Dementia Care*. Practical tips based on these findings are included. Information on research methodology is given later in this summary.

#### ***What does risk mean to people with dementia, family carers and health & social care practitioners?***

Risk means different things to different people. Risks that are acceptable to one person, might not be to another. Acceptability can also change over time. Developing shared understandings of risk between people with dementia, families and practitioners is important to ensure that communications are meaningful and person centred.

#### ***What did people living with dementia think about risks?***

*"It's really important that you can be independent but safe."*

*"If you don't take a chance you get nowhere!"*

- Risk was associated with danger and vulnerability for some individuals.
- Risk sometimes held emotional connotations for example feelings of fear or worry.
- For some individuals, risk made them think about being more careful.
- Others said they did not usually think about risks in their daily life.
- Risk was often thought of as a situation or action having an undesired consequence. Sometimes these consequences had actually happened, sometimes they were things that individuals worried would happen.

- Understandings of risk were informed by life history (including former occupation), psychological processes (personality and emotions) and media, and are continually shaped by experiences and situations encountered.
- The risks that people with dementia talked about the most were going out alone, driving, using the oven, looking after grandchildren alone and hobbies including gardening, socialising or woodwork.
- There was ample evidence of participants with dementia expressing their concerns and wishes around risks with practitioners and family members.
- ~~Both active and passive models of decision making were evident.~~
- Decision making (involving risks) for people with dementia was often strongly connected with emotions.

### **What did family carers think about risks?**

*“Risk is not to be avoided. It is to be managed.”*

- Family carers often associated risk with danger, harm, accidents and being vulnerable.
- Risks were often a source of stress and worry for families.
- Family carers thought of risk as a (negative) consequence rather than as the likelihood.
- Some family members agreed that taking risks could also lead to worthwhile outcomes that outweighed the risk.
- The risks that family carers were most concerned about were driving, falls, financial risks, getting lost and accidents from using electrical appliances.
- For family carers, risk communication often centred on making the person with dementia aware of risks.

### **What did health & social care practitioners think about risks?**

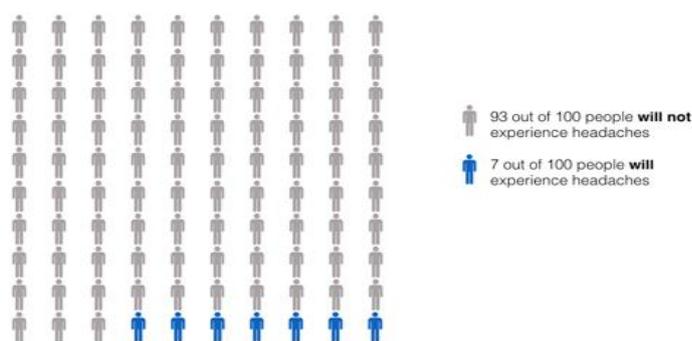
*“Our role is not to come in and dictate to people what’s acceptable or what’s not. It’s about supporting them in what they want to do and keeping them safe”*

- Practitioners saw taking risks as having potential positive and negative outcomes.
- Participants talked about supporting and enabling individuals to take positive risks.
- Practitioners generally did not refer to the likelihood aspect of risk i.e. how often certain risk outcomes were actually occurring.
- Concepts were influenced by the risk management culture, for example risk assessment tools and professional terms such as ‘proportionality’ and ‘liberty.’ Wider discourse on positive risk taking also influenced concepts.
- The risks that concerned practitioners the most included people with dementia being mistreated by others, falling, depression, medications mismanagement and fire.

### **Communicating risk**

- Numeracy is relevant to risk communication in dementia care practice. 86% of health and social care practitioners who participated in our survey were using numbers in their roles. This included assessment scores (for example the Mini Mental State Exam), statistics from team databases and information relating to frequency of side effects of medicines.
- However, practitioners reported that they were typically not using number expressions (such as percentages or frequencies) in their communications with clients and other staff.
- Reasons provided for not using numeric expressions included clients not asking for numbers; staff not feeling comfortable using numbers; or not seeing such communications as appropriate.
- Practitioners showed a preference for verbal expressions of likelihood of side effects of medications for example ‘low’ or ‘most common.’ Such verbal expressions by their very nature are less precise and more ambiguous than using numbers.
- Professionals demonstrated a high level of variance in the verbal expressions they selected as corresponding to specified numeric values. For example 39% of survey respondents described 21 out of 1000 as ‘rare’ while 45% described this value as ‘uncommon.’

- There was also a high level of variance in the numeric values (estimated out of 1000) assigned to the terms 'common' and 'rare'. This high level of variability may lead to a lack of consistency in communications of risk likelihoods in practice.
- Practitioners were markedly overestimating how frequently low probability risks with severe outcomes were actually occurring, compared to recorded data. These risks included having a car accident, causing a fire, being hospitalised after a fall or going missing. This may mean that professionals are being more risk averse than they need to be.
- 80% of practitioners expressed a preference for using visual formats for communicating side effects of medicines to complement verbal statements (icon arrays, 51%; bar charts 29%) rather than a verbal frequency statement alone. Below is an example of an 'icon array' showing how many people out of 100 who take a medication will experience headaches.



- Challenges for communicating risks in practice (ranked in descending order of concern) included: conflicting ideas on client's best interests; person with dementia lacking insight into the risk; unrealistic expectations of services; risk of damage to professional/client relationship; lack of data on likelihoods; and fear of complaint.

### **Practical recommendations for practitioners**

- Be aware of the individual's personal history and how this may make them think about risks – for example their job history, hobbies, personality and experiences.  
*"We might go into a house and think 'gosh that's wild risky' [but] they might have been doing it all of their life"* (professional)
- People with dementia should be supported wherever possible to think about risks for themselves rather than being told what to do. This could involve sensitively bringing the risk to their attention e.g. 'how are you managing with...' or 'the traffic was very bad today, do you also find that?'  
*"I don't like to be treated like a child. I am quite happy to be independent, but sensible"* (person with a dementia)  
*"Instead of telling the person the risk, it's trying to get them to think about and identify the risks themselves"* (professional)
- Choose the right time to talk about the risk with the person with dementia. Some individuals find that there are certain times of the day when they feel more confident making choices.
- Give the person with dementia time to think before making a decision.  
*"You see I am trying to make a decision but there's millions of things going through my head too"* (person with a dementia)
- If you are worried about a person with dementia, sensitively talk through the reasons why you think it may not be safe for that person to continue with a particular activity.  
*"If it makes sense to me then that's fine"* (person with a dementia)
- Focus on solutions rather than problems e.g. 'have you thought about trying...'
- Use positive language in communications for example words such as 'safety' or 'independence.'

- Write down any important points for the individual as a visual reminder of the conversation.
- Practical information for family carers should include advice on dealing with risk in everyday life. This could include general guidance in the form of group information sessions, written materials or personalised advice.
- Translate important professional concepts such as *positive risk taking* and *proportionality* into everyday language for families and people with dementia.
- Consider using visual aids to communicate risks to people with dementia and families.
- Assemble data on frequency of risk outcomes as a reference point for staff. Overestimations of risk might be expected to lead to risk averse practice. Communicating more accurate likelihoods to service users may encourage people with dementia and families to worry less about risks that are actually very unlikely to occur.

## **Research methodology**

### ***What we were interested in***

- How risk is conceptualised by people with dementia, family carers and health and social care practitioners.
- How these groups communicate about risks with each other.
- How this communication can be improved to support people with dementia and families to make decisions about their daily life and care.

### ***What the study involved***

- A systematic narrative literature review of 'risk concepts' and 'risk communication' in dementia.
- Interviews with 17 people with dementia who had recently made a decision where they had to think about risks, for example whether to continue driving, move to supported living accommodation or use assistive technology.
- Five focus groups involving 22 family carers.
- Five focus groups involving 35 health and social care practitioners working in dementia care.
- Web-administered survey with 70 health and social care practitioners (plus 55 partial responses).  
Health and Social Care practitioners included nurses, social workers, doctors, occupational therapists, speech & language therapists, psychologists and support staff.

For more information on this study and for links to published journal articles, please go to <http://www.socsci.ulster.ac.uk/irss/risk.html>

## **Useful reading**

*Risk Communication in Dementia Study* website. <http://www.socsci.ulster.ac.uk/irss/risk.html>

Manthorpe, J. and Moriarty, J. (2010) *Nothing ventured, nothing gained: Risk guidance for people with dementia*, London, Department of Health, available online at <https://www.gov.uk/government/publications/nothing-ventured-nothing-gained-risk-guidance-for-people-with-dementia>

Morgan, S. and Williamson, T. (2014) *How can 'positive risk-taking' help build dementia-friendly communities?*, York, Joseph Rowntree Foundation, available online at <http://www.jrf.org.uk/sites/files/jrf/Positive-risk-taking-dementia-summary.pdf>

Sedgewick, R. (2014) *Communicating effectively with a person living with a dementia*. HSC Public Health Agency: Belfast. Available online at [http://www.publichealth.hscni.net/sites/default/files/dementia%20booklet\\_07\\_15.pdf](http://www.publichealth.hscni.net/sites/default/files/dementia%20booklet_07_15.pdf)

## 7. Pathways to impact

The pathways to impact for this project include, in addition to the comments in the above *Personal and Public Involvement* (section 5) and *Practice and Policy Implications* (section 6):

- A. peer-reviewed journal articles;
- B. oral conference presentations;
- C. poster conference presentations;
- D. web dissemination to professionals; and
- E. other mechanisms to impact.

These are discussed in turn.

### • 7 A Journal outputs

As in the grant application, a journal article has been prepared in relation to each main stage of the project. All papers except the paper on the final stage of the project have now been accepted for publication in high-quality peer-reviewed journals. The papers include the addition of the paper on involving co-researchers in data analysis further to those promised in the grant application.

- Stevenson M, Taylor BJ & Knox J (2016). Risk in dementia care: searching for the evidence. *Health, Risk and Society*, 18(1-2), 4-20. doi:10.1080/13698575.2015.1119256.  
(Cited as: Stevenson et al., 2016)
- Stevenson M, McDowell ME & Taylor BJ (in press). Concepts for communication about risk in dementia care: A review of the literature. *Dementia: The International Journal of Social Research and Practice*. doi:10.1177/1471301216647542 [Advance Access published 13 May 2016] (Cited as Stevenson, McDowell et al., in press)
- Stevenson M, Savage B & Taylor BJ (in press) Perception and communication of risk in decision making by persons with a dementia. *Dementia: the International Journal of Social Research and Practice*, doi:10.1177/1471301217704119. [Accepted 14 March 2017]  
(Cited as Stevenson, Savage et al., in press)
- Stevenson M & Taylor BJ (in press) Involving individuals with dementia as co-researchers in analysis of findings from a qualitative study. *Dementia: the International Journal of Social Research and Practice*, doi:10.1177/1471301217690904. [accepted 5 Jan 2017]  
(Cited as Stevenson & Taylor, in press, a)
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(Cited as Stevenson & Taylor, 2016)
- Stevenson M & Taylor BJ (in press) Risk communication in dementia care: professional perspectives on consequences, likelihood, words and numbers. *British Journal of Social Work*, doi:10.1093/bjsw/bcw161. [accepted 13 October 2016]  
(Cited as Stevenson & Taylor, in press, b)
- Taylor BJ, Stevenson M & McDowell M (submitted 10juni17) Communicating risk in dementia care: survey of health and social care professionals. Submitted to *Health and Social Care in the Community* (Cited as Taylor et al., submitted)

### • 7 B Oral dissemination

A number of oral presentations have been undertaken to disseminate the work, in Denmark, Germany, Portugal and the UK.

- Stevenson M & Taylor BJ (June 2015). *Risk taking & dementia*. Department of Finance and Personnel: Dementia Innovation Laboratory, Belfast.
- Stevenson M & Taylor BJ (November 2015). *Risk communication in dementia care: experiences of family carers*. Ulster University: Integrated Care in Dementia symposium.
- Stevenson M & Taylor BJ (March 2016). *How do people with dementia and family members conceptualise and approach risk?* Decisions, Assessments, Risk and Evidence Studies in Social Work seminar series: Ulster University.
- Stevenson M & Taylor BJ (December 2016). *Risk communication in dementia: key messages from a multistage study*. HSC NI Dementia Navigators Trust-wide meeting: Clotworthy House, Antrim.
- Stevenson M & Taylor BJ (February 2017). *Risk communication in dementia: survey of community services professionals*. Decisions, Assessments, Risk and Evidence Studies in Social Work seminar series: Ulster University.
- Stevenson M & Taylor BJ (February 2017). *Risk communication in dementia: key messages from a multistage study*. Western Health & Social Care Trust: Waterside Hospital, Derry.
- Stevenson M & Taylor BJ (March 2017). *Involving people with dementia as co-researchers in analysis of qualitative data*. Social Work & Social Care Research in Practice conference: Belfast Castle.
- Taylor BJ, McDowell & Stevenson M (June 2015) *Concepts and Communication about Risk in Dementia Care: Project Outline and Literature Synthesis*. Harding Centre for Risk Literacy, Max Planck Institute for Human Development, Berlin.
- Taylor BJ & Stevenson M (April 2016). *Risk communication in dementia care: experiences of family carers*. Oral presentation at Sixth European Conference for Social Work Research: Catholic University of Lisbon, Portugal.
- Taylor BJ & Stevenson M (April 2017). *Telling it with words AND numbers?: Survey of health and social care professionals on communicating risk in dementia care*. Seventh European Conference for Social Work Research: Aalborg University, Denmark.
- Taylor BJ & Stevenson M (May 2017) *Risk Communication by Dementia Care Professionals: Survey Findings*. Oral presentation at the Harding Centre for Risk Literacy and the Adaptive Behaviour and Cognition Research Group, Max Planck Institute for Human Development, Berlin.
- **7 C Conference poster dissemination**
- Stevenson M & Taylor BJ (June 2016) *Risk communication and decisions in dementia: Professional practice perspectives*. Poster presented at the 16<sup>th</sup> European Meeting of the Society for Medical Decision Making, Royal College of General Practitioners, London.
- Stevenson M & Taylor BJ (July 2016) *Risk communication and decisions in dementia: Professional practice perspectives*. Poster presented at the 4<sup>th</sup> Decisions, Assessment, Risk

*Risk Communication in Dementia Care*. CI: Prof Brian Taylor, Ulster University. Sept 2017

*and Evidence in Social Work Biennial International Symposium*, Templepatrick: Northern Ireland.

- Taylor BJ & Stevenson M (2016, September) *Communicating Risk in Community Dementia Care: Professional Perspectives and Perceptions*. Poster presented at 14th International Conference on Communication in Healthcare (ICCH) organized by the European Association for Communication in Healthcare (EACH), Heidelberg University, Germany.

- **7 D Web dissemination to professionals**

A 'leaflet' for professionals **will be** hosted on the Ulster University website within the Decision, Assessment, Risk and Evidence research cluster web pages. The current draft text is included in section 6 above. Progress is currently awaiting a major restructuring of the University website, as development of new web materials has been put on hold for a period. The weblink for this will then be circulated through the HSC Knowledge Exchange email system and other channels.

- **7 E Other knowledge transfer**

*Dissemination to local service managers*

Throughout the project the Chief Investigator and Research Assistant joined regularly the bi-monthly meetings of the managers of dementia services in each of the HSC Trusts. This provided an important communication channel for the project, to report on progress and seek their views on the next steps. Through this process these managers were kept fully informed about the progress and findings of the project. Similarly, our contact within Alzheimer's Society has ensured communication with that organisation.

*Book material*

In April 2017 the third edition of the Chief Investigator's book on risk in social work was published. This third edition cites the articles already published from this project (i.e. those with a doi) as at January 2017. It is anticipated that papers published subsequent to this will be cited in the fourth edition.

Taylor BJ (2017) *Decision Making, Assessment and Risk in Social Work (3<sup>rd</sup> Ed.)*. London: Sage.

*International influence*

Although the Advisory Panel members were recruited primarily in relation to what they could contribute to the project, there was of course a two-way process whereby they were informed about the project. The list of Advisory Panel members is in the Acknowledgements section below.

*Dissemination to policy makers*

Throughout this project communication has been maintained with Dr Priya Bahri, Principal Scientific Administrator at the European Medicines Agency. Dr Bahri has a lead role in formulating policy on communication about risks of medicines for the Agency, which in turn advises the relevant European Union body in formulating directives to member countries. Although Dr Bahri was unable to serve on the Advisory Panel in a formal capacity, she has taken a keen interest in the project.

*Wider impact*

This project was an important element in the Chief Investigator being invited to author a key chapter in a forthcoming book on research in relation to risk communication about medicines.

Taylor BJ and Moorhead A (**in press**) Social Sciences [chapter in Part II: Tackling the challenges – Considerations and methods for medicinal product risk communication research]. In Bahri P (Ed.) *Communicating about Risks and Safe Use of Medicines: Real Life and Applied Research*. Heidelberg: Springer.

*Dissemination to education and training providers*

In addition to the above mechanisms, informal opportunities to disseminate information about the project have been used throughout the life of the project. This has included in particular colleagues in social work education and training. When the final journal article from the project is accepted, staff teaching the health and social care professions at both Queen's University Belfast and Ulster University will be informed through a list of publications so that these can be added to course reading lists. This list of articles will also be made available through:

2. the all-Ireland network of Social Work academics (through the emailing list) and
3. the *Decisions, Assessment and Risk Special Interest Group* of the *European Social Work Research Association*.

## 8. Acknowledgements

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We would like to thank the Harding Centre for Risk Literacy at the Max Planck Institute for Human Development, Berlin for their expertise and support throughout the research. The research environment that you have created nourished our creativity!

We would like to thank the senior managers of dementia services in the five Health and Social Care Trusts in Northern Ireland without whose support this project would not have started! Your ongoing support was very much appreciated.

We would like to thank Alzheimer's Society for their collaboration in the interviews of people with dementia; for facilitating access to the Service User Review Panel; and for their support in recruitment and co-facilitation of the focus groups with family carers. You kept us grounded!

We would like to thank all those who participated in the study: people with dementia; the participants from the Belfast group of the *Alzheimer's Society Service User Review Panel*, for their involvement as co-researchers; family carers; and the professionals in community dementia services who took time to participate in the focus groups and respond to the survey. Your enthusiasm encouraged us onwards!

We would like to thank our Advisory Panel for their advice on various aspects of the project. Your guidance helped to polish our endeavours!

- Dr Eleanor Bantry White, Lecturer in Social Work, University College Cork
- Ashley Brown, Outreach Nurse Practitioner, Northern Health & Social Care Trust [from 2016]
- Dr Edward Cokely, Presidential Research Professor at the *National Institute for Risk and Resilience*, and Associate Professor of Psychology at University of Oklahoma, USA
- Dr Frank Dobbs, General Medical Practitioner & Professor Emeritus in Epidemiology, Ulster University, Northern Ireland [from January 2015]
- Dr Rocio Garcia-Retamero, Associate Professor: Experimental Psychology Department, and Senior Member: *Learning, Emotion, and Decision Research Group*, University of Granada, Spain [from May 2015]
- Mrs Geraldine Fleming, Social Care Commissioning Lead, Mental Health & Learning Disability, Health and Social Care Board
- Professor Dr Gerd Gigerenzer, Director of the *Harding Centre for Risk Literacy*, and Director, *Adaptive Behaviour and Cognition (ABC) Research Group*; at the Max Planck Institute for Human Development, Berlin
- Marc Harvey, Team Leader, Dementia Behavioural Team, Northern Health & Social Care Trust [from 2016]
- Professor Gerry Leavey, Director, Bamford Institute for Mental Health, University Ulster
- Professor Brendan McCormack, previously Professor of Nursing Research, Ulster University and Chair of the Board of Trustees of AgeNI [to summer 2015]
- Dr Anne Moorehead, Lecturer in Health and Interpersonal Communication & leader of the Health Communication Research Group, School of Communication, Ulster University
- Professor Assumpta Ryan, School of Nursing, Ulster University [from January 2016]
- Mrs Ruth Sedgewick, Speech & Language Therapist, Belfast Health & Social Care Trust [from Mar 2016]

We are grateful to the organisations, particularly Ulster University, that made it possible to attend conferences and other events where the study findings were disseminated.

Last but not least, the Chief Investigator would like to thank Miss Mabel Stevenson, Research Assistant, who undertook the detailed work on this project in an exemplary fashion, and Dr Michelle McDowell, our principal collaborator at the Harding Centre for Risk Literacy, Max Planck Institute for Human Development, Berlin, who provided such a warm welcome to their marvellous research environment as well as contributing her international expertise in risk communication.

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## 10. Appendices

- **Appendix 1: Data Extraction Table for Literature Review**

Study details	Participants	Method & Analysis	Types of risks identified	Perceived risk/protective factors	Relevant themes
Adams et al. (2001) United Kingdom	N=24 ( <i>carers</i> ); 9 male, 15 female.	Qualitative. Recording of domiciliary meetings between caregivers and professionals. Discourse analysis.	Alcohol.	Not specified.	<i>Perceptions and constructions of risk:</i> Social construction of risk.
Beattie et al. (2005) United Kingdom	N=61 ( <i>professionals and paid carers working with YPWD<sup>1</sup>, minority groups</i> ).	Qualitative. Interviews. Grounded theory.	Risks to others (aggression, shouting), wandering/escaping from facilities.	Not specified.	<i>Perceptions and constructions of risk:</i> Social construction of risk.
Beattie, A. et al. (2004) United Kingdom	N=14 ( <i>YPWD</i> ); 9 male, 5 female; mean age 59.43 yrs (range 41 - 66 yrs); 10 living with carers at home, 3 living alone and 1 in a residential home.	Qualitative. Semi-structured interviews. Grounded theory.	Wandering and using public transport.	Not specified.	<i>Approaches towards risk:</i> Risk-tolerance, risk-aversion and risk-balancing.

<sup>a</sup> YWPD: younger person with dementia

Bond, J. et al. (2002) United Kingdom	N=1 ( <i>PWD</i> <sup>2</sup> ); AD <sup>3</sup> , male. N=1 ( <i>carer</i> ); female, spousal carer.	Qualitative. Case study discussion.	Personal injury, getting lost.	Engaging in a leisure activity, lack of insight of PWD.	<i>Approaches towards risk</i> ; Risk-tolerance, risk-aversion and risk-balancing.
Buri, H., & Dawson, P. (2000) United Kingdom	Stage 1: N=7 ( <i>carers</i> ); caring for parent or spouse. Stage 2: N=6 ( <i>carers</i> ); 1 husband, 3 daughters, 2 son-in-laws; 3 male, 3 female. Care recipients; moderate to severe dementia; wife, mother and 2 mother-in-laws; 0 male, 4 female.	Qualitative. Stage 1: pre-pilot focus group, unstructured. Stage 2: unstructured interviews. Grounded theory.	Falls.	Environment and supervision	<i>Perceptions &amp; constructions of risk</i> . Care crises and risk.
Clarke, C. L. (2000) United Kingdom	N=23 ( <i>carers</i> ). N=85 ( <i>professionals</i> ); health, social and voluntary sectors.	Qualitative. Phase 1: personal document (diaries) and interviews. Phase 2: questionnaires. Phase 3: diary and interview. Grounded theory.	Not specified - reported that risk taking extended beyond physical care into psychological and social care.	Not specified.	<i>Perceptions &amp; constructions of risk</i> . Social construction of risk. <i>Approaches towards risk</i> : Risk-tolerance, risk-aversion and risk-balancing.
Clarke, C. L. et al. (2009) United Kingdom	N=46 ( <i>professionals</i> ); nurses (7), other health care (2), care	Qualitative. Organisational survey. Thematic analysis.	Driving, falls, meal provision, medication, security, using appliances	Lack of insight of PWD, risks associated with engaging in activities	<i>Approaches towards risk</i> : Acceptable and reasonable risk taking; Risk-

<sup>b</sup> PWD: person with dementia

<sup>c</sup> AD: Alzheimer's Disease

	coordinators (2), service/home managers (28) and not specified (7).		and wandering.	including domestic and leisure tasks.	tolerance, risk-aversion and risk-balancing.
Clarke, C. L. et al. (2010) United Kingdom	N=55 (PWD) and their nominated carer and practitioner. Paper draws on the experiences of 4 PWD.	Qualitative. Interviews. Symbolic interactionism.	General home safety, driving and isolation (not specifically referred to as risks in the text).	Engaging in activities including socializing, going out, smoking and domestic tasks.	<i>Perceptions &amp; constructions of risk:</i> Social construction of risk.
Clarke, C. L. et al. (2011) United Kingdom	N=20 (professionals); social work, occupational therapy, podiatry and nursing.	Qualitative. Collaborative learning groups. Thematic analysis.	Not specified.	Not specified.	<i>Approaches towards risk:</i> Risk-tolerance, risk-aversion and risk-balancing.
Cott, C. A., & Tierney, M. C. (2013) Canada	N=20 (people with cognitive impairment); 5 male, 15 female; >65 yrs old and living alone). N=20 (carers); primary family members or friends; mainly middle aged, married and with own children.	Qualitative. Semi-structured, in-depth interviews. Grounded theory.	Diet and meal preparation, drinking, driving, falls, independence, institutionalisation, medication and self-esteem.	Changing abilities related to dementia, decline in physical health, change in family circumstances, risks from strangers, support and supervision.	<i>Perceptions &amp; constructions of risk:</i> Care crises and risk. <i>Approaches towards risk:</i> Acceptable and reasonable risk taking; Risk-tolerance, risk-aversion and risk-balancing.
Delazer, M. et al. (2007) Austria	N=19. (PWD); mild AD; 5 male, 14 female; mean age 74.3 yrs.	Quantitative. Neuropsychological background tests. Experiment: Game	N/A	N/A	<i>Decision making involving risk information.</i>

	N=25 (control group).	of Dice Task. Statistical analysis: ANOVA <sup>4</sup> , paired sample t tests, regression, chi squared tests, Pearson product moment correlations, Krustal-Wallis tests, ROC <sup>5</sup> curves.			
Delazer, M. et al. (2009) Austria	N= 19 ( <i>PWD</i> ): PDD <sup>6</sup> ; 8 male, 11 female. N=20 ( <i>PD</i> <sup>7</sup> <i>patients without dementia</i> ); 15 male, 5 female. N=20 (control group).	Quantitative: Neuropsychological background tests. Experiment: Iowa Gambling Task & Probability Associated Gambling task. Statistical analysis: Krustal-Wallis tests, Mann-Whitney tests, repeated measures ANOVA, paired sample t-tests, one-way ANOVAs, post hoc comparisons, Spearman rank-order correlation analysis.	N/A	N/A	<i>Decision making involving risk information.</i>

<sup>4</sup> ANOVA: analysis of variance

<sup>5</sup> ROC: receiver operating characteristic

<sup>f</sup> PDD: Parkinson's Disease Dementia

<sup>g</sup> PD: Parkinson's Disease

Delazer, M. et al. (2013) Austria	N=51 ( <i>cognitive impairment but not dementia</i> ); 25 female, 26 male.	Quantitative: Neuropsychological background tests. Experiment: Health Numeracy Task. Statistical analysis: Krustal-Wallis tests, three-way ANOVA, hierarchical regression analysis, multiple mediation analysis, Mann Whitney tests.	N/A	N/A	<i>Risk communication:</i> Health numeracy
Gilmour, H. et al. (2003) United Kingdom	N=10 ( <i>PWD</i> ); living alone; 2 male, 8 female; mean age - 83.3 yrs (range 74 to 93 yrs). N= 12 ( <i>carers</i> ); 3 male, 9 female. N=25 ( <i>professionals</i> ); care staff (9), GPs (6), district nurses (4) and social workers/assistants (6).	Qualitative. Semi-structured interviews. CarenapD used to gather background info. Barthel index used to carry out standard assessment of activities of daily living. Template approach.	Cooking, falls, getting lost, heating, managing money, nutrition, road safety and wandering.	Informal surveillance in the community (knowledge of the individual) and levels of contact/supervision.	<i>Perceptions &amp; Constructions of Risk:</i> Congruence of risk perceptions and reality.

Ha, J. et al. (2012) South Korea	N=14 ( <i>PWD</i> ); mild to moderate AD. N=16 (control group).	Quantitative. Neuropsychological background tests. Experiment: computerized risky decision making task. Statistical analysis: t-test, Fischer's exact test, Mann-Whitney U test, Wilcoxin signed rank test, ANOVA, ANCOVA <sup>8</sup> , Partial Correlation analysis.	N/A	N/A	<i>Decision making involving risk information.</i>
Harris, P. B. (2006) North America	N=15 ( <i>PWD</i> ); early stage AD (13) or MCI <sup>9</sup> (2); 2 male, 13 female; mean age 75.4 yrs (range 60-87 yrs); living alone. N=10 ( <i>carers</i> ); 6 daughters, 2 sons, 1 cousin, 1 sister; 7 female, 2 male, 1 not specified; mean age 51 yrs (range 38-60 yrs).	Qualitative. Interviews. Grounded theory.	Autonomy (involvement in decision making), driving, independence and social withdrawal (referred to as concerns rather than risks by <i>PWD</i> ).	Coping strategies of <i>PWD</i> , support and assistance (both formal and informal).	<i>Approaches towards risk: Risk-tolerance, risk-aversion and risk-balancing.</i>

<sup>8</sup> ANCOVA: analysis of covariance

<sup>i</sup> MCI: Mild Cognitive Impairment

Henry, J. D. et al. (2009) Australia	N=34 ( <i>PWD</i> ); community dwelling; 16 male, 18 female. N=38 ( <i>people with MCI</i> ); 19 male, 19 female. N=34 (control group).	Quantitative. Neuropsychological background tests. Experiment: danger rating tasks (faces and situations). Statistical Analysis: ANOVA, Tukey tests, discrepancy analyses, tests of simple effects	N/A	N/A	<i>Perceptions &amp; constructions of risk: Congruence of risk perceptions and reality.</i>
Horvath, K. J. et al. (2005) North America	N=17 ( <i>professionals</i> ); 6 male, 11 female; nursing, social work, occupational therapy, housing, homecare and administration backgrounds.	Qualitative. Semi-structured interviews. Interpretive phenomenology and constructivist grounded theory.	Cooking, medication management and wandering.	Caregiver knowledge and skills of dementia and safety issues, environmental hazards, family support, impaired judgement of PWD, previous safety incident, supervision.	
Johansson, I. et al. (2009) Sweden & Norway	N=28 ( <i>professionals</i> ); nurses (10) & nurse assistants (18) working in nursing homes; all female; age range 30-59 yrs.	Qualitative. Interviews. Phenomenographical analysis.	Falls.	Cognitive and physical functioning, physical environment, psychosocial environment, knowledge of staff and ratio of staff to residents.	<i>Approaches towards risk: Risk-tolerance, risk-aversion and risk-balancing.</i>

<p>Lach, H.W. (1995) North America</p>	<p>N=35 (<i>carers</i>); caring for persons with AD; spouses (25), daughters (5), sons (2); mean age 59 yrs (range 29-95 yrs). Care recipients; 5 lived alone, 30 with caregiver; 23 had mild dementia, 12 moderate to severe dementia; mean age 73 yrs (range 56-94 yrs).</p>	<p>Quantitative. Telephone interviews. CDR<sup>10</sup>. Statistical analysis: Fishers exact test and chi-square test.</p>	<p>Risks as categorised in the <i>Home Safety Inventory</i> - wandering, cooking, driving, antisocial or aggressive behaviour, eating/ swallowing, using appliances, falling, smoking, adapting for temp/heat, not paying attention, using sharp objects, other judgement problems, taking medication.</p>	<p>History of accidents, supervision and modification of home environment.</p>	<p><i>Perceptions &amp; constructions of risk:</i> Congruence of risk perceptions and reality.</p>
<p>Ledgerd, R. et al. (2015) United Kingdom</p>	<p>N=719 (<i>professionals, people with dementia, carers and academics</i>). Professionals (613) - health sector, social care sector, emergency services and voluntary; Academics (20); Carers (54); People with dementia (4); Others (28).</p>	<p>Quantitative. Survey. Statistical analysis: Chi-Square test and Fisher's exact test.</p>	<p>Domains of crisis categorised as: behavioural and psychological, physical health, vulnerability, family carer and environment.</p>	<p>Domains of crisis categorised as: behavioural and psychological, physical health, vulnerability, family carer and environment.</p>	<p><i>Perceptions &amp; constructions of risk:</i> Care crises and risk.</p>

<sup>1</sup> CDR: Clinical Dementia Rating

McDonald, A. (2010) United Kingdom	N=14 (professionals); social workers.	Qualitative. Document review and semi-structured Interviews. Grounded theory.	Not specified.	Not specified.	<i>Approaches towards risk:</i> Risk-tolerance, risk-aversion and risk-balancing.
Morgan, K. (2009) United Kingdom	N=1 (PWD); AD, female.	Qualitative. Case study: personal narrative. Discussion and personal reflection.	Losing control over life, risks to family life, risks to personhood.	Society and systems.	<i>Approaches to Risk:</i> Risk-tolerance, risk-aversion and risk-balancing.
Oyebode, J. R. et al. (2013) United Kingdom	N=6 (carers); caring for people with FvFD <sup>k</sup> ; 4 male, 2 female ; 3 husbands, 1 wife, 1 daughter, 1 brother; 5 resided with PWD, other PWD resided in a home.	Qualitative. Indepth, semi structured interviews. Interpretative phenomological analysis.	Burns, road safety.	Lack of judgement of PWD.	

<sup>k</sup> FvFD: Frontal-variant frontotemporal dementia

<p>Pertl, M. T. et al. (2014) Austria</p>	<p>N=25 (<i>people with MCI</i>); 12 male, 13 female; median age 73 yrs. N=164 (control group).</p>	<p>Quantitative. Neuropsychological background tests. Experiment: health numeracy task. Statistical analysis: Mann-Whitney tests, Spearman's rho.</p>	<p>N/A</p>	<p>N/A</p>	<p><i>Risk communication:</i> Health numeracy.</p>
<p>Robinson, L. et al. (2007) United Kingdom</p>	<p>N=19 (<i>professionals, carers and PWD</i>); N= 10 (professionals); 1 clinical psychologist, 1 psychiatrist, 1 occupational therapist, 1 social worker, residential &amp; nursing home managers, nursing home staff and inpatient ward managers. N=3 (carers); 2 spouses and 1 daughter; N=6 (PWD); mild.</p>	<p>Qualitative. Focus groups: thematic framework approach. Constant comparison.</p>	<p>Wandering.</p>	<p>Use of assistive technology (viewed as both reducing risk of getting lost and increasing risk of being a target for theft).</p>	<p><i>Approaches towards risk:</i> Acceptable risks; Risk-tolerance, risk-aversion and risk-balancing.</p>

<p>Sandberg, L. et al. (2015) Sweden</p>	<p>N=12 (<i>PWD</i>); mild to moderate (9 Alzheimer's, 2 Vascular Dementia, 1 Lewy body dementia); 6 male, 6 female, age range 67-87 yrs; 4 living alone, 8 co-habiting.</p>	<p>Qualitative. Interviews. Content analysis approach.</p>	<p>Using public transport, managing mail (failing to pay bills or missing appointments), completing tax returns, driving, getting lost outdoors, managing medications, managing money, forgetting meals, cooking.</p>	<p>Experiencing situations as unfamiliar and confusing, not being able to recall events, environment (family, neighbours, technical aids and home modifications).</p>	<p><i>Perceptions &amp; constructions of risk:</i> Social construction of risk.  <i>Approaches to Risk:</i> Risk-tolerance, risk-aversion and risk-balancing.</p>
<p>Sinz, H. et al. (2006) Austria</p>	<p>N=22 (<i>PWD</i>); probable mild AD; 4 male, 18 female; mean age 76.6 yrs.</p>	<p>Quantitative. Neuropsychological background tests. Experiment: Iowa Gambling Task &amp; Probability Associated Gambling task. Statistical analysis: independent sample t tests, paired sample t tests, repeated measures ANOVA, Pearson product-moment correlations</p>	<p>N/A</p>	<p>N/A</p>	<p><i>Decision making involving risk information.</i></p>

Tsunaka, M., & Chung, J. C. C. (2012) Hong Kong & Singapore	N=14 ( <i>carers</i> ); mean age 50 yrs old. Care recipients; mean age 81 yrs; 5 make, 9 female.	Semi-structured and in-depth interviews. ACS-HK <sup>12</sup> . Quantitative analysis: descriptive statistics. Qualitative analysis: based on PEO <sup>13</sup> framework.	Not specified.	Participation in activities, support and resources available.	
Tuokko, H. et al. (1999) Canada	Study 1 - not applicable to synthesis. Study 2 - N=152 ( <i>PWD</i> ); living alone (82), living with spouses (70).	Quantitative. Study 1: N/A Study 2: retrospective chart review of service records (demographics and neuropsychological tests). Completion of a risk behaviour checklist on basis of information in service records. Statistical analysis: t-tests, chi-square analyses and logistic regression.	Nutrition, money management, medication management, hygiene, fire, falls, delusions, paranoia, depression and wandering.	Living arrangements.	<i>Perceptions &amp; constructions of risk: Congruence of risk perceptions and reality.</i>

<sup>1</sup> ACS-HK: Activity Card Sort-Hong Kong version

<sup>m</sup> PEO: Person-Environment-Occupation

Walker, A.E. et al. (2006) United Kingdom	N=89 ( <i>carers</i> ); 35 male, 54 female; 45 spousal, 34 children, 6 other relatives, 4 friends; mean age 65.6 yrs (range 30-90 yrs). Care recipients; AD; 27 male, 62 female; mean age 80.6 yrs (range 59 – 96 yrs); 36 mild dementia, 35 moderate dementia, 18 severe dementia.	Quantitative. Caregivers: HADS <sup>14</sup> , interview. Care recipients: MMSE <sup>15</sup> , ADCS-ADL <sup>16</sup> , NI <sup>17</sup> . Statistical analysis: Mann-Whitney tests, Spearman's rho, linear regression.	Falls, safety issues relating to fire, water and electricity, self-neglect, wandering/getting lost.	Environmental safety hazards, previous incidents, risks from strangers and supervision.	<i>Perceptions &amp; constructions of risk:</i> Congruence of risk perceptions and reality.
Watts, D. et al. (1989) North America	N=1 ( <i>PWD</i> ); 94 yrs old; male; living alone.	Qualitative. Case report: written from perspective of medical professionals. Case discussion.	General home safety, using appliances	Judgement/ability to evaluate risk, supervision, support from services.	<i>Approaches towards risk:</i> Risk-tolerance, risk-aversion and risk-balancing.
Waugh, F. (2009) Australia	N=5 ( <i>professionals</i> ); social work (2), nursing (1), occupational therapy (1) & teaching (1). Care recipients: PWD living alone.	Qualitative. In-depth interviews. Sequential thematic analysis.	Depression, falls, financial exploitation, physical and emotional harm, fire, isolation, loneliness, and wandering.	Risks from strangers, supervision, diagnosis, changes in person's behaviour, decline in physical health and skills, withdrawal of support and decline in community tolerance.	<i>Perceptions &amp; constructions of risk:</i> Care crises and risk. <i>Approaches towards risk:</i> Risk-tolerance, risk-aversion and risk-balancing.

<sup>n</sup> HADS: Hospital Anxiety and Depression Scale

<sup>o</sup> MMSE: Mini-Mental State Examination

<sup>p</sup> ADCS-ADL: Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory

<sup>q</sup> NI: Neuropsychiatric Inventory

<p>Zamarian, L. et al. (2015) Austria</p>	<p>N=20 (<i>PWD</i>); mild dementia of Alzheimer's type; 6 male, 14 female; mean age 77.85 yrs.</p>	<p>Quantitative. Neuropsychological background tests. Experiment: Information Sampling Task (part of the Cambridge Neuropsychological Automated Battery). Statistical analysis: descriptive statistics, Spearman rank order correlation.</p>	<p>N/A</p>	<p>N/A</p>	<p><i>Decision making involving risk information.</i></p>
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