Sight loss, dementia and meaningful activity:
A scoping study

Report for Thomas Pocklington Trust

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Executive summary

Introduction

The prevalence of health conditions causing or contributing to sight loss increases with age (Girdler et al, 2008). Yet, despite this, little research has focused on a population that has both sight loss and dementia, tending instead to focus on each condition in isolation.

'Meaningful activity' has been linked to quality of care and the health and wellbeing of older people (NICE 2013) and better outcomes for individuals with dementia (Wenborn et al. 2008). Regular engagement in meaningful activity has been shown to reduce severe behavioural symptoms of dementia, reduce reliance upon medicated solutions (Menne et al. 2012), slow functional decline associated with dementia and help to address the challenges of social isolation and 'problematic passivity', characterised by a decrease in gross motor movement accompanied by apathy and a lack of interaction with the environment (Conti et al. 2008). Loss of opportunities for, or access to, meaningful activities has been linked with depressive symptoms and affective distress in people with Age-related Macular Degeneration (AMD) (Rovner and Casten 2002).

Despite this, the term 'meaningful activity' has rarely been well defined (Marshall and Hutchinson 2001; Phinney 2006). The concept appears difficult to pin down, and precise and/or concise definition remains elusive. A number of terms have been used in the literature to express similar concepts, including 'personally valued activities or occupations' (Egan et al. 2014), 'perceived purposeful activity' (Roach and Drummond 2014) and 'valued discretionary activities' (Rovner and Casten 2002).

Aims of the study

The present scoping study was commissioned to explore issues in relation to meaningful activities for people with both dementia and sight loss living in both community and residential settings.

The primary aims of the project were:

• To determine the extent of the evidence base relating to meaningful activity for people with sight loss and dementia, and to summarise what is known;

• To collect data on the availability and use of guidance, training and other relevant resources in this area; and

• To provide insights to inform the potential development of new or improved guidelines in this area.

The aims of the research have been addressed through a combination of literature review (including online lateral searches), interviews with expert informants, and survey questionnaire on the provision of meaningful activity distributed to relevant stakeholder groups.

Literature reviews

Searches of electronic bibliographic databases identified 985 unique references. These were then filtered for relevance to the research on the basis of article title, leaving 40 apparently relevant items for full text examination. Three of these were subsequently excluded before full text review and three were unavailable within the review timeframe, but two further potentially relevant papers were identified via lateral searches making 36 full texts available for examination. Of these, 25 met the criteria for inclusion (they described or reviewed research studies; related to people with sight loss and/or people with dementia; and focused on meaningful activity) and were reviewed and evaluated.

The included literatures relating to meaningful activity for people with dementia and to people with sight loss revealed both similarities and differences in approach. The dementia-specific publications highlighted overarching concerns with best practice based on person-centred approaches. In reviewing the meaning of 'person-centred care' in the context of supporting people with dementia, Brooker (2003) identified four key principles: recognising the person with dementia and their carers as being of value in society and as worthy of respect as anyone else; not defining them by their dementia but treating them as an individual with a unique set of attributes and experiences; trying to understand their subjective experiences and their perspectives; and

providing a positive social environment in which they are supported to enjoy as full a range of relationships and interactions as possible.

Interpretations of meaningful activity emphasised the centrality of emotional components or a sense of contribution in activities regarded as meaningful by people with dementia, and literature suggested conflicting interpretations by people with dementia and their care-givers. People with dementia viewed meaningful activity as being related to how they experienced the quality of an activity without attaching too much importance to the type of activity. On the other hand care-givers primarily perceived meaningful activity as physical activity for the purposes of health or cognitive improvement. There was insufficient sight loss-specific literature to draw corresponding comparisons between the views of people with sight loss and their care-givers.

The literature also exposed differing mechanisms to achieve meaningful activity engagement. Within the literature relating to dementia the emphasis is on the roles of professionals or family support networks in identifying the need for, assessing abilities to participate in and/or facilitating engagement in meaningful activity. Included sight loss literature suggested that people with sight loss are more likely to be encouraged to use peer support, share mutual experiences and gain self-confidence for individual motivation to engage with meaningful activities.

Interviews

Semi-structured interviews were conducted with ten 'expert informants' drawn from organisations and professional groups with roles related to the provision of meaningful activity and the support of people with sight loss and dementia.

Four core themes emerged from analysis of the interviews: the challenges of supporting people with sight loss and dementia; interpretations of meaningful activity; the use of resources/training; and future resources or guidance.

In the main, interviewees focused on the challenges faced by key supporting people when attempting to engage people with both sight loss and dementia in activity of any sort. The concept of meaning is

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discussed, but usually in relation to primarily sensory activities and measurable outcomes, such as the reduction in stress and distress. It may be that, reflecting the findings of the literature review, the majority of those interviewed adopt a generally outcome-orientated view of 'meaningful' whereas people with sight loss and dementia have different priorities and expectations around 'meaningful activity'.

This focus by interviewees may be the result of formal service provision increasingly provided only to those people with more severe symptoms and higher levels of support need but it suggests that there is a need to examine further the question of what resources need to be developed, how they should be informed, and who they are ultimately for.

Survey

The survey was aimed primarily at professionals with an interest in the provision of meaningful activity. The survey was online, but respondents were also invited to contact the research team to complete the survey by telephone if preferred. Links to the survey questionnaire were made available to potential respondents in mid-May 2015 by a range of different organisations and groups with interests in supporting people with dementia and sight loss via website postings, social media, and inclusion in newsletters. A total of 117 usable responses to the survey were received. Respondents were based mainly in England or Scotland, 90% were female, and most were aged between 25 and 64 years. The largest groups represented were healthcare professionals (36%), allied healthcare professionals (18%), direct support workers (16%) and family carers (15%).

Survey respondents generally had a person-centred understanding of the term 'meaningful activities', describing them as being about the person being supported and understood as having meaning, importance, purpose or value for them. Meaningful activities could be routine daily tasks, occupational or recreational in nature, but were generally regarded as being enjoyable, stimulating and interesting to the person engaging in them. The most frequently offered alternatives to 'meaningful activities' were 'purposeful activity', 'activities of daily living', and 'hobbies'.

Nearly three-quarters of survey respondents (87 people) had direct experience of supporting people with both sight loss and dementia. Of these, 90% had experienced particular challenges in assisting people with both sight loss and dementia to access activities, with two thirds perceiving those challenges as relating to the interaction of a person's sight loss and dementia. Misconceptions about, or lack of awareness of, the abilities of people being supported and carer attitudes to risk were perceived to be common.

The majority of respondents indicated that they would seek guidance from dementia specific and sight loss specific charities (84% and 69% respectively) when supporting people with dementia and sight loss, with smaller numbers likely to seek guidance from specific organisations, or other sources including colleagues, the internet, and GPs.

The most widely used resources from a list identified by the survey were: 'Getting to Know Me', a profile for collecting information about a person needing support (47%); the 'Living Well Through Activity in Care Homes' Toolkit (24%); the 'Pool Activity Level' ('PAL') toolkit (20%) and 'Making Every Moment Count: A guide for everyday living' (19%). 14% of respondents said that they used 'Other' resources, varying from bespoke toolkits to RNIB and Macular Society leaflets on activities of daily living.

The higher levels of use of the 'Getting to Know Me' profile sheet are probably due to respondent characteristics specific to this survey. The resource was jointly developed by the Scottish Government and Alzheimer Scotland. Since its launch in May 2013, the resource has been widely used in Scottish acute hospitals settings. More than half of all respondents (54%) were health professionals or allied health professionals, and 59% of respondents were based in Scotland. Analysis shows that there are statistically significant relationships between each of these attributes and use of the 'Getting to Know Me' resource.

The low levels of use of the other resources identified in the survey suggest limited use (and from additional comments provided by respondents possibly limited knowledge of) resources across disciplines and/or areas of employment.

Survey respondents had identified a range of effective methods to support people with sight loss and dementia to engage in meaningful activities. More than two thirds of respondents (72%) offered suggestions for effective support which related to key actions prior to supporting engagement in activities, pointers around delivery of support, and suggestions for activities respectively.

97% of respondents felt that they needed further guidance on how to support people with sight loss and dementia to engage in meaningful activities, with face-to-face training (70%), case studies (47%) and online learning and training (32%) seen as the most likely forms of resource to be highly useful.

Conclusions and recommendations

There is a paucity of peer-reviewed academic literature directly relating to meaningful activities for people with dementia and sight loss. Qualitative studies make up a significant proportion of the research evidence base which, though limited, is of relatively high assessed quality. There is an equally limited 'grey' literature directly on this topic.

The studies reported in the academic literature generally focus on activity in the context of each condition individually. Identified grey literature tends to address issues in the provision of support for people with both conditions more frequently.

The academic and grey literatures reflect significantly different foci. The scientific literature centres on: meaningful activity as best practice, interpretations of meaningful activities, and mechanisms to achieve meaningful activities for people with sight loss and dementia. The grey literature focuses on 'strategic planning', 'empirical research', and 'information and practical tools'.

Common themes run through the literature review, interviews with expert informants and survey responses. These include the need for support for meaningful activities to be person-centred, to be informed and underpinned by awareness and understanding of the ways in which the cause and severity of a person's sight loss and the type and severity of their dementia might affect their support needs, and to be flexible and adaptable in approach.

Interviewees representing a range of professional groups tasked with, or involved in, the provision of support for activities tended to focus discussion on the use of primarily sensory activities and on a limited range of outcomes. Many survey respondents similarly appeared to be primarily considering activities appropriate to people with severe cognitive and visual impairments. People with sight loss and dementia may have different priorities for and expectations of 'meaningful activity' when compared to family and paid carers. There may be a need to develop more nuanced guidance which takes the full spectrum of combinations of condition severity into account and provides information on how best to support people with lower levels of impairment. Further research should explore these potential differences in foci and how they might affect the delivery of support services.

This scoping study has revealed demand across health and care provider groups for more resources to help caregivers to improve the support that they give to people with dementia and sight loss to participate in meaningful activities. This could represent a paucity of suitable materials but might also indicate a lack of knowledge of what is already available: although 97% of survey respondents felt that they needed further guidance on how to support meaningful activities for people with sight loss and dementia, significant numbers of respondents were not aware of or did not use existing resources identified in the survey.

The findings point to a need to clarify what such resources aim to achieve and to examine more fully questions around whether additional resources need to be developed, how they should be informed, and who they are ultimately for. Further research should also explore how awareness of existing resources could be improved as well as examining the most appropriate forms for new guidance.

Contents

1. Introduction

It has been well documented that the prevalence of health conditions causing, or contributing to, sight loss increases with age (Girdler et al. 2008). Yet, despite this, little research has focused upon a population that has both sight loss and dementia, tending instead to focus on each condition in isolation. As a result, the experiences of individuals with both dementia and sight loss are poorly understood and underrepresented in the literature (Lawrence et al. 2008; Lawrence and Murray 2009; Goodman and Watson 2010), an issue that is particularly pertinent in relation to engagement in meaningful activity (Phinney 2006).

The concept of meaningful activity has developed from psychosocial models of ageing such as activity theory (see, for example, Havighurst and Albrecht 1953), which suggests that older people who remain engaged with the world around them experience higher levels of physical and psychological wellbeing than those who do not, and continuity theory (Atchley 1989) which holds that older people's preferred adaptive choices are both tied to their past experiences of themselves and their social world and intended to produce continuity in inner psychological characteristics, social behaviours and social circumstances.

Although a number of terms have been used to express similar concepts, including 'personally valued activities or occupations' (Egan et al. 2014), 'perceived purposeful activity' (Roach and Drummond 2014) and 'valued discretionary activities' (Rovner and Casten 2002), the term 'meaningful activity' seems to have been the most frequently used, particularly in the literature relating to activities for older people. However, it has rarely been well defined (Marshall and Hutchinson 2001; Phinney 2006). The concept appears difficult to pin down, and precise and/or concise definition remains elusive. For example, the definition of 'meaningful activity' as used in Quality Statement 1 of the NICE quality standard on 'Mental wellbeing of older people in care homes' (NICE 2013) runs to 104 words and is more of a guide on what might be considered meaningful activity than an explicit statement as to what constitutes meaningful activity:

'Meaningful activity includes physical, social and leisure activities that are tailored to the person's needs and preferences. Activity can range from activities of daily living such as dressing, eating and washing, to leisure activities such as reading, gardening, arts and crafts, conversation, and singing. It can be structured or spontaneous, for groups or for individuals, and may involve family, friends and carers, or the wider community. Activity may provide emotional, creative, intellectual and spiritual stimulation. It should take place in an environment that is appropriate to the person's needs and preferences, which may include using outdoor spaces or making adaptations to the person's environment' (NICE 2013: 19).

Meaningful activity has been linked to quality of care and the health and wellbeing of older people (NICE 2013) and better outcomes for individuals with dementia (Wenborn et al., 2008). The regular engagement of people with dementia in meaningful activity has been shown to reduce severe behavioural symptoms of dementia and reduce reliance upon medicated solutions (Menne et al., 2012) and to slow the functional decline associated with the onset of severe dementia and help to address the challenges of social isolation and problematic passivity (Conti et al 2008). 'Problematic passivity' is defined as 'a diminution of behaviour - that is a decrease in gross motor movement accompanied by apathy and a lack of interaction with the environment' (Kolanowski 1995: 191).

Conti et al draw on the Need-driven Dementia-compromised Behaviour ('NDB') model proposed by Algase et al. (1996). The model conceptualises so-called 'disruptive behaviours' commonly exhibited by people with dementia such as compulsive walking, vocalisations and aggression as having meaning and/or purpose for them. Behaviours are explained as the most meaningful responses available to an individual in the pursuit of goals or expressing felt needs given their personality and current capabilities, the ways in which they are affected by their dementia, and the social and physical environments in which they find themselves. Conti et al. (2008) argue with reference to the NDB model that passive behaviours may constitute attempts to communicate needs for stimulation through engagement in meaningful activities and interaction. Persistent passivity is of concern because persistent lack of

activity and engagement can contribute to a decline in functional abilities.

Loss of opportunities for, or access to, meaningful activities has been linked with depressive symptoms and affective distress in people with Age-related Macular Degeneration (AMD) (Rovner and Casten 2002) and lower visual acuity, adjustment to visual loss and depression have all been found to influence activity limitation, largely independent of severity of visual loss and even in relation to less vision specific tasks (Tabrett and Latham 2011).

With global attention shifting towards the implications of dementia care on legal, financial, social and health services (Roach and Drummand, 2014) the challenges of providing individuals with both dementia and sight loss with opportunities for meaningful activity have never been so pressing. The present scoping study was commissioned to explore issues in relation to meaningful activities for people with both dementia and sight loss living in both community and residential settings.

2. Aims and objectives
The primary aims of the project were:

•   To determine the extent of the evidence base relating to meaningful activity for people with sight loss and dementia, and in particular to summarise what is known about what people with dementia and sight loss, their families and paid carers want and need, the challenges that exist in delivering meaningful activities, and the contextual factors which may act as facilitators or barriers to successful delivery;

•   To collect data on the availability and use of guidance, training and other relevant resources in this area; and

•   To provide insights to inform the potential development of new or improved guidelines in this area.

3. Approach and methods
The aims of the project have been addressed through the use of a combination of literature reviews (including online lateral searches),

interviews with expert informants, and survey questionnaire on the provision of meaningful activity to be completed by members of relevant stakeholder groups. The research brief detailed a number of specific research questions. Table 1 sets out the research methods used, the research questions which they were designed to address, and assumptions made.

Table 1   Research questions, study methods and assumptions

Research method	Research questions that this method informs or addresses	Assumptions
Literature review	What does the existing literature tell us about what people with dementia and sight loss, their families and paid carers want and need, the challenges in this area, and what works?	That where evidence-based advice or guidance had been produced or where evidence-based activities or training had been developed there would be reference to these in the research literature.
Interviews with expert informants

Survey questionnaire for relevant stakeholder groups on the provision of meaningful activity | How are people/ organisations tailoring existing activities?

Is there training in how to organise and deliver activities for people with dementia and sight loss

What advice/ guidance already exist in relation to promoting meaningful activity among people with dementia and with sight loss?

Is there a need for new dedicated guidance or the augmentation of existing guidance? If so, what are experts' views on the key criteria for the development of new/ improved guidance? | That both interviews and survey will inform the same key research questions.

That interviews will allow topics to be explored in greater depth and will inform the design of the survey, allowing data on the same topics to be gathered from a wider group of relevant stakeholders.

That the survey will provide an indication of the extent to which there is consensus between different stakeholder groups as |

			to what is required.

4. Literature reviews

4.1 Review of peer-reviewed academic literature

In keeping with the scoping nature of the research brief, we carried out a 'rapid review' of the literature relating to sight loss, dementia and meaningful activity. Although there is no standard methodology for such reviews Gannen et al. (2010) define rapid reviews as those 'that use methods to accelerate or streamline traditional systematic review processes', usually due to urgent need for the results or because of project resource constraints. In this instance, due to time and resource constraints our review methodology has been tailored in relation to lateral search strategies and in terms of the numbers of included publications evaluated.

4.2 Search and evaluation strategies

The search terms used for the review of peer-reviewed academic literature, electronic databases searched, and scoring system used as a final filter to select items for full text review are provided in Appendix 1. Results from individual bibliographic databases were uploaded to RefWorks bibliographic management software. These were then combined and duplicates within and between results from individual databases were removed to leave 985 unique references. These references were then filtered for relevance to the research on the basis of article title, leaving 40 apparently relevant items for full text examination. Appendix 2 lists these publications.

Three of the 40 items were excluded before full text review for lack of peer review (one book review and two conference presentations). The full text versions of a further four publications were not available within the review timeframe. Three additional potentially relevant papers were identified following an enquiry to an author of one of the conference presentations. In total 36 full texts were examined, of which 25 met the criteria for inclusion (they described or reviewed research studies;

related to people with sight loss and/or people with dementia; and focused on meaningful activity) and were reviewed and evaluated.

Project team members completed a structured report on each included item using the 'Stirling literature review proforma'. This is an online proforma developed at the University of Stirling which allows the capture of bibliographic and content-related data and facilitates a research design specific quality assessment of reviewed texts. The proforma has been used successfully and is described in detail in a number of other studies (Dawson et al 2015; Bowes et al 2013a; Bowes et al 2013b).

After recording basic information about the text, reviewers are asked to identify the research design used in the publication being reviewed, after which routing within the proforma takes the reviewer to a quality assessment section specific to that type of research. Reviewers are guided through the criteria contained in the selected assessment section, and then asked to rate (and record their reasons for rating) the publication as of Low, Medium or High quality based on whether the full text has revealed major, important, or minor limitations in the study methodology as reported in the publication. The assessment produces a quality rating compared to the archetype for studies using the same research design and thus provides an indication of the degree of caution that should be attached to a study's findings and conclusions: it does not allow for quality comparison across research designs.

4.3 Quality and coverage of literature

Table 2 summarises the types of research studies included and evaluated in the review and indicates the quality assessments for each type. More than 80% of the included studies (21/25) were assessed as being of high or medium quality. Unlike some systematic review procedures, no research designs are either privileged or excluded when using the Stirling Proforma. Where research evidence is sparse, as in the present case, a more exclusive approach might lead to the conclusion that no work had been done and in new fields of enquiry smaller studies with what might be thought less rigorous designs may still provide useful indicative material.

Table 2 Research design and quality of included publications

Type of study	Quality assessment			
	High	**Medium**	**Low**	**Total**
Controlled Before/After Study		1	1	2
Cohort Study	1	2		3
Literature review	3		1	4
Qualitative study	4	6	1	11
Other	1	3	1	5
Total	9	12	4	**25**

Table 3 provides an indication of the focus of the included research in terms of participants/subject. It is notable that the searches identified very little work relating to people with both dementia and sight loss, suggesting a need to focus specifically on this group in future research.

Table 3   Focus of research (participants/subject)

Focus of research	Number of items
People with Dementia or Cognitive Impairment	14
People with Sight Loss or Visual Impairment	8
People with both Dementia/Cognitive Impairment and Sight Loss/Visual Impairment	0
Family or Caregivers of People With Dementia or Cognitive Impairment	2
Other*	1
Total	**25**

Table 4 gives a breakdown of the types of outcomes considered by the included publications. Most studies included more than one category of

outcome. The large majority of included items consider emotional outcomes and engagement-related outcomes in relation to meaningful activity. Only 3 of the 25 included studies discussed physiological outcomes in relation to such activity. Fourteen studies touched upon function-related based outcomes, reflecting the concern of many of the included articles with movement-based activities with and without purpose.

Table 4   Types of outcome considered

Type of Outcome	Number of Publications
Emotional health-related outcomes	24
Engagement, patterns of engagement, or other engagement-related outcomes	18
Function-related outcomes	14
Service use-related outcomes	10
Cognition-related outcomes	9
Physiological health-related outcomes	3
Economic outcomes	1
Behavioural and Psychological Symptoms of Dementia (BPSD)	1

Table 5 provides a breakdown of types of activities that in the included literature were considered to be, or assessed as, meaningful. Studies frequently referred to and considered multiple types of activities; however the results suggest that movement-based activities in particular are often seen as meaningful, even when the movement itself serves no outward purpose.

Table 5   Types of activity viewed as meaningful in the literature

Type of Activity	Number of Publications
Movement-based activities with specific purpose, e.g. household chores, gardening	14
Activities designed to produce a tangible end product, e.g. knitting, pottery, cooking, etc.	13
Movement-based activities without other purpose, e.g. walking in the garden, yoga or tai chi exercises	12
Activities designed to produce sensory stimulation	10
Music-related activities, e.g. singing, playing an instrument	9
Other	6

4.4 Narrative review of the literature

The purpose of this literature review was to examine published studies relating to meaningful activity for people with sight loss and dementia. Despite an extensive and detailed search of the selected electronic bibliographic databases, no peer-reviewed academic publications were identified that focused specifically on meaningful activity for individuals with both conditions. Instead, sources fell into two fields: meaningful activity for people with sight loss, and meaningful activity for people with dementia. Outlined below are the main themes that emerged when considering the literature as a whole: meaningful activity as best practice, interpretations of meaningful activities, and mechanisms to achieve meaningful activities for people with sight loss and dementia.

4.4.1 'Meaningful activity' in the context of models of dementia and sight loss

A number of publications included in the review consider engagement in meaningful activities in the context of models which have been developed to help both people with dementia and with sight loss and those tasked with supporting them to understand how different factors influence the ways in which people experience their conditions and suggest potential coping strategies.

For example, Judge et al. (2009) present a theoretical 'stress process model' that outlines the experience of dementia over time and provides a

basis on which to explore the relationship between stressors associated with living with dementia. The model identifies 'Background and context', 'Primary stressors', Secondary strains', 'Outcomes' and 'Mediators' and proposes a series of direct and indirect pathways through which other identified variables affect Outcomes. In the model 'Background and context' includes variables such as age, education, living arrangements etc., 'Primary stressors' fall into two categories: objective stressors, such as cognitive or functional status, and subjective stressors, including role captivity and perceived distress and dependency. 'Secondary strains' include role strains, e.g. family, work, social and dyad role strains, and 'intra-psychic strains' such as self-esteem and self-efficacy. The model identifies both 'internal mediators' such as personality, life orientation and spirituality and 'external mediators' including social supports and financial resources. 'Outcomes' considered in the model include quality of life and aspects of physical and emotional well-being.

Judge et al. (2009) see a number of potential uses for their model: as a 'starting point to promote discussion, debate, and theoretical discourse' (2009: 300); as 'a useful heuristic for conceptualizing the illness experience, developing treatment goals, and adapting therapeutic techniques' (ibid.); and, suitably simplified, as a framework that can help people with dementia and their families 'to understand the changing circumstances of their lives' (ibid.). They believe that such models can play an important role in helping to inform the development of interventions to prevent or reduce negative stressors. Subjective stressors and role and intra-psychic strains might all potentially be ameliorated by interventions which provide people living with dementia with personally meaningful and satisfying activities.

Garnefski et al. (2010) developed a statistical model of the relationships between selected cognitive coping strategies, a goal-related coping strategy that involved multiple processes, and depressive symptomatology with a view to identifying targets for psychological intervention to help people to cope better with severe visual impairments. The three cognitive coping strategies considered were: rumination, defined as dwelling on feelings or thoughts without taking action; catastrophizing, dwelling on the terror of an experience; and positive refocusing, consciously thinking about pleasant issues. The

former two are seen as leading to poorer psychological adjustment and well-being, whilst the latter is conversely associated with lower levels of depressive symptoms.

In developing their model, the authors also considered a goal-related coping strategy involving multiple processes. The development, pursuit and attainment of goals is seen as central to psychological well-being, and perceived inability to attain goals in different life areas, for example as a result of sight loss, may cause psychological distress. Processes of disengaging from unattainable goals and re-engaging in alternative, meaningful goals are seen as central to restoring well-being. The success of this coping strategy thus relies on a person's ability to complete both processes.

Following statistical analysis of data from structured interviews with 67 people with sight loss, Garnefski et al. (2010) found that ruminative responses to visual impairment were associated with more depressive symptoms and that both positive re-focusing and the development of alternative goals were related to reduced depressive symptoms in respondents, making the latter strategies potential targets for intervention. They concluded that interventions for people with visual impairments should include components which help people to move away from ruminative thinking about their impairments and components which support people to be flexible in their goal-setting, disengaging from goals obstructed by their vision loss and re-engaging in alternative ones.

4.4.2 Meaningful activity as 'best practice'
Meaningful activity as 'best practice' emerged as one of the overarching themes of the review. To an extent, context dictates what is understood by 'best practice'. Perleth et al. (2001) define best practice in a healthcare context as 'the 'best way' to identify, collect, evaluate, disseminate, and implement information about as well as to monitor the outcomes of health care interventions for patients/population groups and defined indications or conditions' (2001: 237-238). Ferguson (2003) argues for a critical approach to considering 'best practice' in social work and social care that extends the concept beyond evidence-based practices to include 'practice-based evidence' including the felt, lived experience of best practice'.

Vernooij-Dassen (2007) argues that dementia care professionals are in a strong position to institute meaningful activities through integrated activities and strategy evaluations. Altus et al.'s (2002) controlled before and after study on a locked, long-term care unit with six participants with dementia or Alzheimer's disease supports this contention. Their study examined the effects of a simple, inexpensive recording and feedback procedure designed to increase resident engagement in which Care Nursing Assistants' (CNAs) use of activity prompts, praise or other contact with residents was observed four times a week using a time sampling process. The unit's activity director was asked to look at the observation data and give immediate, positive feedback to the CNAs on a daily basis. Over the observation period this simple change in staff management procedures led to a four-fold increase in CNAs use of engagement strategies with unit residents.

Dementia affects the ability to initiate activities, and for those providing support one of the challenges is selecting appropriate, personally meaningful activities. Wenborn et al (2008) assessed the reliability and validity of the Pool Activity Level (PAL) Checklist (Pool 2002), a tool designed to assist carers in this task. The PAL Checklist consists of a series of four statements about each of nine skills or functional abilities. Carers are asked to select the statements that best describe the ability level of the person with dementia in the preceding fortnight. Responses to each statement map on to one of four 'activity levels' which describe the kinds of activities that the person assessed would be able to engage in and might find meaningful.; planned, exploratory, sensory and reflex. The activity level on to which the highest number of selected responses maps is deemed to be the most suitable activity level for the person assessed and the Checklist provides examples of the kinds of activity which may be suitable for and meaningful to them.

The PAL Checklist describes a person at the 'planned' activity level as able to work towards goal directed activities with tangible outcomes or end results and only requiring support where problems occur in the process. Someone at the 'exploratory level' has the capacity to carry out familiar tasks in familiar surroundings, but may be more interested in doing the activity than in any end product or outcome. Those assessed as suited to the 'sensory' activity level have high levels of cognitive

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impairment. They may only be capable of simple, one-step activities and their primary interest is in experiencing the sensation of doing. The 'reflex' activity level describes those individuals who have limited awareness of their own bodies or of their immediate environment and for whom movement is a reflex action in response to stimulus.

Wenborn et al (2008) used a widely circulated postal questionnaire to assess content validity of the Checklist. Criterion, concurrent and construct validity, internal consistency, inter-rater and test-retest reliability were all tested with Checklist data from a sample of sixty older people with dementia drawn from a day hospital, an in-patient ward and continuing care services. Wenborn et al. concluded that the checklist had adequate validity and reliability and was suitable for use in clinical practice, suggesting in addition that 'it will also be useful in research with people who have dementia.' (2008: 208).

The sight loss literature discussed 'best practice' in terms of participation opportunities. Alma et al.'s (2012) study found that an individual's physical ability, rather than their level of sight loss, impacts upon their participation rates. Their study applied a bio-psycho-social perspective to investigate determinants of self-reported performance of participation in 176 newly registered visually impaired older clients of Royal Dutch Visio (North Netherlands), a low-vision rehabilitation provider. Participation was explored across: (1) domestic life; (2) interpersonal interactions and relationships; (3) major life areas; and (4) community, social, and civic life. Alma et al. found variance in participation which could only partially be explained by sight loss. The authors acknowledged inferences of causality were limited due to the nature of the cross-section methodological design. The authors postulated that accuracy around the measurement of participation can be difficult due to multiple determinants.

Beverley et al.'s (2004) systematic review of the literature on the health needs of visually impaired adults found that factors such as access to services, timing of service delivery, content and medium must be taken into consideration when determining factors associated with participation. Alma et al. (2012) added availability of public transport and accessibility of buildings to this list.

A qualitative study by Phoenix et al. (2015), published too recently to have been identified by the literature searches and considered for inclusion in this review, sought to explore barriers and facilitators to participation in physical activity for older people with acquired sight loss later in life. In addition to factors such as the physical and built environments, variety, sustainability and consistency of supported opportunities to participate and transport identified in other studies, the authors found that awareness of opportunities, personal factors such as confidence, fear and concern for personal safety and perception of the health benefits of physical activity affected participation for the 48 older people who participated in the study.

4.4.3 Interpretations of meaningful activity
There was consensus across the included literature that best practice around meaningful activity must entail a person-centred approach and a shift away from medical perspectives towards one which is centred on people with sight loss and/or dementia. From such a perspective the assessment of what constitutes meaningful is a subjective one and interpretation of 'meaning' could include affecting a person's feelings or providing a sense of contribution in doing something which is perceived as needing to be done and to have value to the household or to other family members.

Cohen's (2006) study supports the need for a person-centred approach towards meaningful activity engagement. Cohen conducted longitudinal research on the effects of art therapy as part of meaningful activity engagement by people with dementia living in the community. Three-hundred participants across three sites completed a comprehensive annual questionnaire. The results indicated that, for respondents, meaningful activities need to contain personal meaningfulness, with some individuals preferring pursuits such as poetry, dancing or music to physical activities. Cohen noted that preferences may be age-related: participants in the study had a mean age of 80 years.

Harmer and Orrell's (2008) study explored concepts of meaningful activity as defined by older people with dementia living in care homes, staff and family carers. It drew on data from focus groups conducted in three care homes involving a total of seventeen residents, fifteen members of staff and eight family carers. The authors found that whilst

residents viewed meaningful activities as those with psychological or social benefits, emphasising quality over the type of activity, staff and family carers tended to view activities that maintained physical abilities as meaningful.

Further evidence of how carers and/or supporters understanding meaningful activity can be found in Roland and Chappell's (2015) study of 906 Canadian informal care-givers caring for people with dementia for a minimum of three hours over three days. During an interview for a larger study on the effectiveness of a drug therapy that the person they cared for was receiving, care-givers were asked 'What do you believe getting involved in activities outside the home means for someone with dementia?' Just under 80% of carers thought that activity outside the home was beneficial to those they cared for with a further 7.8% seeing it as beneficial but difficult to arrange. Almost one in ten carers (9.5%) saw it as conferring no benefit to the person with dementia.

Interviewed carers tended to view activities as meaningful to the person being cared for if they conferred identifiable benefits, with the main benefits identified as: maintaining a sense of social connection beyond the caring partnership (19.6% of interviewees); stimulation, in terms of either cognitive stimulation or change from routine (24.9%); maintaining a sense of self, of self-worth and self-esteem (13.7%); enjoyment or positive affect (10.4%); health (9.7%); and sense of independence and self-reliance (7.1%). The relative importance that carers ascribed to the benefits of activities for those they cared for varied by severity of dementia, with social connectedness and sense of self regarded as important benefits for people with mild dementia, while relieving boredom/monotony and improving affect were seen as key benefits for people with severe dementia.

The reviewed literature also highlights the fact that people with dementia often view activity as meaningful where it provides them with a sense of doing or providing something of value to others For example, Genoe and Dupuis (2014) found that their research participants 'experienced well-being when they were able to manage daily life and make contributions to their families and communities' (2014: 54). The authors used an innovative photo-elicitation technique to understand the meaning and

experience of leisure for people living with dementia. Four participants, aged seventy to eighty-two, were given cameras and were asked to take pictures of their day-to-day lives. The photographs were later used as prompts to complement qualitative analysis of repeated interviews, participant observation, and photovoice, a participatory action research method in which participants are given cameras and asked to take photos of their everyday lives.

Genoe and Dupuis' participants stressed the importance to them of *giving* as well as receiving care and support. Activities that allowed them to feel that they were still able to make a valued contribution generated happiness and a sense of connection with others. Such activities took many different forms, from sharing household chores and tasks with partners and family members, to supporting someone else to carry on leisure activities, for example by being a dance partner, to providing advice and reciprocal support to others in peer group situations.

Their participants reported little differentiation between meaningful activities and leisure activities, prompting Genoe and Dupuis to call for further research into the subjective meaning of leisure, without simply assuming that it is synonymous with meaningful activity.

The reciprocal support to engage in personally meaningful activities provided by people with dementia and their carers noted by Genoe and Dupuis assumes further significance when considered in light of Hwang et al.'s (2009) findings in relation to carers of people with Alzheimer's disease. Their analysis of responses from 54 longer-term primary carers revealed a significant negative correlation between perceived caregiving burden and carers' participation in personally meaningful activities, i.e. reduced carer ability to participate in desired activities leads to an increased perception of burden of care.

Roach and Drummond (2014) also found that for some people with dementia a sense of contribution is central to activity being regarded as meaningful. Their study focused on people younger than sixty-five years with early onset dementia and their efforts to maintain engagement in purposeful activity. A qualitative repeated interview method was used with nine families (20 participants, all male). Discussions of meaningful activity illuminated two subthemes: (1) the traumatic cessation of work;

and (2) the need for purposeful activity. Participants' feelings were bound up with the sense of loss around masculine identities, loss of a bread-winner role and loss of contributory employment. Roach and Drummond noted that a study with female participants may provide alternative insights before concluding that there is a need to investigate potential methods of minimizing the trauma of leaving the workforce and the loss of employment as purposeful activity. The authors advocated investment in resources and purposeful activity creation for those diagnosed with a dementia at an early age.

4.4.4 Supporting engagement in meaningful activity
Both sight loss and dementia literatures discuss the roles of key individuals or groups in supporting and facilitating engagement in meaningful activity, particularly occupational therapists, families and, in relation to sight loss, peers.

Several included studies relating to people with sight loss highlighted the role that occupational therapists can play in facilitating continual meaningful engagement, whether through work, leisure, or everyday routines. For example, prompted by population ageing and anticipated changes in age at retirement Ellexson (2004) considered the role of occupational therapy in supporting older adults with age related visual impairment, focusing on evaluation processes. An Australian study by Girdler et al. (2008) used focus groups to gather the views of a purposive sample of older people with sight loss, aiming to describe the impact of ageing-related vision loss, identify factors influencing adaptation, and illuminate perceived problem areas. Participants were aged 65 or older with a diagnosed visual impairment, living in independent accommodation in the community (i.e. not in a hostel or nursing home), and Snellen best-corrected visual acuity equivalent to 6/12 or less in both eyes. Findings supported the need for investment by occupational therapists in the development of evidence-based interventions that support participation and 'specialized and robust programs' that support older adults to effectively manage the impact of sight loss on their lives.

A number of publications relating to meaningful activity for people with dementia focused on the role of family support. Phinney (2006) conducted an interpretive phenomenological study with eight families

supporting relatives with dementia living in the community to determine how family members support involvement in activity of persons with dementia and what it means to families. Participants were eight families: four men and four women with dementia, whose ages ranged from 64 to 88 years, each with a family care-giver (two male and six female, with ages ranging from 52 to 87 years). Analysis of repeated individual interviews (six per family) with the person with dementia and a family member revealed three family support strategies: (a) reducing demands, (b) guiding, and (c) accompanying.

Participants identified a range of strategies to reduce demands on the person with dementia which centred on making the most of that person's abilities whilst protecting them from situations in which they might feel overwhelmed, embarrassed or vulnerable. Strategies included: taking care in conversations to avoid questions which they might not be able to answer and which might therefore end a social interaction; structuring activities around the home in ways which encourage active participation but avoid the potential for disheartening failure, e.g. by not allocating more complex tasks; actively identifying opportunities and supporting a person to participate in activities affirm their sense of self, e.g. supporting a musician to continue to perform.

Guiding strategies revolved around giving written or oral instructions or reminders to support the person with dementia to play an active part in everyday life and to maintain a sense of connection with the world around them. Strategies around 'accompanying' each other or being accompanied by other family member or friends to places or events of individual or mutual interest were similarly designed to provide the person with dementia with activity, involvement and stimulation whilst feeling secure and protected. Phinney (2006) argued that these strategies allowed families to sustain meaning both for the person with dementia and for the family itself.

Cochran et al. (2001) explored some of the challenges in encouraging continued family support in a residential care setting. The study evaluated a three-year programme designed to provide opportunities for family members to participate in meaningful activity and engagement with relatives with late stage dementia living in a long-term care home in

the USA. The authors noted that many family members experienced distress and struggled to maintain connection with their loved ones during visits, particularly where the visits coincided with events or times of year that would previously have been celebrated as a family. A protocol was developed for a programme of events themed around different annual events, with each event structured to include supported interaction between residents and family members, favourite foods for that occasion or season (some of which was provided by family members), and themed activities.

The authors found that participation from family members at events was maximised where family and staff worked together to decide on themes for the coming year, information was provided to family members as far in advance as possible, and family members received telephone reminders about scheduled events six weeks ahead of time. Families were encouraged to enhance residents' experience of activities by providing stimulation for all the senses: for example memorable music, favourite fragrances or foods. The study concluded that the programme provided supportive, calm and person-centred environments through which families could jointly engage in meaningful activities with their relatives.

Peer support, i.e. the help and support that people with lived experience of the same issues or impairments are able to give each other, emerged from the sight loss literature as a significant mechanism to achieve meaningful activity. Kleinschmidt (1996) described and evaluated an Orientation Programme for people with sight loss and their families based in Utah in the USA. The programme began in 1992 and by 1995 had provided peer support during 22 cycles to 363 users. Evaluation forms in large print were sent to each participant immediately after each orientation session to determining the helpfulness of each of the session's components: simulation goggles, video, discussion, and information packet. Analysis showed that respondents found discussion and information packets to be the most useful elements of the program, with 92% of visually impaired respondents, 97% of spouses, and 96% of other family members finding discussion either "helpful" or "very helpful" and 94% of visually impaired respondents, 97% of spouses, and 96% of

other family members finding information packets either "helpful" or "very helpful".

Kleinschmidt's (1996) evaluation underlined that discussion with those facing similar challenges can be perceived by people with visual impairments as a meaningful and valued activity in and of itself, and provided useful insight into the beneficial effects that peer support can bring to users, their families, friends and associated health service providers. Alma et al. (2012) affirm the value of peer support as an activity, suggesting that 'Group rehabilitation, instead of an individual approach, is advised because it facilitates sharing experiences and coping strategies between the visually impaired, and may extend the social network' (Alma et al., 2012: 94).

4.5 Lateral searches for literature
Due to the size and scope of the project, lateral searches for literature were limited to contact with one of the authors of a conference presentation identified during the searches of peer-reviewed academic literature as detailed above and a series of online searches. The online searches were designed to identify key 'grey' publications or resources not found during searches of the peer-reviewed academic literature and used the search strings for the academic literature review as detailed in Appendix 1.

It is worth noting that the specificity of the search strings may have led to a failure to identify potentially relevant resources aimed at supporting older people more generally. For example, the College of Occupational Therapists' 'Living well through activity in care homes' toolkit (**https://www.cot.co.uk/living-well-care-homes**) which 'supports statements on participating in meaningful activity and personal identity in the NICE quality standard for mental wellbeing of older people in care homes' was not identified during the online lateral searches. This is likely to be because the main landing page for the resource does not contain any reference to either sight loss or dementia, and since all of the search strings used contained either a sight loss-related or a dementia-related term this resource would not have been amongst those ranked as most relevant by the Google search engine.

Eleven sources were identified that were considered relevant to the topic of meaningful activity for people with sight loss and dementia. These were categorised as referring to 'service planning and delivery', 'empirical research', and 'information and practical tools' respectively and are discussed below.

4.5.1 Service planning and delivery

There are two identified sources in this category. National Institute for Health and Care Excellence (NICE) Quality Standard 50, 'Mental wellbeing of older people in care homes', ('NICE QS50') published in December 2013, concerns promoting the mental wellbeing of people aged 65 years or over receiving care in care home settings, including residential, day care and respite care contexts.

The purpose of NICE quality standards is to identify and define care and service-related areas for quality improvement, providing a series of measurable statements to assist continual improvement. NICE quality standards are expected to be considered in meeting the general duty to secure continuous improvement in quality in the planning and delivery of care services set out in The Health and Social Care Act 2012.

NICE QS50 contains six quality statements, of which the most relevant to this discussion are Statements 1 and 4:

> 'Statement 1: Older people in care homes are offered opportunities during their day to participate in meaningful activity that promotes their health and mental wellbeing.'
> Statement 4: Older people in care homes who have specific needs arising from sensory impairment have these recognised and recorded as part of their care plan.'
> (NICE 2013: 16)

After setting out the included statements, NICE QS50 subsequently discusses each in depth, setting out amongst other things the rationale, associated quality measures, and implications of each statement for service providers and commissioners.

The rationale for Statement 1 highlights the link between opportunity to take part in activity and maintaining or improving health and mental wellbeing and suggests that involving service users and whenever

possible their carers and families in the choice and definition of activities both helps to ensure that activities are meaningful to the person and helps to develop and maintain relationships. Statement 1 also provides an inclusive definition of 'meaningful activity' as set out in the introduction to this report.

Recognising and recording specific needs due to sensory impairment as per Quality Statement 4 is deemed necessary because 'Mild but progressive sight and hearing losses are a common feature of ageing and may go unnoticed for some time, but can have a serious effect on a person's communication, confidence and independence' (NICE 2013: 28). Undetected sensory impairments can lead to social isolation and deterioration in service users' quality of life.

NICE QS50 notes that care-givers play an important role in identifying signs and symptoms of sensory impairment, recording these, and sharing information with relevant healthcare professionals, including GPs, who can make referrals for assessment to appropriate support services. According to NICE QS50, Statement 4 implies that care home providers, allied health professions and local authorities need to adopt appropriate strategies for enabling staff to recognise and report sensory impairments, including providing/requiring: appropriate sensory impairment awareness training for staff; monitoring levels of provision of basic checks for sensory impairments; and incorporating the needs of people with sensory impairments into care plans and person-centred service delivery protocols.

Ayrshire and Arran 'Sensory Locality Plan, draft Plan and Consultation Document' (2014) provides an example of sensory impairment strategic planning at local authority level. The draft Plan was subsequently incorporated into the 'Ayrshire and Arran Sensory Locality Plan 2014-2024', launched in August 2014. The Plan is steered by a pan-Ayrshire partnership group, jointly chaired by the Head of Community Care, East Ayrshire and the voluntary sector and representing public and voluntary sector organisations engaged in the provision or commissioning of health and/or social care services. The Plan seeks to enhance sensory impairment support services for people living in Ayrshire and Arran and

to drive forward the local response to the Scottish Government's 'See Hear' strategy.

The Ayrshire and Arran Plan recognises the need for work to identify and address sensory impairments and how failure to do so can be particularly damaging to people with both dementia and visual impairment when sight loss is not the primary condition presented:

'Hidden and/or untreated sensory loss can lead to withdrawal from social interaction. Sensory impairment is a major contributory factor in falls and subsequent admissions to hospital, which is, itself, a major contributory factor to admission to a care home. To a person with dementia, failure to recognise and respond to a sensory loss will result in greater isolation, will generate behaviours that can be misinterpreted as symptoms of advancing dementia, and can lead to a failure to respond appropriately to basic physical needs'. (East Ayrshire Council, 2014: 10)

The Plan describes the challenges of achieving efficiency in times of scarce resources. In addressing these, Ayrshire and Arran are adopting an asset based approach to care and service delivery which stresses the centrality of user control and person-centred models of care provision.

The Plan highlights the use of care pathways as a useful tool, in particular the pathway model contained in the Scottish Government's 'See Hear' sensory impairment strategy (see Appendix 3).

4.5.2 Empirical research

Four sources were related to research in the area of meaningful activity for people with sight loss and/or dementia.

A study commissioned by Thomas Pocklington Trust and conducted by Lawrence et al. (2008) took the form of 17 case studies of older people with sight loss and dementia, family carers and care professionals who worked with them. Interviews with participants with sight loss and dementia explored how they shared their daily lives, the activities that they enjoyed, the impact of their conditions on their own lives, and the help they received and needed. Carers' interviews provided insight into

their perceptions of the lives of those they cared for, the impact of caring on their own lives and the help that they received and needed. Interviews with professionals focused on their assessments of participants' quality of life and support needs, and a general discussion about their own experiences of working with this client group.

Lawrence et al.'s analysis identified six core challenges to those living with sight loss and dementia, their families and care professionals: increased risk of disorientation, threats to independence, difficulties accepting multiple losses, increased vulnerability to isolation, increased frequency of disruptive and distressing hallucinations, and challenges for sight loss services. In addition to recommendations for further research into the prevalence of co-occurring dementia and sight loss, the use of reality orientation and validation therapy and counselling to develop adaptive coping strategies with people with sight loss and dementia and best practice in the management of visual hallucinations, their findings led Lawrence et al. to recommend a series of measures to help each of the groups concerned, including:

- For people living with sight loss and dementia
    - Promoting people's sense of orientation and confidence in their environments, possibly using techniques such as reality orientation and validation therapy
    - Increasing one-to-one contact with paid carers and volunteers to help maintain valued pastimes and reduce isolation and loneliness
    - Managing threats to independence by supporting people to carry out valued activities in safe environments
    - Greater availability of services capable of meeting both sight-related and dementia-related needs
- For family carers
    - Guidance on how best to manage visual hallucinations and provide reassurance
    - Improved support services, including respite, day care and provision of information and advice
- For health and care professionals
    - Specific training on working with people with dementia for vision rehabilitation workers

- o Greater awareness of sight-related needs by dementia care workers
- o Improved coordination, communication, information sharing and joint working by mental health and sensory impairment professionals

In 2010, Evers gave a presentation on behalf of Thomas Pocklington Trust and the Alzheimer's Society titled 'Sight loss and dementia: Developing effective services' (Buchanan and Evers 2010) to the Alzheimer Europe Conference 2010, held in Luxemburg. The presentation provided the context for developing services and summarised the findings of Lawrence et al's (2008) study on the needs and experiences of people with dementia and serious visual impairment and Bartlett and McKeefry's (2009) scoping study of models of care for people with dementia and sight loss, both commissioned by the Trust, before offering a series of 'Good Practice Tips' on environments, occupation and activity, and eye tests respectively.

In another study commissioned by Thomas Pocklington Trust, Cattan et al. (2010) explored the needs of frail older people with sight loss, in particular those living in supported accommodation. Cattan et al.'s study combined a literature review identifying relevant research with in-depth interviews with 24 older people living in care homes and sheltered housing, a care-house manager and two sheltered housing wardens. Cattan et al.'s findings suggest that frail older people with sight loss require a period of adjustment when they experience sight loss. Difficulties caused by peoples' declining physical abilities were exacerbated by poor provision of practical help and security and lack of individualised services and emotional support.

Drawing on their findings, Cattan et al. (2010) made a series of recommendations. In relation to policy and practice, key recommendations included: that residential accommodation providers need to ensure that support is equitably provided to all residents; that both practical and emotional support is provided to frail older people with sight loss; that assessment and monitoring systems must be sensitive to the needs of residents with visual impairment; and that there should be

improved communication, information sharing and coordination between support organisations and institutions. The authors also set out recommendations for further research which, they suggested, should explore a wider range of support and service needs of frail older people with sight loss and examine the extent to which the findings of their study were generalizable to other residential contexts.

Similar themes were picked up by a 2012 review (Watson and Bamford 2012) of the evidence on undetected sight loss in care homes carried out by International Longevity Centre – UK ('ILC-UK') and supported by Thomas Pocklington Trust. Watson and Bamford set out the background for the review, highlighting evidence relating to aging populations, higher levels of depression in people with sight loss, and the need to include older people with sight loss in meaningful activity, before outlining and providing a critique of the legislative and regulatory requirements around sight testing in care homes. Their review took a broad approach to eye health, specifically including eye conditions related to forms of dementia and stroke and distinguished between sight testing, carried out by 'eye health professionals' (including optometrists, ophthalmic medical practitioners and dispensing opticians), and sight checking, simple processes that could be carried out by appropriately trained others, such as care home workers.

In considering the UK policy context, Watson and Bamford (2012) note that the 'UK Vision Strategy', launched by Vision 2020 UK as a response to World Health Assembly Resolution 2003 to reduce avoidable blindness by the year 2020, details three main outcomes: improving the eye health of the people in the UK; eliminating avoidable sight loss and delivering excellent support for people with sight loss; and inclusion, participation and independence for people with sight loss (UK Vision Strategy 2008).

Watson and Bamford identified a number of issues and barriers to improving the detection of sight loss in care homes, including:
- Lack of awareness of symptoms and associated health problems of sight loss and visual impairment at all levels, including of residents and their families, care home staff and managers

- Lack of priority given to eye health, particularly for residents living with dementia
- Insufficient attention to eye health as an indicator of general health
- Organisations allowing little time for, and organisational practices often not including, informal sight checking
- Limited delivery of eye health and sight loss training due to operational and practical constraints

The authors made recommendations to address these issues and for additional research in this area, including:
- A national awareness campaign to educate and guide different stakeholders on the issue of sight loss in older people
- Incorporating eye health indicators into Care Quality Commission assessment criteria for all care to stimulate the provision of staff time for informal eye checking
- Encouraging care home providers to add eye health and sight loss testing to their key performance indicators
- Conducting research to examine the effects of restrictions to the General Ophthalmic Services contract on the provision of domiciliary sight testing and explore the case for change
- Commissioning qualitative research to fully understand the barriers to good eye health practices for care home workers, managers and providers and inform subsequent development of interventions and tailoring of existing resources.

4.5.3 Information and practical tools

The remaining five sources provided information or practical tools to assist with meaningful activity for people with sight loss and dementia.

In 2011, the Dementia and Sight Loss Interest Group (DaSLIG), part of VISION 2020 UK, produced a series of three posters: 'Activity, sight loss and dementia: what works?', 'Supporting people with sight loss and dementia in care homes' and 'Dementia and Sight Loss Interest Group'. All three present facts on the estimated prevalence of sight loss and

dementia in the UK and the main causes of age-related sight loss. The 'What works' poster (DaSLIG 2011) also presents information on the challenges and opportunities for meaningful activity and provides suggestions for making activities accessible, including: talking books and audible newspapers; better lighting; tactile and large print games; activities incorporating sensory stimulation, such as cooking or hand massages. The 'Supporting people' poster includes information on identifying sight loss in care home residents and improving care home environments for residents with visual impairments. The DaSLIG poster introduces the group and its members, details its aims and objectives, and lists sources of further information about dementia and about sight loss.

'Staying involved and active', the Alzheimer's Society's Factsheet 521LP, reviewed in March 2013, discusses the importance of remaining active, provides tips for carers on how to help a person with dementia to accomplish everyday tasks, and suggests activities suitable for people living with different levels of severity of dementia. The publication outlines the benefits of activity, including 'improved quality of life for the person with dementia, as well as for those around them' and asserts that activity can 'also encourage independence, social inclusion, communication or expression of feelings' (Alzheimer's Society 2013). The techniques for engagement detailed included life histories, physical exercise and trying out new ventures. A section on activities for people in the later stages of dementia with sight loss suggests: using assistive technologies and brighter lighting to make the most of whatever visual abilities remained; reducing visual clutter and obstacles; providing a verbal commentary and description of events; using activities which stimulate or make use of other senses, e.g. massage, music, tactile games, audio books and newspapers.

'Supporting people with dementia and other conditions: A case study-based guide to support the social care workforce working with people with dementia who have other conditions' (Skills for Care 2015) includes nine case studies, the first three of which are related to sight loss and dementia. The first case study is about Wycliffe Home, a care home with places for 48 older people with sight loss run by Vista, a long-

established local sight loss charity based in Leicestershire and Rutland. The case study explores how Vista supports residents through: understanding their sight loss and diagnosis and how it affects their life in order to make best use of residual visual abilities; creating a sight loss and dementia-friendly environment through thoughtful use of lighting, colour contrast and sensory elements; keeping areas clutter- and obstacle-free to reduce the risk of falls; providing programmes of meaningful activities that reflect residents' interests and supporting residents' choices of activities; working with residents and those significant to them to develop comprehensive support plans.

The second and third case studies in the Skills for Care (2015) resource both feature service users with dementia and visual impairment. Case study two concerns the care provided by Alternative Futures Group, one of the UK's largest health and social care charities, for Arthur, an 86-year old man who is registered blind with failing hearing and a recent diagnosis of dementia. The case study focuses on the notion that service providers 'cannot deliver personalised support if we don't know what matters to people and how best to support them from their perspective' (Skills for Care 2015: 6) and the critical role of one-page profiles in providing that information. The third case study highlighted the importance of 'whole family' assessments in working with someone with a dementia diagnosis through the story of Mr and Mrs L, a couple in their nineties, and the support that they received from service provider Carers Trust 4all.

In a publication too recent to have been incorporated in bibliographic databases at the time of the searches for relevant scientific literature, Lloyd and Stirling (2015) reported on a study to validate the concept of the 'Activity Support Tool', a tool developed by the authors based on the findings of previous qualitative research by them and designed to assist dementia service workers to adopt a person-centred approach to supporting the needs of people with dementia living alone in the community. The analysis of interview and observational data from seven people with dementia living alone suggested that people with dementia use objects and spaces within their homes to maintain or re-enact identities from the past. Thematic results from the interviews informed

the development of the 'Activity Support Tool', which was then subject to concept validation using the 'Delphi technique'. An expert panel was convened and sent three rounds of a questionnaire soliciting opinion on the wording, presentation and usefulness of the tool, clarity of instructions, possible professional users of the tool, point of service delivery, and context of use. Eighteen panel members returned round one of the questionnaire, reducing to six panel member returns for round three.

The results of the Delphi study suggested that the 'Activity Support Tool' was perceived by panel members to be appropriately simple, reflect the person-centred ideal, and have a wide range of potential uses. However, some panel members expressed concerns regarding its practicability in the face of care worker time constraints, whether the tool should specifically address risk management, gender stereotyping, and the use of the word 'dementia' in 'Activity support for clients with dementia', the full title of the tool. The authors concluded that healthcare experts on the panel 'found the concept of person-centred care compelling, but their responses indicated that they lacked tangible, enduring structures to translate it into practical action' (Lloyd and Stirling 2015: 8). They argued that the study provided three main implications for improved practice: that user-friendly mechanisms are required to translate person-centred approaches to meaningful activity into practice; that there may be a requirement for some service user and provider needs to be recorded in a standardized way that is recognisable by and intelligible to a diverse range of health and social care professionals who may support the service user at different points in their dementia journey; and that a person-centred approach need not be overly time-consuming.

Finally, Elder Options, a Florida-based not-for-profit organisation providing direct services to benefit older people, people with disabilities, and their informal caregivers, posted a video titled 'Step-by-step: Building Meaningful Activities for Persons With Dementia' on their 'Savvy Caregiver' website (Elder Options 2015). The video draws on their 'Savvy Caregiver' training programme and demonstrates the steps caregivers need to address in order to set up meaningful activities for people with dementia, using the example of making the bed. The video focuses on: basics of everyday activity; areas of cognitive loss and how

they affect involvement and level of satisfaction; bringing a step-by-step approach to activities; and awareness of how caregivers offer support.

4.6 Summary
The included literatures relating to meaningful activity for people with dementia and to people with sight loss revealed both similarities and differences in approach. The dementia-specific publications highlighted overarching concerns with best practice based on person-centred approaches. Interpretations of meaningful activity emphasised the centrality of emotional components or a sense of contribution in activities regarded as meaningful by people with dementia, and literature suggested conflicting interpretations by people with dementia and their care-givers. People with dementia viewed meaningful activity as being related to how they experienced the quality of an activity without attaching too much importance to the type of activity. On the other hand care-givers primarily perceived meaningful activity as physical activity for the purposes of health or cognitive improvement. There was insufficient sight loss-specific literature to draw corresponding comparisons between the views of people with sight loss and their care-givers.

The literature also exposed differing mechanisms to achieve meaningful activity engagement. Within the literature relating to dementia the emphasis is on the roles of professionals or family support networks in identifying unmet need for, assessing and/or facilitating engagement in meaningful activity. Included sight loss literature suggested that people with sight loss are more likely to be encouraged to use peer support, share mutual experiences and gain self-confidence for individual motivation to engage with meaningful activities.

5. Informant interviews

5.1 Introduction
Semi-structured interviews were conducted with ten 'expert informants' drawn from organisations and professional groups with roles related to the provision of meaningful activity and the support of people with sight loss and dementia. Table 6 presents generalised descriptions of each participant's areas of specialism. Pseudonyms have been used to protect participants' anonymity.

Table 6   Interviewees

Participant pseudonym	About the participant: Job role, employer, country
Barbara	Occupational therapist, professional representative body, England
Adam	Rehabilitation worker for visually impaired people, local authority, England
Carol	Dementia consultant, regulatory body, Scotland
Donna	Occupational therapist clinical researcher, NHS Trust, England
Elizabeth	Team manager, private healthcare service provider, England
Fiona	Trustee, sight loss charity, England
Gail	Vision support officer, sight loss charity, England
Helen	Dementia consultant, NHS Trust, Scotland
Isobel	Rehabilitation worker for visually impaired people (ROVI), local authority, Scotland
Jacqui	Director, activity provision charity, England

Four core themes emerged from analysis of the interviews: the challenges of supporting people with sight loss and dementia; interpretations of meaningful activity; the use of resources/training; and future resources or guidance. These are discussed in turn below.

5.2 Challenges and enablers when supporting people with sight loss and dementia

The majority of interviewees highlighted a general lack of awareness among some health professionals, family members and care-givers of how best to support people with co-occurring sight loss and dementia to engage in meaningful activities. For instance, Carol and Elizabeth both discussed the time constraints facing a limited staff resource working in residential care settings, the impact that this has on encouraging and providing activities for residents, and how this often leads to organisations adopting generic approaches towards meaningful engagement which are less effective in addressing the needs of people with sensory and cognitive deficits. As Carol explained, it is easier to work with individuals who are highly communicative, cognitively alert and require no additional support.

Elizabeth (healthcare provider team manager) recounted a request for assistance from a care home where staff struggled to engage in a meaningful way with two residents with dementia who were also registered severely sight impaired (blind). She described her response:

> *'To overcome those challenges, we have run some workshops on the use of sensory engagement techniques ... and that was very hands on. With the delegates' permission, we disabled them in various ways including covering their eyes or their ears etc. They found it very insightful that they could actually do things whilst they had these losses.... It is about helping people to understand the different techniques that are so simple and to someone like me may be commonsensical and getting over those challenges to support people with sight loss and those with sight loss and dementia.* Elizabeth

Carol (dementia consultant) talked about a new project being set up in the Lothians area of Scotland to train 'Sensory Champions'. The scheme is designed to provide training to a small number of people working in care home settings who could then diseminate learning around the needs of people with co-occurring sensory impairments and other long-term conditions such as dementia throughout their workplaces. Such a scheme might, for example, encourage staff to be more aware of how often to change batteries in residents' hearing aids, help them to identify signs of potential over-stimulation, e.g. from a television, and to be alert to the potential impact of environmental design on residents with sensory and cognitive impairments.

Adam (visual impairment rehabilitation worker) hesitates when asked to deliver training specific to particular causes of visual impairment since there are many different eye conditions, each of which can affect different individuals in different ways. He prefers to provide training on general support techniques that can be applied across a range of contexts. For instance, sighted guided assistance training can demonstrate to attendees how to let a person with sight loss take their elbow or link arms for extra support, how to avoid dragging or pushing

the person that they are supporting, and how to gently attract their attention through touch.

Most interviewees were able to give examples both of supportive environmental changes and ones which would be unhelpful to people with visual and cognitive impairments. Many highlighted the use of colour as a key enabler for people with sight loss and dementia. In terms of a potentially positive change, Donna (OT and researcher) gave the example of grab rails in a contrasting colour to that of the surrounding walls, as contrast can help both people with sight loss and people with dementia to distinguish objects. In providing an example of a change that might negatively affect people with dementia and visual impairment, Donna highlighted the use of 3D designs on walls, something which she had seen used recently in a care home, and how these can create confusion. Expensive, full-sized 3D pictures of a post box and a telephone box had been placed at either end of a corridor. Donna reflected: *"They were wondering why people were standing around banging on the wall. The reason was they thought they were trying to get into the telephone box or trying to post a letter."*

Fiona (sight loss charity trustee) mentioned research in 2014 by the University of Stirling and Thomas Pocklington Trust which looked at the design of living spaces for people with sight loss and dementia, and which she felt illustrated beautifully the potential for overlaps in good practice in supporting people with sight loss and dementia.

Fiona felt that it was not necessary to have different strategies for supporting people with differing severities of visual impairment and agreed with the emphasis in the literature around using a person-centred approach which emphasises the need to be with the individual, to find out what is important to them and to shape service delivery in response. Fiona felt that difficulties arose when, rather than recognising a person's needs as unique and requiring an individualised approach, carers and supporters tried to rely upon prescriptive lists. Adam felt that good Activities Organisers needed *"...soft skills of communication, spark, fire and inventiveness",* personal qualities that could not necessarily be ensured by legislation, courses and qualifications, asserting that *"you have got it or you have not got it."*

The majority of interviewees discussed challenges relating to fully assessing the needs of people with both sight loss and dementia. For instance, Gail felt that care workers were not always properly trained to assess people's needs and intimated that she is in discussions with groups responsible for care staff training to address what she perceived to be gaps in care workers' core learning. She felt that key learning outcomes are currently primarily focused on physical elements of the job such as health and safety, moving and handling, safeguarding policy and adult protection, with insufficient attention currently being paid to emotional elements of the work such as the identification of a person's sensory or communication needs. Gail (vision support officer, sight loss charity) felt that if 'Visual impairment awareness sessions' are integrated into social work staff training, this learning would subsequently be reflected in greater sensitivity to sensory needs in assessment processes which at present often require the person being assessed to be able to see in order to complete different assessment tools.

Gail noted that some people living with dementia can appear to understand and show affirmative body language such as nodding or smiling. However, close observation may reveal incomplete comprehension of the conversation. She explained that a single visit was not always sufficient to fully assess the capabilities and needs of people, and that in some cases it might take multiple observations to build a detailed picture of somebody and to understand how their support needs might change at different times of the day, in response to medication, or between familiar and unfamiliar locations. Barbara (OT professional body representative) agreed with the desirability of observation across a range of contexts for full assessment, but highlighted the fact that occupational therapists often felt that insufficient time was available to allow them to carry out repeated observations, especially in hospital settings. She also suggested that where possible it would be best to assess people in familiar surroundings since it reduces stress or confusion associated with unfamiliar places.

Adam (rehabilitation worker) outlined a similar strategy when conducting assessments with people with sight loss. The key areas addressed in assessments generally include assistive equipment, training, advice and networking. Adam felt that, for people with sight loss, lack of self-

confidence was a common barrier to engaging in activity. He noted that it takes time to learn new routines or routes, how to use auditory cues, use a long-cane, and to cope with situations where environmental cues are missed, such as bus stops. Peer support has been found to be a useful method to enable people with sight loss to share coping strategies and ideas and put their situations into perspective. Adam argued that more work needed to be done in this area in order to facilitate social interactions that would provide opportunities for peer support without forcing individuals upon each other.

There was consensus among interviewees that a working knowledge of common eye conditions would improve caregivers' awareness of the needs of people with sight loss. Carol (dementia consultant) described how increased awareness could influence caregivers approaches to support and Gail (vision support officer) gave the example of how, without appropriate knowledge and awareness, visual hallucinations associated with Charles Bonnet Syndrome can be mistaken for dementia-related confusion. The symptoms of Charles Bonnet Syndrome can persist for a number of years after a person has lost their sight and those affected experience exclusively visual hallucinations, often of small people or animals.

Carol and Adam touched on strategies in relation to Age-related Macular Degeneration ('AMD'). Carol noted that greater awareness of how this condition affects people might, for example, lead care home staff to think about the best place in a communal area for a resident with AMD to sit on a sunny day in order to maximise their visual perception and encourage interaction with others whilst avoiding any discomfort caused by sensitivity to bright light. The same condition can create challenges when people use stairs. Adam suggested that:

> *'Macular degeneration can make stairs seem like an icy slope. There is no sense of step by step. All you see is this chute in front of you and you might suddenly go rigid. And you wonder 'Why has someone gone rigid?' With them, they are thinking, they are safe holding me, but what they are seeing is not stairs, it is something much more frightening'.* Adam

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The majority of interviewees had had first-hand experience of assisting a person with sight loss and/or with dementia to engage with an activity at some point in time. Barbara (OT professional body representative) observed that if people lost their sight before the onset of dementia, then new routines have already been learnt and, with assistance, can continue. She perceived that challenges arise more when an individual with mild dementia starts to lose their sight. In that case it may be difficult for them to retain changes in routines or approaches to everyday activities.

Adam (rehabilitation worker) recounted work with an elderly gentleman which raised ethical dilemmas. The gentleman had suffered a stroke, triggering his dementia, and lived alone at home. Adam examined the best strategy to respond to difficulties with lining the kettle up with the cup in order to make a cup of tea. Adam's dilemma was whether or not he should stop supporting the man to do this independently, if safely making a cup of tea was particularly challenging to him, and instead set up a care package providing external assistance which would ensure that he received appropriate hydration. The following quote from Adam demonstrates his thinking throughout the process:

> *'Do you teach someone to adapt their normal technique to try and pour in a different way, or do you teach a new technique like put it in the microwave and boil it in the microwave, which is a lot simpler and safer, but is completely unfamiliar to him - he would not have made his cup of tea in that way? He puts it in there, puts the microwave on and it goes ping and he forgets about it. It is also out of sight because it is in the microwave. It's about trying to work out what is the best because he is at risk of scalding himself as well if he cannot line it up correctly'.* Adam

Barbara, Donna and Elizabeth, who all had backgrounds in occupational therapy, touched on activities based on sensory stimulation as useful techniques of engagement for people with sight loss and/or with dementia, particularly for with those with more severe dementia. They had experienced using such techniques in residential settings and in

community living environments. All had considered people's life histories to identify key activities or sensory experiences which might be meaningful to them. For instance, Donna worked with a blind lady with dementia who used to sew. Donna and other support workers put together an apron covered in buttons, different fabrics and ribbons for her. The woman enjoyed the tactile sensations and would spend periods of time feeling the additions to the apron whilst engaging with people around her.

Barbara used sensory rummage boxes and bags. She pointed out that when supporting people with sight loss and dementia tone of voice was also very important. Questions needed to be concise, direct and said with warmth. Where the person is unable to see or cognitively follow instructions, to encourage movement in order to complete tasks, for example drinking a cup of tea, the facilitator can use touch to become an extension of the supported person's body. The facilitator's hands around the person's hands when holding a beaker provides security without invasive manipulation; the elbow can then be supported to bend, accompanied by a gentle calm verbal description "drink".

Donna and Barbara note that it is vital to keep watching for reactions and body language. As Barbara explained, one of the main challenges for people affected by sight loss can be the shift from a visual learning platform to auditory, touch or smell:

> *'Somebody with dementia will take in visual cues all the time to read what to do. They will watch closely and try and mirror what other people are doing to make sense of what is going on around them because instructions might be too complex. If they cannot see visually what to do and how to be cued in, then they really are reliant on that guiding voice and that guiding touch'.* Barbara

Elizabeth recounted working with a man with gradual sight loss during the onset of dementia, where a multi-sensory approach enabled retention of activity engagement. His wife reported that her husband felt a lot of frustration in connection with his inability to continue different activities and playing certain music, Bruce Springsteen for example, helped her husband to release emotional tension. The man was formerly

a keen sportsman, and Elizabeth managed to source an adapted exercise bike which he rode for at least ten minutes a day until he reached a point where he forgot how to push the pedals. Elizabeth recalled that his smiles of pleasure showed his appreciation. Through observation it was discovered that the man reacted positively to a toy belonging to one of his grandchildren which made animal noises. This seemed to trigger engagement with others and to lead to short games of ball throwing in response to verbal cues.

5.3 Interpretations of meaningful activity

The majority of participants viewed the concept of meaningful activity as person-centred in nature and relating to activities that brought meaning to a specific person. Some interviewees revealed that they used alternative terms to meaningful activity in everyday speech. Those with backgrounds in occupational therapy tended to say 'purposeful', while those from sight loss support backgrounds talked about 'enjoyable' or 'valued' activities.

Adam (rehabilitation worker) reported that in their work with people with sight loss they try to find out what activities people find enjoyable. He explained that for him and his colleagues, the word 'meaningful' held an implicit assumption that there had to be an active component to the activity or that it should lead to something, whereas sitting in the garden 'doing nothing' may greatly benefit a person's sense of wellbeing. Adam felt that given the need for a person-centred approach it was impractical and inappropriate to suggest separate lists of meaningful activities for people with sight loss and for people with dementia.

Barbara (OT professional body representative) echoed this sentiment. In her role as an occupational therapist she concentrated on 'doing', and tended to ask what people 'liked to do' rather than what they found 'meaningful'. Barbara gave the example of cooking. For any given person cooking may have meaning attached to their role within the family unit, or it may provide a form of relaxation, or it may assist a person with monitoring their nutritional needs, or any combination of these and other meanings. Fiona (sight loss charity trustee) remarked that stereotypes can mean that when people retire there can be a sudden pressure to participate in what others define as meaningful activity. However, given the diversity in both age range and interests of

those past statutory retirement age, activities perceived to be popular with 'older people', such as playing a game of bingo, are unlikely to be meaningful to everybody.

All the interviewees acknowledged that there were occasionally degrees of difficulty in determining both what was and what is now meaningful to somebody. Gail (vision support officer) remarked that it was very important that caregivers or family members refrained from 'colouring' potential choices with their own preferences or assumptions. In many cases interviewees adopted a 'trial and error approach', trying out various activities to gauge interest.

A common method in trying to understand what might be meaningful to a person was the use of life history, including a detailed examination of a person's 'everyday' life. Elizabeth (healthcare provider team manager) explained that an important part of her role was spending time to assess, for example, whether a person prefers to get up and then have a cup of tea or get up, get dressed, and then have a cup of tea. All the interviewees touched on the importance of routine, particularly for people with dementia, in providing a sense of security and familiarity with, and cues to the timing of everyday activity and behaviour.

Fiona (sight loss charity trustee) spoke of how, for people with dementia, meaningful activity can be intimately connected to their past and with times and activities where that person felt more in control of their life:

> *'[W]hat gives [activity] something that makes it feel as if it has meaning for you and your life and is worth doing? Very often for people with dementia that may be something that they can relate to in terms of their past life because when they are going back into the past that is the bit they can remember, that is the bit they feel they have control over. If you can help people to have activities in their life that are familiar from the past then that may help people to feel they have more control and so it may be very meaningful. ... Meaningful has to be person centred'.* Fiona

5.4 Reflecting on existing guidance

While discussing which guidance they drew upon to support individuals with both sight loss and dementia, most interviewees were able to identify and speak about various tools and resources that they had discovered and now used as part of their roles. Several mentioned making use of resources such as those produced by Jackie Pool (Elizabeth, Donna) or specific leaflets (Gail, Adam), but these were often discussed in the context of addressing specific challenges, such as reducing the likelihood of falls (Adam). However, whilst these resources were almost exclusively discussed in relation to working with individuals with both sight loss and dementia, interviewees rarely discussed specific methods they used to facilitate meaningful activity.

There appears to be a tendency to create organisation / discipline-specific resources in this area, even when existing more general guidance is known to exist. When reflecting on guidelines for general use by health and social care professionals, the majority of interviewees focused on the use of guidelines and toolkits that had been constructed in-house either by themselves or by their colleagues;

> *'In 2013, we did a resource for care homes that was aimed at residents in care homes, family and friends, but also aimed at care home staff and care home managers. It is really explaining and giving tips about how to support people to remain active within their lives and to think about how as we get older we can still live a quality of life and it does not just become about existing and personal care'.* Barbara (OT professional body representative)

> *'The team have been writing a handbook to support Activity Coordinators and it is based on occupational therapy principles. It is designed to be a very practical handbook. It has hints and tips on how to plan activities; how to accommodate for different people's interests, abilities and support needs they may have. There is a big section in there about how you overcome hearing impairment, visual impairment, physical impairment etc. […] A lot of [staff] facilitate really good sessions, but they do not necessarily understand why it is working, so we are*

trying to underpin their experience with more knowledge so that they can apply it more effectively'. Elizabeth (healthcare provider team manager)

Such resources were often described as meeting identified (and up to that point 'unmet') needs for the group concerned, even when participants showed a significant knowledge of existing literature providing guidance on similar issues published by other bodies, agencies or companies.

Some existing mechanisms for the dissemination and sharing of existing resources may have in-built limitations. For example, some participants, such as Carol, a dementia consultant working for a Scottish regulatory body, discussed the way in which the organisation that she used placed key resources in an online information 'hub' to which service providers can be directed;

> *'Any kind of information that we have - within [my organisation] we have an information hub - if I get any kind of best practice, I will put it on there. If it is there [my colleagues] can then see it. If they are out on a service and see somebody that is not being supported appropriately or well, they can then signpost the staff to have a look at these resources and materials'.* Carol

Although the intention is to make the information widely accessible to those directly supporting people with dementia and visual impairment, knowledge and/or resources contained in the information hub are only successfully disseminated if key individuals are directed to them during service assessments. Resources held by the hub are only signposted to workers at assessed facilities providing suboptimal care for individuals with sight loss and dementia: workers in services deemed to be meeting the needs of this group may either not be referred to the hub or not feel that it is necessary for them to look at the resources provided.

There is a need to identify the optimal pathways for dissemination of new research findings and guidance on best practice in this area and the best mechanisms for achieving continuous improvement across all services.

The benefits of understanding the causes and where possible addressing visual impairment for people living with dementia may need to be stressed more strongly than is the case in existing guidance. Some interviewees discussed the idea that a diagnosis of dementia may be a key factor impeding a sight-loss diagnosis. A number of interviewees reflected that the reduced expectation that often accompanied a dementia diagnosis led to sight problems often being overlooked by paid carers and families:

> *'The biggest challenge is to be understanding - understanding of not only the visual impairment, but also of the dementia - people really understanding what it means to live with dementia; what someone is able to do; how to encourage people to participate and an expectation that they can participate. Sometimes people are not included in things because there is no expectation that they will be able to. That is sometimes an attitudinal barrier. If there is no expectation, then there is no offer'.* Carol (dementia consultant)

> *'People sometimes think the person has fallen because they are unsteady or because of this, that and the next thing, but they do not automatically think it might be to do with the lack of vision which has meant that they have had a trip or a fall'.* Gail (vision support officer)

Interviewees discussed a variety of other challenges, from the difficulty of finding family and support staff willing to try different approaches and allow calculated risk, as discussed by Adam (rehabilitation worker), to raising awareness among key people who would be able to use the resource in practice. Fiona, in particular, highlighted a significant issue that had arisen when she and her colleagues realised that despite having their pathway included in the UK governmental strategy, it was still not being engaged with at the level of care provision; '*What we realised having drawn it, that it is broken and that people are not doing what they ought to be doing. […]. That is what we are struggling with now'.* Fiona (sight loss charity trustee)

There is a need to ensure that resources meet health and social care professionals' needs and that the guidance such resources provide becomes embedded in care practice. Many interviewees discussed the specific challenges involved in ensuring that those supporting individuals with sight loss and dementia engaged with training and resources, and used them in the long term. Adam discussed the challenges that can be perceived around training staff who are perceived to have limited interest or ability, citing issues with written guidelines as care workers are often '*Not naturally drawn to reading materials […] they are good with people, but not particularly good at reading or digesting stuff*'.

Some participants seemed to avoid such issues by using smaller, specifically targeted resources. Gail discusses the way in which booklets on particular problems can be used to facilitate better care, by providing them when they actively relate to the problems being experienced by the person with dementia, their families and those providing them with professional support. Similarly, Carol (dementia consultant) describes the way in which training in dementia is often broken down into specific modules, and how useful it would be to have a resource that focused specifically on sight loss and dementia together.

There is consensus around the need for and value of appropriate awareness raising and training for health and social care professionals to support meaningful activity for people with dementia and sight loss. However, interviewees identified a number of challenges, including persuading employers to integrate such activities into their training schedules in the face of budgetary constraints and competing training priorities, and ensuring that appropriate training was available when they did so.

When discussing the value of training, interviewees universally suggested that either they had found it valuable themselves, or that they had received feedback from those who had attended training attesting to its importance. Gail explained that part of the value of training around sight loss in particular was its ability to shift the way in which support staff thought about providing care:

> '*It is about looking at what their paperwork looks like in their working environment; can they integrate vision into*

their assessments where they are important; can they integrate vision into the work that they are doing with individuals and / or if you are a carer, how can you support someone who has a vision problem - basically, that is what it is about. It is bringing vision to the forefront of people's minds rather than an add-on; it should be integrated into their practice'. Gail (vision support officer)

Carol discussed the way in which providing staff with hands on training around the effects of sight loss had led to better understanding and care:

'Once people could understand [the effects of visual impairment], it made sense then why [those they support] do these things. It gives people more understanding. In some ways, the diagnosis of dementia can be a barrier towards exploring further whether there is any degree of sight loss there and the behaviour around it'. Carol (dementia consultant with regulatory body)

Despite interviewees' strong support for and belief in the value of guidance and training in this area, several significant challenges were identified by interviewees whose roles involved providing guidance and training to care providers rather than to people with dementia and sight loss themselves. Issues associated with raising awareness of the needs of individuals with both dementia and sight loss were a common theme running through all of the interviews. Interviewees discussed how, despite key people expressing their enthusiasm for a particular training initiative and seeing its value, it was often excluded from the core training of their staff due to budgetary or time constraints:

'I have gone to speak to the managers in social work. They think it should be part of their core training. I had a meeting with the staff development officer who is responsible for their training and adult services training last week. […] The problem is their core training main priorities are things like health and safety and they have to do that first - moving and handling, safeguarding policy and adult protection etc. - all the legislative things have to be done first, but they still think it is really important

because what I am saying is "If you do not understand about vision and you do not integrate it into your assessment, how valid then are your assessments, and the result and the finish that you get back from that?"' Gail (vision support officer)

Furthermore, where managers and senior staff might be agreeable to arranging specific training for their staff, there was an indication that it was not always readily available. Carol (dementia consultant with regulatory body) mentioned the limited availability for training, despite there being a 'huge demand' for it, with Barbara suggesting that increases in demand may be due to an increased awareness of the ways in which sensory degradation may affect cognitive ability:

'There is a growing awareness now about the importance of senses and there is a growing understanding around that. And there has been an acceptance that for older people what to expect - your sight is going to go, your hearing is going to go - and I think problems do not get picked up until later on, particularly if someone has dementia. And we know that if any sensory impairment can be corrected or helped, then that is going to help someone's cognitive function and day to day functioning as well'. Barbara (OT professional body representative)

This shift towards a view of supporting people with dementia that more routinely includes understanding sight loss as a factor that should be considered is a positive trend. However current guidance, which was described as existing predominantly in small, specialised resources, may be insufficient. Even where interviewees such as Carol had an extensive knowledge of existing literature, they were not able to identify any single inclusive resource around supporting individuals with sight loss and dementia, let alone a resource designed specifically to guide supporters in enabling people with both sight loss and dementia to engage in meaningful activity.

5.5 Views on the development of future resources

Following on from their thoughts around existing resources, interviewees expressed a number of views on key issues relating to the development of any future resources.

Ensuring that new resources both promoted *and* were used in a way that was consistent with person-centred approaches was a theme that ran through all the interviews. Interviewees expressed concerns that certain types of resource might be used in ways which did not properly consider the supported person's own life experiences:

> *'What it would not be is a list of things that visually impaired people can do or would find interesting. […] For me it is not about the sight problem, fundamentally, it is about the person [being supported], what they want to do and activities in general, and then getting [the health or social care professional supporting them] to think about what that particular person's sight, hearing or cognition problems are and work back to the activity.*
>
> *If I said to you in a leaflet "Make things brighter, help them read the crossword", if brightness creates glare for them or they cannot hold a magnifier because they have a trembling hand or such like then that would be no good…. You can have a list of resources on where to get magnifiers or where you can get large crosswords from. That is useful, but it is coming about it from the wrong end. I think it is about the person, what they want to do and how you adapt their disability to that'.* Adam (rehabilitation worker)

Many interviewees suggested that training or resources should provide an interactive experience which would help recipients / users to understand the lived experience of people with visual and cognitive impairments. Interviewees suggested that this type of insight frequently prompts carers and supporters to question and to re-evaluate their assessments of the reasons behind observed behaviours, such as why an individual is leaving food on their plate, seems to have lost interest in previously enjoyed activities or becomes agitated whenever in particular

locations. Such solutions promote empathy and help supporters to understand situations from the perspective of the person with dementia and sight loss. However, this type of training, which is typically provided by a specialist trainer in a dedicated training session can be perceived by service providers as burdensome and expensive.

Some interviewees suggested the use of case studies as an alternative approach to helping professionals to develop insights into the lived experience of people with dementia and sight loss and promote person-centred practice. Elizabeth explains why she is using case studies in a forthcoming team training event to provide a valuable means of exploring avenues for better practice without sacrificing the person-centred aspect of care:

> *'Case studies are very powerful tools. [They] help people to problem solve and think creatively because there may not be a black and white answer. What I am expecting in the event [is] that someone will say "In my experience I would do this" and in someone else's experience they would do that. It gives people confidence to think that either there is not a black and white answer or, if I try this and it does not work then that is fine because I can try something else'.*
> Elizabeth (healthcare provider team manager)

Other interviewees discussed the use of case studies in a similarly positive light. Case studies were perceived as a means to convey an understanding of the difficulty being described, change the way that staff members perceived challenges, allow people to discuss, reflect on, and learn from the outcomes of different approaches taken by others in similar circumstances, become more comfortable with the idea that there may be no single 'right' answer, and encourage them to approach problems from a different angle.

Other types and forms of resources were discussed by some interviewees, including: instructional DVDs (Donna, OT and researcher); specific modules to add to existing training (Carol, dementia consultant with regulatory body); and integrated online resources (Gail, vision support officer). However, despite supporting

online modules, Gail is clear that they should be a supplement to face-to-face training, not a replacement for it.

Fiona (sight loss charity trustee) provided a helpful reminder, drawn from a sight loss-specific context, of the importance of not making assumptions about what is needed and including the perspectives of people with sight loss and dementia in the development of any new resources.

> *'I think there is a whole range needed in terms of meaningful activity. It is wider than [a single] activity. A telephone befriending service or a befriending service of some kind can give people what they need. […]–[A]t our AGM a few years ago, I had an open forum and invited our members to come along and tell us what they thought [my organisation] should be concentrating on […] And what people were saying is… "We do not want you to have a social group - we want you to help us to be able to meet each other and then do whatever it is that we want to do", be it talk about technology or go to craft fares. Very often that is what people need'.* Fiona

The views of those living with both conditions are largely missing from the discourse surrounding meaningful activity for people with both sight loss and dementia. It is important to fully understand what people want for themselves and for future guidance or training resources to reflect this.

5.6 Summary

Although some enablers were identified, in the main interviewees focused on the challenges faced by key professional carers and supporters when attempting to engage people with both sight loss and dementia in activity of any sort. Challenges included: lack of awareness of how people's vision was affected by different sight loss conditions and how cognitive impairment might exacerbate the difficulties that people experienced; resource constraints which limited the opportunities to provide one-to-one support for participation meaningful activity in some care contexts; lack of specialist training or resources on how to fully assess the needs of people with dementia and visual impairment; and

reliance on prescriptive lists of activities rather than person-centred approaches which tailored activities to the needs and preferences of the person being supported.

Interviewees used a range of different terms to describe what this study refers to as 'meaningful activity'. Those with backgrounds in occupational therapy tended to say 'purposeful', while those from sight loss support backgrounds talked about 'enjoyable' or 'valued' activities. The concept of 'meaningful activity' was most often discussed in relation to primarily sensory activities and to measurable outcomes, for example when Elizabeth discusses two people with dementia and visual impairment that had been supported by providing sensory activities (sensory apron and exercise bicycle and animal recordings respectively) in their environment, focusing on measureable outcomes of engagement in activity and the reduction of distress. This focus by interviewees may be the result of formal service provision increasingly being provided only to people with more severe symptoms and higher levels of support need, but it suggests that there is a need to examine further the question of what resources need to be developed, how they should be informed, and who they are ultimately for.

A number of points emerged from interviewees' consideration of existing guidance. There appears to be a tendency to create organisation / discipline-specific resources in this area, even when existing more general guidance is known to exist. Some existing mechanisms for the dissemination and sharing of existing resources may have in-built limitations: there is a need to identify the optimal pathways for dissemination of new research findings and guidance on best practice in this area and the best mechanisms for achieving continuous improvement across all services. The benefits of understanding the causes of and where possible addressing visual impairments for people living with dementia may need to be stressed more strongly than is the case in existing guidance, as many interviewees felt that identifying visual impairments and providing treatment or adaptations which could help individuals to cope with these was given a lower priority when people had a diagnosis of dementia. Interviewees perceived a need to ensure that resources meet health and social care professionals' needs and that the guidance such resources provide becomes embedded in

care practice: the forms in which current resources are provided were not always seen as optimal for target audiences. Although regarded as extremely helpful to front-line staff, interviewees expressed concerns that some forms of awareness training are perceived by employers as difficult to access and expensive.

Interviewees expressed a number of views on key issues relating to the development of any future resources. They saw it as important to ensure that any new resources can and will be used in a way that is consistent with person-centred approaches to support. Providing recipients with realistic insight into the lived experiences of people with dementia and sight loss was seen by interviewees as a critical requirement of future training or resources. Understanding health and social care professionals' preferences and tailoring the forms in which training and guidance are provided accordingly was perceived to be key the success of new resources. Finally, they felt that it was important to recognise the context in which training was likely to take place and to understand and meet service providers' needs for training and resources which are easily accessible and perceived as affordable.

6. Survey
The survey was designed to complement the interviews with expert informants by allowing views on key themes discussed with interviewees and propositions relating to the need for and development of future resources emerging from the interviews to be gathered from a wider group of relevant stakeholders. The survey was primarily health and social care professionals working with people with dementia and/or sight loss. In particular, it was hoped that the survey would provide an indication of the extent to which there was consensus between different stakeholder groups as to the need for additional guidance in this area and as to the preferred form(s) of any future training or guidance.

The online survey questionnaire was created using Qualtrics survey software, and links to the survey were made available to potential respondents in mid-May 2015 via website postings, social media, inclusion in newsletters by a range of different organisations and groups with interests in supporting people with dementia and sight loss. The

survey remained 'live' for a period of two weeks. Two respondents requested to complete the survey by telephone.

Following an opening section designed to collect data on respondent characteristics, the questionnaire contained a mix of closed and open-ended questions designed to gather data on what 'meaningful activity' means to respondents, what they see as the challenges of providing meaningful activities, and whether they feel there is sufficient guidance available to assist them and others working in this area.

6.1 Respondent characteristics

The survey was started a total of 179 times, from which 117 substantially completed responses were received. Respondent characteristics are described in Table 7. Data from the 62 incomplete survey responses was excluded from analysis on the grounds that the partial responses lacked context and depth.

Table 7   Survey respondent characteristics

Characteristic		Number	% of those providing data
Sex (n=115)	Female	104	90
	Male	11	10
Age (n=105)	<25	4	4
	25-44	47	45
	45-64	51	49
	65+	3	3
Location (n=117)	Scotland	69	59
	England	45	38
	Wales	1	1
	Northern Ireland	0	0
	Outside UK	2	2
Role Type	Direct Support Staff	19	16
	Allied Healthcare Professional	21	18
	Healthcare Professional	42	36
	Academic	2	2
	Person with	1	1

Characteristic		Number	% of those providing data
	dementia and/or sight loss		
	Family carer	18	15
	Management	11	9
	Other	3	3
Time supporting (years, n=99)	<2 years	6	6
	2-5 years	33	33
	>5 years	60	61
Who respondent supports (n=113)	People with dementia	42	37
	People with sight loss	6	5
	People with both dementia and sight loss	56	50
	Other	9	8
Support environment (n=111)	Residential	21	19
	Community	33	30
	Both	57	51

The overwhelming majority of respondents (90%) were female and most (94%) were aged between 25 and 64 years old. Nearly all of those substantially completing the survey were located in either England or Scotland, with one in Wales and two respondents located in the USA. In terms of role type, the largest categories of respondents were 'healthcare professionals' (36%) followed by allied healthcare professionals (including occupational therapists) (18%), direct support workers (16%) and family carers (15%). The majority of respondents (61%) had been supporting people with dementia and/or sight loss for more than five years, with many having been providing support for significantly longer. Half of all respondents (50%) supported people with both sight loss and dementia, with a further 37% supporting people with a diagnosis of dementia: only 6 respondents supported people with sight loss but not dementia. Just over half of the survey respondents (51%) support both people living in the community and people in residential accommodation, with just under a third working exclusively with people

living in the community and just under a fifth working exclusively with people living in residential environments.

6.2 Definitions of 'meaningful activity'

Respondents were asked 'How would you describe "Meaningful Activity"?'. Descriptions varied considerably in length and focus, for example:

> *'… any activity which has an outcome/purpose and or brings pleasure to an individual'* Healthcare professional

> *'… an activity that is part of the patient's life history, interests, routine and personality. Meaningful activities are activities that help describing our identity e.g. when we first introduce ourselves to a group we would say something like: "Hello I am John, I am a bus driver and I enjoy reading the newspaper every day"; "driving" and "reading the paper" are meaningful activities because they help describing who we are and why we are different than everybody else'.* Physiotherapist and researcher

> *'Something that someone enjoys doing with their time'.* Care home activities manager

Survey respondents in aggregate had a person-centred understanding of the term, describing 'meaningful activities' as being first and foremost about the person being supported, with activities having meaning, importance, purpose or value for them. Activities could be related to daily tasks, occupational or recreational in nature but respondents saw being enjoyable, stimulating and/or interesting to the person being supported as a core component of meaningful activity. Many respondents stressed what they saw as the 'elective' nature of such activities, i.e. something which a person choses to do. Others highlighted the interactive nature of many activities regarded as meaningful. Respondents' definitions also frequently focused more on the outcomes of meaningful activity than prescribing the activities themselves. Meaningful activities were seen as resulting in a range of emotional and psychological benefits, such as increased self-confidence, sense of independence, achievement or self-identity, feelings of 'normality' associated with carrying out familiar activities.

Eighty-eight respondents provided some comment when asked for suggestions for alternatives to the term 'meaningful activity'. Many respondents had already used the alternative terms that they suggested in providing their definition of 'meaningful activity' earlier in the survey, suggesting that for many people these terms are interchangeable.

Box 1 presents selected alternatives offered by respondents. The most frequently offered alternative was, or included reference to, 'purposeful activity', with either the activity deemed intrinsically purposeful or as having purpose for the person carry out the activity: 12 respondents made suggestions of this type. Around a tenth of those offering an alternative suggested, or included reference to, 'activities of daily living' with around a tenth specifically mentioning 'hobbies'.

Box 1   Selected alternatives to 'meaningful activity' offered by survey respondents

- Activities of daily living, leisure pursuits or activities which promote quality of life.
- Fun!
- Most people might call them hobbies, or leisure pursuits. Anything that might indicate that it's not a chore or obligation.
- Occupational, vocational, therapeutic
- Social
- Purposeful activity, client-centred
- These are often ad hoc, diversional activities for people with dementia.
- Productive, personal, individual, person centred , valuable, essential
- Could also be something physically and mentally beneficial to an individual
- Goal-directed, person-centred
- Participatory, interactive, stimulating
- Diversional therapy
- Things that are important to me
- Engaging, interesting, challenging but within limits
- Personal, evocative, calming
- Giving purpose, still feeling connected, fun, engaging, stimulating, re-assuring, confidence building, re-establishing a sense of self

- The ordinary everyday things we all do for self-care, work, pleasure, play and communication.... and what we do as human beings to stay connected to who and what matters to us
- The opportunity to engage and connect with other people and the world around, draw on personal preferences and life story including roles; routine; occupation and past and present interests
- Relevant to the person and something they wish to engage in

6.3 Finding help and guidance on delivering support

Although only 50% of respondents did so at the time of completing the survey, nearly three-quarters (87 people) had directly supported people with both sight loss and dementia at some point, of whom 90% had experienced particular challenges in assisting people with both sight loss and dementia to access activities. Respondents primarily related those challenges to the interaction of a person's sight loss and dementia: two thirds of those experiencing challenges attributed them to this rather than to the person's sight loss (5 respondents) or their dementia (8 respondents).

Thirteen respondents (17% of those who had experienced challenges) attributed the challenges that they had encountered to other factors. Five offered further explanation on what they saw as being responsible for making support challenging for them:

> *'Because it can be hard to engage with someone with sight loss and carers worry about risk, people can be forgotten about and ignored'* Occupational therapist.

> *'[The perception] that because someone has dementia they are unable to take part'* Healthcare professional, family carer support.

> *'The issues more often lie in the staff understanding the capability of people with dementia and limiting them, not realising the importance of the environment in the success of an activity, and trying to make one size fit all'.* Service provider and care staff trainer
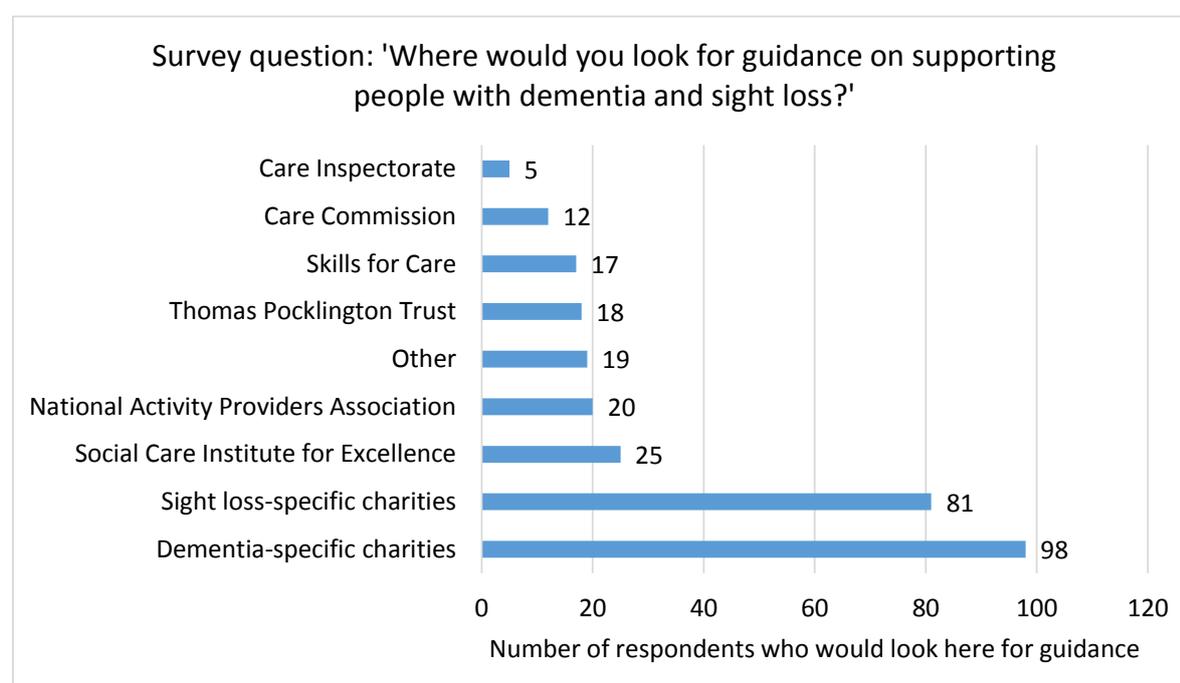
'The environment isn't well suited to helping people with dementia and sight loss, and public knowledge isn't good to help people'. Health care professional, acute general hospital

'The challenges vary not just from person to person but from task to task'. Healthcare professional, educator and trainer

The survey responses suggest that respondents feel that challenges are often the result of misconceptions or lack of awareness of the abilities of people being supported, or heightened, and perhaps undue concern for their safety.

Figure 2   Where respondents would look for guidance

Survey question: 'Where would you look for guidance on supporting people with dementia and sight loss?'

Source	Number of respondents who would look here for guidance
Care Inspectorate	5
Care Commission	12
Skills for Care	17
Thomas Pocklington Trust	18
Other	19
National Activity Providers Association	20
Social Care Institute for Excellence	25
Sight loss-specific charities	81
Dementia-specific charities	98

The survey asked respondents where they would look for guidance in supporting people with sight loss and dementia. Figure 2 (above) illustrates responses to this question. The question allowed for selection of multiple sources from a list based on suggestions from experts interviewed as part of the research. Specific organisations in the list included: the Social Care Institute of Excellence (SCIE); the National Activity Providers Association (NAPA); Thomas Pocklington Trust; Skills for Care; and the Care Commission / Care Inspectorate (the independent scrutiny and improvement body for care services in Scotland, responsibility passing from the Commission to the

Inspectorate in April 2011). The list also included generic charity categories and an 'other' category.

The majority of respondents indicated that they would seek guidance from dementia specific and sight loss specific charities (84% and 69% respectively). Around or just under one-fifth of respondents would look to each of the specific organisations listed in the question, and approximately the same number (16%) indicated that they would use 'other sources'.

When asked where else they would look for guidance in supporting people with sight loss and dementia, many respondents suggested multiple sources, the most common of which were:

- Colleagues, including colleagues in partner organisations and in professional representative and governing bodies
- Local sensory impairment services or teams
- The internet
- Family carers and service users themselves
- Local sight loss or dementia charities
- GPs

A number of specific organisations or resources were also mentioned, including

- NICE
- RNIB
- University of Stirling (Dementia Services Development Centre)
- Age UK
- The Care Quality Commission (CQC)
- Blind Veterans UK - formerly St Dunstan's
- VISION 2020 UK website
- Dr Gemma Jones' 'Communication and Care Giving' materials

One respondent, an occupational therapist working in an acute hospital setting, explained that it could be hard to access appropriate support materials when needed:

> *'It is very difficult within an acute hospital environment to access sufficient support due to quick turnaround of patients and limited*

time-frames. Also I have an extremely busy caseload therefore do not have the time to seek support'.

Respondents were asked to indicate if they had used any of a selected list of resources or collections of resources. Again, the list was informed by the literature review and interviews with experts carried out as part of the research. The survey included clickable hyperlinks for each resource to either the resources themselves or to further internet-based information about the resource. Table 8 provides information about each of the resources and Figure 3 illustrates survey responses regarding their use.

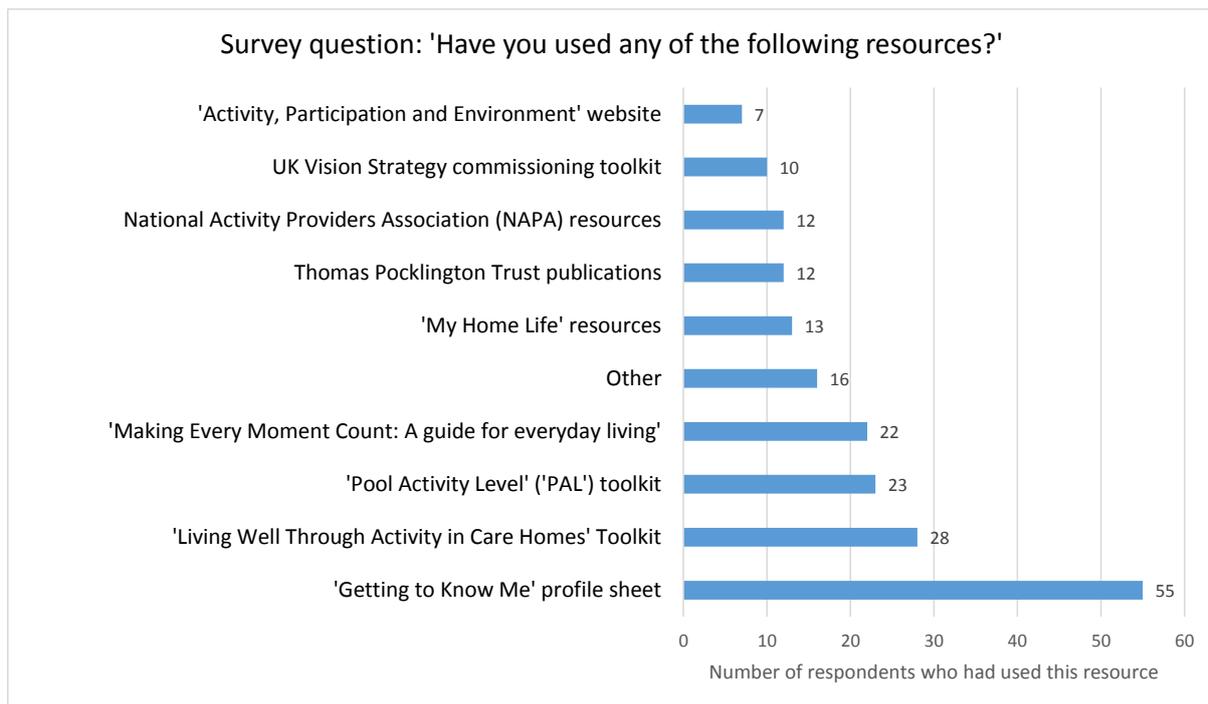**Table 8   Specific resources identified in the survey**

Resource	Further information
'Getting to Know Me'	A profile for collecting information about a person needing support developed in 2013 by Alzheimer Scotland and The Scottish Government from original work by NHS Lanarkshire. **http://www.scottishcare.org/docs/037_280__gettin gtoknowme_1369954145.pdf** .
'Living Well Through Activity in Care Homes' Toolkit	The toolkit contains a series of guides for different groups, including residents and their families, care home staff, care home owners and managers, care home inspectors, and occupational therapists, as well as a poster detailing how the resources was developed. It was first published in 2013, and updated in July 2015, by the College of Occupational Therapists. **https://www.cot.co.uk/living-well-care-homes** .
'Pool Activity Level' ('PAL') toolkit	The toolkit includes the PAL Instrument, a research-based and validated tool for developing a profile which includes assessment of the level of cognitive ability of the person being assessed, information which can then be used by those supporting them to tailor offered activities. **http://www.jackiepoolassociates.org/products/pool**

Resource	Further information
	-activity-level-pal/
'Making Every Moment Count: A guide for everyday living'.	An information leaflet developed by the Care Inspectorate, the body which regulates and inspects care services in Scotland, and launched in February 2013 setting out key messages for supporting older people in both community and residential environments. The resource was subsequently rolled out across more than 1,700 care services for older people in Scotland. **http://www.careinspectorate.com/index.php/guidance?id=2736**
'My Home Life' resources	'My Home Life' began in 2006 as an initiative by National Care Forum and Help the Aged and is now a UK-wide initiative promoting quality of life and delivering positive change in care homes for older people that is supported by national residential care providers and the Relatives and Residents Association. **http://myhomelife.org.uk/resources-and-information/**
Thomas Pocklington Trust publications	As part of its charitable mission, Thomas Pocklington Trust funds social and public health research initiatives to identify practical ways to improve the lives of people with sight loss. A wide range of publications for different audiences informed by this research are made available on the organisation's website. **http://www.pocklington-trust.org.uk/researchandknowledge.html**
National Activity Providers Association (NAPA) resources	NAPA is a registered charity and limited company focused on promoting high quality activity provision for older people through delivering best practice training and support, disseminating useful information, promoting, encouraging and researching best practice, and raising the status of activity providers.

Resource	Further information
	http://www.napa-activities.com/
UK Vision Strategy commissioning toolkit	The toolkit, contained in 'Driving local change for effective and efficient eyecare services', was published by RNIB and launched in November 2014 following the Department of Health-funded 'Commissioning for Effectiveness and Efficiency (CEE) project'. **http://www.ukvisionstrategy.org.uk/sites/default/files/FINAL_APDF_UKVS_CEE_Toolkit.pdf**
'Activity, Participation and Environment'	A website signposting other resources designed to help AHPs support carers to provide opportunities for meaningful activities to people living with dementia. **http://www.knowledge.scot.nhs.uk/dementia/communities-of-practice/national-ahps-best-practice-in-dementia-network/activity-participation-and-environment.aspx**

The most widely used resource was 'Getting to Know Me'. This resource had been used by 55 respondents (47% of those responding). The next most widely used, the 'Living Well through Activity in Care Homes' Toolkit was used by just under a quarter of all respondents (28 people). Twenty-three people (20% of respondents) had used the 'Pool Activity Level' ('PAL') toolkit. A similar number (19%) had used 'Making Every Moment Count: A guide for everyday living'. The remaining specified resources had been less well used. 11% of respondents had used web-based 'My Home Life' resources. Thomas Pocklington Trust publications and National Activity Providers Association (NAPA) resources had each been used by 10% of respondents. 9% had used the UK Vision Strategy commissioning toolkit. 6% visited 'Activity, Participation and Environment'.

Figure 3. Use of selected resources by survey respondents

Survey question: 'Have you used any of the following resources?'

Resource	Number of respondents who had used this resource
'Activity, Participation and Environment' website	7
UK Vision Strategy commissioning toolkit	10
National Activity Providers Association (NAPA) resources	12
Thomas Pocklington Trust publications	12
'My Home Life' resources	13
Other	16
'Making Every Moment Count: A guide for everyday living'	22
'Pool Activity Level' ('PAL') toolkit	23
'Living Well Through Activity in Care Homes' Toolkit	28
'Getting to Know Me' profile sheet	55

Sixteen respondents (14%) said that they had used 'other' resources, including:

- Local community workshops
- Bespoke toolkits
- Skills for Care resources
- The Butterfly Approach – a model for supporting people with dementia in care homes
- RNIB and Macular Society leaflets on activities of daily living
- Dr Gemma Jones' 'Communication and Care Giving' materials
- 'Good Practice in the Design of Homes and Living Spaces for People with Dementia and Sight Loss' (**http://dementia.stir.ac.uk/design/good-practice-guidelines)** and other online guides
- Alzheimer Scotland Personal Support Plan and other personal support plans
- Playlist for Life.

6. 4 Respondents' suggestions for providing support

Survey respondents were asked to identify any particularly effective methods that they had found to support people with sight loss and dementia to engage in meaningful activities. More than two thirds of respondents (72%) offered suggestions for effective support. These tend to fall into three categories: key actions prior to supporting engagement in activities, pointers around delivery of support, and suggestions for activities.

Key actions prior to engaging someone in activities:

- Using the Pool Activity Level toolkit checklist
- Knowing a person's interests, background, life history; talking to them and their carers and families to find out
- Knowing and understanding a person's sight loss condition and dementia type and how these conditions might affect their ability to participate in activities
- Taking time to build a therapeutic relationship with the person
- Provide the right environment, de-clutter and remove obstacles
- Ensure that those delivering support are appropriately trained
- Ensure access to resources to engage in activities.

Pointers around delivery of support:

- Adapt activities according to abilities, simplifying if necessary
- Listen to people's worries and fears and reassure
- Talking through and describing activities
- Make session length appropriate to the person being supported
- One-to-one sessions suggested above group activities
- Use of touch
- Engaging family carers and enabling them to support rather than do things for the person
- Be flexible and accepting of failure.

Suggestions for activities

- Activities that the person being supported has chosen
- Sensory activities, particularly those involving tactile stimulation
- Talking books, poetry read aloud

- Music, listening e.g. Playlist for Life, or as 'music and movement' and dancing
- Singing, including 'Singing for the brain'
- Ignite Sessions - themed sessions discussing famous works of art, based on Montessori principles
- Reminiscence, using boxes or bags of familiar objects, or foods to taste
- Personalised 'fiddle cushions' or other tactile objects.

In addition, some respondents shared advice about activity for a specific context:

'Attempting to assess mobility whilst patient requesting to go to the toilet or another self-initiated task can be helpful rather than asking patients to walk for no reason other than assessment. Where possible, assessment in patient's home environment may be helpful'. Healthcare professional, rehabilitation and hospital discharge assessment.

Others acknowledged that people were individuals and that there was no 'one' solution. One respondent asserted that there could be many acceptable approaches:

'Any method or approach will be effective if it is person centred and knowledgeable. You are only limited by your own creativity in finding/designing a solution so it is good to speak to others and ....through discussion....find new ideas and thinking' Healthcare professional and family carer.

6.5 Further guidance or training – perceived need and preferred formats
Almost all respondents felt that there was a need for further guidance or training on how to support people with sight loss and dementia to engage in meaningful activities. Of the 110 people who answered this question, only three said that felt no further training or guidance was needed. Two provided explanation for their answer:

The final questions on the survey asked respondents to rank six types of resources from most useful to least useful. The types listed included: checklists; online learning; online peer support; case studies; face-to-face training; and 'other', with respondents invited to detail 'other'. Figure 5 illustrates the range of responses.

Figure 5   Numbers of respondents ranking resources 1ˢᵗ or 2ⁿᵈ in terms of usefulness
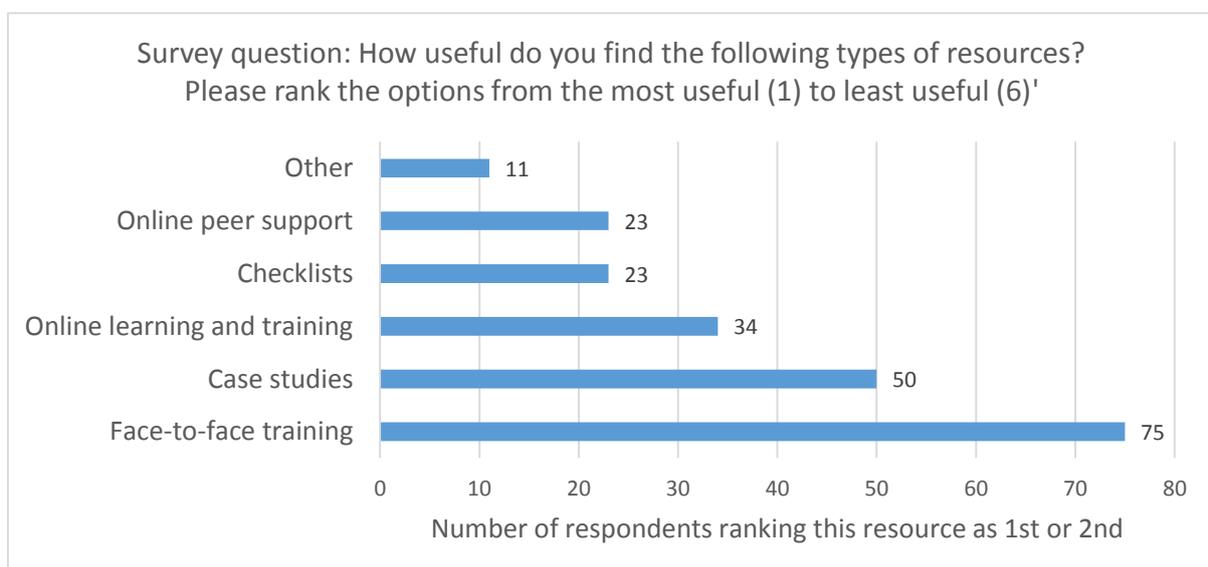
Data suggest that respondents may not always have been clear about what was being asked for in this question, with several ranking options as all 'most useful' or all 'least useful'. Considering the number of respondents who ranked an option either 1ˢᵗ or 2ⁿᵈ gives a broader indication of what types of resource might be perceived to be useful.

Respondents find face-to-face training to be the most useful form of resource, with 75 respondents (70% of the 107 people who answered this question) ranking this type of resource either 1ˢᵗ or 2ⁿᵈ in terms of usefulness. Case studies were also popular, with 47% of respondents ranking them highly, followed by online learning and training (32%), checklists (21%) and online peer support (21%). Eleven people ranked

'Other' as 1st or 2nd in terms of usefulness. The 'other' resources which they felt would be very useful to them included:

- Guides for people with dementia and carers
- Supervision by more experienced mentor
- Websites with practical information and links to other services/organisations that may be able to help
- Online toolkits
- The work of Dementia Care Matters
- Personal experience from acquaintances with one or both conditions
- Alzheimer Scotland website.
- Peer support ('actual' as opposed to 'online')
- Networking events
- Experiential learning.

6.6 Summary

The range of occupations represented by the survey respondents suggests that the survey invitation reached its intended target groups, that is to say health and social care professionals involved in supporting people with dementia and sight loss. 90% were female, reflecting the gendered nature of many of the occupations within that general description. There was a health-related bias in the respondent group, with healthcare professionals and allied healthcare professionals accounting for 54% of respondents. This is likely to have influenced some results, for example around the most commonly used resources or preferred resources types, which might be expected to reflect predominant learning styles in these groups.

Survey respondents generally had a person-centred understanding of what constituted 'meaningful activities', as might be expected given policy and practice emphases. Whilst there was general consensus that meaningful activities had to be understood from the perspective of the person being supported, in line with difficulties noted in the literature reviews there was little agreement on other elements of a definition. Respondents often used meaningful and terms such as 'important', 'purposeful' or 'valued' interchangeably. Respondents were unwilling to

detail specific activities, but variously identified routine daily tasks, occupational or recreational activities as having the potential to be meaningful, as long as they were enjoyable, stimulating and/or interesting to the person engaging in them. Again, this points to a person-centred approach which focuses on positive outcomes for the person being supported.

Almost all respondents with direct experience of supporting people with both sight loss and dementia had experienced particular challenges in assisting them to access and participate in activities. Commonly identified challenges related to: the interaction of a person's sight loss and dementia; misconceptions about or lack of awareness of the abilities of people being supported; and carer attitudes to risk. The first of these is specific to the person being supported, but ready access to general condition-related information and to tools such as the 'Getting to Know Me' information template might help health and social care professionals to establish this for the individual in question. The latter two could be addressed through educational information and training for both professionals and family carers.

The majority of respondents indicated that they would seek guidance from dementia specific and sight loss specific charities (84% and 69% respectively) when supporting people with dementia and sight loss. This suggests that such organisations have a key role to play in raising awareness of new guidance, tools and toolkits which might be helpful in this context, and ways of reaching these organisations should be considered as part of dissemination strategies whenever new resources are planned or developed.

There may be some bias as a result of the occupational groupings of respondents, but most widely used resources from a list identified by the survey were also ones which had been widely disseminated and were freely and easily available. The most widely used, the 'Getting to Know Me' profile for collecting information about a person needing support, was launched in May 2013, at which time the Scottish Government and Alzheimer Scotland jointly funded 10,000 copies for distribution, initially to acute hospital settings, but with the intention that it would also be used in primary care and care home settings. A code was created to allow hospitals to purchase further copies through procurement,

encouraging its repeated use, and the profile is also widely available to download as a PDF and print off from a range of websites, including those of umbrella organisations Scottish Care and Health and Social Care Alliance Scotland (the ALLIANCE). Clearly it will not be possible for every new resource to have the same level of support, but since professionals' use of guidance or tools relies on awareness of them then perhaps novel lower-cost ways should be sought to promote and make helpful materials available.

Survey respondents identified a range of methods which from experience they had found to be effective in supporting people with sight loss and dementia to engage in meaningful activities. More than two thirds of respondents (72%) offered one or more suggestions relating to: key actions prior to supporting engagement in activities; pointers around delivery of support; and suggestions for activities. Although the numbers are relatively small and much further work would be required, these potentially constitute a starting point for the development of an experience-based resource.

There is overwhelming support from respondents for further guidance or training on how best to support people with sight loss and dementia to engage in meaningful activities. Face-to-face training, case studies and online learning and training were the forms of training that respondents saw as most useful to them, but because of the relatively small number of respondents and the potential bias introduced by their occupational grouping, this would need further investigation.

7. Conclusions and recommendations

The literature searches conducted as part of this study reveal a paucity of peer-reviewed academic literature directly relating to meaningful activities for people with dementia and sight loss: 25 publications were found to be relevant on full text examination. Qualitative studies make up a significant proportion of the research evidence base which, though limited, is of relatively high assessed quality. Lateral online searches suggest an equally limited 'grey' literature directly on this topic; eleven sources were identified that were considered relevant to the topic of meaningful activity for people with sight loss and dementia.

Academic research generally focused on activity in the context of each condition individually. This is not surprising, since a number or previous studies in other contexts (e.g. Lawrence et al. 2008; Lawrence and Murray 2009; Goodman and Watson 2010) have highlighted underrepresentation of the experiences of individuals with both dementia and sight loss in the literature. Grey literature tended more frequently to address issues in the provision of support for people with both conditions.

Three main themes emerged when considering the peer-reviewed academic literature: meaningful activity as best practice, interpretations of meaningful activities, and ways to support participation in meaningful activities for people with sight loss and dementia. The grey literature could be broadly categorised as referring to 'strategic planning', 'empirical research', and 'information and practical tools' respectively.

Common themes running through the literature review, interviews with expert informants and survey responses included the need for support for meaningful activities to be person-centred, i.e. to take account of the history, interests and preferences of the individual being supported, to be informed and underpinned by awareness and understanding of the ways in which a person's sight loss condition and type of dementia might affect their support needs, and to be flexible and adaptable in approach.

This scoping study has revealed that there is demand for more resources to help caregivers across health and care provider groups to improve the support that they give to people with dementia and sight loss. There is a need to examine more fully questions around what resources need to be developed, how they should be informed, and who they are ultimately for.

The interviewees participating in this research, who represented a range of professional groups tasked with or involved in the provision of support for activities, tended to focus discussion on the use of primarily sensory activities and on a limited range of more easily measurable outcomes. Many survey respondents similarly appeared to be primarily considering activities appropriate to people with severe cognitive and visual impairments. This focus may be the result of publicly provided service

provision increasingly being provided only to those people with more severe symptoms and higher levels of support need. The academic literature suggests that people with sight loss and dementia may have different priorities for and expectations of 'meaningful activity' when compared to family and paid carers. One interviewee highlighted how service users had tried to explain that what they wanted was to be facilitated to make their own choices around meaningful activity. There may be a need to develop more nuanced guidance which takes the full spectrum of combinations of condition severity into account and provides information on how best to support people with lower levels of impairment. Further research should explore these potential differences in foci and how they might affect the delivery of support services.

97% of survey respondents felt that they needed further guidance on how to support meaningful activities for people with sight loss and dementia, but significant numbers of respondents were not aware of or did not use existing resources. Further research ought to explore how awareness of existing resources could be improved as well as examining the most appropriate formats for new guidance.

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(PAL) Checklist for use with older people with dementia. *Aging & Mental Health*, 12 (2), pp. 202-211. DOI: 10.1080/13607860801984375.

Appendices

Appendix 1 Summary of literature review method

The databases listed in Table 1 were searched using search strings constructed from the search terms listed in Table 2. Where possible searches were carried out using Boolean operators (AND and OR) and appropriate bracketing of terms to allow the use of single search strings which cover all relevant permutations. This was possible for all databases except Social Care Online, where multiple searches were carried out with different permutations of individual search terms which cumulatively identified articles that would have been identified had it been possible to use the same single search strings as for other databases. The results of searches are provided in Table 3. All searches were carried out between 1st and 8th April 2015.

Table 1 Bibliographic databases searched as part of the literature review.

Databases searched
- ProQuest Social Science (incorporates 15 individual databases, including ASSIA, IBSS, Social Service Abstracts and Sociological Abstracts)   - EBSCOHost (for combined search of CINAHL (Cumulative Index to Nursing and Allied Health Literature), Health Source, and PsycINFO)   - Cochrane Library   - ScienceDirect   - Social Care Online (an index to journal articles, websites, research reviews and government documents in the field of social care)   - PubMed (includes MEDLINE and citations from a wide range of life science journals)   - Web of Science Core Collection (incorporates a number of individual databases including science, social science and arts and humanities citation indexes)

Table 2 Search terms used in the interrogation of bibliographic databases

Category	Terms
Vision related	sight loss OR visual* impair* OR blind OR "partially sighted" OR "seeing difficulties" OR visual problem* OR eye condition* OR "low vision" OR "vision problems"
Dementia related	dementia* OR Alzheimer* OR cog* and impair*
Action related	engagement OR participation
Nature of activity related	meaningful OR purposeful OR valued
Combined nature and activity related	"meaningful activity" OR "meaningful activities" OR "purposeful activity" OR "purposeful activities" OR "valued activity" OR "valued activities"

Table 3   Results of searches of bibliographic databases

Search string	ProQuest Social Science	EBSCOHost (CINAHL, Health Source, and PsycINFO)	Cochrane Library	ScienceDirect	PubMed (includes MEDLINE) (Search title/ abstract)	Web of Science Core Collection	Social Care Online
1. Any vision related term AND any combined nature and activity related term	8	6	11	1	5	20	72
2. Any dementia related term AND any combined nature and activity related term	70	103	1	6	60	72	35
3. Any dementia related term AND any activity related term AND any nature of activity related term	69	94	2	8	51	185	461
4. Any vision related term AND any activity related term AND any	43	30	1	4	23	187	266

nature of activity related term							
Total 'hits' including duplicates across search strings	190	233	15	19	139	464	834

NB: Visual inspection of search results from Social Care Online suggested that the need to carry out multiple searches of different search term permutations produced a higher number of duplicates across individual searches and the 'totals' provided for this database should be interpreted accordingly.

Appendix 2   Items identified from database searches and selected for examination of full text

a) Included items

Alma, M.A., Van der Mei, S.F., Groothoff, J.W. and Suurmeijer, T.P.B.M. (2012) Determinants of social participation of visually impaired older adults. *Quality of Life Research*, 21 (1), pp. 87-97.

Altus, D.E., Engelman, K.K. and Mathews, R.M. (2002) Finding a practical method to increase engagement of residents on a dementia care unit, *American Journal of Alzheimer's Disease and Other Dementias*, 17 (4), pp. 245-248.

Alzheimer's Society of Canada (2011) Guidelines for care: person-centred care of people with dementia living in care homes: framework. Toronto: Alzheimer Society of Canada.

Beverley, C.A., Bath, P.A. and Booth, A. (2004) Health information needs of visually impaired people: a systematic review of the literature. *Health and Social Care in the Community*, 12 (1), pp. 1-24.

Bruce, I., Harrow, J. and Obolenskaya, P. (2007) Blind and partially sighted people's perceptions of their inclusion by family and friends. *British Journal of Visual Impairment*, 25 (1), pp. 68-85.

Cochran, V., Tice, P., Clair, A.A., Otto, D.W. and Johnson, G. (2001) Family ties: Activities for family and significant others dealing with late stage dementia. *Activities, Adaptation & Aging*, 26 (2), pp. 45-60.

Cohen, G.D. (2006) Research on creativity and aging: The positive impact of the arts on health and illness. *Generations*, 30 (1), pp. 7-15.

Conti, A., Voelkl, J.E. and McGuire, F.A. (2008) Efficacy of meaningful activities in recreation therapy on passive behaviors of older adults with dementia. *Annual in Therapeutic Recreation*, 16, pp. 91-104.

Ellexson, M.T. (2004) Access to participation: occupational therapy and low vision. *Topics in Geriatric Rehabilitation*, 20 (3), pp. 154-172.

Forbes, D., Thiessen, E.J., Blake, C.M., Forbes, S.C. and Forbes, S. (2013) Exercise programs for people with dementia, *Cochrane Database of Systematic Reviews*, (12), pp. CD006489.

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Hwang, J.E., Rivas, J.G., Fremming, R., Rivas, M.M. and Crane, K.R. (2009) Relationship between perceived burden of caring for a family member with Alzheimer's disease and decreased participation in meaningful activities. *Occupational Therapy in Health Care*, 23 (4), pp. 249-266.

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Kirkcaldy, A. and Barr, W. (2011) Coming to terms with sight loss: impact of RNIB's 'Finding Your Feet' programmes on participants' Quality of Life. *British Journal of Visual Impairment*, 29 (2), pp. 145-154.

Kleinschmidt, J. (1996) An orientation to vision loss program: Meeting the needs of newly visually impaired order adults. *Gerontologist*, 36 (4), pp. 534-538.

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Phinney, A., Chaudhury, H. and O'Connor, D.L. (2007) Doing as much as I can do: the meaning of activity for people with dementia, *Aging & Mental Health*, 11 (4), pp. 384-393.

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Roland, K.P. and Chappell, N.L. (2015) Meaningful Activity for Persons with Dementia: Family Caregiver Perspectives. *American Journal of Alzheimer's Disease and Other Dementias* 2015 Mar 18. pii: 1533317515576389. [Epub ahead of print].

Russo, A. and Bowen, D. (2013) Visual impairment: setting sights on an independent life. *Nursing and Residential Care*, 15 (1), pp. 38-40.

Vernooij-Dassen, M. (2007) Meaningful activities for people with dementia, *Aging & Mental Health* 11 (4), pp 359-360.

Wenborn J, Challis D, Pool J, Burgess J, Elliott N and Orrell M (2008) 'Assessing the validity and reliability of the Pool Activity Level (PAL) Checklist for use with older people with dementia', *Aging & Mental Health*, 12 (2), 202-211. DOI: 10.1080/13607860801984375.

b) Excluded articles and reason for exclusion

Publication	Reason for exclusion
Bartlett, R. and McKeefry, D. (2011) Rethinking the experiences and entitlements of people with dementia: taking vision into account. *Journal of Care Services Management,* 5 (2), pp. 105-114.	Article does not engage with the idea of activity, or meaningful activity, in a significant fashion.
Black, B.S., Johnston, D., Rabins, P.V., Morrison, A., Lyketsos, C. and Samus, Q.M. (2013) Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study. *Journal of the American Geriatrics Society,* 61 (12), pp. 2087-2095.	Paper mentions 'meaningful activities' as an unmet need but does not provide further discussion on meaningful activity.
Bollin, S., Menne, H. and Whitlatch, C.J. (2011) Lifestyle and lifespan: Continuing meaningful engagement and interactions	This is a conference abstract. Authors were contacted to see if peer-

| Publication	Reason for exclusion
after the diagnosis of dementia. *Gerontologist*, 51, pp. 215-215.	reviewed article had been published.
Cendoroglo, M.S. (2014) Exercise programs for people with dementia. *Sao Paulo Medical Journal*, 132 (3), pp.195-6.	Article is a descriptive review of a Cochrane review by Forbes et al. (2013). Original review has been included.
Dizazzo-Miller, R. (2010) Review of Movement with meaning: A multisensory program for individuals with early stage Alzheimer's disease. *Activities, Adaptation & Aging*, 34 (1), pp. 76-77.	Article is a book review for Larsen, B. (2006) Movement with meaning: A multisensory program for individuals with early stage Alzheimer's disease'.
Ferreria, N., Owen, A., Mohan, A., Corbett, A., and Ballard, C. (2015) Associations between cognitively stimulating leisure activities, cognitive function and age-related cognitive decline. *International Journal of Geriatric Psychiatry*, 30 (4), pp. 422-430.	Article looks at preventative measures for cognitive decline, but does not specifically include reference to sight loss or dementia as such.
Hill, A. (1999) Vision welfare: inter-professional co-operation or fragmentation? *British Journal of Visual Impairment*, 17 (3), pp. 105-110.	Article does not engage with the idea of activity, or meaningful activity.
Iliffe, S. Lenihan P, Orrell M, Walters K, Drennan V, and Tai SS (2004) The development of a short instrument to identify common unmet needs in older people in general practice. *British Journal of General Practice*, 54 (509), pp. 914-918.	Article does not relate to either activity in general, or to meaningful activity.
Kirrmann, K. (2010) CoolTan Arts - enhancing well-being through the power of creativity. Mental Health and Social Inclusion, 14 (2), pp.12-16.	Article does not relate to people with sight loss or dementia.
Mackenzie, A. (2001) Symposium on	Publication requested but

Publication	Reason for exclusion
improving care of the elderly. Training to engage residents with dementia in activities. British Journal of Therapy & Rehabilitation, 8 (11), pp. 406-409.	did not arrive within literature review timeframe.
McFadden, S.H. and Basting, A.D. (2010) Healthy aging persons and their brains: promoting resilience through creative engagement. Clinics in Geriatric Medicine, 26 (1), pp. 149-161.	Publication requested but did not arrive within literature review timeframe.
Menne, H.L. and Whitlatch, C.J. (2012) 'I Don't Want to be Useless': Meaningful Activity for Individuals with Dementia. Gerontologist, 52, pp. 651-651.	This is a conference abstract. Authors were contacted to see if peer-reviewed article had been published.
Myers, C. (2007) "Please listen, it's my turn": instructional approaches, curricula and contexts for supporting communication and increasing access to inclusion. *Journal of Intellectual and Developmental Disability,* 32 (4), pp. 263-278.	Article does not relate to people with sight loss or dementia.
Painter, W. (1999) Keeping it real. Even people with dementia need purposeful activities. Contemporary Longterm Care, 22 (4), pp. 19.	Publication requested but did not arrive within literature review timeframe.
Phoenix, C., Griffin, M. and Smith, B. (2015) Physical activity among older people with sight loss: a qualitative research study to inform policy and practice. *Public Health,* 129 (2), pp. 124-130.	Talks about barriers to physical activity but does not discuss meaning, purpose or value in relation to activities.
Thwaites, S. and Henderson-Greene, M. (2013) Towards meaningful activity and engagement. *Journal of Dementia Care,* 21 (1), pp. 18-19.	Article focuses on the successful use of the Pool Activity Level (PAL) as checklist for engagement, but does not discuss

Publication	Reason for exclusion
	'meaningful' activity as such.
Woods, B. (2012) Well-being and dementia - how can it be achieved? Quality in Ageing and Older Adults, 13 (3), pp. 205-211.	Publication requested but did not arrive within literature review timeframe.

Appendix 3 See Hear: A strategic framework for meeting the needs of people with a sensory impairment in Scotland

See Hear (2014) sets out a cradle to grave framework for sensory impairment in Scotland. The framework is seen as a lever for change, promoting the seamless provision of assessment, care and support to people with a sensory impairment.

- It recognises that different types of sensory impairment will require different responses
- It recognises that the responsibility for systems of care lies with the statutory agencies, but can be delivered across and wide range of agencies and settings. It therefore requires a partnership approach and the active involvement of a wide range of statutory and third sector agencies in the health, education and social care sectors
- It identifies practical steps that can be taken to address the above issues across all types of sensory impairment to ensure that needs are recognised and responded to in an outcomes focussed way.
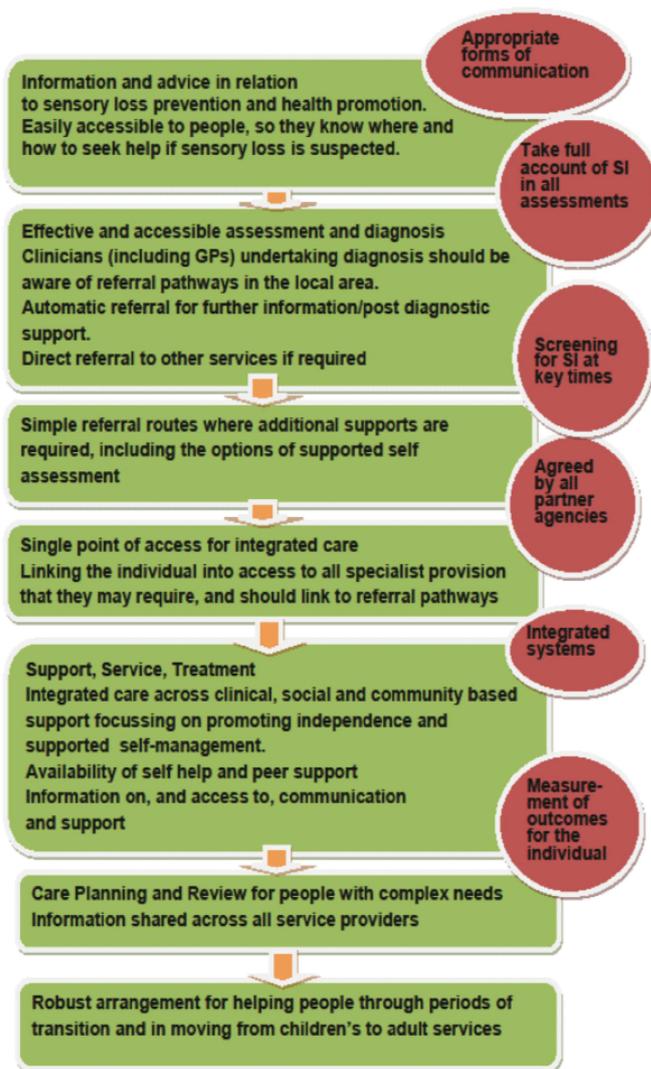
The Scottish Government's See Hear Pathway Model