Executive Summary

Risk Communication in Dementia Care

Brian Taylor, Professor of Social Work, Ulster University
Mabel Stevenson, Research Assistant, Ulster University

Contents

EVIDENCE BRIEF

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 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.

1. Background

Globally there are an estimated 46 million people living with dementia with this figure projected to increase to 131.5 million by 2050. Global population ageing and the associated increase in prevalence of dementia present a major international health and policy issue with global economic and societal impacts. 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. Importantly, these changes can make an individual more susceptible to risks of daily life, such as falls; risks associated with driving or walking about (often referred to as 'wandering'); mismanagement of medication; increased vulnerability to abuse; and psychological risks such as loneliness and loss of identity.

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, 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.

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. Effective communication about risks between service users, professionals and family carers is fundamental to support informed, shared decision making processes. 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 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. 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. Policies seeking to prevent people being admitted to hospital or long-term care unnecessarily 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 to enable independent living. Effective risk management requires clear communication between individuals with dementia, family carers and professionals. Shared decision making – often within the context of 'assessment' - presents challenges in terms of managing risk. The concept of 'enablement' includes some sense of balancing potential benefits from taking risks against possible harm. This presents challenges with the increasing attention given to risk management within

clinical and social care governance and respect for client choice. Good risk communication is essential for effective risk management. Interpersonal risk communication involves exchange of information about risks, increasingly viewed in terms of both potential benefits as well as possible harm). 'Risk literacy' is increasingly recognised as integral to health literacy and shared decision making in health and social care. Including people with dementia in decision making contributes to quality of life, personhood and autonomy. However involvement remains limited and there are challenges in communicating about risks.

Effective risk communication requires an understanding of how risks are conceptualised, which may vary across contexts. Individuals with dementia and family carers may conceptualise risk more as an action or consequence than as likelihood. 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. 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. Verbal expressions of likelihood are widely used in everyday discourse but may be more ambiguous, particularly in the correspondence between numeric values and verbal expressions. Use of verbal descriptors to present side effects of medications may lead to overestimating risks. 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 although individuals with low numeracy skills may have comprehension difficulties. Low numeracy has been associated with reduced understanding of health risks; increased susceptibility to framing effects; and avoiding involvement in shared decision making. Optimal risk communication methods may

therefore depend on numeracy skills. Frequency formats have shown robust effects in improving understanding, although individuals with cognitive impairments such as dementia may experience difficulties with numeric risk data.

Visual displays of risk information, including graphs, charts, and icon arrays, may enhance understanding of probabilistic information in some contexts, although the format has also been found to influence risk perception. Individual differences in numeracy and graph literacy influence effectiveness of specific visual aids.

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 – are prone to overestimation bias. '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. Individuals with low numeracy may be more susceptible to factors that may bias their interpretations of quantitative data such as emotions and presentation formats.

A key issue for dementia care in the future will be the communication of risks in the context of providing community services for increasingly complex and demanding health and social care situations. This study aims to address this issue by exploring the topic of risk communication in dementia care.

2.   Aims and 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.

3. Methods

This project comprised seven parts:

i.   Literature searching involving a rigorous search methodology

ii. Literature appraisal and synthesis

iii. Qualitative study of people with dementia involving seventeen interviews with people with mild-moderate dementia

iv. Engagement of people with dementia in data analysis

v.   Qualitative study of family carers of a person with dementia using five focus groups involving twenty-two participants

vi. Qualitative study of professionals in community dementia services using five focus groups involving thirty-five participants

vii. Survey of professionals in community dementia services sent to 270 staff of whom 70 completed and 55 partially-completed the web-administered questionnaire.

The reader interested in further detail of the methodology is referred to the full Report on the project and the relevant academic paper(s) which are listed below.
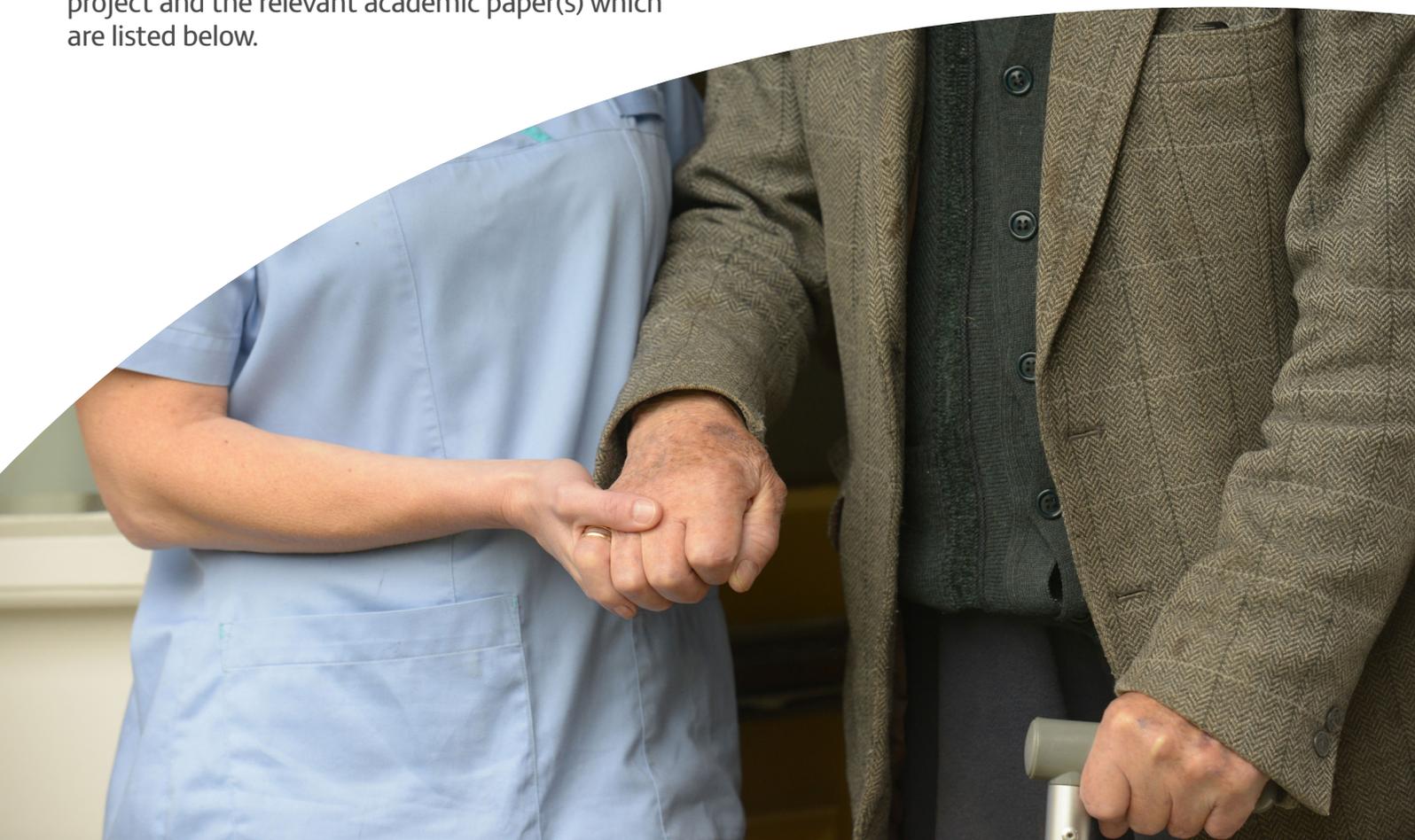
4. Personal and Public Involvement

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.

5.   Main Findings

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.
- 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.

5.   Main Findings Continued

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.

93 out of 100 people **will not** experience headaches

7 out of 100 people **will** experience headaches
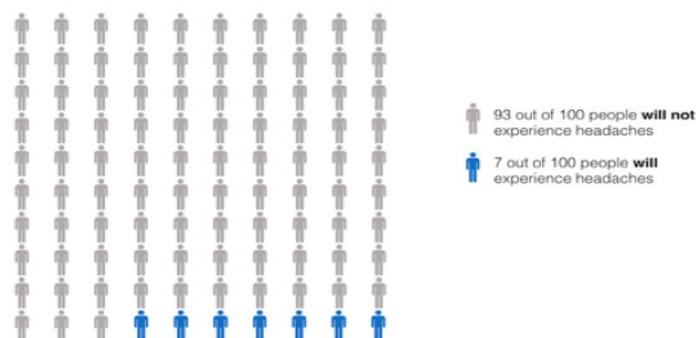
- Challenges for communicating risks in practice (ranked in descending order of concern) included: conflicting ideas on client's best interests; person with dementia lacking insight into the risk; unrealistic expectations of services; risk of damage to professional/client relationship; lack of data on likelihoods; and fear of complaint.

6.   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 evaluation 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 from the literature on risk concepts in dementia care were synthesised according to recurring themes:
  - o types of risk;
  - o perceptions and constructions of risk;
  - o approaches to dealing with risk; and
  - o decision making involving risk.

Empirical findings from this project
- 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.

7. Practice and Policy Implications

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.

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

8. Pathway to Impact

The pathways to impact for this project include, in addition to the comments in the above Personal and Public Involvement and Practice and Policy Implications:

    A. peer-reviewed journal articles;

    B. oral conference presentations;

    C. poster conference presentations;

    D. web dissemination to professionals; and

    E. other mechanisms to impact.

- **Journal outputs**

- 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.

- 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

- 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.

- 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.

- Stevenson M & Taylor BJ (2016). Risk communication in dementia care: Family perspectives. Journal of Risk Research. Advance Online Publication. doi:10.1080.13669877.2016.1235604

- 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.

- 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

- **Oral dissemination**

- 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.

- **Conference poster dissemination**

- Stevenson M & Taylor BJ (June 2016) Risk communication and decisions in dementia: Professional practice perspectives. Poster presented at the 16th 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 4th Decisions, Assessment, Risk 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 organized by the European Association for Communication in Healthcare, Heidelberg University, Germany.

- **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 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.

- **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 (3rd 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 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.

9.   References

For the purposes of this Executive Summary, references have been omitted other than listing (above) publications arising from the project. The interested reader is referred to the Final Report on the project and to the published journal articles.

10. Acknowledgements