SCoR
THE SOCIETY & COLLEGE OF RADIOGRAPHERS

The Society and College of Radiographers

Practice Guideline Document

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)

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Glossary

Databases

AMED Allied and Complementary Medicine Database

ASSIA Applied Social Sciences Index and Abstracts

BEI British Education Index

CENTRAL Cochrane Central Register of Controlled Trials

CINAHL Cumulative Index to Nursing and Allied Health Literature database

CPCI Conference Proceedings Citation Index

ERIC Education Resources Information Center

HMIC Health Management Information Consortium

IBSS International Bibliography of the Social Sciences

MEDLINE

MeSH Medical Subject Headings thesaurus

PICO (Patient/Population, Intervention, Comparison, Outcome) framework

PsycINFO

Research terms and tools

GRADE (Grading of Recommendations Assessment, Development and Evaluation) approach to guideline development

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-Analyses

SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool

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Care practice and training principles and tools

ADQ approaches to dementia questionnaire

BPTI brief psychosocial training intervention

CASP Critical Appraisal Skills Programme tool

CES Caring Efficacy Scale

CMOC context mechanism outcome configuration

MBI modified Barthel Index

MMSE mini mental state examination

PIE Person, Interactions and Environment qualitative practice development tool

SEWDR staff experiences of working with demented residents questionnaire

SPACE principles: Skilled staff who are informed and have enough time to care; Partnership working with carers; Assessment and early identification of dementia; Care plans that are person-centred and individualised; Environments that are dementia-friendly

VIPS model of care: Valuing people with dementia and those who care for them; treating people as Individuals; looking at the world from the Perspective of the person with dementia; a positive Social environment

Organisations, programmes and services

DEEP Dementia Engagement and Empowerment Project

DRC dementia research centre

DSDC Dementia Services Development Centre

NICE National Institute for Health and Care Excellence

NIHR National Institute for Health Research

RCN Royal College of Nursing

RDS Rare Dementia Support service

SCoR Society and College of Radiographers

UCL University College London

WHO World Health Organization

Abbreviated modalities in clinical imaging and radiotherapy

CT Computerised Tomography

MRI Magnetic Resonance Imaging

LINAC Linear Accelarator

1 Executive summary

The Society and College of Radiographers (SCoR) undertook a review of a 2015 document, Caring for people with dementia: a clinical practice guideline for the radiography workforce (clinical imaging and radiotherapy). The 2019/20 review found that research studies published since 2015 had main themes about caring for people with dementia. The reviewers agreed and grouped the themes under the headings of:

- Communication
- Deficiencies in person-centred care
- Need for role-specific and tailored training
- Dementia-friendly environment
- Time and resource pressures
- Optimisation of patient and carer experience.

Expert stakeholders noted the need for an important additional theme in order to support people with dementia:

- Identifying people with dementa in clinical imaging and radiotherapy.

Collectively the themes support and reinforce the original recommendations. There have been minor changes to the language used in the recommendations, which emphasise the ability of and need for people with dementia to continue to live well with a good quality of meaningful life.

The review of clinical practice guidelines ensures that the guidance remains evidence based to support clinical imaging and radiotherapy healthcare professionals, people with dementia, their families and carers. The recommendations have been reviewed systematically, using evidence from research and expert opinions that include those of family carers and practitioners. The recommendations have been subject to peer, professional and lay assessment. These guidelines will be of value to people with dementia, families, carers, individual practitioners, service managers and academic institutions.

2 Introduction

How was the topic identified?

The original Society and College of Radiographers (SCoR) 2015 guidance, Caring for people with dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy), see ***Appendix 1***, was intended to provide evidence-based advice for the staff who were supporting patients and carers in clinical imaging and radiotherapy. The 2015 document indicated that a review would be necessary to ensure that the recommendations remained in line with future policy and practice while still meeting the needs of people with dementia.

Why is it important?

The guidance is important because a significant percentage of the patients that radiographers support have a diagnosis of dementia or undiagnosed dementia. In addition, it should be pointed out that more generally: a) a number of patients/service users who attend clinical imaging and radiotherapy departments are carers for their own family members and friends who are living with dementia; b) SCoR members also care for or support people living with dementia in their own personal lives; and c) clinical imaging and radiotherapy staff may themselves be diagnosed with dementia and require support to remain at work. Employers have a duty to make reasonable adjustments to enable people affected by dementia to continue to work while they wish and it is still safe for them to do so [1]. Accordingly, there are multifactorial issues, experiences and needs of the people present within clinical imaging and radiotherapy departments. The main focus of this particular 2020 document review, however, was to examine and update the 2015 evidence-based advice that was offered to staff who were supporting patients and carers in clinical imaging and radiotherapy.

2.1 Global dementia policy

Since the publication of the 2015 SCoR guidance, a range of new national and international policies and plans have been issued. The World Health Organization (WHO) published a global action plan on the public health response to dementia in 2017 [2]. The WHO plan outlined seven key action areas and set targets for countries to achieve by 2025 with respect to:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for carers
6. Information systems
7. Dementia research and innovation.

There were some contradictions within the publication because the plan was written from a public health paradigm with a focus on risk factors, issues of control and compliance, and lifestyle modifications [3]. However, the WHO plan paid great attention to human rights, calling for national governments to take action and provide government funding toward finding causes, cures and best care for people with dementia – moving away from generic approaches to caring for a person with dementia or deficit-thinking [3].

An overall ethos was that people with dementia and their families can and should be able to live well and enjoy a good quality of life [2]. Further 2018 guidance, Towards a dementia plan: A WHO guide [4], also had an emphasis on work to support people with dementia around diagnosis, treatment and care along with a primary prevention focus for people in midlife. There has been concern that if levels of dementia continue to increase then public health approaches of prevention could foster cultures of blame and shame that reinforce stigma toward people with dementia [3]. However, given that there is no cure for dementia, and improved lifestyles could decrease the risk of dementia in some individuals by up to 30%, then arguably an emphasis here should be that all health professionals must have a role in providing advice to individuals on risk factors and lifestyle. Alongside that responsibility, countries need to address the root causes of some of the lifestyle issues that put people at increased risk of dementia (for example, poverty, level of education etc.), emphasising the need for countries to be addressing health inequalities in tandem with healthcare professionals who educate patients.

2.2 UK policy context

National dementia strategies across the UK [5-8] have common themes of: ensuring equitable access for all people with dementia to best practice diagnosis of dementia and support; transforming services and models of care; and creating dementia-friendly communities and environments. Earlier plans appeared to be medically focused, whereas more recent strategies, for example, the dementia action plan for Wales [7], now also have a public health emphasis discussing the importance of brain health, risk reduction and primary prevention, and the role that cardiovascular risk factors play in raising the risk for dementia [3]. A rights-based approach, with an emphasis on autonomy, self-determination, independence, participation, equity and choice is also beginning to be apparent across more recent dementia policy plans [3], such as the Scottish national dementia strategy [8].

The dementia-friendly hospital charter [9] was updated in 2018. It provides guidelines for hospital organisations, students, paid staff and volunteers to work by to try to make the experience of hospital visits and stays better for people living with dementia. Moving beyond simple environmental adaptations (to improve clinical areas, signage, flooring and lighting etc.), the charter highlights that the experiences of healthcare and hospitals for a person with dementia can depend on their type of dementia, the stage of their illness, their personality and also the way other people interact with them.

The culture of care within an organisation needs to support staff to provide good care for people living with dementia by legitimising person-centred practices. This also

means that organisations need to recognise the impact this can have on staff workload and time in some cases and actively work to mitigate any negative results or unintended consequences. Managerial endorsement is a big part of that process.

Managing success in dementia care [10] recognised the importance of managers in training and workforce development. It is a resource of quality assured, freely available materials to support managers and leaders to develop training for their staff, which meets the learning outcomes within the 2018 dementia training standards framework [11] for England. Along with Promoting excellence: a framework for all health and social services staff working with people with dementia, their families and carers [12] in Scotland; Good work: a dementia learning and development framework for Wales [13]; and the dementia learning and development framework [14] for Northern Ireland, these frameworks represent the 'gold standards' for knowledge and skills to deliver dementia care for the health and social care workforce. Intended to guide a more efficient and consistent approach to the delivery of dementia training and education, the frameworks cover a range of subject areas from dementia awareness and dementia risk reduction through to end of life care. Managers for specific settings are advised to assess individual staff roles locally to determine and prioritise the learning outcomes within their country's frameworks that are most appropriate for their staff. The Managing success in dementia care resource is designed to be used along with a dementia training resource list, framework learning outcomes mapping document, and a dementia training design and delivery audit tool and manual, which can be freely downloaded via a dementia training framework link.

The 2018 update of that framework included additions about paying attention to the importance of regular food and drink and maintaining oral health for people with dementia. The framework reflected the scope of the principal mandate requirements and obligations of Health Education England, set out in the Prime Minister's challenge on dementia 2020 implementation plan [15]. Collectively the WHO global and UK national action plans include strategies and actions that reinforce awareness and attempt to maintain each person with dementia's human rights [3].

Alongside staff who are trained and have time to care, the support in imaging and radiotherapy departments should be undertaken in partnership with family/carers, if present, in environments that are dementia friendly and promote each person's independence and well-being. Dementia risk reduction and prevention are now a key aspect of dementia strategies, a move which clinical imaging and radiotherapy staff can support in practice. Updated National Institute for Health and Care Excellence (NICE) quality standards for dementia were published in 2019 [16]. The standards provide seven quality statements, including that people are advised about the risks of developing dementia at midlife and possible reduction of risk by making lifestyle changes. Alongside a prevention agenda, the negative socio-economic determinants of health for people with dementia are now also taking position as a cause for concern. The Health Foundation has produced a 2018 quick guide, What makes us healthy? [17], which provides a short introduction to the social determinants of health.

Clearly, a wide range of local, national, and international resources and training materials for dementia care have been produced since the original SCoR 2015 guidance document. The positive development and advancement of dementia-friendly cultures in

the UK reflects the work of people with dementia, carers, dementia charities, organisations and successful campaigns. For example, the work of Alzheimer's UK and Dementia Friends [18] has positively influenced understanding and support across dementia-friendly environments and communities, such as supporting the training of local adult groups through to primary schoolchildren having access to Dementia Friends training.

2.3 The wider context of radiography

How does the guidance fit with existing radiographic practice and SCoR policy?

Regulation in the UK requires that all healthcare professionals, including those in radiography, provide person-centred care [19]. The publication of a values-based practice training template in diagnostic and therapeutic radiography [20] has been used to highlight that each person brings unique values, preferences and opinions to clinical imaging and radiotherapy departments. Accordingly, SCoR has also worked with patients and the public to develop and publish guidance to support partnership working for patients, public and practitioners [21]. More widely, practitioners may use a number of UK publications that support the development of person-centred health and care, highlighting that additional time spent with patients/service users/people with dementia must be valued, regardless of the perceived impact on departmental workloads[17, 22]. Person-centred or partnership practices are sometimes viewed by staff as 'going the extra mile' or being additional to their workload rather than being an expectation of their role [4] but a review found that when healthcare staff in authority communicated new expectations for standards of care and changes to procedures, they legitimised staff's time and adaptation of care [23]. In the period since the original 2015 document publication, examples of specific actions to support person-centred care have include SCoR championing John's Campaign [24, 25] and Playlist for Life [26, 27] as methods of reinforcing person-centred approaches to care for people with dementia.

3 Scope and purpose

A SCoR practice guideline for dementia was originally published in 2015. The review here was planned to update the evidence base. The practice guideline is intended for use by whole multiprofessional clinical imaging and radiotherapy teams, including all staff, volunteers, students and learners. This includes clinical and non-clinical, registered and other practitioners, service managers, educationists, and researchers. The population covered in the guideline is people with dementia and any family and carers or supporters who may accompany them in a clinical imaging or radiotherapy department.

The setting for the guideline is clinical imaging and radiotherapy departments in the United Kingdom. The purpose of the review was to systematically employ the best available evidence from research and expert opinion, including service users, and subject that evidence to peer professional assessment. The guideline recommendations are for all individuals working within the radiographic workforce, service managers, academic institutions and the Society and College of Radiographers.

4 Guideline objectives and questions

The primary objective of the 2015 guideline was to produce evidence-based recommendations for best practice in radiographic services (imaging and radiotherapy) when caring for people with dementia and their carers. This objective encompassed a series of related questions about:

- The workforce's need for understanding dementia and its manifestations
- Optimising staff behaviours towards people with dementia
- Strategies for optimising the technical outcomes of interventions
- Improving patients' experience
- Suitability of the practice environment.

This 2020 review of the guideline aimed to examine and ensure that the original recommendations were up to date, using current evidence base, and were continuing to model best practice.

5 Guideline review process

5.1 Core group

In April 2019 the lead professional officer, acting as the review core group leader, assembled a core review group of six people. The officer had a dual role, having previously been a family carer for a person living with dementia. In addition to the officer, the five other members had experience as: a full-time carer of a person living with dementia (previously a therapeutic radiographer); a consultant diagnostic radiographer; an academic lecturer in end of life care; a diagnostic radiographer who worked on the original guideline development; and a diagnostic radiographer/safeguarding lead.

5.2 Stakeholder group

Members of the Society and College of Radiographers (approximately 30,000 members) were informed and updated about the review work via SCoR's monthly professional publication, *Synergy News*, and the production of an online webinar presented by the SCoR professional officer in March 2019: Caring for people with dementia in clinical imaging and radiotherapy. Member readers of *Synergy News* and webinar participants were invited to join the review stakeholder group. Webinar participants were also invited to review and comment during the webinar and via a SCoR conference and events coordinator, who forwarded the comments that were received for inclusion in an action log.

The volunteer member stakeholder group for the review comprised 15 individual members. Several of the individual volunteer members were dual experienced as both healthcare staff and also family members and/or carers for people living with dementia, and they naturally also brought that perspective to their feedback.

The names of core and stakeholder group members are included in ***Appendix 2***. Included among the stakeholders were representatives of two dementia research centres and a range of dementia and carer charities and organisations. After being invited to respond, the organisations kindly agreed to offer stakeholder comments and feedback once a draft review document had been completed in March 2020.

The 2015 practice guidelines were circulated to the core and individual members stakeholder groups for comment between June and July 2019. Most stakeholders responded and their comments were assimilated in an action log. An example of the form used to record comments can be found in ***Appendix 3***. Members of the core team then worked on: undertaking an updated systematic review; updating the background information to reflect current policy; and creating a toolbox of information for practitioners in line with the SCoR professional, public and practitioner partnership working document [21].

The SCoR professional officer presented information about dementia guidance and the review at a SCoR patient-led study event, Patients, Public and Professional Partnerships, at the Renaissance Manchester City Centre Hotel in October 2019, with approximately 85 delegates. Feedback was again invited via a conference and events coordinator. Verbal feedback was also received through discussion among patients, public and practitioners during time provided for questions and answers on the day. Key points were noted in the action log. The stakeholder group was updated about actions to date and the possible timeframe for a first draft to be produced in December 2019. A number of stakeholders took the opportunity to engage further, offering helpful links to information and suggestions about resources via email, and these were also placed on the action log.

The core group then worked toward completion of the draft guidance update. It was circulated for further consultation with stakeholders in March 2020. The core group, via email, reviewed the stakeholders' comments. Amendments were then made in line with available evidence and a final consensus was reached. At that point, two academic members of SCoR plus an academic music therapist with specialist experience in dementia, and a family carer for a person with dementia were invited to review the updated guidelines in April 2020. An example form used to record comments can be found in ***Appendix 4***.

5.3 Funding arrangements

No external funding was sought to assist with guideline development. A clinical research radiographer and a consultant practitioner from the core group were each paid £250 to conduct a literature search, perform a quality score, and assimilate the literature review. All other core and stakeholder group members gave their time and expertise voluntarily. The SCoR professional officer was a member of staff in a full-time role, spending time on the review as SCoR resources allowed.

5.4 Conflicts of interest

The SCoR policy and procedure for managing conflicts of interest during the guideline review process was adhered to [28]. All individual members of the core and stakeholder member groups signed a conflicts of interest declaration form. No conflicts of interest were declared. The processes for review ensured that the views and interests of the Society of Radiographers have not unduly influenced the recommendations.

5.5 SCoR approval process

The Society of Radiographers (SoR), as the professional body for the radiographic workforce, gives professional leadership and guides and supports professional development in the interests of patients and high quality health and care services. SoR sponsors the development of practice guidelines. A SCoR professional officer was a member of the core group. The final draft of the practice guideline review was submitted for the approval of the UK Council of the SoR in April 2020.

6 Guideline review methods

6.1 Literature search

The 2019 review included an initial search of the databases Medline, CINAHL, EMBASE and AMED and a focused electronic search of relevant journals. The original document had previously employed literature searches with the PICO (Patient/Population, Intervention, Comparison, Outcome) framework [29]. Comparable with that search in 2013, the majority of studies and publications that were included in the 2019 review did not include either a direct intervention or a comparison approach. Therefore, it was decided to adapt the PICO framework for this context, in line with the previous literature search, [29]. The adaptation of PICO framework was in order to define the search parameters more accurately. The adapted search strategy is outlined below with the search terms used:

Disease/condition	**Focus**	**Setting/staff group**
Alzheimer's	Patient care	Radiography
Dementia	Professional-patient relations	Radiographer
	Person-centred care	Radiotherapy
	dignity	Radiotherapist
	Communication	Radiology
	Quality of care	Acute hospital

The operator OR was used to combine terms within a column and then the operator AND was used to combine all searches between the 3 columns.

Searches returned the following numbers in each database:
Medline: 47
CINAHL: 5
EMBASE: 20
AMED: 2

Total articles found in searches = 74

The following limitations were applied:
- English language
- Published between 2013-2019

In addition to the inclusion and exclusion criteria, conference abstracts were excluded, as were studies conducted in community settings. Duplicates were then removed.

The result was an initial 41 articles. The articles were supplemented by follow-up references and searches of the 'grey literature' to include current guidance around caring for people with dementia.

6.2 Methodology

The focus of this review was to inform clinical imaging and radiotherapy practice; it was evident that care for a person with dementia has been the focus of extensive philosophical, ethical and legal debate. The core group was therefore mindful that a range of evidence should be considered when attempting to review the guidance. The scope of the review was restricted in that it only included initial sources published in the English language between the years 2013 and 2019. An adult population (over 18 years of age) was the main focus due to the nature of dementias. Many of the key principles for patient-centred care that are included in the guidance will be applicable to all patient groups.

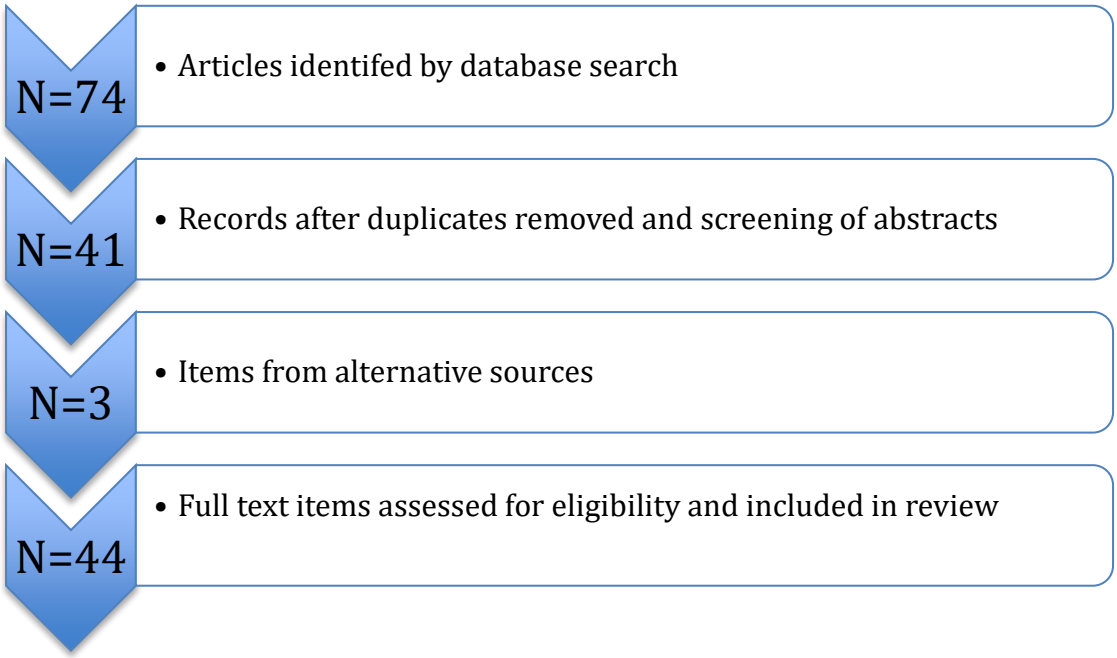
All appropriate full-text articles and documentation underwent assessment for quality using the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system [30]. This approach did have to be adapted for literature sources that did not contain an intervention, but it was still possible to assign a quality rating to each source of evidence. The grading score assigned to the studies was weak. Accordingly, the development of recommendations required debate and the involvement of many stakeholders [31]. However, it was, and still is, important to recognise that different choices and approaches to care will be appropriate for different people with dementia – each individual person, together with any carers or supporters, must be enabled to decide upon a management decision consistent with the person with dementia's own values and preferences [31].

6.3 Literature review

A flowchart indicating the number of sources identified and the final number of sources included is shown in Figure 1. The final number of articles selected for inclusion was 44.

Information about the constitution of the research study methodology/methods, the sample populations and the study settings are provided in the subsections 6.1.1 to 6.1.3 below.

Figure 1: Number of sources



6.3.1 Methods used in the studies
Systematic review, reference numbers [32–35]
Semi-structured interviews, reference numbers [36–47]
A single retrospective case study, reference number [48]
A single prospective case study, reference number [49]
Ethnography including observations of practice, reference numbers [38, 50, 51] [39, 44, 47, 52–55]
A series of case study reports, reference numbers [56, 57] and case reports combined with observational dementia care mapping, reference number [55]
A focused ethnography with conversational analysis of patient–professional interactions, reference number [58]
Focus groups with staff, reference numbers [37] [59, 60]
A cycle of action research, reference numbers [46, 61, 62]

Focus groups with carers, reference number [63]
A satisfaction survey with patients with dementia and/or carers, reference number [55]
International literature review with meta-synthesis, reference numbers [23, 64–68]

6.3.2 **Sample populations**
A single person with dementia undergoing treatment in radiotherapy, reference number [49]
Non-registered staff e.g. cleaners and porters, reference number [36]
Staff delivering care to people with dementia, reference numbers [41–43, 46, 47, 50, 53, 60–62, 69]
Family carers of people treated in an acute hospital, reference numbers [40, 41, 44, 45, 51, 53, 63, 70]
Family carers of people being treated with radiotherapy, reference number [47, 71]
People with dementia, reference numbers [39, 42, 44, 47, 52–54, 71]

6.3.3 **Study settings**
Acute hospital wards in the UK, reference numbers [33, 36, 38, 39, 44–46, 48, 53, 55–58, 61, 62, 67, 70], Japan, reference [69], Finland, reference [40], America, reference [41], Denmark, reference [52], Austria and Germany, reference [60], Malta, reference [54], and Singapore, reference [72].
A UK department of radiotherapy, reference number [47, 49]
An Australian department of clinical imaging, reference number [37]
UK regional cancer treatment centres, reference numbers [42, 47, 71]
A Canadian emergency department, reference number [63]

6.4 Description of how recommendations were developed

The core group considered the new evidence in relation to the original recommendations. Consequently, the original recommendations were used as a foundation to update guidance, using the new evidence sources. Feedback and further recommendations were sought from stakeholders. The approach was in keeping with SCoR guidance [28]. The development of recommendations required debate and the involvement of many stakeholders [31]. However, it was, and still is, important to recognise that different choices and approaches to care will be appropriate for different people with dementia – each individual person, together with any carers or supporters, must be enabled to decide upon a management decision consistent with the person with dementia's own values and preferences [31].

6.5 Main review of evidence

The following review document is one which summarises the 44 sources of evidence that were identified via the systematic literature review. It highlights the key issues that informed the core group in the updating process.

6.6 Summary and critique of articles

Data extraction tables along with summary and critique for each of the 44 literature review articles can be found in ***Appendix 5***. The appendix lists the articles in alphabetical order.

6.7 Themes identified

Core group members identified and agreed by e-mail consensus that six themes were present across the literature that were pertinent for the care of people with dementia in clinical imaging and radiotherapy departments. An additional theme, highlighted by expert stakeholders, was that of the identification of dementia. Four stakeholders highlighted that the identification of people with dementia is crucially important, commenting that many hospital departments, including imaging and radiotherapy departments, do not have a means of identifying people with dementia. This was a key point because in order to tailor any of the recommendations in the guideline for a person with dementia, staff must know that a person has a diagnosis.

The themes were used to develop a summary Word document (***Appendix 6***) and an infographic (***Appendix 7***) for the dissemination of information. The themes are presented below in figure 2:

Figure 2 Summary Themes

7 Limitations of the guidelines

In 2017, the authors of a study of dementia care stated that the evidence base around dementia-friendly interventions was in early development [23]. The authors of a systematic review also undertaken in 2017 remarked that the majority of papers in an exploration of approaches to dementia training were low or medium quality, impacting on generalisability [35]. Similarly, the quality of the papers included in this 2019/2020 SCoR review was graded as weak. The core review team agreed that the quality rating would not affect whether studies were included. The original guidance development team had also taken that same approach. Although receiving a weak GRADE score [31], one strength of the recommendations contained within this guideline was the apparent strong level of agreement between all sources with respect to the key areas of care.

A further limitation of the evidence that informed these guidelines was that few were situated specifically in radiography practice settings. However, the guideline development core group felt that the similarities with other settings in the acute hospital were sufficient to allow for the application of this evidence within clinical imaging and therapeutic radiography.

The review confirmed that key areas from the original guidelines were still pertinent, albeit that significant challenges still arise with respect to: the breadth of research methods adopted; the evaluation of dementia care models used in acute settings; the methods of data analysis; and stratification of results for the multiple confounding patient and clinical imaging examination and radiotherapy treatment-related variables. All of which can have significant impact on the risk of bias and hence the reliability of the results being presented.

8 Background

It is estimated that there are currently over 850,000 people with dementia in the UK [73]. Also that a quarter of hospital beds are occupied by people living with dementia over the age of 65 years old [73]. Therefore, a large proportion of people with dementia use the services of imaging and radiotherapy departments across the UK on a daily basis.

Dementia is an umbrella term generally used to refer to diseases resulting from a range of over 100 conditions, with approximately 200 associated subtypes. All of the conditions result in a situation where the person with dementia's brain function will decline progressively over time. Dementia is defined as a disease that is always progressive over time, it affects more than one aspect of thinking (for example, memory, language, behaviour, visual processing, hallucinations), and it affects everyday life. There is sometimes overlap of symptoms, for example between depression, delirium and dementia, which can lead to delayed diagnosis. NICE guidance and quality standards for dementia outline and aim to address discrepancies [16, 74].

The most common type of dementia is a result of Alzheimer's disease, which tends to be a problem that starts with memory. About 50–60% of people have Alzheimer's disease in terms of the whole group of people with dementia. The second of the most common types of dementia, vascular dementia or vascular cognitive impairment, can be a result of a person's problems with blood supply (vascular). A third type, dementia with Lewy bodies, can present in a similar manner to Parkinson's disease, but tends to start with dementia rather than starting with the changes and/or slowing of movement associated with Parkinson's disease. Fourth is frontotemporal dementia, which affects behaviour and language, generally in a younger age group (under 65).

Young onset dementia is defined as affecting people before the age of 65 years old. Approximately 40,000 people per year are diagnosed with young onset dementia [73]. Together, the four most common types of dementia account for somewhere around 95% of all causes of dementia. The remaining 5% causes of dementia are all relatively rare in comparison but all cause progressive changes in thinking and behaviour. The symptoms of dementia are multiple and varied. For example, the symptoms of behavioural variant frontal-temporal dementia, also referred to as Pick's disease, include: changes in a person's motivation; the development of inappropriate social behaviours; developing obsessive compulsive traits; a loss of empathy; and change in appetite e.g. an increasingly 'sweet tooth' or overeating.

Dementia is not an inevitable process of ageing. Indeed, some types of dementia are possibly preventable, for example with lifestyle modification prior to onset of symptoms [75]. Offering advice to the general public that aims to prevent some dementias is important, but at the same time, care must be taken not to stigmatise or blame people who find that they are living with dementia.

The terminology and language used when discussing dementia is important; for example, the author of a dementia diary tells us that he prefers to be asked "have you any problems with your memory?" as opposed to enquiries about 'suffering from dementia' [76]. The Dementia Engagement and Empowerment Project (DEEP) network

offers advice about the language that people with dementia prefer to be used [77]. A point of patient-centred care is to adapt and use the language that is acceptable for each individual person.

Each individual experience for a person can depend on the type or cause of their dementia, the stage of the illness, the person's own personality and, importantly, the way others interact with the person. Two review stakeholders noted that neuropsychiatric symptoms, such as anxiety, along with cognitive impairments can play a role in how distressing a person may find imaging and radiotherapy departments, for example, being prepared for a scan and the actual procedure itself.

People at later stages of dementia may benefit from some of the same environmental adaptations that people with posterior cortical atrophy (PCA) dementia (which causes particular problems with vision) find useful [78], such as ensuring there is good lighting and good colour contrast for objects that need to be perceived clearly. Common examples of visual disturbance in dementia can result in a person perceiving puddles or black mats to be spaces or holes in the ground and trying to step around them. Advice about caring for people with dementia tends to also include providing clear signage with pictorial symbols at eye height, a calm waiting area with provision of activities e.g. dominoes, Connect 4 etc., and clearly differentiated water stations for hydration.

Knowledge of the type of dementia that a person has can be used to tailor interactions, avoid procedural delays, and try to avoid causing distress to that person. For example, a person with visuospatial difficulties might find it difficult to follow instructions of 'up' and 'down' or 'left' and 'right'. This does not only apply to 'left' and 'right' in terms of space but also to body segments, for example, 'can you move your left foot?' A person may also find it difficult to find or recognise an examination table/bed, to get up the steps to an examination table or to walk through doors. Members of staff can ask if the person would find it helpful to be guided, or alternatively, where verbal directions are not useful, simply ask the person if they are happy to follow the lead of the staff member.

Expert stakeholders noted that staff should reassure patients that staff are able to see them and to communicate with them during examinations and treatment, especially in areas with separate scan rooms (e.g. CT, MRI and Radiotherapy). People with dementia might also find it difficult to keep track of time while in a scanner and should be communicated with throughout a procedure by a staff member or carer, for example, to inform them of how much time is left until the end of a scan sequence.

It is important to tailor care according to the form of dementia the patient has and their personal needs. The staff who will be caring for a person with dementia ideally should be informed about the person's diagnosis, form and stage of dementia beforehand, to allow adequate preparation and adaptations of care. Signposting toward further advice about adaptations of care will be included in the toolbox linked to this review document (***Appendix 8***)**.** University College London (UCL) provide access to a free four-week course that introduces useful information about the experiences of people with the 'many faces of dementia'. The UCL Dementia Research Centre's Rare Dementia Support service website is also useful for further information.

9 Guideline recommendations

9.1 The practice environment – acknowledging the need for special provision

The 2015 SCoR recommendations for this domain were:
The environment in the department should be adjusted by removing excess stimuli and ensuring that it is calm and well organised when patients with dementia arrive for imaging or treatment. The organisational culture of departments should be flexible and enabling, value good practice and support person-centred care. Departments should seek feedback from patients and carers about their experiences and act accordingly. Departments should liaise with people with dementia and/or their carers about appointment times to mitigate factors that might increase stress and try to avoid compromising their normal routines. Departments should consider utilising forms of therapy that may provide reassurance, such as: music, which may be brought in by the patient; or reminiscence, inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment. Departments should investigate the use of dementia identifiers, such as forget-me-nots, blue wrist bands or butterflies, for inpatients (and outpatients where possible). More time should be allowed to perform procedures since this can reduce the need for restraint. Departments should create the role of dementia champion, supported by appropriate training. Departments should consider using appropriately trained volunteers as advocates for people with dementia. Departments should offer support for staff (professional supervision) in recognition of the emotional burden associated with providing dementia-related care. The organisation's management information system (MIS) should support all staff to be fully informed of the patient's diagnosis.

The 2019/20 literature review provided the following evidence.

9.1.1 Acute hospital settings

Across a range of acute hospital settings, there can be issues with regards to identifying that a person has dementia [47]. Six expert stakeholders raised this as an issue. Four suggested that there should be a question on imaging and radiotherapy referral forms or initial assessment forms, which should include a request for information about type of dementia and cognition. A study recommended that there must be clear communication of dementia diagnosis in healthcare records and mechanisms for referral on to the person's general practitioner to follow up in cases of potential undiagnosed memory problems [47]. That study also highlighted a lack of identification of dementia in oncology/radiotherapy services in England and noted that around a quarter of inpatients with dementia do not have a dementia diagnosis recorded at all; this figure was lower for people from Black, Asian and Minority Ethnic backgrounds and also single people, and authors felt accurate records were likely to be lower still for outpatients [47].

A study author provided background that described hospital settings that were busy, confusing places in which care was based on assessing, treating and discharging people as quickly and efficiently as possible [62]. Accordingly, people with dementia and carers can find a hospital to be a stressful environment [63]. The reasons for people with dementia visiting an emergency department, for example, can include injuries sustained from falls, laceration, fever, pain, immobility, infections, agitation and restlessness, dehydration, stroke, and facial paralysis. Consequently, the complexity of developing a guideline to care for people with dementia in clinical imaging was noted to be an intricate undertaking with multifactorial issues. It was possible to draw some comparisons between clinical imaging, radiotherapy and an emergency department setting that are neatly summed up by an observation from the authors of an emergency department study:

> "Patients typically do not present with complaints of dementia, a diagnosis of dementia is not made in this setting; thus the role of dementia care is viewed as indirect." [41]

The authors of a systematic review also noted that acute hospitals form a significantly different context to care homes for the delivery of dementia care training, since staff work across a range of specialisms, most have limited dementia expertise, and patients with dementia are usually acutely unwell during admission with another primary illness diagnosis [35].

Institutional drivers of routines, efficiency and risk reduction can result not only in poor care experiences for patients and carers but also emotional and physical burnout for staff [50]. This burnout can lead to a staff focus on clinical tasks and standardisation [23, 40, 53, 54, 60]. Studies of nurses have found that, for some staff, the stability of existing routines provided a sense of security and control [53, 60], although others did attempt to alter routines to adjust to the needs of people with dementia [60]. The familiar routines in hospitals largely followed the requirements of diagnostics and therapy [60].

Breaking these routines means changing the perspective from disease-orientated to patient-centred care [60]. A study proposed that person-centred psychosocial care includes prioritising patient needs over tasks [72]. Just one study examined the cost-effectiveness of adopting person-centred care models for people with dementias in an acute hospital. The results showed significant cost savings and a gain in quality-adjusted life years for participants with dementia – the authors called for wider adoption of person-centred care models of enhanced care for people with dementias in the acute hospital setting [72].

The challenges of having the time to care, related to high workflow and adequate staffing, were raised in a range of studies [23, 33, 41, 43, 58, 60, 69]. In one study carers were reported to be quick to acknowledge pressures such as staff shortages and also the needs of other acutely ill patients [45]. Carers reported concerns about a lack of essential nursing care, harmful incidents, a decline in patient function, poor staff communication and carers' needs not being acknowledged [45]. Five carer participants in a UK study described incidents in which their relative came to actual or potential harm while in a hospital [45]. It has been suggested that potential solutions exist in a number of approaches associated with the patient, the task, individual staff, team, environment, organisation and institution [33].

The 2019/20 literature review highlights that with respect to acute hospital settings:
Breaking the organisational routines and cultures of clinical imaging and radiotherapy departments means changing the perspective from disease-orientated to patient-centred care **[60]**.
Person-centred psychosocial care in clinical imaging and radiotherapy departments means prioritising each patient's needs over clinical tasks **[72]**.
Potential solutions to the challenges of having the time to care and enough staff should be explored by clinical imaging and radiotherapy teams, taking into account the needs of individual patients, the tasks involved, individual staff skills, the team, environment, organisation and institution [2].

9.1.2 Tempering the effects of hospital admission for people with dementia

A range of studies suggest that overall there are usually negative effects on people with dementia that result from hospitalisation, primarily because of a tension resulting from both the prioritisation of safety and acute medical care for existing comorbidities, which is complicated by insufficient understanding of what constitutes person-centred care in an acute care context [39, 53, 54, 60, 62, 67, 79]. There has also been a lack of the requisite knowledge and skills set in healthcare practitioners [33, 39, 45, 55, 67, 69, 80].

An ethnographic study reported that routinised cultures in healthcare triggered resistance, rejection or refusal of care from people with dementia when there was a

focus on essential planned care over patient need or mood [41]. The patient's needs for social contact and self-esteem (such as dignity and respect) were often ignored and this led to patients feeling devalued [54]. Hospital staff have to be more aware of the holistic needs of patients with dementia in acute settings and the way that care is delivered in order to make up for these unmet needs, thus facilitating person-centred care [54].

A number of authors provide a range of practical examples in which hospital procedures and practices were confusing for people living with dementia [48, 57, 66]. One study refers to the technological focus of modern hospital care [33]. It has also been suggested that in clinical imaging, technology affected the effective interpersonal care of patients with dementia [43]. Specific to clinical imaging, a study found that disrespected personhood, poor communication, limited staff knowledge of dementia, inappropriate time management, negative stereotypes, overly stimulating physical environments and the exclusion of carers from treatment and care procedures were all related to negative experiences [37].

More positive encounters in clinical imaging were associated with: patient-centred care; good communication; high levels of education of staff; inclusive relationships with carers; and effective time management [37]. Overall, radiography department protocols contributed to negative experiences, cited as lack of preparation, lack of dementia protocols, and the use of restraints [37]. Another study confirmed a negative view of restraint, a factor that hindered good care of an older person with dementia, and relatives felt that use of restraints violated patients' dignity [40]. A study advocated a 'no physical restraints' policy [72] but did not consider the effects of verbal restraint. People with dementia have highlighted the negative effects of the use of verbal restraint, typically in the form of nurses forbidding a person to get up and move about. Restraint was considered to be a common source of patient–staff conflicts [40, 44]. The main conclusion of the study set in clinical imaging was that patient care for people with dementia needed improvement: 1) radiographers need training about dementia; 2) imaging services should improve their procedures and physical environments; and 3) staff should work in greater partnership with carers [37].

Patients with dementia can experience a series of circumstances and factors that result in adverse events, including geriatric syndromes that can lead to a downward cascade of interacting problems, resulting in further dependence that can also lead to serious carer strain and dissatisfaction [33]. Delirium (sudden deterioration in mental functioning caused by acute illness, injury or drug intoxication) has links to unfamiliar surroundings, pain, dehydration, constipation and infection. For the recognition and management of delirium an action research group developed a flowchart [61]. The authors posit that training delivered in a clinical setting may be more feasible and have greater potential to enhance practice [61].

One author described the phenomenon of cascade iatrogenesis, whereby a seemingly simple error such as misplacing a person with dementia's glasses [48] ultimately results in poorer care for patients. Another study also highlights the importance of locating missing items such as reading glasses or appropriate footwear [53]. They provide an example where, left without the correct glasses, "Ann was unable to perceive items accurately and this impacted on her recovery period" [53]. Carers have also reported concerns about lost property; dentures, spectacles and slippers were lost, which

affected patients' ability to eat and mobilise safely – such incidents were directly linked with ward moves, and left participants with the impression that their relative was not being cared for adequately [45]. Stakeholders report the use of a securely located locker at the Wellcome Centre for Integrative Neuroimaging in Oxford. The locker 'key' is a hole-punched piece of laminated card with an elastic band attached. This reduces anxiety for some people, who can put the key around their wrist and go into the MRI scanner with it on (for safety in an MRI environment, anyone entering an MRI scan room must be free of metallic objects); the person doesn't have to remember a key or combination.

Changing transitions are particularly difficult for people with dementia [63]. In particular, ward moves can be disruptive and confusing, especially if they take place out of hours [57, 68]. Arguably, the move to visit a clinical imaging or radiotherapy department can be an equally confusing transition for some people. It is also suggested that for people who come into clinical imaging and radiotherapy departments from home, there is a need to liaise with transport locally to allow carers to travel on transport services [8]. On arrival, hospital departments should consider the possibility of providing an observed waiting area [57]. In practical terms this could include trained volunteers to accompany people with dementia, for example to meet and reassure a person and their family and/or carers on arrival and possibly offer a front door greeting service for people while carers park their car or when a person is dropped off by ambulance transport. Observations suggested that once inside a hospital patients found that being in a changing cubicle was a negative experience, as they were isolated from other patients and company [53]. Ward staff, relatives and the patients themselves commented on the positive nature of being in an area with other patients. In one study, a person with dementia, Betty, commented:

> "It's nice to see other people and what they are doing." [53]

The boredom expressed by patients often translated into feelings of entrapment. Both staff and relatives suggested that a way to improve the hospital experience would be to enable patients with cognitive impairment to take part in some form of meaningful activity [53]. It has been suggested that people with dementia benefit from a choice of music (or no music) while waiting for and undergoing treatment [26, 27, 49, 72, 81]. The SCoR has championed the work of the charity Playlist for Life, encouraging clinical imaging and radiotherapy departments to invite people with dementia to bring music with them or to provide the use of music equipment for people in waiting areas [26, 27].

A US study adds the suggestion of re-purposing 'sitters' to 'elder life specialists'. Sitters accompanied people on the American wards, similar to UK practices of providing constant observation for a person (or 'specialling'), but they were underused as a resource to actually engage with patients (e.g. they were observed using their mobile phones and not interacting with patients). The authors suggested that 'elder life specialists' could be trained to tailor their approach to the needs of patients and people with dementia, including engaging activities, room modifications, and enhancing safety [41]. UK studies reported that dementia specialist roles had little organisational impact [39, 70]. In contrast with the American study, UK dementia specialists tended to work at a strategic organisational level rather than on a one-to-one basis with patients.

During visits to hospitals, a study noted that patients were typically slower than the general population and needed longer periods of time for their care [50, 71], or examinations needed to be slowed down [42]. Clinical imaging and radiotherapy departments should offer longer appointment times to people with dementia [47, 66]. When people with dementia make repeat visits to clinical imaging or radiotherapy departments then it will be helpful to have familiar staff, especially for radiotherapy [47, 49].

The 2019/20 literature review highlights that with respect to tempering the effects of hospital admission for people with dementia:
Staff must be aware of the holistic needs of patients with dementia in acute settings and the way care is or could be delivered in order to effectively facilitate person-centred care [54].
Positive encounters in clinical imaging and radiotherapy require patient-centred care; good communication; high levels of education of staff; inclusive relationships with carers; and effective time management [37].
In addition to a 'no physical restraints' policy practitioners should also pay regard to the negative effects that verbal restraints can have upon the well-being of people living with dementia [40, 44, 72].
Particular attention should be paid to ensuring that no person who visits a clinical imaging or radiotherapy department loses their property, for example, spectacles, hearing aids, walking aids, jewellery, slippers etc. [45, 48, 53].
There is a need to liaise with local patient transport services to allow carers to travel on transport services where that is not currently happening [8, 47]. Clinical services should inform people living with dementia and their families that it is possible to liaise with transport services and arrange transport for carers if required (so they know they can ask for this). There is also a need to ensure staff are aware this is an option and for staff to ensure they inform patient transport when an escort is required (to ensure their transport budget can be used for this purpose)[47].
Explore the possibility of having trained volunteers to accompany people with dementia, for example to meet and reassure a person and their family and/or carers on arrival and possibly offer a front door greeting service for people while carers park their car, or when a person is dropped off by ambulance transport [47].

When offering appointments, clinical imaging and radiotherapy departments should invite people with dementia to bring music or to provide the use of music equipment for people in waiting areas [26, 27].
Clinical imaging and radiotherapy departments should offer longer appointment times to people with dementia [47, 66].
When people with dementia make repeat visits to clinical imaging or radiotherapy departments then it will be helpful to have the consistency of familiar staff and routines for people with dementia and their carers[47, 49].

9.1.3 Studies of the intersections of cancer and dementia

Because of the nature of their work, clinical imaging and radiotherapy staff routinely work in partnership with patients who are either undergoing routine screening, symptomatic investigation for cancer, or have a diagnosis of cancer. Post treatments, some patients with cancer and dementia also have surveillance imaging. A person with dementia may bring an intersection of the two conditions, dementia and cancer, which requires adjustments to their care in clinical imaging and radiotherapy departments [34, 42, 71]. One 2016 study concluded that further work was needed to establish practice guidelines for the management of cancer in people with dementia [34]. This is important because a recent analysis of UK primary care data found that 7.5% of people with cancer and aged over 75 had a diagnosis of dementia [47].

Authors noted that different rather than more cancer treatment might be appropriate for people with dementia, for example, by considering lower dose treatment for those with greater cognitive impairment [34]. The authors of that 2016 study found only cohort/survey research with no qualitative research exploring the experiences of people with dementia receiving cancer treatment [34]. However, studies in the years after that finding have included the experiences of people with cancer and dementia [42, 47, 71]. The authors of a 2020 paper, which included observations in a radiotherapy department and interviews with therapeutic radiographers, recommended that there should be: a) improved identification (during assessment and consultation) and documentation of dementia in clinical records; b) provision of training and tools for staff to support person-centred dementia care; c) support for people to attend hospital for cancer treatment and care e.g. through appointment flexibility, consistency in staffing and consideration of transport and travel issues; d) a supportive physical environment; e) support for treatment decision making; and f) inclusion and support for families [47].

The 2019/20 literature review highlights that with respect to studies of the intersections of cancer and dementia:
A study provides evidence that there should be:

a) Improved identification (during assessment and consultation) and documentation of dementia in clinical records
b) Provision of training and tools for staff to support person-centred dementia care
c) Support for people to attend hospital for cancer treatment and care e.g. through appointment flexibility, consistency in staffing and consideration of transport and travel issues
d) A supportive physical environment
e) Support for treatment decision making
f) Inclusion and support for families [47].

9.1.4 Environmental design

There is a specific need to improve environmental design to benefit people with dementia [30]. There has been a lack of dementia-friendly spaces [55]. In particular, The King's Fund programme Enhancing the Healing Environment: Environments of care for people with dementia [82] and the University of Stirling Dementia Services Development Centre's Virtual Environments [57, 83] provide information and practical strategies for making environments more supportive for people, including, for example:

- Positioning large clocks on walls, displaying time and date information to help with orientation
- Ensuring that there is clear and pictorial signage
- Providing an unambiguous, secure and safe waiting/observation area for people with dementia
- Painting contrasting colours on door frames and providing toilet seats in a colour that contrasts with surroundings
- Ensuring that there is bright lighting
- Removing dark mats, which appear to be holes to people with visual disturbance
- Providing an area with reduced noise and a calm environment
- Providing opportunities and areas for purposeful activity during waiting times.

It should be noted however that the environment should be tailored to the needs of the person with dementia. For example, a person with posterior cortical atrophy (PCA) dementia may find bright lights distressing or find it difficult to tolerate a bright glare.

The King's Fund environmental assessment tools provide further information.
The King's Fund [82] recommends a system-wide multiple initiative approach to improving the environment, which includes changes to the physical environment, tailored dementia training, and engagement with local dementia groups [64]. One paper makes the point that the use of experts alone could potentially concentrate responsibility for dementia care in a small staff group rather than create a culture where all staff are responsible [23]. People with dementia, carers and local dementia groups must always be partners in the development of care and environments in clinical imaging and radiotherapy departments [21].

The 2019/20 literature review highlights that with respect to environmental design:

The King's Fund Enhancing the Healing Environment: Environments of care for people with dementia [82] and University of Stirling's Dementia Services Development Centre Virtual Environments [57, 83] provide example information and practical strategies for making environments more supportive for people with dementia.
People with dementia, carers and local dementia groups must always be partners in the development of care and environments in clinical imaging and radiotherapy departments [21].

9.1.5 Consent to clinical imaging and radiotherapy procedures

NHS England [84] offers four points for clinical practice that reiterate the principles of the mental capacity legislations that apply across the UK:

- Begin each meeting with a patient by thinking that they can make their own decision.
- Give each person both the time and support that they need to make their own decision about consent to treatment (diagnostic and therapeutic examinations and procedures).
- If you or someone else does not agree with the patient's decision you cannot decide that the patient is incapable of making that decision. A person is not to be deemed incapable to consent because of an unwise decision.
- When a patient cannot make a decision, then they will need help from someone to make it in the best way for them. A decision must be the least restrictive option that does not limit the person's rights of freedom more than necessary. It may be necessary to delay procedures that are not emergencies in cases where there are any concerns.

Consent should be 'in the moment', monitored and discussed with the person with dementia. Signals to stop ongoing consent to treatment can be rehearsed – professionals must maintain assessment for ongoing consent or potential distress [54, 55] and must always respect stop signs [49]. Some people with dementia may find it difficult to maintain physical positioning or to stay still for the amount of time required for some types of imaging.

A study in the UK [26] provided a succinct overview of the consent process in relation to the Mental Capacity Act 2005. The same study included an instance of fluctuating capacity for a person living with dementia:

> "Originally a family member acted as a consultee but later Dorothy gained capacity and consented for herself. Dorothy was aware that she was in hospital." [53]

Advice for practitioners is to recontextualise words and experiences so that people with dementia can hold onto and make sense of them; for example, the hospital was the "big

white house" for one person – this was described as one aspect of making space for creativity and inventiveness in communication strategies [71].

A main point is to remember that an ethos of all mental capacity legislation is to empower those with impaired capacity [85]. The dynamics between carer and patient could possibly make it difficult to establish a person with dementia's capacity to consent. A person's mental capacity is both time and decision specific; capacity to consent can fluctuate [29]. Also, a person with dementia may lack capacity in some areas but still be able to make a decision about their procedures in clinical imaging and radiotherapy [85].

Practically, this means ensuring that differing communication needs are considered, i.e. interpreter services should be used, information should be written in different languages, picture cards should be provided etc. Questions to consider when seeking the consent of a person with dementia include: Does the person have a hearing impairment? Does their hearing aid have working batteries? Do they need additional time for a clearer, slower explanation of the situation? Can a family member/carer or chaperone offer advice about the person's preferred communication style? Does the person have a 'communication passport' with details of their preferences?

Previous wishes and beliefs must still be taken into account when the person lacks capacity; for example, if the person has claustrophobia and previously declined an MRI scan, or if a person wears a headscarf and does not wish to remove it in the presence of male staff [85]. Examples of ways in which people can be supported to make informed decisions include: providing information in different, tailored formats such as pictures and short written summaries [47]; and including families (with permission) in consultations so they can support discussion and decision making [47].

The 2019/20 literature review highlights that with respect to consent to clinical imaging and radiotherapy procedures:
Consent should be 'in the moment', monitored and discussed with the person with dementia. Signals to stop ongoing consent to treatment can be rehearsed – professionals must maintain assessment for ongoing consent or potential distress [54, 55] and must always respect stop signs [49].
A main point is to remember that an ethos of all mental capacity legislation is to empower those with impaired capacity [85]. A person's mental capacity is both time and decision specific; capacity to consent can fluctuate [29].
A person with dementia may lack capacity in some areas but still be able to make a decision about their procedures in clinical imaging and radiotherapy [85].
Previous wishes and beliefs must still be taken into account when the person lacks capacity; for example, if the person has claustrophobia and previously declined an MRI scan, or if a person wears a headscarf and does not wish to remove it in the presence of male staff [85].

9.1.6 Models of care for people with dementia who visit clinical imaging and radiotherapy departments

Patients with dementia have indicated their appreciation of the work of the health professionals who cared for them and expressed their desire to be more fully engaged in their care decision-making [52]. Centred around reducing anxiety and increasing relaxation and support, a study concluded that each individual patient requires a personalised package of care, regardless of disease or cognitive status [49]. There was evidence of cultural differences in approaches to care among the international studies; for example, when a person living with dementia was admitted with agitation on a US adult psychiatry unit, staff viewed their role as modifying behavioural symptoms with medications. That approach was not advocated in the UK, where dementia action groups [41] and the National Institute for Health and Care Excellence (NICE) dementia guidance and quality standards for dementia [16, 74] advise that before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, staff should conduct a structured assessment to explore possible reasons for their distress, and check for and address clinical or environmental causes (for example, pain, delirium or inappropriate care) [74].

A 2016 study reported that although person-centred care was the underpinning ethos for dementia care in many countries, there was limited evidence about the most effective approaches to supporting acute hospital staff to deliver more person-centred care [80]. A 2018 literature review provided information about a person-centred care model that was translated into four key elements known as the VIPS framework [65]: 1) Valuing people with dementia and those who care for them; 2) Treating people as individuals; 3) Looking at the world from the perspective of the person with dementia; and 4) Fostering a positive social environment. A literature review and study with semi-structured interviews with people with dementia raised awareness of a 'triangle of care' model that could help to mitigate concerns and anxieties about ensuring equal partnership between the person with dementia, the healthcare practitioner and the person's family, friends and informal carers [69, 71]. A resultant 'triadic consultation' between the person living with dementia, the healthcare practitioner and the family carer should be considered the norm [71].

There should be skilled staff who are informed and have enough time to care, in line with the SPACE principles [56]. There should be enough time for welcomes and goodbyes from teams [49]. In addition to Skilled staff, the other SPACE principles are: partnership working with carers; assessment and early identification of dementia; care plans that are person-centred and individualised; and environments that are dementia friendly.

There was evidence of a lack of consensus when employing practical aspects of models of caring for people with dementia. For example, during a cycle of action research, patients on a ward were identified by the use of a purple folder replacing a black folder at the end of their bed – the authors note that Alzheimer's Society has deemed purple to be the international colour representing dementia [61]. This was not recognised in another setting where staff instead used a red wrist band to identify people with dementia [57]. Another common discrepancy was an apparent lack of consensus about how to share information – for example, some staff employed a 'traffic light'

communication sheet rather than a this is me document [61]. Alzheimer's Society appreciates the benefit of 'communication passports', and (in partnership with the Royal College of Nursing) has produced the 'This is me' communication passport to support people in an unfamiliar place. The Society and College of Radiographers also advises members that an identification scheme and communication passport can be used in conjunction if this is common local practice. Hospital staff should be trained to use communication passports appropriately when available because they are designed to enhance the person's experience and person-centred care [86].

Alongside models of care, stakeholders were keen to raise awareness among staff about the effects of different types of dementia. For example: a person with posterior cortical atrophy dementia (PCA) may have visual difficulties; a person with primary progressive aphasia (PPA) dementia will have language difficulties; a person with typical Alzheimer's disease (AD) will experience memory difficulties. All will require slightly different interactions by staff, depending on the person's needs. For example, someone with typical AD may find it easier to position themselves on an imaging table/bed compared to someone with PCA, but that person would require more communication throughout the scan as they may lose their sense of time more easily (e.g. forget when the scan started).

The 2019/20 literature review highlights that with respect to models of care for people with dementia who visit clinical imaging and radiotherapy departments:
Each individual patient requires a personalised package of care relevant to their type of dementia, cognitive status and health needs [49].
Consultation between the person living with dementia, the healthcare practitioner and the family carer should be considered the norm [71].
Practitioners should be cognisant of the need to: 1) Value people with dementia and those who care for them; 2) Treat people as individuals; 3) Look at the world from the perspective of the person with dementia; and 4) Foster a positive social environment [35].
An identification scheme and communication passport can be used in conjunction if this is common local practice. Hospital staff should be trained to use communication passports appropriately when available because they are designed to enhance the person's experience and person-centred care [86]. Stakeholders note that communication passports and 'This is me' documents are typically developed with inpatient settings in mind, meaning many of the questions (e.g. around personal care, eating and drinking preferences) are not relevant to outpatient services such as imaging and radiotherapy. Those services may therefore wish to consider using an adapted version of their local inpatient passport to ensure the information they collate is relevant and usable by their service.

9.2 Building relationships with patients and carers to optimise the patient and carer experience

The 2015 SCoR recommendations for this domain were:
Acknowledge that people with dementia have both physical and psychological needs. Provide a patient information pack that has been designed specifically for people with dementia and their carers in advance, and involve lay people in writing it. Encourage patients to bring music, a 'This is me' document or other kind of reassuring material when attending the department. Ensure that patients are accompanied by a familiar person, such as a nurse or informal carer. Work collaboratively with patients and their carers, maintaining the dignity and autonomy of the person at all times. Work collaboratively with other professionals in the patient's pathway, sharing experiences, encouraging dialogue and disseminating best practice; generally learning from each other to share knowledge of the patient.

The 2019/20 literature review provides the following evidence.

9.2.1 Recognition of carer roles

In a study of people who were inpatients in a dedicated ward for people with dementia, the authors posited that staff should be encouraging family members and volunteers to provide companionship to people with dementia [72]. Authors of another study identified the importance of the 'need to be with' the patient e.g. sitting holding someone's hand to display care [55]. Beyond merely providing companionship, families have significant roles to play in the care of a person with dementia in hospital but one study found that they were often excluded [79]. This finding was echoed in another study [87], which found that, despite the many benefits of involving families of people living with dementia in their care, their involvement was far from routine, and varied between and within hospital wards. Importantly, the study also identified the potential for family involvement to override the needs and wishes of people with dementia. Staff must partner with families in a consistent way, with an approach that ensures that a result of family involvement is not at the expense of involving the person with dementia [87].

A study found that to support the involvement of families of people with dementia in oncology and radiotherapy there is a need for oncology services and staff to assess and understand the supportive networks available (or not) to someone with dementia. Assessment should: include relatives' ability and willingness to undertake supportive roles; recognise the additional stress and impact that supporting someone with dementia alongside other comorbidities brings: offer support to the family network as well as the patient; and consider how those who have no family or other supportive networks can be enabled to access hospital-based appointments and treatment [88]. In another study, it was found that when people did have family carers, they were not passive in the face of the disruption of hospitalisation and responded by trying to involve themselves in the care and support of their relative and by trying to work in partnership with members of staff [51]. A US study found that family members or long-term care staff were relied on to provide information [41]. A UK study found that supportive family carers were crucial in enabling people with cancer to access, navigate and undergo cancer care and treatment [47].

A further study highlighted the sense of responsibility that carers feel for assisting both the healthcare professional and the person that they are supporting. The carers described taking on the role of 'relayer of information', utilising their longitudinal and biographical knowledge of the person with dementia and their communication needs [71]. The authors of one study concluded that listening to family carers and using the knowledge they have of the person with dementia was probably the single most practical recommendation to be made from their data [51, 70].

Despite that acknowledgement, disappointingly, a systematic review highlighted that in relation to people with dementia and cancer, the role of family carers was overlooked in studies [34]. Review findings highlighted that carers have concerns when a person with dementia attends an acute hospital [65, 66]. Hospitalisation causes disruptions that can result in consternation or distress for family carers [51, 67]. For some carers, feeling in control was important. Strategies to promote control included trying to protect the person with dementia, making judgements about the quality of care being offered and, sometimes, taking steps to monitor the care [25]. Blaming the system and rationalising care quality problems was another coping strategy [25].

Carers often described a perceived gap in provision of help with personal care needs, for example with dressing/undressing, and the dignified treatment of patients [65, 79]. Some carers felt that hospital staff did not understand some people's basic needs, for example, for help to find a toilet or to drink [65, 66]. The authors of an ethnographic study in the UK noted that at times relatives appeared to prioritise practical elements of the patient's hospital stay, such as whether the person with dementia's clothing was clean and they received adequate food, over the emotional and social requirements of their cognitively impaired relatives [53]. Arguably this was akin to the task-focused prioritisation of physical care that staff have also been shown to take [23, 40, 53, 54, 60].

9.2.2 People with dementia and carers: building relationships and caring for others

A study that explored the experiences of people with dementia found that there was clear appreciation of the healthcare staff's efforts to help a person [52]. During focus

groups, carers also saw perspectives from multiple angles: the person with dementia, the carers themselves, or other family members who might even be in disagreement with each other [63]. People with dementia and carers were also concerned about their fellow patients and families who were present in wards and hospital settings. One study observed that "hospital roommates often feel uneasy or scared because of the behaviour of patients with dementia" [69]. Another study provided evidence of carers' concerns for other patients and staff, with strategies to assist staff caring for people with dementia and also other patients. There was little evidence that this was recognised by staff, which left some carers feeling used and exhausted [51].

Family carers' lives and experiences both inside and outside the hospital were disrupted by the hospitalisation of their family member, attempting to gain a sense of control over the experience, and giving a sense of control to the patient, co-patients and staff [44]. Co-patients on wards experienced disruption from sharing space with the person with dementia and were left feeling vulnerable and sometimes afraid. They too attempted to gain a sense of control over their situation and to give some control back in return by attempting to help the person with dementia, their family/carer and the staff [44].

It may be necessary in some cases to offer general information to fellow patients and families about the possible effects of dementia to enhance understanding and support. With the progression in the UK of dementia-friendly communities, the work of dementia action groups and initiatives such as Alzheimer's Society's Dementia Friends training [18], it is probable that people generally have a greater awareness of dementia, but that knowledge can be limited in scope. The National Institute for Health and Care Excellence (NICE) [74] and the World Health Organization [2, 89] both suggest that healthcare professionals should share knowledge and offer advice to people in a bid to prevent a number of dementias. In doing so they position dementia as a public health priority [3]. Many people with dementia are active in sharing their knowledge and experiences and educating others. For example, the National Dementia Action Alliance [90] has supported a project where people with dementia can now share their thoughts and experiences via Dementia Diaries and @dementiatweets. The diarists hope "that by opening up our lives to the public we will improve understanding of the diverse experiences of living with dementia and how communities and services can best offer support" [76].

Studies in the literature review also gave examples of people with dementia seeking to support others, such as trying to support their fellow patients, offering their carer a drink or snack, or finding their relatives a space to sit [44, 51].

The 2019/20 literature review highlights that with respect to building relationships with patients and carers to optimise the patient and carer experience:
Beyond merely providing companionship, families and carers have significant roles to play in the care of a person with dementia in hospital **[47, 79]**, including in clinical imaging and radiotherapy departments [88]. Advice is to ensure that there is proactive planning and discussion with families around their involvement, with clarity and information about the roles families

can undertake, ensuring staff understand the importance of family involvement and the department's approach to this, and use personal knowledge from families in practice [87].
The National Institute for Health and Care Excellence **[74]** and the World Health Organization [2, 89] suggest that healthcare professionals should take some responsibility by increasing awareness among the public, sharing knowledge and offering advice to people in a bid to reduce a number of potentially preventable dementias.
Many people with dementia are very active and take the lead in sharing their own knowledge and experiences, to educate and support others, while underlining the diverse experiences of people living with dementia. For example, the National Dementia Action Alliance **[90]** supports a project where people with dementia share their thoughts and experiences via Dementia Diaries **and @dementiatweets.**

9.3 Strategies for optimising communication with people with dementia and their carers

The 2015 SCoR recommendations for this domain were:
Liaise with carers and/or people with dementia about appointment times. Keep the number of professional practitioners in the room to a minimum, with one person taking the lead. Observe and value both verbal and non-verbal communication and always assume that some communication is possible. Treat patients as equal partners in communication, even when communication is limited. Approach patients calmly, gently and in a relaxed manner. Find out and use the patient's preferred name. Ensure you have the patient's attention before giving important information. Speak directly to the patient, even if they are unable to respond, and keep eye contact. Speak plainly and avoid complicated idioms of speech.

Use short, simple sentences and a soft tone.

Ask simple questions that require a short answer, e.g. yes/no.

Allow ample response time before repeating information.

Repeat sentences using the same words.

Ensure that interactions are not ended abruptly.

Remain calm if the patient becomes agitated.

Avoid moving or walking around during conversations.

Model the desired behaviour.

The 2019/20 literature review provides the following evidence:

It is imperative that staff are equipped with good communication skills for multiple reasons, including, for example, that communication skills are critical in preventing unnecessary medical complications that might not only lengthen hospital stay, but also shorten the patient's life [48]. The personalities of staff and patients were noted to influence care and communication in one study [43], but interestingly this recognition was not extended to consider the personalities of carers.

With regards to miscommunication, it has been suggested that the decline in linguistic ability associated with dementia may result in a failure to understand or pick up on typical closing cues when a treatment or examination is finished [58]. Researchers have identified three phenomena with recurring misunderstandings: 'open-ended pre-closings', 'mixed messages' and the use of 'non specifics and indeterminate terms' [58]. The authors therefore offered advice to:

> "specifically ask each patient if they have any questions or concerns and reassure that person that you have the time to answer". [58]

To reduce miscommunication and misunderstandings it has been recommended that people with dementia should be invited to complete a 'This is me' booklet in order that staff can understand the specific communication needs of each patient [48]. This should be with the caveat that not every person living with dementia will choose to share that information for various reasons, including, for some, the fear of stigma or discrimination. One study's data, however, placed the onus on healthcare staff, and suggested that use of communications passports, dementia information leaflets, delirium screening scales and dementia care pathways increased following training tailored to staff groups [91].

In a focus group of carers [37], however, participants identified practical issues that could affect the usability of communication tools that included updating information, keeping more than one copy in different locations, and remembering to gather material

back when a patient was being discharged. All participants indicated the need for clarity regarding who is responsible for the document. The carers were skeptical that the information would be used by healthcare staff, who were perceived as not having the time, or possibly the interest, to read the information [63]. Staff appeared to agree, with some description of barriers to implementation of communication passports [53]. It was posited, however, that evidence in the mental health and intellectual disabilities field shows that self-empowerment and advocacy through the use of communication tools can improve care [36]. It was also suggested that encouraging self-empowerment through an exchange of specific dementia information exchange could reduce 'hospital-acquired harm' [63].

Appropriate adjustment should be made to communication methods used in clinical imaging and radiotherapy. It may help to rephrase a request slightly if a person does not understand, for example use simpler words or try to explain things differently [92]. Review stakeholders also underline the importance of speaking to a person at their eye level when they are seated, not standing over them. To aid with communication, one study suggested developing a written contract of care with each patient [49]. It is possible that SCoR members could feel that this may be appropriate for a radiotherapy setting but less so for clinical imaging, which commonly is not repeated. However, the authors of a study of professional–person with dementia interactions emphasised the importance of context in the analysis of healthcare delivery, to avoid a 'one size fits all' approach [26]. Rather than the length of a procedure, it is the needs of each person that should dictate the approach that is then taken.

A care contract could be used to prompt changes to the language used around clinical imaging and radiotherapy, for example, to tailor communication for the person, like remembering that the radiotherapy mask was described as a "wet towel" to enable understanding by one patient [42]. In a study of cancer and people with dementia, a specific adjustment to support treatment included not using written information leaflets for some patients [42]. Having a family carer present within a radiotherapy department, with access to CCTV and intercom to communicate with the patient, was found to have a positive impact in a case study of one person with dementia [49]. Despite examples of adjustments to care, authors of a UK study that included a radiotherapy department considered that people with dementia and families could feel left "in the dark" due to difficulties understanding, retaining and using cancer information, which affected their informed treatment decision making. The authors posit that dementia increased the complexity and burden of travelling to and navigating unfamiliar hospital environments, frequent lengthy periods of waiting in hospital, and self-managing symptoms and side effects at home [47]. Communication is an important factor to ensure that people do not feel in the dark.

Whether a patient's hospital experience was positive or negative was powerfully influenced by family involvement, staff actions and communication in a UK study [53]. SCoR advocates a patient, public and practitioner partnership to improve services in clinical imaging and radiotherapy [21]. A partnership approach is important because the observations of researchers may not always reflect the experiences of patients and carers. A study recommended that time and creativity are required to develop ways of capturing feedback from patients with dementia [45]. The authors of a UK study note that some patients were not able to comment directly on their hospital stay as a whole,

as they were unaware that they were in hospital or that they were receiving medical care. However, they were able to comment on their emotional experience of the immediate context, such as boredom with their surroundings and their immediate responses to interactions with staff members. Emotional experience was paramount to the patient perspective and current emotional experience was often represented by discussing past experiences [53]. Carers have, however, voiced concerns about involving some people in their care or feedback; for example, a carer reported concerns about inaccurate information that a person with dementia gave to nursing staff about her level of ability to mobilise [45]. Accordingly, it is important that clinical imaging and radiotherapy staff work in collaboration with carers and people with dementia. It is imperative to explore and act upon feedback, recognise everyone's contribution and show concern for everyone involved in the care of the person with dementia.

Organisational routines and culture affect the optimisation of communication [42, 60]. For example, studies show that the routines of wards took priority over individual patient needs; staff had little flexibility to respond to patient needs outside of scheduled and quantifiable work. This notion resonates with a range of radiography-based studies. Similarly, staff discussed lack of continuity and cultures that accepted 'not knowing' the patients in their care; communication was typically rhetorical, emphasising a lack of choice for the person or staff caring for them [50]. A study outlined the importance for the person with dementia of having an accompanying carer who they were acquainted with, a 'familiar face' to mitigate the not knowing [42]. A study has concluded that there is particular value in understanding communication tips from family members and topics of conversation the person enjoys (information gained either from the person or family), which can be revisited over subsequent appointments to provide a sense of familiarity and fast-track a positive conversation [87]. The SCoR has previously championed John's Campaign [24], which advocates for the right of all people with dementia to have their carers welcomed and to remain with them at all times during visits to clinical imaging and radiotherapy departments, if they wish to do so.

The 2019/20 literature review highlights that with respect to strategies for optimising communication with people with dementia and their carers:
It is important to "specifically ask each patient if they have any questions or concerns and reassure that person that you have the time to answer" [58].
People with dementia should be invited to bring a 'This is me' communication passport [48] when visiting clinical imaging and radiotherapy departments if they wish to do so.
There is particular value in seeking out communication tips from family members and topics of conversation that the person enjoys (information gained either from the person or family). For departments where a person may have repeat visits, the information can be revisited over subsequent appointments to provide a sense of familiarity and fast-track a positive conversation [87].
Consider developing a written contract of care with each patient [49].

SCoR supports the ethos of John's Campaign [24] of the right of all people with dementia to have their carers welcomed and to remain with them at all times during visits to clinical imaging and radiotherapy departments, if they so wish.
Time and creativity are required to develop ways of capturing feedback from patients with dementia [45]. SCoR advocates a patient, public and practitioner partnership to improve services in clinical imaging and radiotherapy [21].

9.4 Understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs

The 2015 SCoR recommendations for this domain were:
Be aware that patients' behaviour is a form of communication and recognise that withdrawal or passivity is a form of distressed reaction. Patients may exhibit distressed behaviours due to pain, fatigue, hunger or other discomfort; try to identify the cause of distressed reactions and avoid compromising normal routine activities. Accept that people with dementia may have their own sense of reality and that challenging this may cause distress. Utilise forms of therapy that may provide reassurance, such as music, which may be brought in by the patient, or reminiscence, including inviting patients and carers to bring items such as photographs with them to be discussed prior to examination or treatment. The use of restraint should be the last resort; it can present risks to the patient (and others) and should not be used just because not enough staff are available. Identify safe ways to facilitate walking; this can reduce agitation and assist patient safety. Walking in a circular route can decrease agitation.

The 2019/20 literature review provides the following evidence:

In a study of the experiences of people with dementia, the feelings associated with being a patient with dementia were expressed in multiple ways, including negative reactions of self-blame and frustration about not having anything to do while in hospital [52]. A number of studies posit that the behaviour and feelings of patients can also be a response to hospital settings that are threatening and frustrating for some people with dementia [50]. Studies pointed out the need to reconceptualise the term 'challenging behaviours' to instead understand that these are cases of the unmet needs of a person [43, 48, 66].

Unmet needs in a diagnostic imaging study were noted to be due to lack of interpersonal interaction, problems with lighting levels, noise, heat or unarticulated pain [43]. Patients responded to these circumstances with a range of emotions, such as passive indifference, sadness, nervousness, fear, and occasional episodes of anger and violence [52]. When staff were present but not really engaging when carrying out care or procedures, situations could turn positively or negatively depending on the person [67]. If a person with dementia did take the initiative to act, their intentions could end up being misinterpreted as disruptive behaviour; for example, this happened during observations of ward care [52]. It is essential to understand that these behaviours can be interpreted as attempts by the person with dementia to gain a sense of control over the unfamiliar environment and experiences [44].

Similarly, resistance to care was conceived to be a continuum of responses from people living with dementia to the way that care is delivered in a fast-paced and routinised environment [50]. Hospital staff noted situations in the hospital stay that seemed particularly difficult for patients with dementia, such as travelling to different parts of the hospital for treatments [36]. The authors of a literature review focusing upon training for radiotherapy students contend that it is important in the settings of unfamiliar treatment rooms and equipment to recognise a person's distress and to try to listen to, understand and meet the needs of, the person with dementia [66]. A study concurs that the hospital environment did not lend itself well to the management of distressed behaviours, reporting that the emergency department was seen as a chaotic place where, despite national targets for swift assessment, treatment and transfer, the process was slow, exhausting and uncomfortable for people [51]. Clinical imaging staff are involved in part of that process.

As fear and anxiety increased in some people with dementia, their care partners also experienced enhanced worry and concern [37]. Carer involvement and contribution to information sharing enabled them to share their expertise with staff, proactively raising awareness of what may trigger agitation or distress reactions [63]. Arguably, the authors of one study inaccurately conceived 'falls and wandering' to simply be problematic behaviour, but they did recognise that people with dementia can "feel a sense of security and calm down when spending time with their families" [69].

9.4.1 Recognising a person's pain

People with dementia may be at risk for undetected or un(der)treated pain [40, 67]. Approximately 50% of patients with dementia regularly experience pain but may not be able to report their pain verbally – behavioural symptoms may be a result of underlying pain [39]. Another study discussed pain management and the difficulties that people with dementia can have communicating their pain, concluding that the use of a cognitive impairment pain assessment scale was useful [61]. It was noted that physical signs of pain can include fidgeting, fist clenching or changes in eating patterns, and in the presence of pain, reactions to other people can include pulling, pushing people away and striking out [34]. Visual signs of pain include facial expression and speech e.g. appearing tense, groaning or crying out [61].

For a person with dementia, their recognition and signalling of pain therefore can be complex and dynamic [15]. It can be associated with distress and anxiety, and context plays a role in staff recognising that when assessing and managing pain; for example, patients on surgical wards were expected to have, and were asked about, acute pain [39]. In a study set in an oncology hospital, a person with dementia was able to articulate a sense of pain and distress at undergoing personal and intimate clinical investigations. A theme of personal and emotional pain together with feelings of personal invasion were evident, according to the authors [71].

Healthcare staff reported using intuition, experience and their ability to build a picture of the patient to identify whether or not a person was experiencing pain [39]. They reported difficulty in managing pain in some cases when people with dementia can be reluctant to take medication [40]. A further issue for clinical imaging and radiotherapy staff is the limitation of the working environment, complexities of the law and legislation, and in the case of all diagnostic radiographers, a lack of regulatory enablement to independently prescribe pain medicine for a person [93].

Relaxation techniques can be used to help in the long and short term to manage anxiety, avoid panic and support self-sufficiency to aid the person to maintain a sense of being in control and calm [49]. Staff working in clinical imaging and radiotherapy must be mindful to be alert to signs of pain, and provide support at all stages of the patients care before, during and post examinations, procedures and treatments.

The 2019/20 literature review highlights that with respect to understanding patient's behaviour and adopting positive ways to reduce distressed reactions to unmet needs:
Clinical imaging and radiotherapy teams must reconceptualise the term 'challenging behaviours' to instead understand that a behaviour may reflect the unmet needs of a person who is trying to communicate those needs [43, 48, 66].
Unmet needs in a diagnostic imaging study were noted to be due to lack of interpersonal interaction, and problems with lighting levels, noise, heat or unarticulated pain [43].
It is essential to understand that distressed behaviours can be interpreted as attempts by the person with dementia to gain a sense of control over an unfamiliar environment and experiences [44].
Situations that seemed particularly difficult for patients with dementia included travelling to different parts of the hospital for treatments [36].
Physical signs of pain can include fidgeting, fist clenching or changes in eating patterns. In the presence of pain, reactions to other people can include pulling, pushing people away and striking out [34]. Visual signs of pain include facial expression and speech e.g. appearing tense, groaning or crying out [61].

Relaxation techniques can be used to help in the long and short term to manage anxiety, avoid panic and support self-sufficiency to aid the person to maintain a sense of being in control and calm [49].

9.5 Carer partnerships

The 2015 SCoR recommendations for this domain were:
Family members and informal carers should be involved in care and considered assets. Carers should be viewed as a source of expertise. Staff should work collaboratively with patients and carers. Staff should acknowledge that carers may also need information and reassurance and should avoid adopting a defensive or confrontational approach to them.

The 2019/20 literature review provides the following evidence:

According to a study of junior radiographers, it was posited that carer presence during diagnostic examinations could have a potential positive or negative effect on the person with dementia [43]. An ethnographic study had parallels, describing the potential for relatives to undermine patient involvement; the authors commented that there were occasions where researchers observed relatives undermine the agency of the patient and it is vital that in any protocol, a balance is achieved between relative involvement in hospital care and ensuring the independence of the patient with cognitive impairment [53].

The authors of a study set in Japan reported that nurses did seek assistance from families but that was not forthcoming [69]. Perhaps related to culture, this did not appear to be the case in the majority of other international studies, although the results of an observational study set in an acute hospital ward in Denmark showed "very little presence of visitors" during the acute admission period for people with dementia [52]. A study set in Finland found that support from close relatives was significant for the mental and social well-being of older dementia patients during their hospital stay. People with dementia felt insecure in their relatives' absence, and missed them [40]. In a study of people living with dementia and undergoing treatment for cancer, informal carers were relied on to provide patient information, advocate for the patient and support decision making – patients with dementia got through treatment with the help of their family [42].

Study authors did recognise that carers could require support and care themselves [16, 45, 47, 65, 74]. Supporting a friend or relative in an acute hospital could result in people

experiencing stressful times [47, 74]. Stakeholders for this review also commented that the experience of supporting a person with dementia during visits to clinical imaging and radiotherapy departments for examination and treatment could at times be overwhelming and emotional for their carers. In one study interview, a participant expressed how much it meant to her when a doctor recognised that and made her a cup of tea [45]. A literature review exploring carer perspectives of care quality described four overarching components of care that influenced carers' experiences: patient care; staff interactions; the carer's own situation; and the hospital environment [35]. Staff can support carers with time to answer questions and consultation for decision making [49]. Literature suggested that carers needed to be informed, involved and supported in order to promote the most positive experiences [65].

The 2019/20 literature review highlights that with respect to carer partnerships:
Informal carers were relied on to provide patient information, advocate for the patient and support decision making – patients with dementia got through treatment with the help of their family [42].
Components of care that influenced carers' experiences were: patient care; staff interactions; the carer's own situation; and the hospital environment [35].
Carers needed to be informed, involved and supported in order to promote the most positive experiences [65].
Staff can support carers with time to answer questions and consultation for decision making [49].

9.6 Staff skills and attitudes

The 2015 SCoR recommendations for this domain were:
Consider that the lives of people with dementia are meaningful; do not assign blame to the patient. Challenge 'us and them' attitudes. Be non-judgemental and show unconditional positive regard for patients and their carers. Do not lose sight of the person and avoid dehumanising behaviours. Appreciate that you can learn from people with dementia.

Recognise and act on patient cues regarding unmet needs and distressed reactions.

Use the initial introduction and identity check to assess the patient's level of understanding.

Request consent and do not assume it in cases where express written consent is not required.

Modify information provided to the patient to include only that which is commensurate with informed consent and directly related to the activity and ensuring safety.

View family members and/or informal carers as assets and involve them in care.

Have an attitude of warmth and firmness.

Employ flexible approaches and be creative.

Be a reflective practitioner, interrogating your own behaviours and attitudes towards people with dementia.

Engage in team-based reflection.

The 2019/20 literature review provides the following evidence:

Literature suggests that staff can devalue and view people with dementia as a nuisance or an inconvenience, not suitable for an acute hospital setting, when organisations have a culture that focuses on safety [2]. A literature review performed in 2016 surmised that this was probably still the majority view among many healthcare workers, although the authors did state that this may be a simplistic representation of a complex situation [67]. Dementia does add complexity to patient care for some people. The inability to deliver appropriate care in acute settings was a source of stress and frustration for nurses [79]. The approach of staff in one study was to expect resistance to care from people with dementia – resistance was both routine and anticipated and staff placed a high value on achieving efficiency and reducing perceived risks to patients [50].

Hospital cultures require wider system review to mitigate against the stigmatisation of patients with dementia and the resulting stresses for staff, patients and carers [33, 79]. It was reported that staff do experience moral distress and burnout in response to institutional barriers limiting care quality. A study raised the issue of underlying societal negative attitudes towards older people, particularly those with dementia, commenting about the 'infantilisation' of people with dementia [33]. Staff working in acute hospitals recognised that they had a lack of knowledge, skills and confidence when caring for people with dementia [80]. Ancillary staff felt that caring attitudes and behaviours in their encounters with patients with dementia were important but challenging to put into practice [36]. A conclusion was that while staff training is championed as a solution to improved care for people living with dementia in the form

of improved staff skills, the underlying barriers are largely due to cultural attitudes and organisational issues rather than lack of training (although study authors conceded that training also helps to improve care). Institutional drivers of routines, efficiency and risk reduction were again highlighted as barriers to person-centred care [50].

Studies have identified that staff experienced a core problem when caring for people with dementia, which they term 'disruption', and a core process, "gaining or giving a sense of control to cope with disruption". Patients who could not adapt to the hospital routine were perceived as disturbing the routine [60]. It was posited that healthcare professionals in one study responded to the disruption in three ways: by acting to preserve the personhood of the individual; by seeking to protect themselves from the stresses associated with caring for the person with cognitive impairment; and by suspending the personhood of the individual [38]. Further, the authors recognised that people with dementia and their carers could also experience disruption when a person attends a hospital [38]. The same authors posited in a further study that disruption adversely affected the person with dementia, triggering some constructive but also disengaged, distressed and neutral behaviours [44].

Clarity in staff's responsibility for patient care was an important resource for improving their autonomy and encouraging them to respond in timely, creative ways to meet individual needs [23]. Staff must also be looked after from a material, psychological and educational perspective to have the ability to care effectively for people with dementia [79]. In a study of diagnostic radiographers, when individual staff perceived themselves as knowledgeable and/or experienced around dementia patients then they had an attitude of confidence in their practice [43]. Experienced nurses who had personal contact with older people in their personal lives gave the impression that they are more prepared than their younger colleagues, who seem to be overstrained by the special needs of patients with dementia [60]. A study suggested that a greater depth of knowledge was required around person-centred dementia care for staff to feel they have efficacy in providing care [80]. It is possible that with age and experience, knowledge and efficacy may increase for some professionals. It has been suggested previously that the inexperience of student radiographers in Norway may have affected their interactions with older people; interventions were designed to have a positive effect on student attitudes, which initially appeared successful [94]. At six and twelve months post intervention, however, it was posited that the students' early experiences of clinical placement, with frequent exposure to very ill and frail people, reduced the initial effects [95]. At 24 months post intervention, attitudinal scores had again increased and qualitative data suggested that interventions should include learning about care for people with dementia [96].

The 2019/20 literature review highlights that with respect to staff skills and attitudes:
Hospital cultures require wider system review to mitigate against the stigmatisation of patients with dementia and the resulting stresses for staff, patients and carers [33, 79].
Institutional drivers of routines, efficiency and risk reduction were highlighted as barriers to person-centred care [50].

Clarity in staff's responsibility for patient care was an important resource for improving their autonomy and encouraging them to respond in timely, creative ways to meet individual needs [23].

9.7 Training needs

The 2015 SCoR recommendations for this domain were:
All staff, clinical and non-clinical, should have additional training and development in dementia-related care. This should challenge dysfunctional cultural norms and include the emotional, social, intellectual and practical aspects of care. Specialist training for the role of dementia champion should be sought. People with dementia and their carers should be involved in training and development opportunities for staff. Development opportunities should be as interactive as possible to encourage reflective practice and use a variety of learning and teaching strategies, including observation, case studies and group discussions. Dementia-related education should be available at pre-registration and post-registration (continuing professional development) levels and continually revisited. The following list of topics is considered essential but is not exhaustive: responding to behaviour that challenges person-centred care; reminiscence and life stories; the legal framework of consent capacity and consent – Mental Capacity Act; deprivation of liberty safeguards (DoLS); best interests safeguarding of vulnerable adults; human rights, dignity and autonomy; well-being; types of restraint (physical, chemical, mechanical, technological and psychological); pain assessment and recognising pain; theories and case studies of dementia care models of ethical decision making; models of reflection and interrogating the self.

The 2019/20 literature review provides the following evidence:

A literature review of carers' perspectives identified a need for improvement in staff training [65]. A series of case studies involving ward staff also demonstrated that not all staff had the knowledge, attitude and skills needed to deliver good care [55]. A literature review highlighted the deficits in education and support for nurses caring for people with dementia in hospital [79]. Lack of training/geriatric knowledge has also

been described as an obstacle for patients in radiography [81]. Similarly, it has been stated that in the future, therapeutic radiographers are likely to see more patients with dementia but may not have had the education and training to provide effective holistic care [66]. Among junior diagnostic radiographers, a lack of quantity and tailored context-relevant education affected professional confidence and ethical practice [43]. One study summarised that while existing evidence of a dementia knowledge and skills gap within the acute care workforce was acknowledged, and could be used to inform the content of educational programmes, an objective was to identify effective approaches to implementing staff training within an acute hospital context [80].

A number of studies have investigated strategies to provide training and education in clinical settings [46, 55, 56, 80]. Challenges associated with training and improving person-centred care include securing staff time to carry out the work and to release staff from clinical areas to attend training [46, 55, 56, 80]. Organisational barriers to care are summarised with training and staff shortages as key issues [46, 48], and lack of time [41, 46, 55]. A review of literature related to dementia training found that most studies were aimed at nursing professions, rather than allied health professionals, including diagnostic and therapeutic radiographers [66]. Another study reports that several porters and domestic staff noted that they would have valued more information about dementia, suggesting the need to improve the dementia-related knowledge and skills of all staff within a department and especially those new to the service[36]. Accordingly, a number of papers make a point of stating that 'non-clinical' or unregistered staff must also receive specific training [36, 43, 57].

A study of junior radiographer participants noted that they lacked confidence in their knowledge around dementia and used a generic rather than person-centred application of the term; recognising only early and late stages of dementia, not different forms [43].

A literature review examined published evidence on the most effective approaches to dementia training and education for hospital staff [35]. Key features of training that appeared to be more acceptable and effective were related to training content, delivery methods, practicalities, duration and support for implementation [35], with training tailored to local contexts [35, 59]. Factors most likely to lead to positive outcomes were: 1) delivery via face-to-face group teaching by a skilled facilitator; 2) tailoring training to learners' roles; 3) using direct involvement, through video or written vignettes, to present the voice of people with dementia and carers; 4) training duration of at least a day, with individual sessions of at least an hour; 5) providing ongoing support via in-service experts or champions. The authors concluded that one-off training is likely to be ineffective [35]. Ongoing training, development and evaluation has been advocated [55].

Authors of one study asserted that while it is essential for all staff to have an up-to-date working knowledge of dementia, this should also include an understanding of the lived emotional experience of the person [48]. A number of papers consider the emotional aspects of caring for a person with dementia and consider that burnout and emotional exhaustion among staff are a result of common methods that professionals take to protect themselves [38, 48, 62]:

> "Knowing the theory behind dementia is only the tip of the iceberg when it comes to enabling a person to feel confident in working effectively with a person who has dementia." [48]

There is a need both to challenge poor practice and for positive development work with healthcare professionals who work in acute hospitals with people with dementia and cognitive impairment, so that they are equipped with the skills, emotional resilience and organisational support to be effective in meeting the needs of people with dementia and cognitive impairment [38]. Staff participants in a further study were aware of the effect of their lack of knowledge and skills on people with dementia and their own work, expressing enthusiasm for training if it was practical, realistic and relevant [46]. Gaps in knowledge about the aetiology of disease processes and managing behaviour were noted in a study where the authors aimed for staff to address attitudes and therefore develop emotional competence, empathy and a non-judgemental approach [22]. Nursing staff in a UK study thought that training increased their awareness of the needs of people with dementia and gave them better understanding of the emotions and behaviour of people, and as a result the staff felt that they had increased tolerance, understanding and confidence [22].

Qualitative analysis of that UK study suggested that delivering skills-based training could develop communication, problem solving and self-directed learning skills, benefitting staff in terms of increased knowledge, skills and confidence [22]. Changes due to training were not reflected in the quantitative results though, and the authors said that measures were not always sensitive to changes in clinical settings [46]. A study that evaluated a 'train the trainer' approach also demonstrated improved staff–patient interactions post training but found little change in hospital environments [91].

A study employing a meta-synthesis concluded that a lack of consistency in training and specialist dementia roles restricted recommendations from a robust evidence base [64]. One study urged that we must not view individual specialist nurses as solely responsible for providing good and person-centred care in hospitals [60]. Training and education is only one element of developing a dementia workforce in an acute setting; a broad system-wide approach is required to enable staff to continue to embed good clinical practice against other commitments and demands [64]. Successful programmes should be targeted at four levels: 1) individual, 2) group/team, 3) organisation, and 4) system or environment [91].

It was posited by the authors of one study that there was no evidence of a standardised education programme for healthcare professionals in dementia care [66]. The authors did not recognise a publication for students and learners at pre-registration level, Dementia UK's curriculum for dementia education [97], nor the role of dementia training frameworks for Wales [13], Scotland [12], Northern Ireland [14] or England [11]. Some stakeholders' comments also reflected an overall view of lack of consistency. Resources should now be employed to provide a consistent approach for UK health and care staff. Leadership and managerial endorsement of the importance of person-centred dementia care is essential to support such an approach [23, 68], with one study suggesting that training for dementia should be targeted at managerial level [14].

Alongside any dementia training, capacity for consent training and regular updates are also required to enable radiographers to meet the mandatory requirements of the Mental Capacity Act 2005 [66]. The SCoR offers clinical guidance in its publications [29, 85]. However, a small-scale study of junior radiographers questioned participants' abilities to actively assess informed consent, stating that there was a need for future research in the area [43].

A review of dementia care literature concludes that, alongside understanding behaviour as communication to improve staff's ability to respond, other factors that contribute to a culture of care for people with dementia include: the role of experiential learning and creating empathy to encourage reflection for responsibilities of care; clinical experts who legitimise priorities for care; staff with confidence to adapt working practices and routines to individualise care; staff with responsibility to focus on psychosocial needs; and building staff confidence to provide person-centred risk management [23]. Staff should be enabled to adapt working practices and routines to individualise care.

Recommendations from one study were that training should: be relevant to the staff's role; consider placement opportunities for staff; include the direct voice and experiences of people living with dementia and their family carers; have a facilitator who is able to role model good practice; not utilise independent study via e-learning; not include materials that are hard to understand e.g. legislation; not rely on individuals to schedule their own training; involve group learning in a classroom setting; be of at least one day duration and delivered in not less than an hour; and consider the development and support of in-service experts [35].

The need for investment in clinical leaders and dementia specialists who can assist improvements and support change has been emphasised, with a need to equip staff with the strategies and confidence to change practice[62].
Alongside the training of individuals, a more systematic approach to developing practice must consider the context and culture of acute hospital care for people with dementia [62]. Outcomes varied across healthcare organisations according to the focus of local actions and measures used [62].

The 2019/20 literature review highlights that with respect to training needs:
Challenges associated with training and improving person-centred care include securing staff time to carry out the work and to release staff from clinical areas to attend training [46, 55, 56, 80].
There is a need to improve the dementia-related knowledge and skills of all staff within a department, including those new to the service [36].
Training factors most likely to lead to positive outcomes were: 1) delivery via face-to-face group teaching by a skilled facilitator; 2) tailoring training to learners' roles; 3) using direct involvement, through video or written vignettes, to present the voice of people with dementia and carers; 4) training duration of

at least a day, with individual sessions of at least an hour; and 5) providing ongoing support via in-service experts or champions [35].
Ongoing training, development and evaluation has been advocated [55].
Successful programmes should be targeted at four levels: 1) individual, 2) group/team, 3) organisation, and 4) system or environment [91].

10 2020 amendments to recommendations

The literature reviewed in this guidance, together with the themes identified by the core review group and comments from stakeholders, provided evidence that the 2015 recommendations remained valid. In the years since 2015 there had been positive developments in the care and services available for people with dementia. This was not least due to the action of people with dementia and carers themselves. For that reason, the core review group agreed that minor adjustments should be made to the wording of the 2015 recommendations to reflect that development, as follows:

'Building relationships with patients and carers to optimise the patient experience' has been changed in this document to read 'Building relationships with patients and carers to optimise the patient and carer experience'.

'Understanding patient's behaviour and adopting positive ways to reduce distressed reactions' has been changed in this document to read 'Understanding patient's behaviour and adopting positive ways to reduce distressed reactions to unmet needs'.

'Carer involvement' has been changed in this document to read 'Carer partnerships'.

11 Implementation strategies

The SCoR will disseminate the guideline through its networks to include senior managers, higher education institutes and SCoR advisory groups. The guidance will be available online and dissemination will also be targeted toward members via online workspaces and professional officer presentations at regional and national conferences and study days.

The core and stakeholder group members developed the following resources in order to support implementation of the guidance:

- A practice guideline summary of 2020 themes in word and infographic format (***Appendices 6 and 7***)
- A toolbox for practitioners (***Appendix 8***)
- A presentation for use at conferences and events in PowerPoint format (***Appendix 9***)

- Updates to an e-Learning for Healthcare (e-LfH) module. *Image interpretation – introduction to dementia* was updated to reflect and signpost to the SCoR guidance.
  The session can be downloaded via the e-LfH portal.

12 Impact measures and audit tools

Departments will be encouraged to use environmental assessment tools to survey departments. This must be in partnerships with service users, carers and local dementia champions. See, for example, the King's Fund assessment tools for developing supportive design for people with dementia in various care settings (including hospitals) as part of the Enhancing the Healing Environment programme.

Departments are also advised to undertake patient and carer experience audits in conjunction with local dementia support groups. Departments should share the findings of their evaluations and any resultant plans with patients, public and practitioners, by a range of means, in order to spread good practice, improvement and innovation.

13 Organisational or financial barriers to implementation

The majority of the recommendations have no financial implications in terms of immediate need for physical resources. There is a requirement for additional training and the need for some additional resources may be ascertained post environmental assessment. The main blocks to implementation are likely to be organisational and cultural since the guidance requires changes to established working practices, for example, from disease-orientated to person-centred care. However, many departments are working through the changes needed to embed person-centred care more fully into daily practice, and this guideline's recommendations should be integral to this process.

14 Recommendations for future research

To date, relatively few research studies have been performed in relation to people with dementia and their carers in diagnostic and therapeutic radiography settings. It is not clear if specific models of care are enacted in those clinical practice settings, or if models could or should be modified for different modalities; for example, interventional radiology, computed tomography (CT), magnetic resonance imaging (MRI), ultrasound, nuclear medicine, radiotherapy, breast screening etc. A stakeholder response to this SCoR review did note that the effects of noise from MRI scanning for people with dementia may be reduced with the next generation of MRI scanners, which are anticipated to be faster and quieter, therefore MRI examinations may be easier for people to tolerate in the future.

A person with dementia may also have other long-term health conditions. Researchers should collaborate to explore the intersections of diseases and conditions where there

is overlap. The intersections of cancer and dementia and also cardiovascular disease and dementia are areas where collaborations have been demonstrated to date.

The following recommendations for future research are drawn from the existing literature on care for people with dementia in clinical imaging and radiotherapy departments:

- There is a need for more research investigating the impact of witnessing dementia symptoms and distress on the emotional well-being of staff, people with dementia, their carers and supporters.
- The WHO global action plan [2] calls for an emphasis on research, data collection and monitoring to provide a further evidence base for clinical practice and service planning.
- There is an apparent need to investigate how ancillary staff (non-clinical) can improve the hospital stay of patients with dementia [36].
- Future research should investigate and evaluate interventions to manage panic and anxiety for patients undergoing radiotherapy procedures and living with dementia [49].
- To fully measure dementia care training in radiotherapy, a primary study should be conducted [66].
- The authors of one study said that their findings called for wider adoption of person-centred care models of enhanced care for people with dementia in the acute hospital setting [72].
- A small-scale study of junior radiographers questioned participants' ability to actively assess informed consent, stating that there was a need for future research in the area [43].
- The authors of a systematic review suggest that attention should be paid in radiography to: patient-centred care (acknowledging the patient's personhood and involving carers in examinations); the environment and physiological factors affecting patients with Alzheimer's disease (e.g. reduce noise, play calming music and personalise the examination room); and obstacles for patients (educate radiographers to increase geriatric knowledge). They conclude that the effectiveness of these strategies warrants further research to validate the proposed strategies and develop and refine educational tools [81].

15 Date of publication, review and updating

The evidence available to inform this guidance must be reviewed at five-year intervals post 2020. That statement is made with an intention to revise the evidence if there is a need for updates. A timeline of five years should ensure that the evidence on which the guidance is based is still valid. An unplanned review may be required in the case of any significant policy changes, newly published evidence, or the emergence of new technologies and interventions. Identifying the need for an unscheduled review is within the roles and responsibilities of the SCoR professional and educational team, under the direction of the SCoR Director for Professional Policy.

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Appendix 1

Copy of 2015
guideline document

docLibrary
Professional & Trade Union Titles

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)

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Summary

This clinical practice guideline is a comprehensive set of evidence-based recommendations for the whole radiographic workforce caring for people with dementia and their carers when undergoing imaging and/or radiotherapy. It has been developed systematically using the best available evidence from research and expert opinion, including service users, and subjected to peer professional, lay and external review. The guideline has recommendations for good practice for individual members of the radiographic workforce, service managers, academic institutions and the Society and College of Radiographers (SCoR).

1. Introduction

1.1 How was the topic identified?

The topic was debated at the Annual Delegate Conference (ADC) of the Society of Radiographers in May 2013; ADC motions 10 and 17. During the debate, delegates made clear their desire for advice and guidance for the radiographic workforce about providing better care for people with dementia who attend for imaging or radiotherapy.

1.2 Why is it important?

This topic is important both because of the prevalence of dementia, and the role of imaging and radiotherapy in the diagnosis and treatment of illness in so many people. It is vital that radiographers and other members of the radiographic workforce are able to understand and support the needs of people with dementia and their carers. Not only is this because all patients are entitled to the best possible, personalised care but, vitally, understanding and meeting the care needs of people with dementia will ensure the best outcomes from imaging and radiotherapy.

The incidence of dementia is increasing, particularly in the over 65s where the total population prevalence is 7.1%[1], and it is this group that is most likely to attend imaging and radiotherapy services. Diagnostic imaging is integral to most clinical diagnoses and is also increasingly being used in minimally-invasive therapeutic interventions. The total number of imaging examinations or tests carried out in England in 2012/13 was 41.1 million and over the past 10 years there has been a 39% increase, with the biggest growth being in MRI[2].

With regard to radiotherapy, in 2011 the number of new cases of cancer in the United Kingdom (UK) was 265,000 and four in ten people will receive a diagnosis of cancer at the present time. Access rates to radiotherapy nationally have been calculated at 38%, but it is estimated that, overall, 50% of people with cancer would benefit from a course of radiotherapy[3].

1.3 How does it fit with existing radiographic practice?

The Society and College of Radiographers (SCoR) gives professional leadership to the radiographic workforce and offers advice and guidance that promotes patient-centred care and the highest quality services. The SCoR document library contains all of its policies, advice and guidance[4]. Of particular relevance is the Code of Professional Conduct 2013, Patient Advocacy 2008, Consent to Imaging and Radiotherapy Treatment Examinations 2007, Consent and Adults with Impaired Capacity 2010 and the Joint Response of the Society and College of Radiographers to the Final Report of the Independent Inquiry into care provided by Mid-Staffordshire NHS Foundation Trust, section 3, 2013.

1.4 The policy context

Government policies over the past 15 years have been directed towards improving the quality of health and social care services through a twin-track approach of implementing systems of clinical governance to ensure consistent high standards, and developing personalisation of care through a person-centred approach[5,6,7]. Person-centred care entails putting patients at the centre of all care and treatment through collaborative working and fostering their active participation in decision-making. In the context of caring for people with dementia, the concept particularly emphasises the importance of not losing sight of the person and avoiding dehumanising actions and behaviours.

This challenging agenda is being taken forward in the area of dementia care and treatment through a number of recent policies and actions. A National Dementia Strategy for England, published in 2009, set new standards for care[8]. A quarter of hospital beds are occupied by people with dementia and every hospital has been asked to commit to becoming dementia-friendly. Funding for hospital dementia risk assessments has been linked to the quality of care and all care homes and community services have been requested to sign up to the Dementia Care and Support Compact.

In Scotland, the Scottish Government Health Department (SGHD), in a national framework 'Reshaping Care for Older People'[9], signalled its intention to fund initiatives that move care from institutions to home and the community. A key focus of the framework is the provision of care at home for people with dementia and greater support for carers. This has been elaborated within the Scotland's National Dementia Strategy[10] and associated dementia care improvement programme.

Similar initiatives are occurring in Wales and Northern Ireland with the publication of strategy documents[11,12] by the devolved administrations leading to programmes of action for service improvements for people with dementia and their carers.

In March 2012, the Prime Minister launched the Dementia Challenge. This set out plans to improve care in three aspects; increasing rates of diagnosis, improving the skills and awareness needed to support people with dementia and their carers and improving research. Progress is being overseen by three groups of champions each focussing on one of three main areas for action; driving improvements in health and care, creating dementia-friendly communities and improving dementia research.

A progress report in May 2013[13] sets out the groups' shared ambition to 'make a real and positive difference to the lives of people affected by dementia'. It goes on 'We want to ensure that people with dementia and their carers receive high quality, compassionate care whether they are at home, in hospital or in a care home. We want the person with dementia, and their family and carer, to be at the heart of everything we do. We also want their wellbeing and quality of life to be first and foremost in the minds of those commissioning and providing services for them'.

Dementia is a world-wide issue and, in December 2013, the UK government hosted a G8 Dementia

Summit with the aim of developing co-ordinated global action. Ahead of this, The Alzheimer's Society and others offered their support for tackling dementia on a global scale, pointing out that there is no cure and few treatments and asking for it to be made a priority. As a result, the profile of dementia in the publics' mind has increased significantly, the need for collaboration in delivering compassionate care has been prioritised and the government has announced that funding for research into finding treatments for dementia has doubled.

2. Scope and Purpose

Developing the guideline was prioritised and initiated by the SCoR Director of Professional Policy (DPP) in the autumn of 2013. Its broad purpose was to produce a practice guideline that both defines and supports the implementation of best practice when caring for people with dementia and their carers.

The proposed project was shared with members of the SCoR Public and Patient Liaison Group (PPLG) at the November 2013 meeting. It received their approval and two lay members of the PPLG agreed to take part in the development of the guideline as members of the stakeholder group.

The resulting practice guideline is for the whole radiographic workforce including students and learners. This encompasses clinical and non-clinical, registered and other practitioners, service managers, educationists and researchers. The population covered in the guideline is people with dementia-related conditions of varying severity and their carers. The setting for the guideline is imaging and radiotherapy departments in the United Kingdom.

3. Guideline objective and questions

The primary objective of the guideline was to produce evidence-based recommendations for best practice in radiographic services (imaging and radiotherapy) when caring for people with dementia and their carers. This objective encompassed a series of related questions to be answered about;

- the workforce's need for understanding dementia and its manifestations,
- optimising staff behaviours towards people with dementia,
- strategies for optimising the technical outcomes of interventions and improving patients' experience,
- suitability of the practice environment.

4. Guideline development process

4.1 The core group

The core group was brought together in November 2013 by the SCoR professional officer for policy, guidance and advice, under the direction of the DPP. The core group leader appointed is an independent education consultant and experienced academic radiographer and senior manager. Other members of the core group were a diagnostic radiographer who is a clinical-academic researcher with expertise in dementia, and the professional officer (policy guidance and advice).

4.2 The stakeholder group

The stakeholder group comprised 20 members; 7 clinical radiographers, 6 academic radiographers, 5 student radiographers and 2 service users. They were drawn from both imaging and radiotherapy communities across the UK. The service users were from the SCoR Public and Patient Liaison Group (PPLG) and other group members either volunteered or came forward as a result of an appeal in Synergy News, which is the SCoR monthly magazine. The names of both core and stake holder group members are listed at the end of the document.

4.3 Peer review and consultation process and outcomes

A first draft of the recommendations was circulated to the stakeholder group for comment on 5th March 2014. Sixteen of the original 20 stakeholders responded and their comments were reviewed at core group meetings on 24th March and 2nd April 2014. In addition to the individual responses from lay members of the stakeholder group, two members of the core group attended the PPLG on 24th March to update them on progress to date and seek further feedback and support.

The comments were overwhelmingly positive with no dissent. Some stakeholders suggested additions because they did not appreciate that the recommendations should arise from the evidence. There was one negative response; the individual concerned questioned the need for a guideline that spelt out in detail how radiographers should care for patients. She interpreted it as an attack on their professionalism. The core group discussed this at their meeting on 24th March. They took the view that the author had misinterpreted the purpose of the recommendations and the core group leader responded appropriately.

The revised recommendations were merged with the draft practice guideline and this document received two separate expert external appraisals during May 2014. It was sent to The Alzheimer's Society for scrutiny and comment, which was also positive. After this, both the practice guideline and draft process manual were reviewed by an independent editorial consultant at a meeting with the DPP and core group. Following this, further improvements were made to both documents.

The finalised practice guideline was sent to three external reviewers, none of whom had had anything to do with its development. The reviewers completed a profoma (Process Manual Appendix H) and signed the conflict of interest declaration. The responses were considered by the core group and the final guideline document produced for UK Council approval.

4.4 Funding arrangements

The core group leader is an external contractor; an independent education consultant from a consultancy services company. She was paid as per contract. The clinical academic researcher was paid specifically to undertake the literature review but gave the remaining time to the core group voluntarily. Stakeholder group members and external reviewers gave their time and expertise voluntarily.

4.5 Conflict of interest

The SCoR policy and procedures for managing conflicts of interest was adhered to (Process Manual Appendix G). Members of the stakeholder group and external reviewers have signed 'conflict of interest' declarations and a list of their names and affiliations is appended. No conflicts of interest were declared. The declarations are available for public scrutiny.

4.6 SCoR approval process

The finalised practice guideline received approval from the UK Council of the SCoR in November 2014.

5. Guideline methodology

5.1 Literature Search

The literature search strategy was developed with the support of an NHS librarian using the following question ‘What evidence is there to assist radiographers and others to give the best care to people with dementia and their carers when attending for imaging or radiotherapy?’

The topic did not conform to the PICO (Patient/Population, Intervention, Comparison, Outcome) framework as there was neither a specific intervention nor a specific comparison. Therefore it was decided to adapt this framework (Table 1 below) and keywords were listed under the domains of patient population, outcome and setting/professional group. An initial search identified a paucity of literature focussed on the imaging or radiotherapy setting in terms of this topic, and therefore the search was broadened to include all settings involving acute hospital services.

Table 1

Domain:	**Patient Population**	**Outcome**	**Setting / professional group**
Keywords	Dementia	Patient care	Radiographer
	Alzheimer's disease	Professional-patient relations	Radiotherapist
		Person centred care	Hospital
		Dignity	Acute hospital
		Communication	Allied health professional
		Quality of care	Nursing staff
			Ward

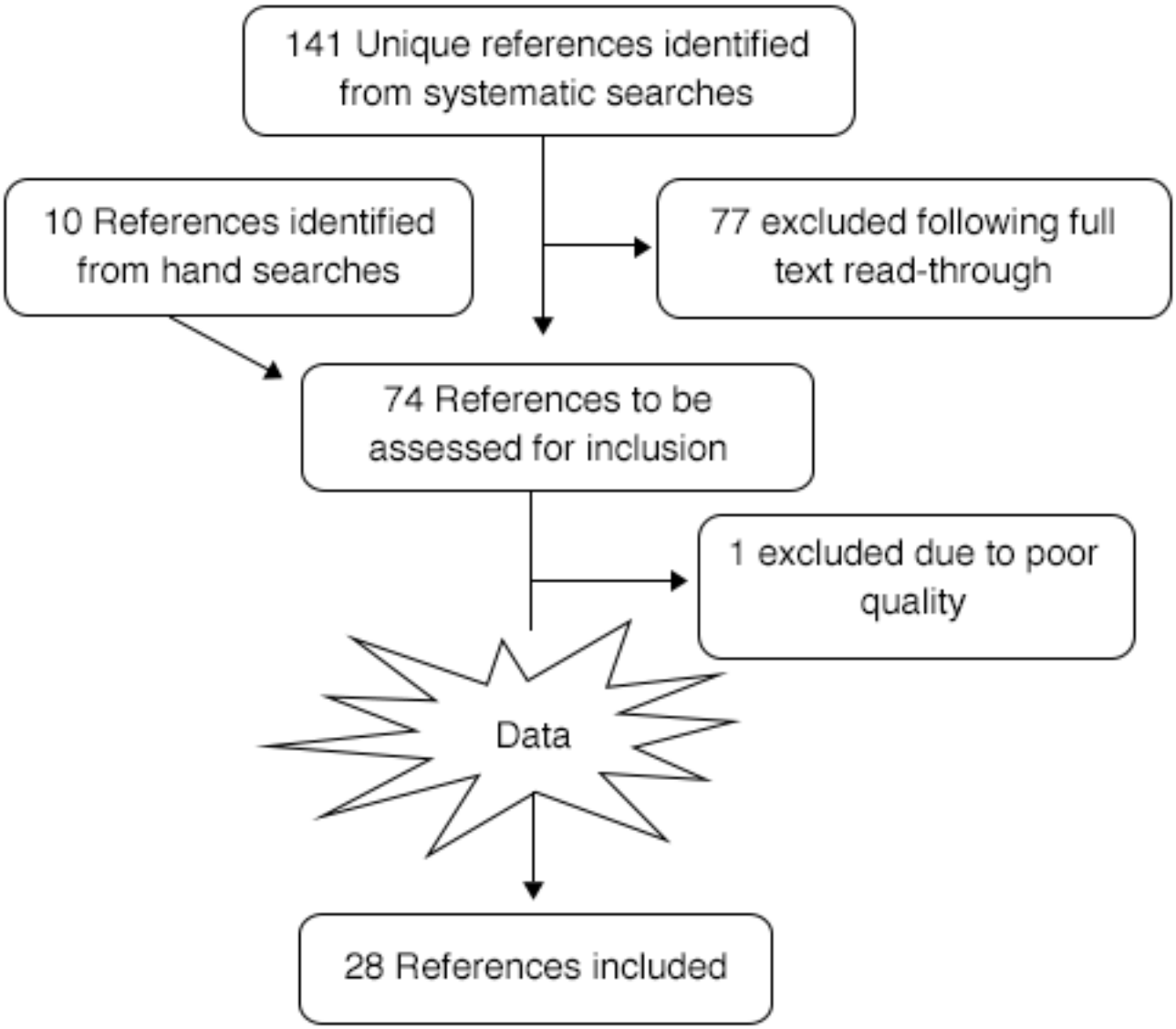
Further restrictions included English language, published between 1997 and 2013, humans, adults. The time period to search was decided based on the seminal work published by Kitwood[14] , which marked an attitudinal shift in dementia care. However, due to the volume of references identified this was further limited to a ten year period: 2003-2013. Searches were conducted using NHS Evidence and the following databases were searched independently: AMED, MEDLINE, CINAHL and Embase.

The search terms for each domain were used to identify MeSH headings, these differed between each database, and where no MeSH heading was available, free text was used. The explode function and truncation was used where it was deemed appropriate. The searches for each domain were combined using the Boolean operator ‘OR’ and to combine the different domains the Boolean operator ‘AND’ was used.

Inclusion was determined by reading the title and abstract to determine if a reference met the inclusion criteria, which was any article where the focus was on care of people with dementia in an acute care setting. Articles were excluded if their focus was on other care settings (e.g. community care, or long term care), if the main focus of the article was on diagnosis or design features rather than on patient care, and if the main focus of the article was on end-of-life care.

References were prioritised for reading by date of publication with the most recent receiving higher priority, and also by likely relevance to the radiography setting determined from the abstract. Data saturation was assessed by two members of the core group and once this was reached it was agreed that further inclusion was not necessary.

Fig 1 Outcome of literature search



5.2 Literature review

All articles were published in peer review journals, although the standard of the journals did vary from those that published primarily informal discussion articles, to those that mainly published primary research.

Of the included articles, 1 was a systematic review, 13 reported primary research findings, 12 were discussion papers and 2 reported case studies. Of the primary research articles 10 were qualitative studies, and 3 were quantitative, which reflects the nature of this specific topic which lends itself to qualitative enquiry. The research methods are outlined in table 2 below.

Table 2

Method	Number of articles
Survey	2
Pre-test/post-test	1
Focus groups	3
Observations/ethnography	3

Interviews	4

Of those studies that recruited participants these included hospital staff/nursing students (8 studies), family carers of people with dementia (2 studies) and people with dementia (3 studies). The majority of the included studies were single site, or used multiple hospital sites within a single Trust. The majority of the research was conducted in the UK, with a single study emanating from each of the following countries: Australia, USA, Republic of Ireland and Canada. In terms of the discussion articles and case studies, the majority of those included focus on the UK healthcare system, with 1 focussing on care in the USA.

The quality of the discussion papers varied with some giving a clear justification for the inclusion of references and providing a comprehensive reference list, whilst others appeared to be less formal providing little detail about where references were found and limited bibliographies. However, as all of the discussion articles appeared to corroborate each other in terms of the general ideas on patient care that were being presented it was decided to include all of the discussion articles. Indeed, due to the nature of the topic and the importance of clinical experiences and the practical application of patient care techniques it was felt that these articles, along with the case study articles, could provide valuable supporting information for this guidance document as they often drew upon the authors clinical experiences and had a practical focus.

5.3 Description of how recommendations were developed

The core group leader and clinical-academic researcher met to consider the evidence and develop the recommendations for the practice guideline. Each article had been summarised using the data extraction tool (Appendix D in the Process Manual). These were reviewed and a judgement made about their quality and value. This enabled a list of raw recommendations to be compiled together with the associated evidence source.

The core group leader undertook a thematic analysis of the raw recommendations, selecting themes according to the initial guideline questions in 3 above and allocating recommendations to these, removing any duplication whilst retaining the source reference details. During this process it became apparent that some themes required further expansion; for example, optimising staff behaviours needed to be disaggregated into specific sections about training needs and relationship building. This draft was circulated to remaining core group members for further comment and refinement prior to undertaking the consultation process outlined in 4.3 above.

The application of GRADE for each individual recommendation within this practice guideline was considered by core group. However, due to the limitations of GRADE, which cannot be applied where a topic area has no clear outcome measures or obvious comparison approaches[15], it was rejected. It is acknowledged by the authors that the body of evidence in this area is not strong, comprising mostly of expert opinion in the form of discussion papers and small single centre observational studies.

5.4 Limitations of the guideline including consideration of possible bias

In terms of the strength of the recommendations contained within this guideline, no contradictory evidence was identified with a strong level of agreement between all sources. The sources from which each recommendation was drawn are highlighted throughout the document. One limitation of the evidence that informed these guidelines is that none of it focussed specifically on the radiography setting. However, the guideline development core group universally agreed that the similarities with other settings in the acute hospital are sufficient to allow for the application of this evidence within radiography.

6. Dementia facts

At the current estimated rate of prevalence, there will be 850,000 people with dementia in the UK in 2015[14]. One in three people over 65 will develop dementia, and two-thirds are women. This figure is increasing because people are surviving historic killers such as heart disease and cancer and living longer. It is estimated that, by 2021, the number of people with dementia in the UK will have increased to around 1 million and doubled by 2040[15,16].

Dementia is a syndrome associated with an ongoing decline of the brain and its abilities. Alzheimer's disease is the commonest cause but there are others, such as vascular dementia[17]. Symptoms include problems with memory, thinking speed, mental agility, language, understanding and judgement. People with dementia can become apathetic or uninterested in their usual activities, and may have problems expressing and managing their emotions, especially in relation to an inability to fully process or communicate what they are thinking or what they want.

Individuals with these conditions may also find social situations challenging, lose interest in socialising, and aspects of their personality may change. A person with dementia may lose empathy or believe things that are untrue. As dementia affects a person's mental abilities, they may also find decision making, planning and organising difficult. Maintaining independence may also become a problem[18].

People with dementia are not a homogenous group, not all the symptoms manifest in each person or in the same way. The severity of symptoms may vary and progress over time. In addition there are a range of other factors that can influence how an individual experiences dementia; including their personality, biography, physical health, environment, and social and cultural factors[19].

Scientists understand less about dementia than they do about heart disease or cancer and there is no cure at the present time, although, if it is detected early, there are ways of slowing down the deterioration and maintaining mental function. The challenge for healthcare workers and others is to support people living with dementia and their carers to manage symptoms and live as well as possible. Each person should be treated as an individual by radiography staff, whilst at the same time contextualising their experience within a broad understanding of the symptoms of dementia and how these may present difficulties within the radiography environment.

7. Guideline Recommendations

The recommendations are divided into specific sections related to the guideline objective and related questions in 3 above.

1. The practice environment –acknowledging the need for special provision

1.1 The environment in the department should be adjusted by removing excess stimuli and ensuring that it is calm and well organized when patients with dementia arrive for imaging or treatment (Heath et al 2010, McGilton et al 2007, Moyle et al 2008).

1.2 The organisational culture of departments should be flexible and enabling, value good practice and support person-centred care (Baillee 2012b, Cunningham & Archibald 2006, Webster 2011).

1.3 Departments should seek feedback from patients and carers about their experiences and act accordingly.

1.4 Departments should liaise with people with dementia and/or their carers about appointment times to mitigate factors that might increase stress and try to avoid compromising their normal routines (Andrews 2012, McCloskey 2004, McGilton et al 2007, Moyle et al 2008, Mowbray 2010).

1.5 Departments should consider utilising forms of therapy that may provide reassurance such as

music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment (Clisset 2013, McCloskey 2004).

1.6 Departments should investigate the use of identifiers such as forget me not, blue wrist bands or butterflies for in-patients (and outpatients where it allows) (Andrews 2012, Duffin 2013).

1.7 More time should be allowed to perform procedures since this can reduce the need for restraint (Borbasi et al 2006, Mowbray 2010).

1.8 Departments should create the role of dementia champion supported by appropriate training (Borbasi et al 2006, Chater 2013, Crabtree 2010).

1.9 Departments should consider using appropriately trained volunteers as advocates for people with dementia (Borbasi et al 2006, Galvin 2010).

1.10 Departments should offer support for staff (professional supervision) in recognition of the emotional burden associated with providing dementia-related care (Andrews 2012, Baillee 2012b, Bridges 2011).

1.11 The organisation’s management information system (MIS) should support all staff to be fully informed of the patient’s diagnosis (Armstrong 2011).

2. Building relationships with patients and carers to optimise the patient experience (Baillee2012, McGilton et al 2007, Nolan 2006)

2.1 Acknowledge that people with dementia have both physical and psychological needs (Clissett 2013).

2.2 Provide a patient information pack that has been designed specifically for people with dementia and their carers *in advance* and involve lay people in writing it (Chater 2013, Mowbray 2010).

2.3 Encourage patients to bring music, a ‘This is Me’ document or other kind of reassuring material when attending the department (Baillee 2012, Heath et al 2010).

2.4 Ensure that the patients are accompanied by a familiar person, such as a nurse or informal carer (Chater 2013).

2.5 Work collaboratively with patients and their carers, maintaining the dignity and autonomy of the person at all times (Bridges 2011, Nolan 2006, Webster 2011).

2.6 Work collaboratively with other professionals in the patient’s pathway, sharing experiences, encouraging dialogue and disseminating best practice; learning from each other to share knowledge of the patient (Bridges 2011, Chater 2013).

3. Strategies for optimising communication with people with dementia and their carers

3.1 Liaise with caregivers and/or people with dementia about appointment times (Andrews 2012, McCloskey 2004, McGilton et al 2007, Moyle et al 2008, Mowbray 2010.).

3.2 Keep the number of professional practitioners in the room to a minimum with one person taking the lead.

3.3 Observe and value both verbal and non-verbal communication and always assume that some communication is possible (Cowdell 2010, Nolan 2006).

3.4 Treat patients as equal partners in communication even when communication is limited (Nolan 2006).

3.5 Approach patients calmly, gently and in a relaxed manner.

3.6 Find out and use the patient's preferred name (Bridges 2011).

3.7 Ensure you have the patient's attention before giving important information.

3.8 Speak directly to the patient even if they are unable to respond, and keep eye contact.

3.9 Speak plainly and avoid complicated idioms of speech (Heath et al 2010).

3.10 Use short, simple sentences and a soft tone.

3.11 Ask simple questions that require a short answer, e.g. yes/no.

3.12 Allow ample response time before repeating information.

3.13 Repeat sentences using the same words.

3.14 Ensure that interactions are not ended abruptly (Clissett 2013).

3.15 Remain calm if patient becomes agitated.

3.16 Avoid moving or walking around during conversation.

3.17 Model the desired behaviour.

4. Understanding patients' behaviour and adopting positive ways to reduce distressed reactions

4.1 Be aware that patients' behaviour is a form of communication and recognise that withdrawal or passivity is a form of distressed reaction (Norman 2006).

4.2 Patients may exhibit distressed behaviours due to pain, fatigue, hunger or other discomfort; try to identify the cause of distressed reactions and avoid compromising normal routine activities (Clissett 2013, Galvin 2010, McGilton et al 2007).

4.3 Accept that people with dementia may have their own sense of reality and that challenging this may cause distress.

4.4 Utilise forms of therapy that may provide reassurance such as music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment (Clissett 2013, McCloskey 2004).

4.5 The use of restraint should be the last resort; it can present risks to the patient (and others) and should not be used just because not enough staff are available (Chater 2013, Gallagher 2011, Galvin 2010).

4.6 Identify safe ways to facilitate walking; this can reduce agitation and assist patient safety. Walking in a circular route can decrease agitation (Andrews 2012, Galvin 2010).

4.7 Use diversion or distraction techniques to create a suitably stimulating environment and gain cooperation (Clissett 2013, King 2012). These could include;

Repetitive and familiar tasks e.g. sorting buttons (King 2012),

Use of reminiscence,

Use of all senses: touch – sensory box, textures, tactile stimulation, hearing - personalised music, calming music, sight - visual way-finding cues and lighting (Clissett 2013, King 2012),

Ask a family member to talk soothingly throughout the procedure (intercom),

5. Carer involvement

5.1 Family members and informal caregivers should be involved in care and considered assets (Andrews 2012, Baillie 2012, Borbasi et al 2006, Clissett 2013b, Heath et al 2010, Jurgens 2012), McGilton et al 2007, Moyle et al 2008, Nolan 2006, Webster 2011) .

5.2 Carers should be viewed as a source of expertise (Clissett 2013b).

5.3 Staff should work collaboratively with patients and carers (Bridges 2011, Webster 2011).

5.4 Staff should acknowledge that carers may also need information and reassurance and should avoid adopting a defensive or confrontational approach to them (Nolan 2006, Jurgens 2012).

6. Staff skills and attitudes

People with dementia and their carers coming to the imaging or radiotherapy department may have additional needs that may challenge staff skills and attitudes.

6.1 Consider that the lives of people with dementia are meaningful, do not assign blame to the patient (Nolan 2006).

6.2 Challenge ‘us and them’ attitudes (Cowdell 2010).

6.3 Be non-judgemental and show unconditional positive regard for patients and their carers (McCloskey 2004).

6.4 Do not lose sight of the person and avoid dehumanising behaviours (Cunningham & Archibald 2006, McCloskey 2004).

6.5 Appreciate that you can learn from people with dementia (Cowdell 2010)

6.6 Recognise and act on patient cues regarding unmet needs and distressed reactions (Dewing 2010, Heath et al 2010, McCloskey 2004)).

6.7 Use initial introduction and identity check to assess the patient’s level of understanding.

6.8 Request consent and do not assume it in cases where express written consent is not required (Bridges 2011).

6.9 Modify information provided to the patient to include only that which is commensurate with informed consent and directly related to the activity and ensuring safety (McCloskey 2004).

6.10 View family members and/or informal caregivers as assets and involve them in care (Andrews 2012, Baillie 2012, Borbasi et al 2006, Clissett 2013b, Heath et al 2010, Jurgens 2012), McGilton et al 2007, Moyle et al 2008, Nolan 2006, Webster 2011).

6.11 Have an attitude of warmth and firmness (Heath et al 2010).

6.12 Employ flexible approaches and be creative (Baillie 2012).

6.13 Be a reflective practitioner, interrogating your own behaviours and attitudes towards people with dementia.

6.14 Engage in team-based reflection (Chater 2013).

7. Training needs

7.1 All staff, clinical and non-clinical, should have additional training and development in dementia-related care (Baillie 2012b, Dewing 2010). This should challenge dysfunctional cultural norms and include the emotional, social, intellectual and practical aspects of care.

7.2 Specialist training for the role of dementia champion should be sought.

7.3 People with dementia and their carers should be involved in training and development opportunities for staff.

7.4 Development opportunities should be as interactive as possible to encourage reflective practice and use a variety of learning and teaching strategies including observation, case studies and group discussions (Cowdell 2010, Norman 2006).

7.5 Dementia-related education should be available at pre-registration and post-registration (CPD) levels and continually revisited (Baillie 2012b, Dewing 2010).

7.6 The following list of topics is considered essential but is not exhaustive (Gandesha 2012, Leung 2010)

- responding to behaviour that challenges
- person-centred care (Crabtree 2010)
- reminiscence and life stories
- the legal framework of consent
- capacity and consent – Mental Capacity Act (Mowbray 2010)
- deprivation of liberty (DoLS)
- best interests
- safeguarding vulnerable adults
- human rights, dignity, autonomy, wellbeing
- types of restraint; physical, chemical, mechanical, technological, psychological (Gallagher 2011)
- pain assessment and recognising pain (Galvin 2010, Gandesha 2012)
- theories and case studies of dementia care
- models of ethical decision making (Gallagher 2011)
- models of reflection and interrogating the self (Heath et al 2010, Moyle et al 2008)

The following theoretical frameworks and models were identified in the literature reviews as useful ways for practitioners and others to understand and interpret the evidence.

- Kitwood's (1997) enhancers and detractors.
- PLST Conceptual Model for people with Alzheimer's disease.
- Hall and Buckwater's (1987) Model for understanding stress thresholds and their reduction.
- Antecedents, Behaviour, Consequences (ABC) Tool for understanding behaviour - a reflective tool for practitioners to understand the effect of the environment on behaviour.
- Nolan, M. et al's (2006) The Senses Framework: Improving Care for Older People through a Relationship-Centred Approach. GRIP: University of Sheffield.
- Li et al's (2003) CARE - Creating Avenues for Relative Empowerment. A programme for improving self- efficacy for care givers.

8. Implementation

8.1 implementation and dissemination

The SCoR will disseminate the guideline through its networks. These include regular meetings of managers and conference and study days.

In addition, the core group has developed the following resources;

A summary document outlining the rationale and key recommendations,

Implementation guidance for managers, including resource implications and potential barriers to implementation.

e learning module, Dementia, developed by a core group member, is available on the eLearning for health website, free of charge to all NHS organisations www.e-lfh.org.uk

8.2 Impact measures and audit tools

All employing authorities are required to have governance arrangements in place that include locally developed audit tools for patient experience. It is expected that these will be adapted to measure the impact of the practice guideline recommendations on patients' and carers' experience. An audit check list can be found in the supplementary, supporting information. This is in addition to the national patient experience survey that all NHS organisations take part in.

8.3 Organisational or financial barriers to implementation

The majority of the recommendations have no financial implications. There is a requirement for additional training and some additional resources, which will require budgeting for. These could include changes to ICT systems.

The main block to implementation is likely to be organisational and cultural since some recommendations require changes to established working practices. However, many departments are working through the changes needed to embed person-centred care more fully into daily practice and this guideline's recommendations should be integral to this process.

9. Recommendations for future research

The authors have acknowledged the relatively low quality of the evidence base for the guideline and this provides many opportunities for redress. In particular, the lack of any published evidence from the radiographic setting needs to be addressed.

10. Date of publication, review and updating

January 2015

Three-yearly review unless an earlier review is indicated. This may be required because of changes in policy or published evidence that indicates a need for the practice guideline to be updated. Policy changes are monitored and reviewed by the SCoR team of professional staff. The core and stakeholder groups comprised people with a special interest in dementia, including staff in imaging and radiotherapy departments who are dementia champions. They will be surveyed annually to ask if they are aware of changes to the evidence base that may trigger an early review and update of the practice guideline.

11. References

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12. Appendices

Appendix 1 Dementia Guideline Evidence References

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Appendix 2 Names and affiliations of guideline core and stakeholder groups

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Anna Dowrick Policy adviser, The Alzheimer's Society

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13. Supplementary Supporting Information

Audit checklist

Data extraction template references

External reviewers' feedback

Implementation guidance and advice for managers

Minutes of PPLG meetings November 2013, May 2014

Summary document

Caring for People with Dementia guideline - Audit Checklist

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) January 2015

Introduction

The clinical practice guideline, caring for people with dementia and their carers when attending for imaging or radiotherapy has been approved by United Kingdom Council of the Society and College of Radiographers (SCoR). It can be found within their policy and document library [1].

All employing authorities are required to have governance arrangements in place that include locally developed audit tools for patient experience. This check list has been provided to assist imaging and radiotherapy departments to adapt their audits to measure the impact of the practice guideline recommendations on patients' and carers' experience. **The check list is not exhaustive nor is it intended to be a replacement for local audit measures. It contains suggestions for inclusion of some of the measurable aspects of the guideline recommendation.**

Checklist Themes

The guideline contains recommendations under 7 themes, which you may find useful when developing and adapting audit tools:

1. The practice environment –acknowledging the need for special provision;
2. Building relationships with patients and carers to optimise the patient experience;
3. Strategies for optimising communication with people with dementia and their carers;

4. Understanding patients' behaviour and adopting positive ways to reduce distressed reactions;
5. Carer involvement;
6. Staff skills and attitudes;
7. Training needs.

Specific measures

- Type and extent of any therapies used; e.g. music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment
- System of identifiers in place, such as 'forget me not', blue wrist bands or butterflies
- Dementia champion role identified and/or established
- Numbers of volunteers
- System of professional supervision
- Patient information pack designed specifically for people with dementia and their carer
- Information provided to the patient to gain informed consent has been modified to include only that which is directly related to the activity and ensuring safety
- Numbers of staff, clinical and non-clinical who have received additional training and development in dementia-related care
- People with dementia and their carers are involved in training and development opportunities for staff

References

1. Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)**.** The Society and College of Radiographers (SCoR), January 2015 http://www.sor.org/learning/document-library
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Caring for People with Dementia guideline - Implementation Guidance

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) January 2015

Implementation Guidance for Service Managers

1. Purpose

1.1 This guidance has been written to assist service managers with the implementation of the recommendations contained within the clinical practice guideline; caring for people with dementia and their carers when attending for imaging or radiotherapy. The full guideline has been approved by United Kingdom Council of the Society and College of Radiographers (SCoR) and is available within their policy and document library 1.

1.2 The recommendations represent best practice for the whole radiographic workforce caring for people with dementia and their carers at the time of publication. They have been developed systematically using the best available evidence from research and expert opinion, including service users, and subjected to peer professional, lay and external review.

1.3 The SCoR acknowledges that radiographers and other health workers are accountable for the quality of their practice and some of the recommendations relate specifically to individuals and their personal, professional development. However, the context and culture of the organisation within which radiographers work directly influences their capacity to practice well. Therefore some recommendations in the practice guideline concern the organisation's culture, systems and processes, both at department level and within the whole organisation.

1.4 This document is intended to be helpful and supportive to managers in the role of middle leaders in large organisations with many competing priorities. It is acknowledged that implementation will take time and be the subject of negotiation and compromise. Nevertheless, the recommendations represent best practice and should become embedded over time.

2. Creating a Dementia Action Plan

2.1 This document should be developed to guide the implementation of the practice guideline. This has seven themes and it is recommended that managers structure the action plan according to these. The creation of the action plan will enable managers to identify the resources; human, financial and other, that will be needed and include them in business plans.

2.2 Theme 1, The Practice Environment

Patients with dementia have particular needs that are likely to mean that more time is needed for interventions and the clinical environment requires some adjustments. This includes ensuring that the systems and processes in departments are fit for purpose. In addition, the culture in the department should be one that encourages and inspires staff to practise in respectful, compassionate, patient-centred ways. The appointment of a Dementia Champion is highly

recommended. This person can advocate for patients with dementia, assist with developing the action plan, lead any changes needed and cascade good practice.

2.3 Theme 2, Building Relationships with Patients and Carers

This group of recommendations deepens the building of relationships with patients and their carers beyond what is normally anticipated in imaging and radiotherapy. People with dementia need additional preparation prior to attending and patient reinforcement and reassurance during their visit. Greater collaboration with formal and informal caregivers is also needed to ensure that care is personalised and interventions and examinations more likely to be successful. The dementia action plan should identify how these will be met and prioritise any additional resources required.

2.4 Theme 3, Strategies for Optimising Communication

Good communication is a fundamental aspect of good care and the recommendations in this section do not go beyond what should be good practice for all patients attending for imaging and radiotherapy. The dementia action plan should detail how communication strategies for people for dementia will be appropriately customised.

2.5 Theme 4, Understanding Patients' Behaviour; adopting positive ways to reduce distressed reactions

People with dementia may become distressed about attending for imaging or radiotherapy. Their condition may cause them to exhibit atypical distressed reactions. Staff need appropriate training to understand these and develop a range of strategies for mitigating them. Liaising with carers is the best way of finding out how an individual patient exhibits distress and can be helped to cope with it. On rare occasions, restraint may be necessary but this must always be a last resort. The dementia action plan should identify types of restraint and situations where it may safely be used.

2.6 Theme 5, Carer Involvement

Carers are often the best resource that the department has for enabling successful imaging or radiotherapy. Staff must work in partnership with carers and see them an important resource. The dementia action plan should reflect this and any associated training needs

2.7 Theme 6, Staff Skills and Attitudes

Imaging and treating people with dementia can challenge staff professionalism and this must be acknowledged in the dementia action plan together with identified staff development.

2.8 Theme 7, Training Needs

This section identifies the additional training and development needs for dementia-related care. The dementia action plan should contain a section that demonstrates what training will be offered, to whom and over what period of time.

3. Organisational and Financial Implications

3.1 Implementing these measures will cause time spent with patients to increase, although carers and volunteers can play a big part if used appropriately. Managers will need to review this within their overall department business plans. If changes to systems and processes are identified, this could result in the need for alterations to ICT systems.

3.2 The appointment of a dementia champion will incur training costs but that person will be an invaluable resource for departments, especially through cascading training and development.

3.3 Some additional resources such as preparing an induction pack or reviewing a system of patient identifiers could be a CPD task for an interested member of staff.

3.4 All staff are required to undertake CPD for their professional development and the training and development identified in the dementia action plan can form part of staff CPD activities.

3.5 The main block to implementation is likely to be organisational and cultural since some recommendations require changes to established working practices. However, many departments are working through the changes needed to embed person-centred care more fully into daily practice and this guideline's recommendations should be integral to this process.

3.6 Guideline implementation will need regular auditing; an audit checklist has been included in the practice guideline to assist with this.

4. References

1. Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)**.** The Society and College of Radiographers (SCoR), January 2015 http://www.sor.org/learning/document-library

Caring for People with Dementia guideline - Summary

Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy) January 2015

1. Introduction

1.1 This document summarises the outcomes of the clinical practice guideline for caring for people with dementia and their carers when attending for imaging or radiotherapy. The full guideline has

been approved by United Kingdom Council of the Society and College of Radiographers (SCoR) and is available within their policy and document library [1].

1.2 The recommendations represent best practice for the whole radiographic workforce caring for people with dementia and their carers at the time of publication. They have been developed systematically using the best available evidence from research and expert opinion, including service users, and subjected to peer professional, lay and external review.

1.3 This topic is important both because of the prevalence of dementia, and the role of imaging and radiotherapy in the diagnosis and treatment of illness in so many people. The incidence of dementia is increasing, particularly in the over 65s where the total population prevalence is 7.1%[2], and it is this group that is most likely to attend imaging and radiotherapy services. It is therefore vital that radiographers and other members of the radiographic workforce are able to understand and support the needs of people with dementia and their carers in order to deliver the best possible, personalised care and ensure the best outcomes from imaging and radiotherapy.

2. Guideline Purpose

2.1 The purpose of developing the guideline was to produce evidence-based recommendations for best practice in radiographic services (imaging and radiotherapy) when caring for people with dementia and their carers.

2.2 The resulting document contains recommendations under 7 themes; some of which are simple to implement while others are more challenging. The themes are:

1. The practice environment –acknowledging the need for special provision;
2. Building relationships with patients and carers to optimise the patient experience;
3. Strategies for optimising communication with people with dementia and their carers;
4. Understanding patients' behaviour and adopting positive ways to reduce distressed reactions;
5. Carer involvement;
6. Staff skills and attitudes;
7. Training needs.

3. Specific Recommendations

1. The practice environment –acknowledging the need for special provision

1.1 The environment in the department should be adjusted by removing excess stimuli and ensuring that it is calm and well organized when patients with dementia arrive for imaging or treatment.

1.2 The organisational culture of departments should be flexible and enabling, value good practice and support person-centred care.

1.3 Departments should seek feedback from patients and carers about their experiences and act accordingly.

1.4 Departments should liaise with people with dementia and/or their carers about appointment times to mitigate factors that might increase stress and try to avoid compromising their normal routines.

1.5 Departments should consider utilising forms of therapy that may provide reassurance such as music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment.

1.6 Departments should investigate the use of identifiers such as forget me not, blue wrist bands or butterflies for in-patients (and outpatients where it allows).

1.7 More time should be allowed to perform procedures since this can reduce the need for restraint.

1.8 Departments should create the role of dementia champion supported by appropriate training.

1.9 Departments should consider using appropriately trained volunteers as advocates for people with dementia.

1.10 Departments should offer support for staff (professional supervision) in recognition of the emotional burden associated with providing dementia-related care.

1.11 The organisation's management information system (MIS) should support all staff to be fully informed of the patient's diagnosis.

2. Building relationships with patients and carers to optimise the patient experience

2.1 Acknowledge that people with dementia have both physical and psychological needs.

2.2 Provide a patient information pack that has been designed specifically for people with dementia and their carers *in advance* and involve lay people in writing it.

2.3 Encourage patients to bring music, a 'This is Me'[3] document or other kind of reassuring material when attending the department.

2.4 Ensure that the patients are accompanied by a familiar person, such as a nurse or informal carer.

2.5 Work collaboratively with patients and their carers, maintaining the dignity and autonomy of the person at all times.

2.6 Work collaboratively with other professionals in the patient's pathway, sharing experiences, encouraging dialogue and disseminating best practice; learning from each other to share knowledge of the patient.

3. Strategies for optimising communication with people with dementia and their carers

3.1 Liaise with caregivers and/or people with dementia about appointment times.

3.2 Keep the number of professional practitioners in the room to a minimum with one person taking the lead.

3.3 Observe and value both verbal and non-verbal communication and always assume that some communication is possible.

3.4 Treat patients as equal partners in communication even when communication is limited.

3.5 Approach patients calmly, gently and in a relaxed manner.

3.6 Find out and use the patient's preferred name.

3.7 Ensure you have the patient's attention before giving important information.

3.8 Speak directly to the patient even if they are unable to respond, and keep eye contact.

3.9 Speak plainly and avoid complicated idioms of speech.

3.10 Use short, simple sentences and a soft tone.

3.11 Ask simple questions that require a short answer, e.g. yes/no.

3.12 Allow ample response time before repeating information.

3.13 Repeat sentences using the same words.

3.14 Ensure that interactions are not ended abruptly.

3.15 Remain calm if patient becomes agitated.

3.16 Avoid moving or walking around during conversation.

3.17 Model the desired behaviour.

4. Understanding patients' behaviour and adopting positive ways to reduce distressed reactions

4.1 Be aware that patients' behaviour is a form of communication and recognise that withdrawal or passivity is a form of distressed reaction.

4.2 Patients may exhibit distressed behaviours due to pain, fatigue, hunger or other discomfort; try to identify the cause of distressed reactions and avoid compromising normal routine activities.

4.3 Accept that people with dementia may have their own sense of reality and that challenging this may cause distress.

4.4 Utilise forms of therapy that may provide reassurance such as music, which may be brought in by the patient, or reminiscence; inviting patients and carers to bring items such as photographs to be discussed prior to examination or treatment.

4.5 The use of restraint should be the last resort; it can present risks to the patient (and others) and should not be used just because not enough staff are available.

4.6 Identify safe ways to facilitate walking; this can reduce agitation and assist patient safety. Walking in a circular route can decrease agitation.

4.7 Use diversion or distraction techniques to create a suitably stimulating environment and gain cooperation. These could include; repetitive and familiar tasks e.g. sorting buttons, use of reminiscence, use of all senses: touch – sensory box, textures, tactile stimulation, hearing - personalised music, calming music, sight - visual way-finding cues and lighting and asking a family member to talk soothingly throughout the procedure (intercom).

5. Carer involvement

5.1 Family members and informal caregivers should be involved in care and considered assets.

5.2 Carers should be viewed as a source of expertise.

5.3 Staff should work collaboratively with patients and carers.

5.4 Staff should acknowledge that carers may also need information and reassurance and should avoid adopting a defensive or confrontational approach to them.

6. Staff skills and attitudes

People with dementia and their carers coming to the imaging or radiotherapy department may have additional needs that may challenge staff skills and attitudes.

6.1 Consider that the lives of people with dementia are meaningful, do not assign blame to the patient.

6.2 Challenge ‘us and them’ attitudes.

6.3 Be non-judgemental and show unconditional positive regard for patients and their carers.

6.4 Do not lose sight of the person and avoid dehumanising behaviours.

6.5 Appreciate that you can learn from people with dementia.

6.6 Recognise and act on patient cues regarding unmet needs and distressed reactions.

6.7 Use initial introduction and identity check to assess the patient’s level of understanding.

6.8 Request consent and do not assume it in cases where express written consent is not required.

6.9 Modify information provided to the patient to include only that which is commensurate with informed consent and directly related to the activity and ensuring safety.

6.10 View family members and/or informal caregivers as assets and involve them in care.

6.11 Have an attitude of warmth and firmness.

6.12 Employ flexible approaches and be creative.

6.13 Be a reflective practitioner, interrogating your own behaviours and attitudes towards people with dementia.

6.14 Engage in team-based reflection.

7. Training needs

7.1 All staff, clinical and non-clinical, should have additional training and development in dementia-related care. This should challenge dysfunctional cultural norms and include the emotional, social, intellectual and practical aspects of care.

7.2 Specialist training for the role of dementia champion should be sought.

7.3 People with dementia and their carers should be involved in training and development opportunities for staff.

7.4 Development opportunities should be as interactive as possible to encourage reflective practice and use a variety of learning and teaching strategies including observation, case studies and group discussions.

7.5 Dementia-related education should be available at pre-registration and post-registration (CPD) levels and continually revisited.

7.6 The following list of topics is considered essential but is not exhaustive:

- responding to behaviour that challenges
- person-centred care
- reminiscence and life stories
- the legal framework of consent
- capacity and consent – Mental Capacity Act
- deprivation of liberty (DoLS)
- best interests
- safeguarding vulnerable adults
- human rights, dignity, autonomy, wellbeing
- types of restraint; physical, chemical, mechanical, technological, psychological
- pain assessment and recognising pain
- theories and case studies of dementia care
- models of ethical decision making
- models of reflection and interrogating the self

4. Conclusion

4.1 The majority of the recommendations have no financial implications but they do require staff to be fully engaged with the needs of this particular group of patients and for the organisation to acknowledge that changes to systems and processes may be needed, both at department and organisation levels.

4.2 There is a requirement for additional training and some additional resources, which will have to be budgeted for. It is recommended that departments identify a dementia champion to lead the implementation. All of these changes will take time and need auditing; an audit checklist has been included in the practice guideline to assist with this.

5. References

1. Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)**.** The Society and College of Radiographers (SCoR), January 2015 http://www.sor.org/learning/document-library
2. Dementia UK: second edition. The Alzheimer's Society
3. This is me document. RCN and The Alzheimer's Society http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1604 [accessed 24.11.14]

Source URL: https://www.sor.org/learning/document-library/caring-people-dementia-clinical-practice-guideline-radiography-workforce-imaging-and-radiotherapy

Appendix 2

Core and stakeholder group members

Appendix Two

Review members

The people who contributed to this review felt passionate about improving care for people with dementia and motivated to act, commonly because of their own experiences of dementia. A large number of individual members had stories of lovely people with a range of dementias and experiences. Throughout the stories there was a golden thread of remembering the wonderful people that each person remained to be despite their diagnosis and ultimate progression of dementia.

Core group review:

Lisa Field, Member of SCoR Consultant Radiographer Advisory Group and Consultant Radiographer, Mid Yorkshire Hospital Trust.

Sylvia George, Full time carer for a person with dementia.

Emily Lewis, Diagnostic Radiographer, Mid Yorkshire Hospital Trust.

Dr Tracy O'Regan, professional officer clinical imaging & research, Society and College of Radiographers, former family carer for a person with dementia.

Heather Drury-Smith, MSc Supportive, Palliative and End of Life Care Course Leader, Sheffield Hallam University.

Individual Stakeholder group members:

Mark Harrison, Radiographer RA34405, former family carer for a person with dementia.

Elaine Casey, Assistant Practitioner in Radiology, East Kent Hospitals University NHS Foundation Trust.

Darren Hudson, Magnetic Resonance Imaging Clinical Lead, InHealth, former family member for person with dementia.

Laura Lees, Macmillan Specialist Review Radiographer, Worcestershire Acute Hospitals NHS Trust.

Dilek Ocal, Study coordinator and PhD student, Dementia Research Centre, UCL Queen Square Institute of Neurology.

Thomas Veale, PhD student, Dementia Research Centre, UCL Queen Square Institute of Neurology.

Sarah Bradder, Third year student Therapeutic Radiographer/ Therapeutic Radiographer, former family member for a person with dementia.

Professor Claire Surr, Director of the Centre for Dementia Research, Leeds Beckett University.

Dr Rachael Kelly, Research Fellow in the School of Health and Community Studies, Leeds Beckett University.

Dr Alys Griffiths, Research Fellow in Dementia Studies, Leeds Beckett University.

Dr Laura Ashley, Reader in Health Psychology, Leeds Beckett University.

Claire Duckett, Superintendent Radiographer Education & Professional Development, University Hospitals of Derby and Burton.

Pamela Mitchell, CT/MRI Superintendent Radiographer, University Hospital Ayr.

Dr Alison Tonkin, Head of HE, Stanmore College.

Georgina Charlton, Deputy Freedom to Speak Up Guardian, Guy's and St Thomas' NHS Foundation Trust.

Lara Burgess, Therapeutic Radiographer, East Suffolk and North Essex NHS Foundation Trust.

Emma Warrender, Therapeutic Radiographer, Weston Park Hospital, Sheffield Teaching Hospitals NHS Trust.

Paula Powell, Treatment Lead Radiographer, Northwest Cancer Centre, Altnagelvin Hospital, Londonderry.

Lindsay McMullan, Information and Support Radiographer, Radiotherapy Department, Cancer Centre, Belfast City Hospital.

Organisations who accepted invitation to review draft guideline:

Hospice UK, www.hospiceuk.org

Carers Trust, https://carers.org/

Rare dementia support, https://www.raredementiasupport.org/

Dementia Carers, https://dementiacarers.org.uk/

Contented Dementia Trust, http://www.contenteddementiatrust.org/

Dementia UK, www.dementiuk.org

Royal College of Psychiatrists, https://www.rcpsych.ac.uk/

Alzheimers Scotland, https://www.alzscot.org/

Dementia Carers Count, https://dementiacarers.org.uk/

Peer reviewers final document:

Dr Robert Higgins, Lecturer in Radiography, University of Salford.

Dr Jane Harvey-Lloyd, Associate Professor, School of Health and Sports Sciences, University of Suffolk.

Jodie Bloska, Music Therapist, Clinical Research Fellow & Research Assistant for Homeside (UK), Cambridge Institute for Music Therapy Research.

Appendix 3

Pro forma SCoR stakeholder comments

The Society & College of Radiographers (SCoR)

Template for Stakeholder Consultation Comments

Caring for people with dementia in clinical imaging and radiotherapy: a clinical practice guideline

Please detail below if you are commenting as an individual or on behalf of an organisation	
Stakeholder Organisation:	
Name of commentator:	

Order number	Section Number	Page Number	**Comments** **Please insert each new comment in a new row.**
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Please add extra rows as needed

Please email this form to: *(insert lead officer's name...)*

Closing date: *(insert date...)*

PLEASE NOTE: The Society & College of Radiographers reserves the right to summarise and edit comments received during consultations. SCoR may not publish all comments received, however, you can be reassured that every response will be recorded and will inform guideline development.

Appendix 4

Pro forma SCoR reviewer comments

Appendix 4: External Review Proforma

Thank you for agreeing to be a reviewer for the practice guideline: Care for people with dementia in clinical imaging and radiotherapy. The external review process is not anonymous and your comments will be sent to the development group for their consideration prior to final publication. With your permission, your name as an external peer reviewer will also be included in the final document.

You are required to disclose any conflict of interest that could potentially influence or affect your contribution as an external reviewer. A declaration form is attached.

Please appraise critically the content and presentation, taking into account the following:

Is the purpose of the guideline explained clearly?
Is the language user-friendly?
Is the terminology inclusive and sensitive to gender/race/culture?

Is the development process transparent and robust?
Is there evidence of bias?
Do the recommendations arise explicitly from the evidence? What is your overall opinion of the guideline?

Please do not comment on spelling or grammar; this will be addressed during the proof reading stage.

Guideline Title: Caring for people with dementia in clinical imaging and radiotherapy: a clinical practice guideline.

Date for receipt of comments:

Name:	
Organisation:	
Role:	
e mail:	
Telephone:	
Document section / page numbers:	Comments:

Signature:	
Date:	

Please submit your completed proforma and conflict of interest declaration to:

Appendix 5

Data extraction tables and article summaries

Appendix 5: Data extraction tables and article summaries

Reference:	Allwood, R., Pilnick, A., O'Brien, R., Goldberg, S., Harwood, R. and Beeke, S. 2017. Should I stay or should I go? How healthcare professionals close encounters with people with dementia in the acute hospital setting.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Social Science and Medicine. 191: 212–25.	Part of a wider National Institute for Health Research (NIHR) funded study, the overall aim of this research was to develop and test a communication training intervention for staff caring for people with dementia in acute hospitals.	The authors aimed to video record 40 encounters; it was estimated that would give around six hours of recorded interactions. Conversation analysis was used to examine 41 video recordings of healthcare professional/person with dementia interactions collected	Healthcare professionals were recruited from older person wards at a large teaching hospital in the English East Midlands. A total of 41 professionals, including doctors, nurses, mental health nurses, and allied health professionals (physiotherapists,	There were three phenomena around which, according to the authors, there were recurring troubles in the dataset: 'open-ended pre-closings'; 'mixed messages'; and 'non-specifics and	Authors concluded that moves towards closing an encounter that may represent best practice in other healthcare settings, could in fact serve to confuse a	The authors state that further work was needed to establish the "particular contingencies that can arise in health care professionals' interactions with people with dementia, and to enable professionals to

	The authors focused on the way in which 'healthcare encounters' are ended or closed – a specific area of interaction that had previously received very little attention. There was potentially a conflict between a pressure to manage a patient as efficiently as possible and ensuring person-centred care while dealing with communication difficulties arising from dementia.	from an acute inpatient ward. The average length of a recording was 9.24 minutes. Given the limited verbal capacity of some patients, the authors considered that it was important also to consider non-verbal and paralinguistic features; these were noted alongside the transcriptions. Data was analysed by the authors in monthly group data sessions.	speech and language therapists, and occupational therapists) took part; 26 of them were also video recorded for the study. Twenty-seven patients were recruited to the study, of whom 26 were filmed. In total, 41 encounters were recorded.	indeterminate terms'. Moves towards closing an encounter that appear intuitive to professionals may in fact serve to confuse a person with dementia and create difficulties with closings.	person with dementia and create difficulties with closings. They also emphasised the importance of context in the analysis of healthcare delivery, to avoid a 'one size fits all' approach.	successfully navigate the recurring tensions between person-centredness and workflow". The study was based in an inpatient setting. Further work is needed to establish if the findings are transferable to clinical imaging and radiotherapy.
Recommendations:	Recommendations about how to end conversations can be transferred to the radiography context; for example, specifically ask each person if they have any questions or concerns, give adequate time, and reassure that person that you have the time to answer.					

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Strategies for optimising communication with people with dementia and their carers, the practice environment – acknowledging the need for special provision. Toolbox for practitioners: Give people time and reassurance, encourage and be specific when asking people questions.

Article summary:

The authors make the point that "a detailed examination of closings in healthcare interaction has the potential to contribute to the wider field of professional/client communication". The background provides a fascinating overview of the ending of conversations, with learning that can be transferred to the radiography context; for example, asking if the patient has any questions or concerns and reassuring them that you have time to answer. The authors hypothesised that the decline in linguistic ability associated with dementia may result in a failure to understand or pick up on typical closing cues. The authors contrast the closing of healthcare interactions in ward settings with primary care; the radiographic context is comparable with situations in primary care.

Commonly a pre-closing question is of an 'open-ended' nature, one that asks if the patient has further concerns. Questions from practitioners tilt expectations towards patients raising (or not raising) additional concerns at the end of encounters. In the specific context of dementia care, the fact that there are no clues or boundaries embedded within the question may be particularly problematic. While open-ended questions may be viewed as good practice in healthcare generally, in the sense that they attempt to give the patient an opportunity to drive the agenda of the encounter and to raise issues of importance to them, the authors found that these positive effects were not apparent in the study setting.

The authors concluded that open-ended questions for the general population orientates to person-centredness. For people with dementia, they found that open-ended questions removed cues for an appropriate answer to be produced. People with dementia could then struggle to formulate an appropriate response. The authors found an essential tension between person-centred practice, which emphasises that a patient should have the opportunity to voice unmet needs or concerns, and the use of non-specific, indeterminate and indexical terms that can cause particular issues for people with dementia.

Reference:	Ashton, C. and Manthorpe, J. 2019. The views of domestic staff and porters when supporting patients with dementia in the acute hospital: An exploratory qualitative study.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Dementia. 18(3): 1128–1145.	This study aimed to: investigate the experiences of domestic staff and porters working in an acute hospital, setting with the rationale that they are in regular contact with patients with dementia; explore domestic staff and porters' knowledge, attitudes and beliefs when supporting patients with dementia in hospital; identify and explore any specific	Grounded theory was employed, with a method of semi-structured interviews, undertaken in 2016, with seven domestic staff and five porters to investigate their views and experiences. Some closed questions enabled comparison between participants. Data was analysed thematically by	Purposive sample of seven domestic staff and five porters in one English acute hospital. The manager of the cleaning and portering teams agreed to distribute study information sheets and consent forms. The aim was to recruit domestic staff and porters who had been in	The impact of witnessing dementia symptoms and distress on emotional well-being of staff and requires further research so that ancillary staff can improve the hospital stay of patients with dementia.	Participants observed that caring attitudes and behaviour in their encounters with patients with dementia are important but challenging to put into practice. Several would have valued more information about dementia. Some noted situations in the hospital stay that seemed particularly	None listed in the article. This was a small-scale study at a single site in England. The purposive sample was enlisted with the aid of a manager, which added an element of bias. A copy of the interview schedule was

	difficulties or barriers they encounter in carrying out their daily work in supporting patients with dementia; explore the possible barriers to communication faced by domestic staff and porters when communicating with patients with dementia and their families; and identify any possible unmet training and education needs of domestic and portering staff.	constant comparison technique and theoretical sampling. Themes were identified and concepts developed. Authors noted that the themes identified in the interviews were comparable but the contribution of personal views and experiences added more individualised data.	post for six months or longer (so they were familiar with their jobs) and who had regular contact with patients with dementia in ward areas, excluding, for example, those who worked in children's services.		difficult for patients with dementia, such as travelling to different parts of the hospital for treatments. The study provided evidence of a need for improving the dementia-related knowledge and skills of all non-clinical staff.	not included in the paper.
Recommendations:	The study suggests the need for improving the dementia-related knowledge and skills of all non-clinical staff, especially those new to the NHS. Training should include all staff in clinical imaging and radiotherapy departments.					

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; staff skills and attitudes; training needs.
Article summary: The authors provided a comprehensive and clear overview of current care policy and practice in the UK. They summarised that matters of concern include deficiencies in person-centred care, poor nutrition and lack of attention to patient dignity and respect. They add that all staff should be dementia aware and receive role-specific training amid a dementia friendly environment. It is an interesting point that, in line with the experiences of registered staff, although cleaners perceived talking to patients to be a positive part of their job, this slowed down their work, and consequently some were not willing to, or would avoid talking to people. This echoes studies involving qualified ward outpatient, and primary care staff.	

Reference:	Ashley, L., Kelley, R., Griffiths, A., Cowdell, F., Henry, A., Inman, H., Hennell, J., Ogden, M., Walsh, M., Jones, L., Mason, E., Collinson, M., Farrin, A. and Surr, C. 2020. Understanding and identifying ways to improve hospital-based cancer care and treatment for people with dementia: an ethnographic study.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Age and Ageing. **Article in proof.**	The study authors aimed to examine the hospital-based cancer care and	A two-site ethnographic study in the north of England.	17 people with dementia and cancer, 22 informal carers and 19 staff	The authors performed a thematic analysis with triangulation of their study data, collected via qualitative methods.	The authors list a number of strategies and a range of interventions	The authors outline the limitations of the study. Recruitment

	treatment challenges and support needs of people with dementia, and also to identify potential ways to address them.	Methods of semi-structured interviews, observations and conversations were employed, also medical record review.	members, including therapeutic radiographers. It was not clear how many staff were radiographers.	The authors perceived that people with dementia and their families felt "in the dark" and oncology staff were often "working blind". Supportive family carers were crucial in enabling people with dementia to access, navigate and undergo cancer care and treatment.	with the potential to improve cancer care for people with dementia and their families.	to the study was from a single area of the UK. The sample of patients was from a specific demographic with limited diversity and just one anatomical area of cancer (lung).
Recommendations:		See summary table in appendix two of the paper, which includes specific strategies to transfer to the therapeutic (and diagnostic) context.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; strategies for optimising communication with people with dementia and their carers. Toolbox for practitioners: Appendix two of the Ashley et al. study lists a range of proactive recommendations.				

Article summary:
The authors considered that people with dementia and their families could feel "in the dark" due to difficulties understanding, retaining and using cancer information that impacted their informed treatment decision-making. The authors posit that dementia increased the complexity and burden of: travelling to, and navigating, unfamiliar hospital environments; frequent lengthy periods of waiting in hospital; and self-managing symptoms and side-effects at home. Oncology staff were often "working blind" due to variable documenting of dementia in medical records, dementia training was limited, and time and resource pressures impeded the highly individualised, flexible cancer care required by people with dementia. Supportive family carers were crucial in enabling people with dementia to access, navigate and undergo cancer treatment and care. The authors recommend that there should be improved identification for people with dementia and documentation, provision of training and tools for staff to support person-centred dementia care, support for people to attend hospital for cancer treatment and care, provision of a supportive physical environment, support for treatment decision making, inclusion and support for families and supporters. Moving beyond the conclusions, the authors proactively provide suggestions for implementation at each of these areas.

Reference:	Beardon, S., Patel, K., Davies, B. and Ward, H. 2018. Informal carers' perspectives on the delivery of acute hospital care for patients with dementia: a systematic review.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

BMC Geriatrics. 18(1): 23.	This review aimed to summarise informal carers' perspectives of acute hospital care to inform best practice service delivery. It identified common perspectives of informal carers of people with dementia in the acute hospital setting and highlighted areas to address to improve the experience of an admission for both carer and patient.	A systematic search of bibliographic databases and relevant grey literature. Thematic synthesis analysis to assimilate results of the studies and describe components of care that influenced perceived quality. Elements of the research question were defined using a SPIDER (Sample, Phenomenon of interest, Design, Evaluation, Research type) search tool for qualitative and	Two reviewers searched the databases MEDLINE, Embase, Health Management Information Consortium, and PsycINFO. Twenty papers met the inclusion criteria. Eligibility criteria were: 1) Sample: informal carers of people who have dementia; 2) Phenomenon of interest: delivery of acute hospital care; 3) Design: studies collecting primary data from carers; 4) Evaluation: experiences and perceptions of care; 5) Research type: qualitative	There were four overarching components of care that influenced carer experience and their perceptions of care quality: patient care, staff interactions, the carer's situation, and the hospital environment.	A need for improvement in staff training was identified, also the provision of help with personal care needs, and dignified treatment of patients. Carers need to be informed, involved and supported during hospital admission in order to promote the most positive experience.	The qualitative data in the primary studies was specific to the study context and therefore may not be transferable to other settings. Eight of the selected papers were published by a single research group and reported results of separate analyses from a single RCT. The authors noted that: "Due to the high quality and level of detail in these papers, their results will have contributed more evidence to this review than other included studies and therefore may have influenced the findings disproportionately."

		mixed methods studies.	(interviews or focus groups) or quantitative (surveys). Studies with no full text available or non-English language were excluded. There were no exclusions by date. The search and study selection were performed according to PRISMA (preferred reporting items for systematic reviews and meta-analyses) guidelines. Quality rating did not affect whether publications were included.			The authors made the point that in order to comprehensively evaluate service delivery in practice, the perspectives of patients and healthcare professionals should also be gathered to complete the triangle of care.
Recommendations:		This study provides an excellent range of points that can inform practical ideas, aiding the development of a radiographer toolkit. In particular, it reinforces the stance that SCoR has taken in supporting John's Campaign for carers to remain with people living with dementia in clinical imaging and radiotherapy departments.				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Carer partnerships; staff skills and attitudes; building relationships with patients and carers to optimise the patient and carer experience; the practice environment – acknowledging the need for special provision. Toolbox for practitioners: VIPS and triangle models of care. Supporting John's Campaign.

Article summary:

Multiple studies in this systematic review reported that carers were concerned that hospital staff did not understand dementia. A frequent complaint was the failure to provide for basic care needs e.g. help a person to get to the toilet or to have a drink. The review authors provided background information in the form of a study that supports the application of a person-centred care model, translated into four key elements known as the VIPS framework. These are (1) **Valuing** people with dementia and those who care for them; (2) treating people as **Individuals**; (3) looking at the world from the **Perspective** of the person with dementia; and (4) a positive **Social** environment, in which the person living with dementia can experience relative well-being. They also refer to a triangle of care model with equal partnership between the person with dementia, healthcare practitioners and informal carers. The review findings repeatedly highlighted carers' concerns when a person with dementia attends an acute hospital. The study provided an overview of positive and negative aspects of care as perceived by carers, arranged under thematic headings. It also provided an excellent range of points that can inform practical ideas that aid the development of a radiographer toolkit of resources. In particular, this study reinforces the stance that SCoR has taken in supporting John's Campaign for carers to remain with people living with dementia at all stages of visits in clinical imaging and radiotherapy departments.

Reference:	Bray, J., Evans, S., Bruce, M., Carter, C., Brooker, D., Milosevic, S., Thompson, R. and Woods, C. 2015. Enabling hospital staff to care for people with dementia.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
Nursing Older People. 27(10): 29–32.	The fourth (final) article in a series that resulted from a Royal College of Nursing (RCN) improvement programme.	The article presents case study examples of positive work achieved by trusts who participated in the RCN's development programme to improve dementia care in acute hospitals.	Basildon and Thurrock University Hospitals NHS Foundation Trust (England) made dementia awareness a priority at induction and also with in-depth training tailored to specific staff needs. Nottingham University Hospitals (NUH) NHS Trust (England) focused on standardising pain assessment, with the use of a 'pain assessment in advanced dementia' (PAINAD) tool. A literature review was undertaken at Nottingham City Hospital to identify	An internal survey of existing practice at Nottingham City Hospital and Queen's Medical Centre found that there was no standard method for assessing pain when caring for patients with dementia, including those with communication difficulties. To address this, the trust's nurse specialist in pain management developed an action plan in September 2013 for standardising pain assessment for patients with dementia. The first part of the plan involved conducting a	Observations at Basildon together with pre- and post-training questionnaires showed that "training had an effect on staff behaviour and opinions". The training supported a shift from a medical to psychosocial approach to care, for example, staff joining patients on a walk around the ward rather than telling them to sit down.	The Basildon training did not include carers or people with dementia on the training team. The PAINAD tool used at Nottingham was not implemented in a clinical imaging or radiotherapy setting.

			appropriate pain assessment tools. The literature search was undertaken by the NUH library service through the Cumulative Index to Nursing and Allied Health Literature (CINAHL) database using the search words pain, assessment and dementia. In addition, key documents were reviewed for recommendations about practice. A shortlist of tools was produced. Each tool was evaluated by a multidisciplinary group using a simple form designed by the nurse specialist in pain management to capture feedback. Overall consensus was that the PAINAD tool was most suitable for	short survey of 85 adult nursing staff to explore what they thought would help them improve their ability to assess pain in patients with dementia, in particular those who have difficulty communicating.		

			piloting in the trust over a two-month period. To support the pilot, an evaluation survey was used to obtain feedback from staff about their use of the PAINAD tool.			
Recommendations:		In line with the SPACE principle that there should be skilled staff who are informed and have the enough time to care.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision. Toolbox for practitioners: Signpost to SPACE principles (Skilled staff who are informed and have enough time to care; Partnership working with carers; Assessment and early identification of dementia; Care plans that are person-centred and individualised; Environments that are dementia-friendly).				
Article summary: In line with the SPACE principle that there should be skilled staff who are informed and have the enough time to care, and echoing other studies, the authors posit that a training programme must include other frontline staff, ambulance crews working in patient transport, healthcare assistants, porters and catering staff to improve knowledge and understanding of dementia. The authors remark that staff on elderly care wards have indicated a need for more in-depth training on 'behaviour that challenges'. This gave the impression that the authors were not overtly discussing or recognising wider unmet needs in addition to pain. In addition to the use of a PAINAD tool, the authors did, however, report the importance of carers to outline and recognise signs that could be used to indicate that their relative may be in pain, and what staff can do to try to ease that pain. The literature review indicated that using a pain scale did not mean that the results were acted on and educational programmes to support their use were necessary to make sure that staff understood the reasons and importance behind them.						

Important factors in the success of the pain project included having clear objectives, negotiating time to undertake the project, and identifying early on who the key people were in terms of assisting with and influencing the work. The main challenge faced by the trust was securing staff time to carry out the work and to release staff from clinical areas to attend training.

Reference:	Bray, J., Evans, S., Bruce, M., Carter, C., Brooker, D., Milosevic, S., Thompson, R., Longden, J. and Robinson, J. 2015. Improving the hospital environment for people with dementia.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Nursing Older People. 27(9): 16, 18–20.	The paper was the third in a series that was part of a wider evaluation, looking at the effect of a Royal College of Nursing (RCN) development programme. Case studies were used to illustrate two different	Two case studies were presented. Members of the evaluation team carried out a site visit at the Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust. They also talked to staff about the programme and what had changed	Two acute hospitals in the UK (England).	The hospital environment was found to be often disorientating for people with dementia and could be particularly distressing when a patient was admitted in an emergency. Subsequent ward moves could also	While the approaches focus on specific elements of the hospital environment, they are supported by the implementation of wider training programmes to improve staff awareness and attitudes towards dementia. The effect helped to increase	The case studies provided a report from the perspective of the programme evaluation team rather than patients, carers or staff. There was no evidence of validation from

	approaches to improving the hospital environment for people with dementia.	in the hospital in terms of dementia care. Basildon and Thurrock University Hospitals NHS Foundation Trust aimed to ensure all staff were made aware of the needs of patients with dementia, and to achieve this it updated and improved its dementia training programme.		be disruptive and confusing, especially if they took place out of hours.	staff's understanding of the hospital experience from the patient's perspective.	staff, patients/service users or carers. It was not clear what the authors' classed as 'out of hours' work in an acute hospital environment.
Recommendations:		Consider the possibility of providing an observed waiting area and of trained volunteers to accompany people with dementia, for example, while families and carers park their cars or when a person is dropped off by ambulance transport. Lobby transport to allow carers to travel on transport services.				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision. Toolkbox for practitioners: Signpost to the five SPACE principles for the care of people with dementia in hospital settings, developed in collaboration with people with dementia and carers. See the King's Fund Enhancing the Healing Environment programme and the University of Stirling's Dementia Services Development Centre (DSDC) Virtual Environments models.

Article summary:

At one trust, the main focus was on improving the physical environment, which reflects the RCN SPACE principle of providing environments that are dementia friendly in Commitment to the care of people with dementia in acute hospital settings.

SPACE principles: **Skilled** staff who are informed and have enough time to care; **Partnership** working with carers; **Assessment** and early identification of dementia; **Care plans** that are person-centred and individualised; **Environments** that are dementia-friendly (Thompson and Heath, 2013). The five SPACE principles for the care of people with dementia in hospital settings were developed in collaboration with people with dementia and carers.

Strategies for making environments more supportive for people with dementia included large clocks on the walls displaying time and date information to help with orientation, clear signage, a secure observation area, contrasting colours on door frames and toilet seats, brighter lighting, reduced noise and purposeful activity. Resources to support environmental design were available via the King's Fund Enhancing the Healing Environment programme and the University of Stirling's Dementia Services Development Centre Virtual Environments models.

In support of changes to the physical environment, additional interventions aimed to improve the social environment by focusing on staff training and awareness. It was stated that people with dementia wore a red wrist band that was deemed to be "less stigmatising" than a "marker in plain sight" but the views of people with dementia and carers sometimes contradict that claim. The second hospital trust concentrated on minimising ward moves for people with dementia; moving patients with dementia was recognised as a serious issue by the staff. If a patient on the list was moved then it was raised as a clinical incident. When patients were being escorted between areas of the hospital, security and portering staff were educated to appreciate the importance of good communication and

engaging with patients in a positive way. Training was essential to ensure that non-clinical staff understood and appreciated the importance of approaches to care and felt more empowered to challenge practice that contradicted the SPACE principles.

Reference:	Brooke J. and Ojo, O. 2018. Elements of a sustainable, competent, and empathetic workforce to support patients with dementia during an acute hospital stay: A comprehensive literature review.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
The International Journal of Health Planning and Management. 33 (1): e10–25.	The aim of this literature review was to understand the elements of a sustainable, competent, and empathetic acute hospital	A thematic analysis was applied to develop a meta-synthesis of the data. Due to the different methodological approaches of the studies, a meta-synthesis	Databases were searched for literature published in English from 1 January 2006 to 1 August 2016: CINAHL, MEDLINE, PsycINFO, PubMed and ScienceDirect.	The analysis of outcomes found that dementia awareness training was sustainable, although there was a lack of consistency in the length, content and delivery, which had an impact on the	Themes were: understanding the current workforce; implementation and evaluation of training; and exploration of new and existing roles.	At the discussion section the authors include a subsection 'understanding the current workforce' but unfortunately they only seem to consider doctors and nurses, not

	workforce providing person-centred care for patients with dementia.	rather than a meta-analysis was completed.	12 papers with a range of methodological approaches from various countries were included. Articles published prior to 1 January 2006 were excluded. The authors justify that decision by stating that a global focus on improving care for people with dementia in acute hospital settings commenced in 2006. Only articles reporting primary data on developing and sustaining an acute hospital workforce competent in dementia care	provision of empathetic and person-centred care. The lack of consistency of training and specialist dementia roles restricted recommendations from a robust evidence base.	According to the authors, an important element was the sustainability of acute hospital workforces competent in dementia care, as studies highlighted an ageing nursing population and a high turnover of staff.	wider allied health professionals, excluding diagnostic and therapeutic radiographers. The authors assumed that dementia champions would be nurses.

			were included in the review. Articles were excluded if they were audits/reports of training programmes with no outcome data on the impact on the knowledge, skills, or practices of healthcare professionals.			
Recommendations:		Despite mandatory inclusion of dementia training in all undergraduate healthcare programmes in the UK, this review highlighted healthcare professionals' lack of preparation to care for and support acutely unwell patients with cognitive impairment. Practitioners must be adequately prepared.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision. Toolbox for practitioners: Link to King's Fund Enhancing the Healing Environment.				
Article summary: An important element for the development of the current acute care workforce is further education and training to enable the provision of person-centred care through skilled communication, while simultaneously developing supportive organisational structures, managers and colleagues. Comparable with a range of other reviews, the authors discuss different types and approaches to						

training. The authors also champion the use of a short training video, Barbara's Story The authors do refer to the Dementia Training Standards Framework (2018)noting that implementation and the full impact of training is as yet unclear. The authors state that: "Dementia education and training did not occur in isolation, as most studies simultaneously implemented other initiatives to improve care for patients with dementia. Most hospitals have addressed the recommendations of Kings Fund Enhancing the Healing Environment with a system-wide multiple initiative approach, such as changes to the physical environment, dementia training, engagement with the local Alzheimer Society, use of twiddle-muffs, and implementation of activities by healthcare assistants and volunteers. Therefore, training and education is only one element of developing a dementia workforce in an acute setting; a broad system-wide approach is required to enable staff to continue to embed good clinical practice against other committing commitments and demands." Thus the authors provided a succinct overview, which encompassed the range of approaches that were evident across the other studies in this literature review. It is interesting to note a word of caution from the authors with regards to dementia champions – further robust evaluation of the roles of specialist nurses in dementia in acute hospital settings is required, as this approach relies on a small number or even one member of staff to act as change agents for a large institution. The authors assume that dementia champions are nurses.

Reference:	Butcher, L. 2018. Caring for patients with dementia in the acute care setting.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

British Journal of Nursing. 27 (7): 358–62.	The article explores the knowledge gap concerning the complexity of caring for a person with dementia, and highlights factors that can lead to staff detaching themselves from engaging in meaningful communication with patients.	A case study report from the author's clinical practice.	A single case study and additional vignettes are included in the paper.	The paper raises awareness of the syndrome of 'cascade iatrogenesis' in relation to patients' physical and cognitive decline. Butcher posits that to intervene, more emphasis needs to be placed on addressing these issues to ensure the safety and welfare of people with dementia in hospitals.	The author contends that it is essential for all staff to have an up-to-date working knowledge of dementia, which should include an understanding of the lived emotional experience of the person.	The paper presents a single case study in retrospect. Observations were subjective and anecdotal to the case study. The locality and service setting were undetermined apart from reference to the setting being 'acute'.
Recommendations:	It is essential for all staff to have an up-to-date working knowledge of dementia, which should include an understanding of the lived emotional experience of the person.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision; strategies for optimising communication with people with dementia and their carers.					
Article summary: The author reports that in 2013 the Care Quality Commission (CQC) in England raised concerns that 29% of people with dementia admitted to hospital did not have their dementia status recorded. The author goes on to make a number of important points that will influence the review of SCoR guidance. For example, Butcher raises awareness of cascade iatrogenesis, which she surmises can result from a seemingly simple error such as misplacing a person with dementia's glasses, and provides a number of practical example areas						

in which hospital procedures and practices are confusing for people living with dementia. Butcher considers the emotional aspects of caring for a person with dementia and considers burnout and emotional exhaustion in line with accompanying common methods that professionals take to protect themselves; "knowing the theory behind dementia is only the tip of the iceberg when it comes to enabling a person to feel confident in working effectively with a person who has dementia". Organisational barriers to care are summarised, with training and staff shortages being key issues. The conclusion to this paper was that people with dementia who are admitted to acute care settings have poorer outcomes than those without cognitive impairment. Butcher highlighted that care for people with dementia is complex and requires specialised training to deliver high-quality provision. In acute hospitals, it is essential that health professionals have an understanding of cognitive impairment as a risk factor in itself. Butcher echoes many other studies when stating that it is imperative that staff have the right approach and are equipped with good communication skills. Arguably the hegemony of a patriarchal biomedical model of care was evident; for example, Butcher concluded that change was critical in preventing unnecessary medical complications that might not only lengthen hospital stay but also shorten the patient's life.

Reference:	Carnall, C. and Chianese, J. 2018. The training of therapeutic radiographers in dementia care: a literature review.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of Radiotherapy in Practice. 17(4): 436–40.	The aim of the study was to review the literature regarding training of therapeutic radiographers around dementia	A literature search of electronic databases holding peer-reviewed journals was	Electronic databases holding peer-reviewed journals were accessed, these were AMED,	The authors contend that it is important in the settings of unfamiliar treatment rooms and equipment to	The two main themes that emerged were: education in caring for the person with dementia and the	The paper notes that one of the author's personal experience of clinical practice across three different

	and to use the findings to make recommendations for training in the future in order to provide the best care.	conducted. Search terms were generated using the Population Intervention Comparison Outcome (PICO) method and retrieved articles were evaluated using the Critical Appraisal Skills Programme (CASP) tool. Additional evidence was accessed through snowballing and from grey literature.	CINAHL Plus, Embase, HMIC and MEDLINE. The search terms were generated using the PICO method and combined using Boolean logic. The keywords were provided in a table. Only articles written in English were included. The search failed to find any studies on dementia care education within a radiotherapy setting and only a limited number were found in the	recognise a person's distress and try to listen to, understand and meet the needs of the person with dementia. The literature demonstrated that focused education programmes can improve knowledge and understanding of dementia, but the evidence shows most studies were aimed at nursing professions, rather than allied health professionals, including radiographers.	results of this; and guidelines in caring for the person with dementia. The authors claimed that there was no evidence of a standardised education programme for healthcare professionals in dementia care. In the future, therapeutic radiographers are likely to see more patients with dementia but currently some may not have had the education and training to	radiotherapy centres suggests that radiographers rely on their own previous experiences of treating patients with dementia rather than receiving dedicated training. It is not determined if this was the case nationally or internationally. The authors suggest that a survey of the provision of dementia care training in higher education institutions (HEIs) would help to create an understanding of

			acute care setting.		provide effective holistic care.	the training available. The authors considered there to be a lack of research into dementia care training within the radiography setting, thus most articles included in the study were regarding an acute care setting. They suggest that to fully measure dementia care training in radiotherapy, a primary study should be conducted.
Recommendations:		It is recommended that all patients with dementia undergoing radiotherapy complete a 'This Is me' booklet in order that therapeutic radiographers can understand the specific needs of each patient.				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Understanding patients' behaviour and adopting positive ways to reduce distressed reactions; training needs; staff skills and attitudes; the practice environment – acknowledging the need for special provision. Toolbox for practitioners: Use of the Alzheimer's Society/RCN 'This is me' information booklet.

Article summary:

The authors note that a 2017 survey by the UK Alzheimer's Society found only 2% of carers believed that hospital staff understood the specific needs of the person with dementia. The authors explain that in radiotherapy, the Alzheimer's Society 'This is me' document is particularly useful for staff to support the patient and adapt practices. Carnall and Chianese agree with SCoR policy that longer time slots should be arranged for a person with dementia to "allow patients to move at their own pace, familiarising themselves with the environment and allowing radiographers to deliver more personalised care". The authors of this paper outline the importance of both dementia skills training and also capacity for consent training, to enable radiographers to meet the mandatory requirements of the Mental Capacity Act 2005. They also report the importance of re-conceptualising behaviours that challenge to cases of unmet needs. The authors conclude that "the literature revealed that there is currently no set standard of training in dementia care for health and social care professionals". They essentially dismiss the dementia training standards frameworks for the devolved countries of the UK.

In conclusion, the authors state that it is recommended that all patients with dementia undergoing radiotherapy complete a 'This is me' booklet in order that therapeutic radiographers can understand the specific needs of each patient and combine their training and the booklet to cater to these needs. This should be with the caveat that not every person living with dementia will choose to share that information for various reasons, including fear of stigma for some people.

Reference:	Challen, R., Low, L. and McEntee, M. 2018. Dementia patient care in the diagnostic medical imaging department.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
Radiography.24(1): S33–42.	The aim of this study was to explore the experiences of dementia care in imaging departments through the perspectives of people with dementia, carers, radiographers and student radiographers.	A cross-sectional qualitative study with patient and carer semi-structured interviews and staff focus groups. Interviews and focus groups were transcribed and thematically analysed.	Four people with dementia and six carers participated in individual semi-structured interviews; eight academic radiographers and 19 student radiographers participated in focus groups.	An outcome was the discussion of poor experiences: staff ignoring personhood, poor communication, limited knowledge of dementia and negative stereotypes were related to negative experiences. Contributors to a positive encounter were: patient centred care; good communication; high levels of education; inclusive relationships with carers; and	Negative experiences during imaging were associated with disrespected personhood, poor communication, insufficient staff knowledge of dementia, inappropriate time management, overly stimulating physical environments and exclusion of carers. Departmental protocols that contributed to negative experiences included lack of preparation, lack of dementia protocols,	The qualified radiographers who took part were working in academia not clinical practice; their timescale since working in clinical practice varied between one and ten years, which is a limitation of the study. The study contains a review of Australian government guidance but there is no reference to any relevant professional

				effective time management.	and the use of restraints. The main conclusion of the study was that patient care for people with dementia in the imaging department is an area in need of improvement. The authors suggest that: 1) radiographers need training about dementia; 2) imaging services should improve their procedures and physical environments; and 3) staff should work in greater partnership with carers.	body's information or guidance.

Recommendations:	1) radiographers need training about dementia; 2) imaging services should improve their procedures and physical environments; and 3) staff should work in greater partnership with carers.
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision.

Article summary

This was a cross-sectional qualitative study with patient and carer semi-structured interviews and staff focus groups. Similar to other radiography-centred papers, the authors refer to the fast-paced environment and remark that there was abundant literature with regards to the imaging and diagnosis of dementia but little in the area of patient care specifically for people with dementia in clinical imaging settings. Professional body guidance with regards to dementia care was not reviewed, but there is reference to Australian government guidance.

A good range of powerful quotes are included in the paper. The authors state that this approach provided a holistic approach, taking several viewpoints into account. The qualified radiographers who took part, however, were working in academia, not clinical practice; their timescale since working in clinical practice varied between one and ten years, which is a limitation of the study. The authors attempt to justify the omission of radiographers who were working clinically, citing the timescale for ethical approval as the reason. Study participants described positive and negative experiences during imaging procedures. Ignoring personhood, poor communication, limited knowledge of dementia and negative stereotypes were related to negative experiences. Patient-centred care, good communication, high levels of education, inclusive relationships with carers, and effective time management were contributors to a positive encounter. Overall, people with dementia and their carers had negative experiences, such as distress and pain; radiographers experienced stigma and violence (arguably it is the person with dementia and carers who experience stigma). Negative experiences during imaging were associated with disrespected personhood, poor communication, insufficient staff knowledge of dementia, inappropriate time management, overly stimulating physical environments and the exclusion of carers. Departmental

protocols that contributed to negative experiences included lack of preparation, lack of dementia protocols, and the use of restraints. The authors list a number of recommendations for future research.

The main conclusion of the study was that patient care for people with dementia in the imaging department is an area in need of improvement. The authors suggest that: 1) radiographers need training about dementia; 2) imaging services should improve their procedures and physical environments; and 3) staff should work in greater partnership with carers. The main conclusions therefore echo the original 2015 recommendations of the SCoR guidance for caring for people with dementia.

Reference:	Chang, A., Singh, N., Boyd, L. and Lawson, C. 2016. Strategies to improve radiographic practices for patients with Alzheimer's disease: A systematic review.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of Medical Imaging and Radiation Sciences. 47 (4): 362–6.	The review examined the literature regarding the interaction between Alzheimer's	Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for conducting	The initial search resulted in zero reviewable articles. The search was then expanded to	The review points to three areas relevant to the practice of radiography: the importance of patient-centred	Many strategies relating to care of patients with AD are long term, and cannot be applied in a radiographic setting, where	Chang et al. conclude that they have reviewed studies and applied the findings to radiographic

	disease (AD) patients and other healthcare professionals (e.g. nurses) and the strategies that have been used to improve patient compliance and accommodate functional decline.	systematic reviews were used. PubMed database was searched using the key words: Alzheimer*; AND/OR dementia; AND radiograph*; AND care; AND/OR anxiety. Articles were excluded if they were not written in English, or if they did not relate to patient care or healthcare management. Further exclusions related to articles that considered specific therapies for Alzheimer's patients that could not be transferred to radiographic practice, such as reminiscence therapy,	include nursing, physiotherapy, occupational therapy and healthcare. 36 articles were identified as relevant for the review.	care (acknowledge the patient's personhood and involve carers in examinations); the environment and physiological factors affecting patients with Alzheimer's disease (reduce noise, play calming music, personalise the examination room); and obstacles for patients (educate radiographers to increase geriatric knowledge).	patients may only present once. Transferable strategies for radiographic settings include the support of carers during the examination process, a reduction in noise and use of calming music, and allowing the patient to personalise the examination room by bringing in a photograph or an item of comfort. The authors conclude that simple strategies can reduce the level of anxiety experienced by AD patients, reduce typical behavioural	practice. They do not list any limitations in the paper, instead noting that findings were applied in a hypothetical and theoretical, not practical, application given that this was a systematic review. The theoretical application did not consider therapeutic radiography settings. The authors focus on Alzheimer's disease, just one form of dementia. The authors make assumptions about the

		psychoeducation, and reality orientation. Dementia articles not related to AD were also excluded, as were articles about AD in children. Articles were included if they referred to support of carers, reducing anxiety, and other patient-centred approaches that could be adopted in a one-off setting such as radiographic practice.			symptoms of agitation, aggression and discomfort, and increase patient cooperation and responsiveness.	transferability of treatments to radiographic practice – for example, studies that employed reminiscence therapy (RT) were excluded by the authors (referring to time limitation). It may be possible to use RT in waiting areas and so on, therefore these exclusions were potential limitations of this study.
Recommendations:		Attention should be paid in radiography to: patient-centred care (acknowledge the patient's personhood and involve carers in examinations); the environment and physiological factors affecting patients with Alzheimer's disease (reduce noise, play calming music, personalise the examination room); and obstacles for patients (educate radiographers to increase geriatric knowledge).				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Recommendations for future research; training needs. Toolbox for practitioners: Practical ways to aid personalisation of the examination/treatment room.

Article summary:

There were contradictions within this paper in the terms of the language used, which at times appeared dated/not person-centred; for example, it "investigates strategies that have been used to increase patient compliance". The narrative therefore arguably disempowered people with dementia and their carers at some points. Despite the inconsistent use of language, the review pointed to three areas relevant to the practice of radiography including: the importance of patient-centred care (acknowledge the patient's personhood and involve carers in examinations); the environment and physiological factors affecting patients with Alzheimer's disease (reduce noise, play calming music, personalise the examination room); and also obstacles for patients (educate radiographers to increase geriatric knowledge). The latter point does not take into account younger people with dementia and the authors do not specifically mention young onset dementias.

The authors made assumptions about the transferability of treatments to radiographic practice – for example, studies that employed reminiscence therapy (RT) were excluded, with the authors referring to time limitation. It may be possible to use RT in waiting areas and so on, therefore exclusions are a limitation of this study.

The authors state that the strategies that were reviewed gave evidence of reduced levels of anxiety, reduced agitation, aggression and discomfort and increased patient cooperation and responsiveness. To reduce what they term obstacles for patients, they suggest that educational strategies to improve radiographers' knowledge, skills, and experience can influence how they perceive and manage the care of patients with Alzheimer's disease. The authors suggest that the effectiveness of these strategies warrants further research to validate the proposed strategies and develop and refine educational tools to ultimately provide better care provision during radiographic procedures for the Alzheimer's disease patient cohort.

Reference:	Clissett, P., Porock, D., Harwood, R. and Gladman, J. 2014. The responses of healthcare professionals to the admission of people with cognitive impairment to acute hospital settings: an observational and interview study.					
Source	**Purpose**	**Design**	**Sample**	**Intervention / Outcome**	**Findings**	**Limitations**
Journal of Clinical Nursing. 23 (13): 1820–9	To explore the responses of healthcare professionals to the admission of people with cognitive impairment to the acute hospital setting.	The study consisted of qualitative interviews and non-participation observations. The authors stated that it was based on the principles of ethnography. 72 hours of non-participant observations of care together with semi-structured interviews with family carers of 34 older people who had been admitted to a UK general hospital and had a cognitive impairment. Interview was after discharge at the person's home. One interview was undertaken with each of the 35 carers. Interviews and observations were conducted in 2009 and 2010. Analysis was undertaken using Strauss and Corbin's grounded theory qualitative research framework.	Participants were recruited from two sites of a 1,800-bed teaching hospital providing sole general medical and trauma services for a population of 660,000. All participants	An outcome was the identification of a core problem, "disruption", and a core process, "gaining or giving a sense of control to cope with disruption". Healthcare professionals responded to the	Where healthcare professionals acted to suspend the personhood of the patient, they appeared to be demonstrating signs of 'burnout'. The authors surmise that there is a need both to challenge	Interviews were conducted following discharge to facilitate the involvement of the patient if at all possible. They took place between six and eight weeks after discharge, or after 12 weeks if the patient had died

		https://methods.sagepub.com/book/basics-of-qualitative-research	had been admitted to hospital for acute medical care and had been recruited to a related but separate study. As part of the consenting process for the related study, family carers were invited to indicate whether they would be willing to take part in an in-depth interview.	disruption in three ways: by acting to preserve the personhood of the individual; by seeking to protect themselves from the stresses associated with caring for the person with cognitive impairment; and by suspending the personhood of the individual.	poor practice and for positive development work with healthcare professionals who work in acute hospitals with people with dementia and cognitive impairment, so that they are equipped with the skills, emotional resilience and organisational support to be effective in meeting the needs of people with dementia and	(instead interviewing a carer). Recall bias was a possible limitation. Reasons for non-participation included readmission, fatigue, family disagreements, carer being too ill, other caring responsibilities and paid work. Not all patients had dementia. The range of diagnoses recorded in patient case

			Individuals aged 70 years or over with unplanned admission to one of 12 wards, who had a cognitive impairment or mental health problem on screening (using a range of validated tools) were eligible for inclusion. Recruitment occurred over 12 months.		cognitive impairment.	notes were: dementia (22), depression (four), delirium (one), alcohol (one) and anxiety (one), and no clear diagnosis was recorded in five instances.
Recommendations:		There is a need both to challenge poor practice and for positive development work with healthcare professionals who work in acute hospitals with people with dementia and cognitive impairment so that				

	they are equipped with the skills, emotional resilience and organisational support to be effective in meeting the needs of people with dementia and cognitive impairment.
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Staff skills and attitudes; training needs.

Article summary:

This study was not specific to dementias; a range of conditions were included in the study. The diagnoses recorded in case notes were: dementia (22), depression (four), delirium (one), alcohol (one) and anxiety (one). No clear diagnosis was recorded in five cases.

All parties (patients, family carers and staff) appeared to find the admission to hospital of somebody with a cognitive impairment disruptive and responded in ways that appeared to help them feel in control in the face of this disruption. Healthcare professionals seemed to find it disruptive to their way of working but appeared to have a number of strategies to help them feel in control. This sense of juggling was exacerbated when healthcare professionals tried to find the balance between meeting the needs of the individual and the needs of other patients, some of whom may be critically ill.

Personhood was defined as "a standing or a status that is bestowed on one human being, by another in the context of relationship and social being" in Kitwood's Dementia Reconsidered which is central to the discourse on care for the person with cognitive impairment. Embracing the personhood of the individual gave the staff a sense of control because they were choosing to give care that was considered to be of high quality. During a ward observation, a ward housekeeper was seen to respond to patient distress with great sensitivity. Healthcare professionals had to come to terms with the notion that while the care they were giving was adequate, it was short of ideal. Finally, some healthcare professionals appeared to be trying to gain a sense of control by taking actions that were harmful to the sense of personhood of the confused older patient. These actions tended to be associated with poor communication with both family carers and patients alike and gave the impression that the member of staff was placing their own needs before those of the patient. Some healthcare professionals tended to prioritise the needs of other patients over those of people with dementia.

The authors discuss the links between emotional labour, dissonance and burnout. However, they conclude that organisational factors including facilitating person-centred approaches to care, reducing ward moves, improving environments, reducing staff workload and not prioritising the management of secondary risks (e.g. falls and infection control). Overall, review of staff responses to people with cognitive impairment in the acute setting (as interpreted by researchers, patients and relatives) found that healthcare professionals tended to view working with people with cognitive impairment as being disruptive.

Reference:	Clissett, P., Porock, D., Harwood, R. and Gladman, J. .2013. Experiences of family carers of older people with mental health problems in the acute general hospital: a qualitative study.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of Advanced Nursing. 69 (12): 2707–16.	To explore the experiences of family carers of people with cognitive impairment during admission to hospital. The authors provide information that demonstrated	Using a combination of non-participant observation and interviews, researchers sought to watch, interpret and evaluate the	The sample consisted of family carers of 34 older people who had been admitted to a UK general hospital and had comorbid cognitive impairment. The study was	Hospitalisation caused disruption from carers' established routines at home or in a care home. Disruptions caused consternation and distress for many family carers. Family	A core problem, "disruption from normal routine", was identified, and a core process, "gaining or giving a sense of control to cope with disruption". The interaction of the core problem and the core process	A third of the carers who were invited to be interviewed agreed. The authors noted that interviews took place some weeks after the hospital admission, which would have permitted reflection on events and this may have changed

	the experiences (both practical and emotional) for family carers with a relative with cognitive impairment in an acute hospital.	experiences of older people and their carers when in acute hospitals. The study was informed by the philosophical approach of person-centred care using an interpretive ethnographic approach. Semi-structured interviews were conducted in 2009 and 2010 (the paper was published in 2013). An interview	conducted on two sites of a single NHS trust in the English Midlands, which provided sole medical and trauma services for a population of approximately 660,000. Participants were recruited from a cohort of patients aged over 70 years, who had mental health problems and were admitted to one of 12 general medical, healthcare for older people or trauma orthopaedic wards.	carers responded to disruption proactively by trying to make sense of the situation and attempting to gain control for themselves or the patient. They tried to stay informed, communicate with staff about the patient and plan for the future. Family carers were not passive in the face of the disruption of hospitalisation and responded both by trying to involve themselves in the care and support	resulted in outcomes where family members either valued the support of hospital staff and services or were highly critical of the care provided. The study found evidence of proactivity in trying to deal with disruption. Some family members tried to fill in gaps in care, especially during the early stages of admission where the unfamiliar environment, and stress of the emergency department and the admission ward seemed to cause	opinions. Events may not have actually occurred as reported, or they may reflect misunderstandings, ongoing difficulties or problems outside the hospital. Accordingly, there was a possibility of recall bias.

		guide was used flexibly as a prompt to explore the experiences of the person's stay in hospital. Analysis was undertaken using Strauss and Corbin's grounded theory framework.		of their relative and by trying to work in partnership with members of staff.	most distress to the patient. The authors conclude that listening to family carers and using the knowledge they have of the person with dementia is probably the single most practical recommendation to be made from this data.	
Recommendations:		Advice is to recognise that family carers are a source of expertise in the specific needs of a person with dementia, as a source of direct care for their family member and also as a partner who needs to be welcomed, supported and kept informed.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Building relationships with patients and carers to optimise the patient and carer experience; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; strategies for optimising communication with people with dementia and their carers.				

Article summary:

The authors provide assurance that where patients had capacity, they were asked to give written informed consent. Where they lacked capacity, a carer was invited to act as a personal consultee. In addition, family carers were invited to give written consent for their own participation. Similar to many other studies, the study demonstrated that the hospital environment did not lend itself well to the management of distressed behaviours. For example, the emergency department was seen as a chaotic place where, despite national targets for swift assessment, treatment and transfer, the process was slow, exhausting and uncomfortable. Diagnostic radiographers are often staff involved in part of that process.

For carers, feeling in control was important. Strategies to promote control included trying to protect the person with dementia, making judgements about the quality of care being offered, and, sometimes, taking steps to monitor the care. Blaming the system and rationalising care quality problems was another coping strategy. The study also provides evidence of carers' concerns for other patients and staff, with strategies to assist staff caring for people with dementia. There was little evidence that this was recognised by staff, which left carers feeling used and exhausted. Accordingly, it is important that clinical imaging and radiotherapy staff work in collaboration with carers, recognising their contribution and concern for everyone involved in the care of the person with dementia. Quality of care was perceived to be poor if the family carer said that staff were not listening to them or taking their information seriously; this often served as an indicator that staff really did not know enough about the care of a person with dementia. Advice is to recognise that family carers are a source of expertise in the specific needs of a person with dementia, as a source of direct care for their family member and also as a partner who needs to be welcomed, supported and kept informed. The study therefore supports the original 2015 SCoR recommendations.

Reference:	Dewing, J. and Dijk, S. 2016. What is the current state of care for older people with dementia in general hospitals? A literature review.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
Dementia. 15(1):106–24.	A literature review focusing on the literature directly pertaining to the acute care of older people with dementia in general hospitals from 2007 to 2013.	Databases searched were PubMed, CINAHL, MEDLINE and PsycINFO. The search terms used were 'dementia', 'Alzheimer's', 'confusion' or 'cognitive impairment' in combination with 'acute care', 'acute hospital', 'acute ward' or 'hospital'. Following this, a search using Google Scholar was conducted to find 'grey' literature and articles in other databases. The references in each retrieved paper found were scanned to find	English language papers and reports on the acute care of older people with dementia in general hospitals.	This review highlights that overall there remain mostly negative consequences and outcomes for people with dementia when they go into general hospitals. Although not admitted to hospital directly due to dementia, there are usually negative effects on the dementia condition from hospitalisation. The review suggests this is primarily because there is a tension between prioritisation of acute care for existing comorbidities and person-centred	The overall theme generated was defined as 'consequences of being in hospital'. From this, the authors established seven related subthemes: the care environment; cultures of care; attitudes; challenges for people with dementia; carers; staff and volunteers; and researched service models.	Much of the research to date seems to capture existing poor practice and little research seeks out good practice. Connected to this, evaluation studies are usually small scale, making it difficult to compare outcomes across studies as they are often methodologically different. Clearly, longer term and larger scale studies are needed. In summary, this review suggests that overall there remain negative consequences and outcomes for people with dementia and families or carers when

		further relevant publications. Although most of the literature was from peer-reviewed journals, reports, policy documents and theses were also included where relevant and/ or based on original empirical research. Of a total of 278 papers retrieved, a final total of 53 publications were included in the review. Additional searches were performed with the search terms 'shared care', 'mental health nurse', 'mental health liaison' and 'old age psychiatry'. From this a small		dementia care. This is complicated by insufficient understanding of what constitutes person-centred care in an acute care context and a lack of the requisite knowledge and skills set in healthcare practitioners. Although specialist posts, such as liaison and clinical nurse specialists, and specialist units/shared care wards can enhance quality of care and reduce adverse consequences of hospitalization, they do not significantly impact on reducing length of stay or the cost of care.		they go to general hospitals.

		number of publications were retrieved. The main findings and arguments were summarised and organised thematically. Independent general thematic analysis took place by one of the authors and was then refined by the second author. Any discrepancies were discussed to find agreement.				
Recommendations:		The authors advocate approaches that include improving the physical and psychosocial environment, and improving attitudes to dementia and the understanding and management of behaviours of concern through enhancing staff knowledge and skills, access to mental health expertise and partnerships with family carers.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; staff skills and attitudes.				

Article summary:

Providing background, the authors make an important point that is relevant for SCoR guidance: within all these strategies there is an objective associated with improving the quality of care in general hospitals. The general notion of person-centredness is considered to equate with better, if not best, care across all care settings.

With regard to pain, people with dementia may be at risk for undetected or un(der)treated pain. When staff were absent this created anxiety among people with dementia and the atmosphere changed into a sense of 'homelessness', where they seemed abandoned and lost. When staff were present but not really engaging when carrying out care or procedures, situations could turn positively or negatively depending on the person. A focus on safety by the organisation generates a culture that devalued people with disorientation and where staff viewed people with disorientation/dementia as a nuisance or inconvenience and not suitable for an acute hospital setting (Moyle et al., 2010). The authors found that literature suggests this is probably still the majority view among many healthcare workers, although this may be a simplistic representation of a complex situation. The literature also revealed that in practice, the principles are not always applied, whether as a result of time pressures, an organisational culture focused on curing diseases or negative attitudes towards people with dementia. A person-centred approach to care of people with dementia has been observed in acute hospital settings, although this better/best practice approach is not widely evidenced in the literature on acute care at this point. Fundamental to any culture are the values and beliefs displayed as attitudes and action by staff. Hospitalisation not only disrupts the established routine for the people admitted but also for families and carers. The literature cites a number of service models that have enhanced or may improve the care of people with dementia in hospitals. These interventions range from volunteers and specialist roles, such as a liaison mental health nurse or team, to special care units and training and education. The literature reveals no evidence that specialist roles contribute to upskilling of general staff. Indeed, there is a risk that such short-term specialist roles deskill general staff in the longer term. Based on their review, the authors suggested that specialist wards/units can enhance some aspects of the quality of care and reduce adverse consequences of hospitalisation but do not significantly impact on reducing length of stay; but neither do they add to it. Approaches included improving the physical and psychosocial environment, improving attitudes to dementia and the understanding and management of behaviours of concern through enhancing staff knowledge and skills, access to or integrating mental health expertise with general nursing, and partnerships with family carers.

Reference	Digby, R., Lee, S. and Williams, A. 2017. The experience of people with dementia and nurses in hospital: an integrative review.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of Clinical Nursing. 26 (9): 1152–71.	To identify and examine existing research exploring how people with dementia and nurses view acute hospital care. What impact does dementia have on the experience of patients in hospital? How do people with dementia perceive the attitude of staff to their illness?	An integrative review of literature 2005–2015 reporting the experience of people with dementia and nurses caring for them in an acute hospital setting (n=24). The criteria for inclusion was that the main focus was on the care of people with dementia in hospital, and the research was based on the direct viewpoint	A literature search for relevant material was conducted using the Cumulative Index to Nursing and Allied Health Literature database (CINAHL) and employing Boolean technique in which two or more terms were searched and combined with AND, OR and NOT. The literature of the past 10 years was considered to be appropriate for this review to reflect recent	Hospitals focus on acute medical care; consequently, people with dementia are considered low priority and a disruption to normal routine. Risk management often takes priority over patient dignity. People with dementia are stigmatised. Families have significant roles to play in the care of a person with dementia in hospital but are	Dementia adds complexity to patient care. Inability to deliver appropriate care was a source of stress and frustration for nurses. People with dementia often have a poor experience in hospital due the inability of the hospital system to accommodate the specific needs of this patient group.	The authors felt that the small number of articles that met the inclusion criteria and the similarity of methodological approaches meant that an element of bias may have been introduced. The majority of the articles in the review were conducted in the UK, Sweden or Australia, with only one from the United States, two from Ireland (by the same author and using the data from one study),

	What is the experience of nurses caring for people with dementia in hospital?	of either people with dementia or nurses caring for them. Only primary qualitative studies published in English in peer- reviewed journals during 2005–2015 were considered. Quantitative research was excluded to ensure that the direct opinions of the nurses and patients were the focus. Each article was critically appraised using the Critical Appraisal Skills Programme (CASP) checklist	issues arising from pressures of an ageing population on health systems. In addition, the bibliographies of significant articles were hand-searched for further relevant articles. Articles were excluded if the main focus was residential or community care or the information was the opinion of others such as family carers or students. Theoretical articles, literature reviews, surveys and articles written from a biomedical viewpoint were also excluded.	often excluded, at the expense of specific patient needs.	Enhancing awareness of this problem is a positive step towards rectifying it. This paper highlights the deficits in education and support for nurses caring for people with dementia in hospital. The stigmatisation of people with dementia was identified.	one from Finland, one from Japan and one from Malta. The narrow range of locations makes transferability to other areas problematic. The main identified weaknesses of the articles reviewed in the study were that they were conducted in one specific setting and with a small number of participants.

		for qualitative research.				
Recommendations:	Current hospital culture requires wider system review to mitigate against stigmatisation of patients with dementia. Education on mental health issues is greatly lacking, and the emotional and practical support provided is inadequate. Strong clinical leadership and role-modelling provides opportunities for clinical-based education and skill development.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; building relationships with patients and carers to optimise the patient and carer experience; training needs; staff skills and attitudes.					
Article summary: An integrative review found that nurse education about dementia, practical support, strong clinical leadership and role-modelling was needed. The authors argue that empathy for patients, regardless of diagnosis, must remain a core attribute of nurses. Current hospital cultures require wider system review to mitigate against stigmatisation of patients with dementia. Six recurrent themes were identified: priorities of care; nurse education; stigmatisation of people with dementia; risk management in the ward environment; the input of family carers; and nurse job satisfaction. The authors noted that "a complex array of factors which include in some instances the nurses' lack of interpersonal qualities and education about dementia is blamed for negative experience". The authors take an approach in contrast to those that champion specialist units for people with dementia. The authors report that stigmatising people who have dementia, including suggestions that they should be treated						

elsewhere, is pointless and delays addressing the issues. Nurses must learn to accommodate patients with dementia in general hospital wards, especially in relation to the specific needs created by the patients' compromised ability to understand new environments.

The presence of family can allay anxiety in the patients and provide helpful information and an additional resource for time-poor nurses. In his seminal work 'Dementia reconsidered: the person comes first', Kitwood pointed out that the staff must be looked after from a material, psychological and educational perspective to have the ability to care effectively for people with dementia. This was a barrier for many of the other hospitals in the reviewed articles, which were disproportionately focused on discharge planning, risk management and the treatment of acute illness without due consideration or the financial resources for other factors. The authors make the point that, while it is acknowledged that financial considerations are important, it appeared that in some instances efficiency had been misinterpreted to exclude empathetic care. The fast-paced, noisy, acute hospital environment has the effect of increasing the disorientation and agitation of patients with dementia, adding to the distress already caused by the disruption to normal routine.

Additionally, the dominant medical model of care is focused on acute illness, and dementia is considered low priority. It was important for nurses to understand the complex needs of people with dementia admitted to acute hospital wards. Nurse education on mental health issues was greatly lacking, and the emotional and practical support provided was inadequate. Strong clinical leadership and role-modelling gave nurses opportunities for clinical-based education and skill development.

Reference:	Dowding, D., Lichtner, V., Allcock, N., Briggs, M., James, K., Keady, J., Lasrado, R., Sampson, E., Swarbrick, C. and Closs, S. 2016. Using sense-making theory to aid understanding of the recognition, assessment and management of pain in patients with dementia in acute hospital settings.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

International Journal of Nursing Studies. 53: 152–62.	To provide a revised conceptual model of pain recognition, assessment and management in patients with dementia.	The study was an exploratory ethnographic study that employed nested case sites. Methods consisted of observations, audit of patient hospital records, documentary analysis of artefacts, 56 semi-structured interviews and informal open conversations with staff and family carers.	The sample consisted of 31 patients with dementia nested in eleven wards across four NHS hospital organisations in England and Scotland. Patients were eligible for inclusion if they were over 65 years old and had a diagnosis of dementia in their care records.	The authors proposed a revised theoretical model of decision making related to pain assessment and management for patients with dementia based on theories of sense-making, which they said was reflective of the reality of clinical decision making in acute hospital wards.	Pain recognition, assessment and management is not an individual cognitive activity; rather it is carried out by groups of individuals over time and within a specific organisational culture or climate, which influenced both healthcare professional and patient behaviour. Themes raised were: the patient's pain recognition was complex and dynamic and it can be associated with distress and anxiety; context plays a role in recognising, assessing and managing pain e.g.	The study did not include people with young onset dementia. There appeared to be a lack of consistency across wards and individual nurses.

					patients on surgical wards were expected to have (and asked about) acute pain; pain recognition, assessment and management is a process distributed across individuals and over time.	
Recommendations:		The authors propose a revised theoretical model of decision making related to pain assessment and management for patients with dementia.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; the practice environment – acknowledging the need for special provision.				
Article summary: According to the authors, approximately 50% of patients with dementia regularly experience pain. People with dementia may not be able to report their pain verbally; behavioural symptoms may be a result of underlying pain. The authors explored the process of pain recognition, assessment and management to provide an alternative theoretical framework. The paper provided background with theories of pain recognition. A literature review demonstrated that there were few studies of nurse decision making around the use of interventions for pain management in dementia. The authors report that there can be a reluctance to use analgesia and opioids – this mirrors the choice of patients in a number of other studies in this review.						

The relevant mental capacity legislation for England and Scotland was referenced with consideration of informed consent. In this study healthcare staff reported using intuition, experience and their ability to build a picture of the patient to identify whether or not a person was experiencing pain. Organisational routines and boundaries of professional roles provide a framework within which sense-making occurred. The authors raise an important question: based on the evidence in this review of the low level and inconsistency in person-centred care in acute settings we probably do need to ask: is person-centred care possible in our current busy acute care general hospital settings? Most contemporary strategies are limited by the focus on prioritisation of service activity, including throughput and length of stay targets, plus the tension between responding to acute care for existing comorbidities and person-centred dementia care. This was further complicated by insufficient understanding of what constituted person-centred care in an acute care context and a lack of the requisite knowledge and skills set in many healthcare practitioners. The review found a lack of evidence for the effectiveness of mental health liaison posts and dementia care specialist posts in nursing. The authors posit that these roles and specialist units/shared care wards can enhance quality of care and reduce adverse consequences of hospitalisation, but they do not significantly impact on reducing length of stay or the cost of care.

Reference:	Featherstone, K., Northcott, A. and Bridges, J. 2019. Routines of resistance: An ethnography of the care of people living with dementia in acute hospital wards and its consequences.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

International Journal of Nursing Studies. 96: 53–60.	To explore the ways in which resistance to care manifests within the care setting, was understood and classified, and was managed by ward staff.	Observational fieldwork and ethnographic interviews were collected over 20 months.	The study focus was on staff delivering care to patients with dementia. Interviews with conducted with patients, carers, visitors and staff working on and visiting the ward.	Resistance to care was a routine and expected part of everyday care. The authors posited two major themes, which they labelled 'organisation' and 'resistance'.	Routinised ward cultures triggered resistance in patients. There was a focus on essential planned care over patient need or mood. Institutional drivers of routines, efficiency and risk reduction could result in poor care experiences for patients, and also emotional and physical burnout for staff. Patients were typically slower than the general population and needed longer periods of time for their care.	The authors state that they were unable to generalise from this qualitative study although description may resonate with other practice areas.
Recommendations:		Offer longer appointment times to people with dementia. Recognise that while staff training is championed as a solution to improved care for people living with dementia, the underlying barriers can be cultural and organisational issues, with institutional drivers of routines, efficiency and risk reduction highlighted.				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; staff skills and attitudes; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs. Toolbox for practitioners: Attention to length of appointment times.

Article summary:

This ethnographic study explored the ways in which resistance, rejection or refusal of care manifested on acute hospital wards. Trauma and orthopedics wards (N=5) and medical admission units (n=5) were chosen across hospital sites because of high levels of admissions of patients living with dementia. The participants were people living with dementia and nursing team members. The authors investigated how resistance was understood, classified and managed. Notably during the study, every patient living with dementia resisted care to some extent.

For staff, the authors found that resistance to care from people with dementia was routine and expected, while a high value was placed on achieving efficiency and reducing perceived risks to patients. Routinised ward cultures typically triggered resistance to bedside care from patients, whereas staff prioritised the delivery of scheduled care over patient need. The paper described resistance as non-compliant, deviant or difficult behaviour, which could result in the labelling of patients. In alignment with a number of other studies, the authors noted that the behaviour of patients may be a response to hospital settings that are threatening and frustrating for some people with dementia. Resistance was conceived to be a continuum of responses from people living with dementia to the way that care was delivered in a fast-paced and routinised environment. It manifested as physical or verbal resistance or refusal to comply with timetabled rounds of the ward – notable at particular times of day or on certain bays and wards. The majority of physical resistance was passive, e.g. pushing away equipment, turning away from staff or trying to leave. Staff responses were distraction, questioning, clear directives, and suggesting other people had the power to decide what was happening to the patient ('the doctor has asked for you to do this') while subtly trying to restrict movement, depending on perception of risk to the patient. Resistance was seen as less problematic when a patient was safely contained in a bed; staff in such cases ignored shouting.

The study gives examples of resistance that radiographers will probably also recognise taking place in clinical imaging and radiotherapy departments. Of particular note, the routines of the ward took priority over individual patient needs; staff had little

flexibility to respond to patient needs outside of scheduled and quantifiable work. This notion resonates with a range of radiography-based studies. Similarly, staff discussed lack of continuity and 'not knowing' the patients in their care. Communication was typically rhetorical, emphasising a lack of choice for the person or staff caring for them. The authors note that patterns of care were consistent across wards and institutions, with relational care overshadowed by other drivers. For people with dementia the results were poor outcomes and experiences. For staff there was moral distress and burnout in response to institutional barriers limiting quality care. A conclusion was that, while staff training is championed as a solution to improved care for people living with dementia, the underlying barriers are actually cultural and organisational issues rather than training (although the authors concede that training also helps). Institutional drivers of routines, efficiency and risk reduction were highlighted.

Reference:	Fukuda, R., Shimizu, Y. and Seto, N. 2015. Issues experienced while administering care to patients with dementia in acute care hospitals: a study based on focus group interviews.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

International Journal of Qualitative Studies in Health and Well-being. 10: 25828.	This study aimed to explore the challenges nurses face in providing care to patients with dementia in acute care hospitals in Japan.	A qualitative study using focus group interviews. Eight focus groups were formed. A qualitative synthesis method was used for data analysis.	Set in six acute hospitals with surgical and medical wards in the western region of Japan. Participants were nurses in surgical and internal medicine wards, excluding intensive care units. Nurses with less than three years' working experience, those without experience in dementia patient care in their currently assigned ward, and head nurses were excluded from participation. In total, 50 nurses with an average experience of 9.8 years participated.	The authors described a necessity to care for patients' families and obtain families' cooperation. An outcome of the study was the recognition that "there may be a general characteristic of care administration to patients in acute care hospitals".	The two main issues experienced by nurses while administering care to patients with dementia in Japanese acute care hospitals were: (a) various problems and difficulties faced by nurses were interactive and caused a burdensome cycle; and (b) nurses did their best to adapt to these conditions despite feeling conflicted.	Data was collected from February to December 2008, but the study was not published until 2015. The authors felt that: 1) the study lacked data from larger hospitals and, therefore, the research findings may not fully reflect all opinions; 2) nurses might have been influenced to participate in the study by their directors and head nurses; 3) data collected in this study was based on the recollections of nurses, therefore some data may be affected by recall bias; 4)

						generalisation of these research findings may be difficult because this was an exploratory study.
Recommendations:	The study supports the original guidance theme, building relationships with patients and carers to optimise the patient experience.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; carer partnerships; building relationships with patients and carers to optimise the patient and carer experience.					
Article summary: The authors of this study (set in Japan) position dementia as a major public health problem. They provide a comprehensive overview of sample hospital and participant selection, methods and data analysis. Approaches to enhance credibility and authenticity were applied and the procedure for ethical approval was described. Findings of the study resonate with UK studies although the language used is a little different; for example: "In consequence, problems arise when the problematic behavior of the patient with dementia is repeated when the assistance of the family is impossible to obtain." The authors describe the fact that nurses are expected to care for people with dementia as a "burdensome problem" exacerbated by lack of nurse experience/training and lack of coordination/cooperation among professionals involved in care. The						

authors describe falls and wandering as problematic behaviour, but recognise that people with dementia "feel a sense of security and calm down when spending time with their families". Unique to this study in comparison with the other papers, the authors claim that a recurrent problem was that nurses "need assistance from families; however, such assistance is not forthcoming or is impossible to obtain". Participants reported concerns with regards to obtaining valid consent to treatment. In line with carers who were concerned about fellow patients of people with dementia, the authors state that "hospital roommates often feel uneasy or scared because of the behavior of patients with dementia". The concept of unmet needs of people with dementia was not reflected in the discussion section of the paper. A number of incidents and interpretations of situations were surprising, although it is noted that it is now eleven years since the original study was performed. The ever-present challenge of time to care was raised in this study. While nurses reported taking actions to protect themselves because of organisational pressure, the authors did not indicate or discuss a position where nurses may be protecting themselves emotionally.

Reference:	George, J., Long, S. and Vincent, C. 2013. How can we keep patients with dementia safe in our acute hospitals? A review of challenges and solutions.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of the Royal Society of Medicine.	The authors stated that they were inspired to conduct the review after	A search of MEDLINE over the ten years to February 2012,	No data provided in the body of	Direct causes of harm were inadequate assessment and	The findings of this review led to the conceptualisation of a pathway of harm that	The authors make assumptions about individuals with dementia; for

106(9): 355–61.	speaking at a meeting organised by the Patient Safety and Geriatrics & Gerontology sections of the Royal Society of Medicine. Their aim was to consolidate what is known about patient safety issues that are particularly relevant to patients with dementia to describe strategies that can be taken to keep this "vulnerable group safe in hospital".	using keywords and Medical Subject Headings (MeSH) generated around: 1) dementia, cognitive impairment; 2) patient safety, adverse events, iatrogenicity; and 3) acute hospital care. Additional articles were identified from reference lists and the authors' personal files.	the article.	treatment, also inappropriate interventions. Underlying contributory factors were discrimination and lack of trained staff. Potential solutions exist in a multifactorial, multilevel approach to factors associated with the patient, task, individual staff, team, environment, organisation and institution.	can affect patients with dementia who are hospitalised with an acute illness, and an associated multifactorial approach to patient safety intervention for this group. The authors conclude what is needed is a multifactorial, multilevel approach at the seven levels of care – patient, task, staff, team, environment, organisation and institution. Improving safety and quality of care for patients with dementia in acute hospitals will benefit all patients and is an urgent priority for the NHS.	example, "frailty, comorbidity and reduced functional ability rather than age alone – all of which are characteristics of patients with dementia". The agency of people with dementia was not acknowledged nor the role of the wider healthcare professions beyond doctors and nurses. There is a lack of information about sample selection, inclusion and exclusion criteria etc.

Recommendations:	Potential solutions exist in a multifactorial, multilevel approach to factors associated with the patient, task, individual staff, team, environment, organisation and institution.
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Staff skills and attitudes; the practice environment – acknowledging the need for special provision.

Article summary:

The background presented in this paper arguably had an organisationally rather than individually themed focus. For example, there was a suggestion that improving acute hospital care for patients with dementia may result in considerable financial cost savings. A number of papers included in this review raised challenges to NHS cultures, which focus heavily on safety issues. The articles appear to take an alternative approach, to advocate for risk management individualised to the person. The body George et al.'s paper does, however, state that oraganisational risks should be managed; for example, for patients with dementia it is important to encourage mobility, even though this may increase the risk of falls, and the authors advocate for risk enablement or management that takes calculated risks.

The authors compartmentalise person-centred care in their list of seven interventions as a patient factor. This does not take into account the complex interplay of truly person-centred care. Overall, their table of seven safety interventions, with bullet point actions, are comprehensive and easy to follow. The authors do raise awareness of safety issues, including that frail older patients experience not only those types of adverse events also experienced by younger people (e.g. procedure-related complications, healthcare associated infections, adverse drug events), but also can acquire a range of ''geriatric syndromes'' and associated consequences (namely delirium, falls, incontinence, poor nutrition, immobility, functional decline and pressure sores) during a hospital admission. Unfortunately, the paper refers only to training for doctors and nurses, dismissing the role of the wider allied health professions and the important roles of support staff employed within the NHS.

Similar to Miller et al., the authors refer to the technological focus of modern hospital care. Also comparable with a wide range of papers, the rapid pace of healthcare is again noted, which the authors contend is a direct cause of harm to people with dementia. The issue of underlying societal negative attitudes towards older people, particularly those with dementia, is raised with a comment about

infantilisation of people with dementia. In summary, the authors state that patients with dementia are prone to a series of circumstances and factors in modern acute hospitals that result in adverse events, including the geriatric syndromes that can lead to a downward cascade of interacting problems, resulting in further dependence that can also lead to serious carer strain and dissatisfaction.

Reference:	Hackman, E., Tomlinson, L., Mehrez, A. and Mackereth, A. 2013. Reducing patient distress: a model for dementia care.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/Outcome**	**Findings**	**Limitations**
British Journal of Nursing. (Oncology supplement). 22(4): S13–8.	The authors provide a case study report.	This was a single retrospective case study.	A single patient (person with cancer and dementia) undergoing preparation and treatment in a radiotherapy department, accompanied by a family member.	The development of a contract of care resulted in a situation where patient sedation was avoided; instead the patient was accompanied by complementary approaches to learning mindfulness (CALM) service therapists. There was a familiar therapeutic radiographer and two CALM therapists at each session. 'In the moment' consent was monitored and discussed with the patient at each session. A family carer was	Sedation should be avoided, with relaxation techniques and validation therapy considered first line in care. The framework of care for patients, carers and families of people with dementia can be agreed in a contract of care. Relaxation techniques can	A single case study with retrospective evaluation. There were no opportunities to compare interventions or outcomes. Reported comments and observations are subjective and anecdotal to the case study, locality and service. There was

				present and had access to CCTV and intercom communication when the patient underwent radiation treatment. All staff supported the carer, answering questions and the carer was involved in decision making. There was a choice of music (or no music) during treatment. Staff should ensure time for welcomes and goodbyes with radiotherapy and CALM teams. A CALM therapist accompanied the patient at weekly review meetings.	help in the long and short term to manage anxiety, avoid panic and support self-sufficiency. To aid the person to maintain a sense of being in control, calm and successful, provide support before, during and post procedure. Ensure the person gives ongoing consent and rehearse agreed stop signs. Maintain observation for agreed stop signs and when	no evidence of service user/carer validation of the report.

					these are used, all professionals should respect them. Every person is an individual requiring an individual package of care regardless of disease or cognitive status.	
Recommendations:	Future research should formally evaluate interventions to manage panic and anxiety related to radiotherapy procedures with people living with dementia. Each individual patient requires a personalised package of care, regardless of disease or cognitive status.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; building relationships with patients and carers to optimise the patient and carer experience; strategies for optimising communication with people with dementia and their carers; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; carer partnerships. Toolbox for practitioners: A contract of care, music, relaxation techniques and validation therapy; plan for withdrawal of consent.					
Article summary:						

A multidisciplinary team of authors provided the background rationale for the study; offering statistics associated with treatment mask anxiety in radiotherapy and also anxiety especially for patients who have young onset dementia. They introduce and describe a complementary approaches to learning mindfulness (CALM) service at a single specialist cancer hospital site in the UK. A single retrospective case study is presented from the point of view of a medical student who observed a patient with dementia (ten years since dementia diagnosis) and his carer (wife), both of whom attended for a number of radiotherapy sessions. Types and stages of dementia are outlined, also issues of consent and the Mental Capacity Act 2005, followed by the case history. The team introduced a contract of care for the patient, drawing upon theories of progressive muscle relaxation, classical conditioning and validation therapy to inform care. A number of person-centred approaches were therefore used to support the patient and his carer. The authors acknowledge that comments and observations were subjective and anecdotal to the case study, locality and service. They posit that future research should investigate and evaluate interventions to manage panic and anxiety for patients undergoing radiotherapy procedures and living with dementia. Eight key points are provided, centred on anxiety, relaxation and support. The conclusion is that each individual patient requires a personalised package of care, regardless of disease or cognitive status.

Reference:	Handley, M., Bunn, F. and Goodman, C. 2017. Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/Outcome**	**Findings**	**Limitations**

BMJ Open. 7(7): e015257.	To identify features of programmes and approaches to make healthcare delivery in secondary healthcare settings more dementia-friendly, providing a context-relevant understanding of how interventions achieve outcomes for people living with dementia.	A realist review was conducted in three phases: (1) stakeholder interviews and scoping of the literature to develop an initial programme theory for providing effective dementia care; (2) structured retrieval and extraction of evidence; (3) analysis and synthesis to build and refine the	Articles were retrieved from PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Library, NICE Evidence, Scopus and grey literature. Studies not reporting patient outcomes or contributing to the programme theory were excluded.	Studies reporting interventions and approaches to make hospital environments more dementia-friendly were included. Six context- mechanism-outcome configurations (CMOCs) were found in the phase two papers: understanding behaviour as communication to improve staff's ability to respond; the role of experiential learning and creating empathy to encourage reflection for responsibilities of care; clinical experts who legitimise priorities for care; staff with confidence to adapt working practices and routines to individualise care; staff with responsibility to focus on psychosocial needs; building staff confidence to	Staff capacity to understand that the behaviours of people living with dementia are a form of communication of an unmet need, combined with a recognition and valuing of their role in their care, prompted changes to care practices. Endorsement from senior management gave staff the confidence and permission to adapt working practices to provide good dementia care. Key contextual factors were the availability of staff and an alignment	Searches were limited to 2000–2016 to reflect the impact of the work of Kitwood and Bredin on dementia care practices that recognise the importance of person-centred care and the promotion of personhood. There was no consideration of a number of authors' critiques of the work of Kitwood and Bredin. The authors felt that testing theory was problematic; evidence was limited and

		programme theory.		provide person-centred risk management.	of ward priorities to value person-centred care approaches. A preoccupation with risk generated responses that were likely to restrict patient choice and increase a person with dementia's distress. The review suggested that dementia awareness training alone will not improve dementia care or outcomes for patients. Instead, how staff are supported to implement learning and resources by	descriptive, and there were few evaluations of interventions and approaches. There were limited descriptions of setting and component parts of the interventions. Most studies included in the review reported little information around patient characteristics (e.g. type and severity of dementia), so were unable to establish how the characteristics of people living with dementia interacted with the components

					senior team members with dementia expertise was a key component for improving care practices and patient outcomes.	of the interventions to influence outcomes.
Recommendations:	How staff are supported to implement learning and resources by senior team members with dementia expertise is a key component for improving care practices and patient outcomes. The authors posit that there were three roles for change agents that could lead to improved outcomes: to support staff awareness and learning; to possess the authority to institute and sustain changes; to be a resource for staff as a clinical expert. Managerial endorsement was important – it was suggested that training for dementia should be targeted at managerial level.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision.					
Article summary: The authors provided an excellent introduction, and also a section of the paper provides a definition of what 'dementia-friendly' actually means, including supporting the independence and safety of people living with dementia. Acknowledging that the evidence base around dementia-friendly interventions is in early development, the authors assert that care is contingent upon multiple factors, including staff knowledge and skills in dementia care, the care environment, and competing demands on staff time and attention. During phase one, the authors sought to define the conditions necessary to achieve: (1) staff outcomes, such as taking action to investigate the cause of patient behaviours and applying best practice with people living with dementia; and (2) patient outcomes, such as reduced distress, reduction in adverse incidents and improved well-being. The authors posit that there are three roles for						

change agents that could lead to improved outcomes: to support staff awareness and learning; to possess the authority to institute and sustain changes; and to be a resource for staff as a clinical expert. The paper includes clear signposting to interventions with the use of in-text tables. The paper does not take the stance of a number of others, which felt that the use of experts alone could potentially concentrate responsibility for dementia care in a small staff group rather than create a culture where all staff are responsible. In common with other papers, the authors report that task-focused ways of working alongside organisational expectations for the completion of documentation and risk reduction contribute to staff apprehension about adaptations to care that are not prioritising medical and physical needs. The authors found multiple papers that highlight that the impact of changes to staff's work needed to be recognised and supported. For example, studies reported there was reduced capacity to work with previous levels of patient allocation. Clarity in staff's responsibility for patient care was an important resource for improving their autonomy and encouraging them to respond in timely, creative ways to meet individual needs. The culture of care within an organisation needs to support staff to provide good care for people living with dementia, legitimising practices so staff value them. This means organisations need to recognise the impact this has on staff workload and roles, and the changes that are necessary to ensure care provision can be adaptive to the needs of the patient. Staff need to have a clear understanding of the expectation for care standards and be confident that colleagues and senior staff accepted these changes if they are to improve the way care is provided for people living with dementia. Managerial endorsement was important – there was a suggestion that training for dementia should be targeted at managerial level.

Reference:	Houghton, C., Murphy, K., Brooker, D. and Casey, D. 2016. Healthcare staffs' experiences and perceptions of caring for people with dementia in the acute setting: Qualitative evidence synthesis.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
International Journal of Nursing Studies. 61:104–16.	The aim of this qualitative synthesis was to explore health care staff's experiences and perceptions of caring for people with dementia in the acute setting. Qualitative synthesis was intended to bring together isolated findings in a meaningful way that could inform policy development.	A screening process, using inclusion/exclusion criteria, identified qualitative studies that focused on healthcare staff caring for people with dementia in acute settings. Framework synthesis was employed using values, individualised, perspective and social (VIPS) framework and psychological as concepts to guide synthesis. The VIPS framework had previously been used for exploring approaches to caring for people with dementia.	Twelve reports of nine studies were included for synthesis. A research assistant, with support from a librarian, conducted the search using a list of databases. The search terms included all possible combinations of: 'dementia' or 'Alzheimer'; 'staff'' or 'health professional'; 'qualitative' or 'grounded theory' or 'ethnography' 'action research'; 'hospital' or	The papers examined: infrastructure and care pathways; person-centred approaches to care; how the person interacts with their environment and other patients; and family involvement in care decisions. Specifically, the authors found outcome themes and subthemes: Valuing: pathways of care, culture of care. Individualised:	The synthesis identified barriers to appropriate care for the person with dementia. These include ineffective pathways of care, unsuitable environments, inadequate resources and staffing levels, and lack of emphasis on education and training for staff caring for people with dementia. Leadership is required to instil the values needed to care for this client	Further research is needed, with a particular emphasis on measuring the effectiveness of some of the initiatives that have been introduced in the acute setting in recent years. The review explored only the perspectives and experiences of staff, but the authors state that it provides further scope

		Quality appraisal was conducted using Critical Appraisal Skills Programme (CASP) and NVivo software facilitated sensitivity analysis to ensure confidence in the findings. Data extraction was conducted on each report by two researchers.	'acute care' or 'clinical setting'; 'perceptions' or 'attitudes'; 'interviews' or 'focus groups'. Language and year parameters were not set, in order to capture as much relevant literature as possible. Articles were translated into English for full text screening.	piece of the puzzle, barriers to person-centred care. Perspective**:** interactions and impact on other patients; the built environment. Social and psychological: forming relationships; family involvement.	group in an effective and person-centred way.	for evidence synthesis focusing on care in the acute setting from the perspective of the person with dementia and their carers.
Recommendations:		The authors conclude that ultimately, there needs to be capacity, in ethos, organisation and structure, to care effectively for people with dementia in a person-centred way.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision.				
Article summary: The paper provides a short background that justifies the approach taken in the synthesis. The authors state that the paper adds to what is already known about dementia care with two main points: 1) there is a need to create capacity in the ethos, organisation and environment in which care is provided to people with dementia in acute settings; 2) capacity can be created through education,						

leadership and structural design changes to the acute environment. The authors defend the synthesis design and conceptual framework in a logical manner. Similar to this review, the authors contend that it was recognised that studies of low methodological quality can still generate insights derived from the data. Therefore, the authors noted that the purpose of quality appraisal in this review was not to exclude studies but, rather, to distinguish between studies in terms of overall contribution and methodological rigour.

Of note, once in the acute setting, patients were often transferred between settings for investigations. This could be difficult for patients with dementia. A focus on safety meant that attending to fundamental physical and psychosocial needs became less of a priority. The authors concluded that ultimately, there needs to be capacity, in ethos, organisation and structure, to care effectively for people with dementia in a person-centred way. Leadership was required at a senior level to instil the values needed for appropriate care and to ensure standards and procedures were in place within an organisation. They also describe a need to focus on ways to enhance the environment.

Reference:	Hopkinson, J., Milton, R., King, A. and Edwards, D. 2016. People with dementia: what is known about their experience of cancer treatment and cancer treatment outcomes? A systematic review.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Psycho-Oncology. 25(10): 1137–46.	The objective of the study was to report a systematic review of	A mixed-methods systematic review employed an analytic plan and inclusion/exclusion	Searches were conducted in MEDLINE, CINAHL, PsycINFO and	The psychological perspective of unmet needs underpinned the majority of papers:	The authors concluded that further work was needed to establish	The search found only cohort/survey research with no qualitative

	what is currently known about the experience of cancer treatment and cancer treatment outcomes in adults with dementia.	criteria were specified in advance of the search process in a protocol. The authors identified 5,214 titles and abstracts that were assessed against eligibility criteria and 101 were selected for full-text examination by two researchers, who agreed inclusion of nine papers, extracted data independently, then conducted a content analysis and narrative synthesis. Reporting followed PRISMA guidelines.	the Cochrane Library for publications about people with cancer and a pre-existing dementia. Search limits were: English language; 2000 to 2015 for adults; >18 years old.	when the behaviours of a person with dementia impacted cancer treatment and care then there was potential for psychosocial and behavioural interventions to contribute to improving outcomes in people with dementia who develop cancer.	practice guidelines for the management of cancer in people with dementia. The authors concluded that different rather than more cancer treatment might be appropriate for people with dementia, for example, lower dose treatment for those with greater cognitive impairment.	research exploring the experiences of people with dementia receiving cancer treatment.
Recommendations:		The authors suggested that different rather than more cancer treatment might be appropriate for people with dementia, for example, lower dose treatment for those with greater cognitive impairment.				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; building relationships with patients and carers to optimise the patient and carer experience.
Article summary: The search found only cohort/survey research with no qualitative research exploring the experiences of people with dementia receiving cancer treatment. Research into how the cancer team manages the particular needs of people with dementia and their family members was limited to one study that reported how a cancer team managed the particular needs of seven people with dementia. The authors stated that further work was needed to establish practice guidelines for the management of cancer in people with dementia. They felt that the role of family carers was overlooked. They concluded that different rather than more cancer treatment might be appropriate for people with dementia, for example, lower dose treatment for those with greater cognitive impairment.	

Reference:	Hynninen, N., Saarnio, R, and Isola, A. 2015. Treatment of older people with dementia in surgical wards from the viewpoints of the patients and close relatives.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

Journal of Clinical Nursing. 24(23): 3691–9.	The aim of this study was to describe the treatment of older people with dementia in surgical wards from the viewpoints of the patients and their close relatives.	A qualitative and descriptive design was used for this study, set in Finland. The data was collected using unstructured interviews with inductive content analysis. The data was collected from older people with dementia while they were hospitalised. The purpose was that older people with dementia could describe what they were going through at that moment. Both the older person and the close relative had the opportunity to	The data was collected at four surgical wards of a Finnish university hospital. The four wards had 90 beds altogether. The wards were treating orthopaedic, traumatology, gastroenterology, cardiac and thoracic surgery patients. Interviews with older persons with dementia (n=7) were conducted between March and October 2012. All the interviewed patients had been diagnosed with mild or moderate Alzheimer's disease, and consisted of five women and two men aged 74–85 years (average age 81 years). There were four individual interviews, and three joint	Support from close relatives was significant for the mental and social well-being of older dementia patients during their hospital stay. People with dementia felt insecure in their relatives' absence and missed them. For the relatives, the patients' hospital stay was emotionally heavy. The relatives desired more emotional support from the nursing staff. The participating patients hoped that the nursing staff would spend more time discussing their cases with	To improve treatment for people with dementia, the authors suggest that close relatives need to participate in planning the nature of care for the patients. The authors stated that the results were applicable for efforts to improve the abilities of nursing staff, physicians and close relatives in the treatment of older people with	Head nurses instructed the nursing staff to identify patients aged 65 years and older with a memory disorder diagnosis during the process of admission to the ward. As such, not all eligible patients may have been approached – it appeared that dementia may not have been documented in patient notes. Patients were recruited from surgical settings only.

		take part in the interviews as an individual or together. A further two interviews were conducted individually with only a relative.	interviews (n=2) with close relatives. The patient interviews were conducted inside the hospital surgical ward.	them. One of the factors that hindered good care of an older person with dementia was use of restraints. Relatives felt that use of restraints violated patients' dignity. The following main categories were used to characterise a person with a dementia-related disorder: (1) the personal self; (2) the self that clings to the present; and (3) the illness-related self.	dementia in acute care settings.	
Recommendations:		To improve the treatment of the people with dementia, the authors suggest that close relatives need to participate in planning the nature of care for patients with dementia.				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; carer partnerships. Toolbox for practitioners: Partnership with person and carers to plan care – care plans.

Article summary:

The authors provided detailed information about recruitment, consent, ethics and data analysis. The authors state that in older people with dementia, the 'personal self' is characterised by a desire to be in familiar surroundings; the 'self that clings to the present' was apparent in these patients' desire to return home from the hospital. Emotions expressed by patients included concern about ending up in a nursing home after the treatment, longing for home and family, refusal to give up on life, and worry about the well-being of attendant relatives. The 'illness-related self' was evident in patients' reduced cognitive function.

The authors state that results "confirm" that in this study the knowledge or resources available in acute care settings when caring for older people with dementia are "insufficient to meet the criteria of good practice".

The following main categories were used to characterise the special care needs of older people with dementia: (1) treatment required as a result of illness; (2) consideration for the patient's negative attitude; (3) the effect of the physical environment on return to convalescence; and (4) actively participating relatives. Patients also reported verbal restraints, typically in the form of nurses forbidding the patient to get up and move about. Restraints have been a common source of patient–staff conflicts. Additionally, nursing staff were focused on tasks related to the physical well-being of the patients. The authors discuss their concerns about the treatment of pain in people with dementia being related to reluctance to take medication and the use of restraint, which nurses felt was justified in some cases related to patient safety (in contrast to relatives and people with dementia, who viewed restraint as constraining liberty).

Reference:	Jensen, A., Pedersen, B., Olsen, R., Wilson, R. and Hounsgaard, L. 2018. "If only they could understand me!" Acute hospital care experiences of patients with Alzheimer's disease.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Dementia. (online publication 26 December).	The study was part of a larger study that also explored staff experiences of caring for patients with dementia in acute care settings. This particular paper concentrated on the experiences of patients.	Using participant observation, longitudinal data was gathered by following patients on day and evening shifts within a specialist orthopaedic hospital ward, commencing at patient admission and concluding at time of discharge. The data was interpreted from a phenomenological-hermeneutic perspective, inspired by Ricoeur's Interpretation Theory The study attempted	This paper investigates the care of three patients with Alzheimer's disease in an acute setting, as comorbidity to a hip fracture, and focused on patients' experiences of care during admission. The setting was a hip fracture unit in an orthopaedic surgery ward in Denmark. The	Some nurses failed to take into account the comprehensive needs of patients with dementia in terms of timely information exchange and clinical relevance. Patients expressed the desire to be more fully engaged in care decision making, together with indicating their appreciation	The process of getting to know the patient at the beginning of every shift left little room to alleviate the distress patients experienced by being in hospital. This resulted in patients who were less involved in the caring situation, or, if a patient took the initiative to act, intentions ended up being misinterpreted as	The authors point out that the decision to use a passive observer role had the consequence that the recorded dialogue was between staff and patient, and not between patient and observer directly, possibly missing

		to “overcome the fragmentation of data limitation identified in other observational studies” with a focused observation of one complete patient journey, with collection of data for one patient at a time.	unit had 13 beds, consisting of five single-bed rooms and two four-bed rooms. Staff involved in caring for the patients comprised of nurses with various levels of responsibility and experience. Detailed participant selection and consent details were included in the paper.	of the work of the health professionals who cared for them. Patients responded to this circumstance with a range of emotions, such as passive indifference, sadness, nervousness, fear, and occasional episodes of anger and violence. The experience of being a patient was expressed in multiple ways, such as self-blame and frustration about not having anything to do while in hospital, but also as a clear appreciation of the staff’s efforts	disruptive behaviour. A recommendation arising from this study was that nursing staff increase their focus towards sharing knowledge during shift changeover, regarding who the patient is as a person, and how he/she can be included in the daily activities of the ward. Improved knowledge transfer between nursing staff, combined with further professional development about the characteristics of dementia, could lead to staff forming a more positive view about	important information the patient would have liked to convey to the observer. The experiences of carers was not explored.

				to help them recover.	providing quality and appropriate care for patients with dementia.	
Recommendations:		Improved knowledge transfer between nursing staff, combined with further professional development about the characteristics of dementia, could lead to staff to forming a more positive view about providing quality and appropriate care for patients with dementia.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Strategies for optimising communication with people with dementia and their carers; building relationships with patients and carers to optimise the patient and carer experience; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; carer partnerships.				
Article summary: A comprehensive overview of the methodology and methods used in the study and issues around ethics and consent are provided. The authors refer to the World Health Organization (WHO) 'Global action plan on the public health response to dementia 2017–2025', and also to training programmes aimed at improving staff knowledge about the patient with dementia, such as the Getting to know me programme from Alzheimer Scotland The authors highlight that compared to the number of studies that represent views of acute dementia care from a care staff perspective, only a relative few studies have documented feelings about, and experiences of, acute care seen from the perspective of the patient with dementia, using techniques such observation and/or interviews. That is an important point not often raised in the literature reviewed for this SCoR guidance review.						

During observations the authors noted that although the process of informing the patient and seeking consent was prioritised by the staff, the time lapse (up to 10 minutes to confirmation) led to a disconnect between the patient's and staff's understanding of the situation. The analysis also demonstrated that the needs of the patients were superseded by set ward routines, for example, specific mealtimes. This resulted in disruption of the patients' sleep, once they had found rest, and a mealtime experience that could be quite stressful. The results in this study showed very little presence of visitors during the acute admission period – similarly Fukuda et al. also found a culture where carers found it difficult to engage on acute wards.

Reference:	Leggett, A., Connell, C., Dubin, L., Dunkle, R., Langa, K., Maust, D., Roberts, J., Spencer, B. and Kales, H. 2019. Dementia care across a tertiary care health system: What exists now and what needs to change.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of Post-Acute and Long-Term Care Medicine (JAMDA). 26(10): 1307–12.	Aimed at quality improvement of dementia care for people living with dementia (PLWD), the authors describe how the team tried to identify common	A grounded theory approach was used. Qualitative interviews were conducted with key stakeholders in dementia care	49 interviews were conducted with a purposive and snowball sampling of healthcare professionals (physicians, nurses, social workers, administrators)	The outpatient setting offered expertise, a multidisciplinary clinic, and research opportunities, but needed to respond to long waiting lists, space limitations, and a lack of consensus about	Five key recommendations were provided, including: outpatient staff education; a dementia care management programme to link services; internet-based training for	The purpose of the study was quality improvement, therefore the authors stated that the IRB (institutional review board) deemed the project not regulated.

	challenges and opportunities for care improvement and suggest viable and scalable solutions to improve the quality of care of PLWDs and their carers.	across geriatric outpatient clinics, medical and psychiatric emergency departments, and a main US hospital between 2016 and 2017. Qualitative interview guides were developed by the study team to assess the process of care and strengths and challenges to delivering that care. The stakeholders were interviewed by the project manager. Key themes from the	and families in a large, academic healthcare system.	who owns dementia care. The emergency department offered a low nurse/patient ratio and expertise in acute medical problems, but experienced competing demands and staff turnover; additionally, dementia did not appear on medical records, which could impede care. The hospital offered consultative services and resources, yet the physical space was confined and chaotic; sitters and antipsychotics could be overused, and placement outside of the	providers; and repurposing sitters as elder life specialists.	It was not clear how many family members were interviewed or how they were recruited. Definitive numbers of PWLD were probably underestimated: "Estimates come from billing data or clinician-identified problem lists for a given encounter, thus likely underestimates." The authors also stated that interviewees were important stakeholders within the healthcare system involved in dementia care, yet

		interviews in each care setting were presented.		hospital for PLWDs was a challenge.		the information provided may not reflect the opinions or process of care for all. Generalisability may be limited in examining one rather than multiple healthcare systems.
Recommendations:		Suggestion to repurpose "sitters to elder life specialists". Sitters were underused as a resource to actually engage with patients (e.g. using their phone and not interacting with patients). Elder life specialists could be trained to tailor their approach to the needs of the PLWD, including engaging activities, room modifications, and enhancing safety.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; building relationships with patients and carers to optimise the patient and carer experience; training needs.				

Article summary:

The authors provided argument that increasing numbers of people living with dementia in the US posed a growing care challenge for health systems. They estimated that there were 3.4 admissions per person living with dementia (PLWD) on average, a figure that is comparable with UK estimates. The background and lack of investment in coordinated and person-centred care in this US setting reflected the findings of studies across a range of countries.

Several hospital-based programmes and services in this study assisted with care for people with dementia. For example, the No One Dies Alone initiative provided a volunteer to sit with a patient at the end of life, while 'elder life' volunteers spent 30 minutes twice daily with patients to prevent delirium, falls, and restraints, and reduce length of stay. The adult psychiatry unit at the hospital, if a person with dementia was admitted with agitation, viewed their role as modifying behavioural symptoms with medications – not an approach taken in the UK or advocated by the National Institute for Health and Care Excellence (NICE) or dementia action groups.

Comparisons between radiography and the emergency department (ED) setting of this study can be drawn: "Patients typically do not present with complaints of dementia, a diagnosis is not made in this setting; thus the role of dementia care is viewed as indirect." Family members or long-term care staff were relied on to provide information. The ED was described as an "exceptionally unfriendly place for anybody with dementia" because of its chaotic nature, lack of natural light, staff turnover, and uncomfortable, disorienting environment.

This study brought a suggestion, novel to this review, to repurpose "sitters to elder life specialists". Sitters were underused as a resource to actually engage with patients (e.g. using their phone and not interacting with patients). Elder life specialists could be trained to tailor their approach to the needs of the person with dementia, including engaging activities, room modifications, and enhancing safety. Optimising quality and efficiency of care, individualising dementia care, ensuring an adequate, qualified workforce, and developing comprehensive models for dementia care, services and support were all key themes and recommendations from stakeholders. No information was included about the number of families who were interviewed or their contribution to the study.

Reference:	McCorkell, G., Harkin, D., McCrory, V., Lafferty, M. and Coates, V. 2017. Care of patients with dementia in an acute trauma and orthopaedics unit.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Nursing Standard. 31 (36): 44–53.	To increase awareness of the needs of patients with dementia in a trauma and orthopaedics unit at an acute hospital, and to collaborate with staff on the unit to identify ways of improving the care experienced by patients and their families.	Three action research cycles included training in the use of a toolkit that was developed by staff. The cycles involved the implementation of the toolkit and training in its use, repeat observations post implementation of the toolkit and comparison of pre and post implementation audit results.	20 patients with dementia who were admitted to the unit for treatment.	The researchers identified deficiencies in care related to communication, pain management and recognition of delirium. Staff on the ward developed a dementia toolkit with training for nurses.	Audit results post implementation of the toolkit indicated a significant improvement in all aspects of care for people with dementia. Action research was used to inform and improve clinical practice. Dementia champions were trained on the ward.	
Recommendations:						

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs. Toolbox for practitioners: A table of advice about how to communicate with a person with dementia was included in the paper.
Article summary: For a large proportion of people with dementia admitted to the ward, there was no record of what type or stage of dementia the person had. A first cycle of action research agreed the development of a toolkit for staff. The toolkit consisted of information, charts, documents and advice to overcome the deficiencies in care that were identified by an audit. Patients were identified by the use of a purple folder replacing a black folder at the end of their bed. The authors note that Alzheimer's Society has deemed purple to be the international colour representing dementia – this contradicts the action noted by Bray et al. (2015) on the use of a red wrist band to identify people with dementia. A 'traffic light' communication sheet was used rather than a 'This is me' document. The authors discuss pain management, including difficulties that people with dementia can have communicating pain, and outline the use of a cognitive impairment pain assessment scale. It was noted that physical signs of pain can include fidgeting, fist clenching or changes in eating patterns. In the presence of pain, reactions to other people could include pulling, pushing people away and striking out. Visual signs of pain include facial expression and speech (e.g. appearing tense, groaning or crying out). The paper raised awareness of delirium (sudden deterioration in mental functioning caused by acute illness, injury or drug intoxication) with links to unfamiliar surroundings, pain, dehydration, constipation and infection. The group developed a flowchart for the recognition and management of delirium. The authors posit that training delivered in a clinical setting may be more feasible and have greater potential to enhance practice.	

Reference:	McWilliams, L., Swarbrick, C., Yorke, J., Burgess, L., Farrell, C, Grande, G., Bellhouse, S. and Keady, J. 2018. Bridging the divide: the adjustment and decision-making experiences of people with dementia living with a recent diagnosis of cancer and its impact on family carers.

Source	Purpose	Design	Sample	Intervention/Outcome	Findings	Limitations
Ageing and Society (published online 25 October 2018).	The authors sought to explore the cancer and decision-making experiences of people who live with both dementia and cancer and their family carers. The authors included participants' recollections and experiences of radiotherapy care.	A qualitative design using semi-structured interviews.	The study was set in a regional cancer centre (tertiary care) in North West England.	The authors describe a number of themes: 1) reaching a diagnosis of cancer; 2) adjusting to the cancer diagnosis when living with dementia; 3) weighing up the cancer treatment options; and 4) undergoing cancer treatment. Participants and carers discussed the fluctuating cycles of awareness and unawareness of disease states.	The authors add the intersection of gender with dementia, noting high levels of female diagnosis, which raised issues of health inequality. People living with dementia often had intertwined diagnostic and long-term conditions.	Recruitment was from a single cancer centre. This was a cross-sectional time-limited study. Participants were of limited ethnic diversity.
Recommendations:	Dementia is best managed through clinical leadership, staff education, and person-centred collaborative care. Advice was to slow down procedures for people with dementia and to recontextualise words and experiences so that people with dementia can hold onto and make sense of them e.g. the hospital was the "big white house" for one person.					

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Building relationships with patients and carers to optimise the patient and carer experience; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; the practice environment – acknowledging the need for special provision.

Article summary:

The study highlighted the sense of responsibility that carers can feel for assisting both the healthcare professional and also the person that they support. Carers described taking on a role of relayer of information, utilising their longitudinal and biographical knowledge of the person and their communication needs. A person with dementia was able to articulate a sense of pain and distress at undergoing personal and intimate clinical investigations. A theme of personal and emotional pain together with feelings of personal invasion was evident.

Participants and carers spoke about fluctuating cycles of awareness and unawareness of disease states. As with other studies, advice was to slow down procedures for people with dementia. Triadic consultation between the person living with dementia, the healthcare practitioner and the family carer should be considered the norm. The authors discuss current human rights legislation and mental capacity law and reminded the reader that people with dementia make decisions and sense of the world around them with a limited palette of communication, spatial and remembering abilities. Advice was to recontextualise words and experiences so that people with dementia could hold onto and make sense of them e.g. the hospital was the "big white house" for one person. This was described as one aspect of making space for creativity and inventiveness in communication strategies. The conclusion reminded practitioners that people living with dementia may have intertwined diagnostic and long-term conditions.

Reference:	McWilliams, L., Farrell, C., Keady, J., Swarbrick, C., Burgess, L., Grande, G., Bellhouse, S. and Yorke, J. 2018. Cancer-related information needs and treatment decision-making experiences of people with dementia in England: a multiple perspective qualitative study.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
BMJ Open. 8(4): e020250.	The aim of this study was to explore the cancer-related information needs and decision-making experiences of patients with cancer and comorbid dementia, their informal carers and oncology healthcare professionals (HCPs) at a regional cancer	A cross-sectional qualitative study employed semi-structured interviews that were conducted face to face with participants.	Participants were a purposeful sample of ten patients with a diagnosis of cancer and dementia, nine informal carers and twelve oncology HCPs.		Four themes were identified: (1) leading to the initial consultation – HCPs require more detailed information on the functional impact of dementia and how it may influence cancer treatment options prior to meeting the patient; (2) communicating clinically relevant information –informal carers are relied on to provide patient information, advocate for the patient and support decision making; (3) adjustments to cancer care –patients with dementia get through treatment with the	The authors suggested a longer prospective study would offer further insights. They concluded that future research is essential to develop suitable interventions for people living with dementia before, during and after cancer treatment.

	treatment centre.				help of their family; and (4) following completion of cancer treatment – there are continuing information needs, and oncology teams should strive to involve healthcare staff with dementia expertise as early as possible in the cancer pathway	
Recommendations:		The study outlined the importance for the person with dementia of having an accompanying carer who they were acquainted with, a "familiar face". This reinforces SCoR's support for John's Campaign for carers to remain with people with dementia in hospital, should they wish to do so.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Carer partnerships; the practice environment – acknowledge the need for special provision; strategies for optimising communication with people with dementia and their carers. Toolbox for practitioners: A need to 'slow down' was again a feature of providing better care. Adjustments to support treatment included not using written information leaflets for some patients. Changes to the language used around radiotherapy should also be made and tailored for the patient, for example, the radiotherapy mask was a "wet towel".				

Article summary:
The authors assert that little is known about the cancer experience and support needs of people with dementia. Family members for eight patients provided proxy consent and a thematic analysis was performed with themes outlined in the table above. Of particular note, the authors found that there was limited healthcare professional awareness of the potential impact of dementia on cancer diagnostic investigations. The role of healthcare professional perceptions about dementia impacted on care, reflected also in the work of Miller et al. in the table below (2019). The authors suggest a longer prospective study would offer further insights. They concluded that future research is essential to develop suitable interventions for people living with dementia, before, during and after cancer treatment.

Reference:	Miller, P., Booth, L. and Spacey, A. 2019. Dementia and clinical interaction in frontline radiography: mapping the practical experiences of junior clinicians in the UK.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Dementia. 18 (3): 1010–24.	An exploration of "how a patient's dementia can impact on everyday clinical practice and	Extended semi-structured interviews took place with six participants. Mean interview length was 40 minutes.	Six 'junior' radiographers (mean 3.5 years' diagnostic radiography experience). Recruitment was	Analysis resulted in three overlapping superordinate themes relating to the experiences of	The basic education of participants was insufficiently tailored to practical clinical contexts.	A small sample size from two centres, concentrated upon what the authors contend were 'junior

	practitioners in the patient facing medical imaging professions". The authors aimed to add nuance to the broader social scientific literature on the work of healthcare practitioners involved in the care of individuals with dementia.	Analysis with interpretive phenomenological analysis. Triangular consensus validation was used to reach consensus on the validity of themes.	from two NHS hospitals in the north of England – theoretically-informed opportunity sampling.	the participants: (1) confidence, experience and education; (2) practical and technological constraints on effective practice; and (3) complexities of carer input. The authors stated that a broader examination of more senior imaging professionals is required.	There were implications around junior radiographers' ability to actively assess informed consent (a need for future research in the area). Junior radiographers required more training to actively manage people with dementia.	clinicians' although that is not a term used in practice. It was not clear which modalities the participants worked in. The paper refers to "those naturally dissociated from dementia", which essentially dismisses the intersection of life and work experience – staff have personal and social experience of dementia in addition to professional life.
Recommendations:		Junior radiographers require more training to actively manage people with dementia. There were implications around radiographers' ability to actively assess informed consent (a need for future research in the area).				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision; staff skills and attitudes; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs. Toolbox for practitioners: Consider the effects of too many people being present in an examination room and an examination being too noisy. Discuss the importance of familiar objects for some patients, for example, bringing in a carrier bag full of belongings.

Article summary:

This qualitative study employed six semi-structured interviews with 'junior radiographers' (average 3.5 years' diagnostic radiography experience). The authors stated that there was no substantial literature to date studying staff in medical imaging and dementia, essentially dismissing the work of Challen, Low and McEntee (2018) (in table above).

Miller, Booth and Spacey found that participants lacked confidence in their knowledge around dementia and used a generic rather than person-centred application of the term, recognising only early and late stages of dementia, not different forms. Negative aspects related to care included: institutional time pressures; lack of quantity and tailored context-relevant education, affecting professional confidence and ethical practice; the potential positive or negative effects of carer presence; and technology affecting effective interpersonal care of patients. When individual staff perceived their self as knowledgeable and/or experienced around dementia patients, then they were confident in their practice.

Lack of time was cited as a reason for lack of nuanced care, in line with other studies, despite the potential to "actively agitate" people with dementia – an interesting point. The study linked the effects of technology to detrimental interpersonal relationships between staff and people with dementia. Carers were regarded as either a beneficial familiar presence or translator or paradoxically as damaging to the examination – referred to as interpersonally difficult variables added by significant others. The personalities of staff and patients were also mentioned as influencing care, but not carers.

The authors linked “uneven practice” to lack of education of staff, including “non-clinical” members of imaging teams. The authors recognise that specific behaviours of people with dementia (sometimes referred to as challenging) can indicate unmet needs, including lack of interpersonal interaction, problems with lighting levels, noise, heat or unarticulated pain. The authors attempt to differentiate between the ‘that’ of dementia and the ‘how’ of dementia to inform best clinical practice. However, they go on to state that the value of better training and education for professionals was still foregrounded as essential for “standardising practice” among all clinical and non-clinical staff within a medical imaging department. Standardisation of care is not necessarily an intention of this SCoR guidance review, rather an ethos of individualised and person-centred care.

Reference:	Nayton, K., Fielding, E., Brooks, D., Graham, F. and Beattie, E. 2014. Development of an education program to improve care of patients with dementia in an acute care setting.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of Continuing Education in Nursing. 45 (12): 552–8.	The authors describe the development and delivery of a tailored education programme to improve the quality of care	Action research design included: a survey and audit of current attitudes and self-rated knowledge of participating staff; an audit of the	The programme was delivered to 49 participants from two wards in late	Designed for a specific context, environment and knowledge levels, the programme was developed from multiple inputs, including expert	The areas in which staff were most hoping to improve were communicating with people with dementia and the ability to	The authors described a range of actions that were taken to develop a training programme, but it is unclear

	for people with dementia in a large, urban hospital in Australia. Specifically, the programme aimed to provide staff with tools, including evidence-based assessment and observation techniques, to better understand the needs and experiences of an acutely ill person with dementia and to be reflective about their practice.	hospital environment; informal discussions with family carers; and a literature review of workplace and dementia care training programmes. The authors suggest a need for post-education strategies in the form of dementia champions and a sustainability-focused workshop.	2012. Participants included 45 nurses, three occupational therapists and one social worker.	opinion, literature on workplace and dementia care training, and feedback from participants. The programme was delivered to acute care nurses and allied health staff in an outcome-based, microteaching model. The broader applicability of the development and delivery techniques used in the programme was also discussed. The programme was expected to provide the foundation upon which longer-term cultural change could be built.	assess their condition in practice (e.g. pain, agitation, depression).	how many family carers were consulted or who the 'experts' were.
Recommendations:		A tailored dementia education programme can help address identified knowledge deficits and local barriers to implementation.				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Training needs.

Article summary:

The authors comment that with a rise in the number of people with dementia, acute care settings will be disproportionately affected because they tend to have an older population than, for instance, the primary care setting. Other studies dispute that statement, although that was perhaps the case in Australia in 2014. The authors do align with other studies when they report that concerns have been raised about the ability of acute care staff to care for acutely ill people with dementia, with lack of knowledge about dementia and negative attitudes being cited as barriers to providing quality care. This can result in the inappropriate use of physical and chemical restraints.

Prior to taking part in the programme, many staff expressed that they experienced difficulty and strain caring for people with dementia, as well as a lack of understanding of behaviours and factors that influence dementia outcomes.

The authors describe a range of actions that were taken to develop a training programme, but it is unclear how many family carers were consulted or who the 'experts' were.

Reference:	Parke, B., Hunter, K., Schulz, M. and Jouanne, L. 2019. Know me – A new person-centred approach for dementia-friendly emergency department care.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
Dementia. 18(2): 432–47.	A research study to determine the feasibility of a communication-tool intervention. An aim was to determine the feasibility of the structure, format, and content of eight hospital-readiness communication tools in French and English. The following research questions guided the investigation. What are caregivers' perceptions of the strengths and	An interpretive, qualitative, exploratory design. Data collection involved English and French-language carer focus groups in two Canadian provinces. The focus group process followed three steps. First, participants reflected on their experience of coming to and leaving the emergency department.	Purposive and snowball sampling to recruit 14 carer participants whose relatives had visited an emergency department (ED).	The participants identified practical issues that could affect the usability of the tools that included updating information, keeping more than one copy in different locations, and remembering to gather the tools back when being discharged from the ED. All participants indicated the need for clarity regarding who is responsible for the tool. Responsibility involved the following aspects:	The carers' role in accompanying older people with dementia to the emergency department was supported by the hospital-readiness tools. The seven modified hospital-readiness tools had the potential to promote safety and support successful hospital visits. These findings have the potential to: (a) improve safety in emergency care to older people living with dementia and their carers: and (b) offer cost-effective	The authors state that the findings were limited to female participants' views. Male carers' perspectives should be sought to avoid gender bias.

	weaknesses of the communication tools? How can access to the communication tools by potential caregivers be supported and facilitated? What do caregivers recommend be changed in the communication tools to improve their usability and feasibility?	Second, participants silently reviewed a hard copy of each tool in succession, and made handwritten notes, later collected at the end of the focus group. Finally, a facilitated discussion using a semi-structured interview guide concluded the focus group.		who fills out the document; who is the keeper of the information in the document for updates; and where the documents should be located for timely access.	communication tools for web-based knowledge translation activity in acute care. The final version of the tools can be downloaded in both French and English on the Alzheimer Society of Canada website.	
Recommendations:						

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; building relationships with patients and carers to optimise the patient and carer experience; strategies for optimising communication with people with dementia and their carers; understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs. Toolbox for practitioners: The final version of the hospital-readiness tools can be downloaded in both French and English from the Alzheimer Society of Canada website.

Article summary:

Participants reported reasons for their relative coming to the emergency department (ED) as injuries sustained from falls, laceration, fever, pain, immobility, infections, agitation and restlessness, dehydration, stroke and facial paralysis. Participants felt that sharing information contained in the tools with emergency department staff could decrease the likelihood of responsive behaviours occurring in a very stressful environment. This suggested that improvement in the experience could be achieved for carers, people with dementia, and healthcare professionals providing ED services.

During focus groups carers could see perspectives from multiple angles: the older person with dementia, the carers themselves, or other family members who might disagree with each other. They were skeptical that the information would be used by ED nurses, who were perceived as not having the time, or possibly the interest, to read the information. Participants raised the concern that ED staff lack knowledge about what constitutes a 'normal' response from someone living with dementia. The authors asserted that self-empowerment through the hospital-readiness tools was a useful way to diminish unintentional harm that may arise from traditional ED care practices. They made comparisons with evidence in the mental health and intellectual disabilities field that shows that self-empowerment, advocacy and communication tools can improve care. Participants agreed that the hospital-readiness tools encouraged self-empowerment through an exchange of specific dementia information. Participants also agreed that information exchange could reduce hospital-acquired harms.

The self-advocacy approach promoted by the hospital-readiness tools was considered by the authors to be different from other communication tools because the definition of crucial information was determined by the direct experience of study participants. Changing transitions were particularly difficult for people with dementia. As fear and anxiety increased in the person with dementia, their care partners also experienced enhanced worry and concern. Carer involvement and contribution to information sharing enabled them to share their expertise with the emergency nurse, proactively raising awareness of what may trigger agitation or distress reactions.

Reference:	Pinkert, C., Faul, E., Burgstaller, M., Kamleitner, D., Mayer, H. and Saxer, S. 2018. Experiences of nurses with the care of patients with dementia in acute hospitals: A secondary analysis.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Journal of Clinical Nursing. 27 (1): 162–72.	To describe nurses' experiences in caring for people with dementia in acute hospital settings. The authors asked: How do nurses	A qualitative secondary analysis was conducted. Data was collected using audio-recorded focus group discussions with nurses in Germany and Austria. Two similar qualitative studies based on focus group interviews had been	Overall, twelve focus group discussions, which were part of two larger research projects in Germany and Austria, were expanded into a qualitative	Themes were formed: alterations in nursing care routines; sticking to routines; becoming involved; breaking routines; establishing a new normality;	Hospitals must minimise constraints to give every nurse the chance to perform person-centred care. Furthermore, it is important to sensitise nurses	No validation from original focus groups. Focus on the nursing profession only. It was not clear what

	experience the care they provide for people living with dementia? What are the general conditions related to the provision of nursing care for people with dementia in hospitals?	conducted in Austria and Germany. The research questions for the Austrian study were: (1) What types of problems in the care of patients with dementia do nurses face in acute hospitals? and (2) What are the strategies nurses use to handle these problems? The German study attempted to answer the following research questions: (1) How do hospitals handle the challenge of treating people with dementia in the hospital? (2) Which difficulties/problems lead to the development of dementia-specific care concepts? and (3) What specific measures are being implemented to improve the care of people with dementia?	secondary analysis (a content analysis). The methods of the two primary studies were comparable: the focus groups raised similar questions and were based on semi-structured guidelines, audiotaped, transcribed verbatim and analysed using content analysis. Austrian and German healthcare systems are roughly equal in terms of the education and working conditions of	contextual constraints; interdisciplinary collaboration; professional role of nurses; skills and education; and staff and time resources.	and give them sufficient training and education to enable them to care for people with dementia.	areas of acute hospitals the nurses worked in.

		Analysis allowed an examination of existing data from another perspective and answered a new research question based on a broader sample.	nurses and the development of dementia care in acute care practice. The focus groups were conducted in similar settings under similar conditions.			
Recommendations:		Not only a team approach but also a philosophy of care throughout the entire institution is important when implementing person-centred care. The VIPS framework for person-centred care goes beyond this idea and highlights the importance of valuing people with dementia. The authors champion the introduction of on-ward volunteers, the systematic involvement of family carers and the improvement of communication between institutions to reduce uncertainty.				
Aspects of the guidance document the reference can inform:		Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; staff skills and attitudes; strategies for optimising communication with people with dementia and their carers.				
Article summary: As is the norm in dementia papers, the figures and projected figures for people living with dementia were quoted, along with explanation of the presenting conditions and also poor outcomes that can arise for people with dementia in acute hospitals. Similar to other international studies, nurses in both Austria and Germany described their daily routine as task orientated and standardised. For some nurses, the stability of existing routines provides a sense of security and control. Others attempt to alter routines to adjust						

nursing care to the needs of people with dementia. Patients who cannot adapt to the hospital routine were perceived as disturbing the routine.
The authors contended that to become involved with people with dementia, nurses must stray from familiar routines and become creative. Rigid routines and standardised care plans were not suitable for an individualised approach. However, nurses felt uncomfortable when they did unusual things, such as looking at photo albums with patients. Nurses' engagement was characterised by uncertainty because they feel torn between the perceived need to become involved and their duty to abide by organisational constraints that hamper person-centred care. Interestingly, the authors state that the familiar routines in hospitals largely follow the requirements of diagnostics and therapy – reflecting the work of radiographers. Breaking these routines also meant changing the perspective from disease-orientated to patient-centred care.

The creation of a dementia-friendly design was one factor that should contribute to a familiar, home-like environment and a better orientation. Another approach was offering an activity programme that helped structure the day and prevent boredom among patients. Communication training and education about dementia helped increase nurses' awareness of the specific needs of people with dementia. The strategies described were not solely supported by the commitment of individual nurses but are the result of an organisational strategy to make the hospital dementia-friendly. Nurses who recognised the need for change in care routines often referred to contextual constraints as hindering factors. Experienced nurses who have personal contact with older people give the impression that they are more prepared than their less experienced colleagues, who seemed to be overstrained by the special needs of patients with dementia. The lack of time and staff were the most frequently mentioned limiting factors of good dementia care. The authors concluded that healthcare teams should work together to prevent situations in which only individual nurses advocate for people with dementia. The literature in this review tends to confirm that approach and adds that teamwork should be undertaken alongside people with dementia and carers.

Reference:	Porock, D., Clissett, P., Harwood, R. and Gladman, J. 2016. Disruption, control and coping: responses of and to the person with dementia in hospital.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
Ageing and Society. 35 (1): 37–63.	This qualitative study aimed to gain insight into the experience of hospitalisation from the perspectives of the older person with dementia, their family carer and other patients sharing the ward (co-patients). The study was part of a wider, quantitative study, not reported in this paper.	Non-participant observation of care on acute hospital wards was supplemented by semi-structured interviews with family carers and four co-patients following discharge. Staff often spoke to the researchers in the course of the observation and field notes from these ad hoc conversations were used to support contextual descriptions. The study involved 72 hours of non-participant observations of	Recruitment was from two major hospitals that were part of a single NHS trust within the East Midlands region of the UK. Observations on eleven acute hospital wards. 39 semi-structured interviews with 35 family carers and four co-patients following discharge. All participants had been recruited to the cohort study and had been admitted to	Constant comparative analysis produced a 'core problem' facing all those involved – disruption from normal routine. Disruption adversely affected the person with dementia, triggering some constructive but also disengaged, distressed and neutral behaviours.	Using Kitwood's seminal model of person-centred care, these behaviours were interpreted as attempts by the person with dementia at gaining a sense of control over the unfamiliar environment and experience. Family carers' lives and experiences both inside and outside the hospital were disrupted by the hospitalisation. They too attempted to gain a sense of control over the experience and to give a sense of control to the	There are no details as to who undertook the analysis of data. The authors report that the study was limited by the reluctance of co-patients to be interviewed after discharge – just four people agreed. Another limitation was the reliance on observation to reveal the patient's experience rather than

		care on 45 occasions on eleven wards of the study hospital, including orthopaedic surgery, health care of older people and general medicine. Most observation periods lasted between one and two hours (range 45–180 minutes).	hospital for acute medical care. Typically, patients were admitted with a very wide range of medical diagnoses, often associated with a non-specific presentation such as falls, immobility or worsening confusion. All participants for the present study were identified by the researchers on the cohort study and had some loss of cognitive function using the mini mental state examination (MMSE). Recruitment		patient, co-patients and staff. Co-patients experienced disruption from sharing space with the person with dementia and were left feeling vulnerable and sometimes afraid. They too attempted to gain a sense of control over their situation and give some control by helping the person with dementia, the family carer and the staff.	interviewing the patient while they were in the hospital environment.

			occurred over 12 months.			
Recommendations:		There must be recognition that disruption from normal routine does not just affect the person with dementia in hospital but also affects the way in which family carers interact with their relative, the staff and the other patients in the ward.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Understanding patients' behaviour and adopting positive ways to reduce distressed reactions to unmet needs; the practice environment – acknowledging the need for special provision; staff skills and attitudes.				

Article summary:

This study is relatively rare in that it seeks the experiences of people living with dementia, their family members and fellow ward patients about their care, rather than staff perceptions. The authors considered that, although the study aimed to understand the experience of the person with dementia, the reality was that "these patients could not always tell us their stories, particularly while acutely ill, or reflect back on their experience in hospital", which "meant that inevitably there would have to be interpretation: indeed interpretation beyond that normally expected in qualitative research".

There was a comprehensive description of the study design and analysis although it is not clear who undertook that analysis. The authors found that when a person with dementia was admitted to hospital they experienced disruption of normality; behaviours and responses were different and often unanticipated, routines were broken and the consequence of this was difficulty and distress. There was a great deal of disruption for family carers. Not only did they have the worry over the acute illness and the need to get to the hospital each day to visit, but the services that they had in place at home or in the care home were at risk, which could cause further

disruption, difficulty and vulnerability when the person with dementia was discharged. Another source of disruption was with the 'system' itself. Implicit in family members' comments on the organisation of care was the idea that staff were not adequately trained on how to care for the person with dementia. For one nurse who spoke to the researcher during an observation on a ward, the problem was not only the organisation of care but also the philosophy or purpose of the hospital in relation to the person with dementia; "hospitals are about cure rather than care. Here we cure, in the nursing home we cared". Without adequate understanding through training, or without adequate change in the system, hospital health professionals will continue to be left at a disadvantage in caring for people with dementia. The authors go on to describe 'core processes' taken to gain control in the environment.

The authors provided information about their theoretical framework (rarely discussed in other studies). These findings can be better understood when considered in the light of two theoretical concepts: The Therapeutic Quadrangle and Systemic Theory In these terms, the patients with dementia appeared to seek a feeling of control by constructive, disengaged, distressed or neutral behaviours. The study therefore contributes an interpretation of the actions of people with dementia, carers and co-patients – it gave people with dementia agency and provided staff with explanation for possible behaviours that they may encounter in clinical practice.

Reference:	Prato, L., Lindley, L., Boyles, M., Robinson, L. and Ableу, C. 2018. Empowerment, environment and person-centred care: A qualitative study exploring the hospital experience for adults with cognitive impairment.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/Outcome**	**Findings**	**Limitations**

Dementia. 18(7): 2710–30.	The study aimed to explore the positive and negative experiences of older adults with cognitive impairment (dementia and delirium) and their relatives and/or carers, during an acute hospital stay, from admission to discharge.	A qualitative, case study methodology. Data was collected via ethnographic, observational periods at each stage of the hospital journey and through the use of semi-structured interviews with relatives, carers and healthcare staff, including medical staff, nursing staff, physiotherapists and ward managers. Ethnographic observations and 18 interviews with ward staff and relatives were undertaken. Interpretive phenomenological analysis was used to facilitate data analysis.	One large NHS foundation trust in the north of England acted as a single case, with patients being followed throughout their hospital stay from admission through to discharge. Six participants with cognitive impairment, eight relatives and 59 members of the healthcare	An outcome of the interviews was that participants identified a requirement for a ward-based activity service for patients with cognitive impairment.	Three superordinate themes were determined from the data that authors described as crucial in determining the quality of the hospital experience: 1) valuing the person; 2) activities of empowerment and disempowerment; and 3) the interaction of environment with patient well-being. Whether the patient's hospital experience was positive or negative was powerfully influenced by family involvement and ward staff actions,	The authors stated that due to the limited sample size, it was not possible to generalise to alternative populations. The sample was biased towards adults with cognitive impairment who are able to vocalise and mobilise, either with assistance or independently. Therefore, the experience of the participants will not reflect the experience of adults with advanced cognitive dementia.

			team were recruited. The recruitment criteria considered an older person to be someone over the age of 55. Five patient participants were recruited from an assessment suite and one participant from the emergency department.		also communication. The authors supported a move towards care that explores measures to improve and expand relative involvement in hospital care.	The ethics committee stipulated the requirement for consent from a personal consultee. This meant that researchers were only able to recruit participants with an available family member. Consequently, the sample is biased towards adults admitted from home, since potential participants admitted from a residential facility were usually accompanied by professional

						carers not relatives.
Recommendations:	Emotional experience was paramount to the patient perspective. Staff should be aware that current emotional experience was often represented by discussing past experience. There were occasions where researchers observed relatives undermine the agency of the patient, and it was considered to be vital that in any protocol a balance is achieved between relative involvement in hospital care and ensuring the independence of the patient with cognitive impairment.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Strategies for optimising communication with people with dementia and their carers; the practice environment – acknowledging the need for special provision; building relationships with patients and carers to optimise the patient and carer experience. Toolbox for practitioners: Emotional experience was paramount to the patient perspective. Staff should be aware that a person with dementia's current emotional experiences were often represented by discussing past experience.					
Article summary: The authors commented that to ensure the research was principally patient focused, extracts from informal conversations with participants with cognitive impairment were included in the results section of this paper. The authors provided a succinct overview of the consent process in relation to the Mental Capacity Act 2005, including an example of fluctuating capacity for a person living with dementia; for example: "Originally a family member acted as a consultee but later Dorothy gained capacity and consented for herself. Dorothy was aware that she was in hospital." The authors note that some of the patients were unable to comment directly on their hospital stay as a whole, as they were unaware that they were in hospital or that they were receiving medical care. However, they						

were able to comment on their emotional experience of the immediate context, such as their boredom with their surroundings and their immediate responses to interactions with staff members. Emotional experience was paramount to the patient perspective.

Current emotional experience was often represented by discussing past experience. At times, relatives appeared to prioritise practical elements of the patient's hospital stay, such as whether their clothing was clean and whether they received adequate food, over the emotional and social requirements of their cognitively impaired relatives. Ward staff acknowledged that there may have been some discord between the person-centred care that they would ideally like to provide and the reality of the care provided in the acute setting.
Nurses stated that they should find out the background of a person to treat them as an individual; however, researchers observed that in reality ward-based staff limited their knowledge to everyday information, such as "drinks that they prefer, or what they like to be called", according to a staff nurse. Ward staff identified that information cards were able to help facilitate an empowering and positive hospital experience. However, staff identified that there are some barriers to utilising the cards appropriately in the ward context; "those information cards are good, on the tables, they're good. But it's just getting time to hand them out sometimes, and then getting the relative to fill it in", said a student nurse. Echoing the findings of other studies, carers and relatives identified that where staff were task orientated, there was a negative and disempowering impact on their relative's hospital experience.

Another issue was around locating missing items, such as reading glasses or appropriate footwear; "Left without the correct glasses, Ann was unable to perceive items accurately and this impacted on her recovery period". With regards to environment, observations suggested that patients found being in a cubicle a negative experience, as they were isolated from other patients and company. Ward staff, relatives and the patients themselves commented on the positive nature of being in an area with other patients. Betty, a person with dementia, commented: "It's nice to see other people and what they are doing." The boredom expressed by patients often translated into feelings of entrapment. Both staff and relatives suggested that a way to improve the hospital experience would be to enable patients with cognitive impairment to take part in some form of meaningful activity.

The authors concluded that discussion frequently focuses solely on the concept of patient-centred care, which positions the nurse as the subject, acting upon the passive object of the patient. The study showed that participants, although cognitively impaired, were able to take an active role in their care and seek a relationship with ward staff in which they are empowered, equal partners. However, there were occasions when researchers observed relatives undermine the agency of the patient, and concluded it was vital that in any

future protocol a balance be achieved between relative involvement in hospital care and ensuring the independence of the patient with cognitive impairment.

Reference:	Sampson, E., Vickerstaff, V., Lietz, S. and Orrell, M. 2017. Improving the care of people with dementia in general hospitals: evaluation of a whole-system train-the-trainer model.					
Source International Psychogeriatrics. 29 (4):. 605–14.	**Purpose** To evaluate a 'train the trainer' model of implementing dementia training in the UK. The authors in this study used a person, interactions and environment (PIE) qualitative practice development	**Design** A multilevel mixed methods design, using a change framework, with data collected at individual, ward and organisational level. Use of validated questionnaires pre and post training and at a three-month interval. A PIE tool to structure	**Sample** Eight acute NHS hospital trusts in London, UK.	**Intervention/ Outcome** Each observation (unit) identified was assigned to a key theme and subtheme: (1) interaction; subthemes – frequency, initiation, consistency of approach across staff, inclusivity of the person with dementia,	**Findings** There was a significant improvement in staff's sense of competence in dementia care and the quality of interactions with patients. Hospitals adopted person-centred tools and pathways. Work is required to investigate if these changes improve	**Limitations** Institutional ethical approval was not obtained – the authors assert that the PIE structured observations were a quality improvement tool. Individuals were asked for

	tool to describe the culture of care experienced by people with dementia.	observations of practice. Authors tested for a difference in treatment effect in subgroups by trust in which the participant worked. Intervention effect estimates by subgroup were displayed in a graph. The number of missing observations was reported. Descriptive comparisons and chi-squared statistical tests, to see if those who completed the follow-up questionnaire were different, compared to those who only completed the		responding to patient cues; (2) connecting in a meaningful way; subthemes – knowing the patient as a person, helping the person to participate in care; and (3) environment; subthemes – orientation and support (including mobility, hearing, toileting and bathing, privacy and dignity, allowing to walk around and flooring).	hospital outcomes for people with dementia. Organisational level data suggested increased use of a carer's passport, 'This is me' documentation, dementia information leaflets, delirium screening and work to scales and pathways. PIE observations demonstrated improved staff–patient interactions but little change in hospital environments.	verbal consent only. People with dementia were not involved in the description of their experience, a limitation of the study.

		baseline questionnaire.				
Recommendations:		Strategies to improve care should be targeted at four levels: 1) individual, 2) group/team, 3) organisation, and 4) system or environment.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Training needs; strategies for optimising communication with people with dementia and their carers.				
Article summary: The authors of this paper provided a clear audit trail that details the development of a 'train the trainer' package. The approach proposed that successful programmes should be targeted at four levels: 1) individual, 2) group/team, 3) organisation, and 4) system or environment. The authors in this study used a person, interactions and environment (PIE) qualitative practice development tool to describe the culture of care experienced by people with dementia. Despite the hospitals in the study adopting person-centred tools and pathways the authors considered that work was required to investigate if the changes improved hospital outcomes for people with dementia. People with dementia were not involved in that description of their experiences therefore that was an area for future research.						

Reference:	Scerri, A., Scerri, C. and Innes, A. 2018. The perceived and observed needs of patients with dementia admitted to acute medical wards.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
Dementia (published online 27 November 2018).	The aim of the study was to categorise the perceived and observed needs of people with dementia admitted to acute medical wards and to explore whether these needs were being or had been met.	Semi-structured interviews were conducted to elicit each participant's experiences of their hospital stay and whether their needs were perceived to have been/were being met. Routine care with the same participants was observed using the University of Bradford's Dementia Care Mapping™ approach Maslow's Hierarchy Of Needs was used as a framework to categorise care needs.	Set in Malta, participants were 13 people with dementia in three acute medical wards, who could verbally communicate with the researcher and were purposively selected as research participants. Recruitment commenced following discussion with the charge nurse of each ward, who went through the patients list during the time of data collection and identified patients with a known	The patients' need for social contact and self-esteem, such as dignity and respect, was often ignored and this led to patients feeling devalued. Hospital staff have to be more aware of the holistic needs of patients with dementia in acute settings and the way care is delivered in order to make up for these unmet needs, thus facilitating person-centred care.	Basic needs such as toileting, feeding, drinking, continence and comfort were not always met. The largest gap between met and unmet needs was found in patients who were either under constant observation or unable to communicate. Too much emphasis was perceived and observed to be given to what staff considered as safety needs at the expense of other needs.	The authors "noted that the decision to restrict selection from medical wards only, was taken in view of the fact that patient turnover in these wards is generally lower than in other surgical and critical care wards so that it was possible that patients would have been staying in hospital for quite some time". The authors also noted that this was a small-scale study conducted in one acute hospital and the findings are therefore not

			history of chronic cognitive impairment and dementia who met the inclusion criteria.			generalisable. Moreover, the sample was focused on patients with cognitive impairment who were able to participate in both interviews and consented to being observed.
Recommendations:		Patients with dementia in acute hospitals were able to express a whole array of subjective needs and wanted to be treated as adults irrespective of their cognitive status.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: The practice environment – acknowledging the need for special provision.				
Article summary: The study was published by University of Salford but gave background figures for dementia specific to Malta. Later, the figures quoted also refer to the UK – the information was quite confusing. In addition to interviews, patients were observed for nine hours using Dementia Care Mapping™ (DCM). Field notes were categorised as containing personal detractors or personal enhancers. The authors stated that the picture that began to emerge bore a striking resemblance to Maslow's categorisation of needs; physiological, safety, belongingness, esteem and 'being' needs. The authors did recognise critique of Maslow's hierarchy of needs. Issues of informed consent, continuing consent and confidentiality were also critically considered. Most of the exploratory studies highlighted unmet relational and esteem needs. However, the findings of this						

study also indicate that basic physiological needs such as nutrition, hydration, toileting and maintaining comfort were not always being met. Patients who were unable to communicate these needs were often ignored, while patients and relatives who could voice their needs to ward staff were reluctant to do so. Both patients and relatives seemed to sympathise and occasionally excuse staff due to their heavy workload and time pressures. The lack of attention given to the physiological needs of patients with dementia could partly explain the higher risk of negative hospital outcomes, including longer hospital stays, delayed discharge, incontinence, delirium and functional decline, when compared to cognitive patients. The findings of this study indicated that too much emphasis was perceived and observed to be given by staff to safety needs at the expense of other needs such as 'esteem' and 'being' needs. Multiple studies, across multinational settings, discuss the notion of task orientation and a high concern for patient safety, reflecting organisational concerns that do not necessarily fit with the care needed or wanted by people living with dementia.

Reference:	Simpson, K. 2016. Improving acute care for patients with dementia.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Nursing Times. 112 (5): 22–4.	To research the experiences of people with dementia when in hospital by exploring their carers' views	A qualitative approach using semi-structured interviews. Interviews were conducted from January to June 2009. Once	Participants were recruited in three ways. Local carer organisations sent out letters to potential subjects, the author attended a local carer	Participants were concerned about a lack of essential nursing care, harmful incidents, a decline in patient function, poor staff communication	Care can be improved through further training, more effective communication, consideration of the appropriate place to care for people and	Literature review details refer to a "broad search of the literature" but not the databases used or keywords. The author acknowledges

	about the care that their loved ones received when admitted to hospital.	transcribed, a thematic analysis was completed, and common themes identified. Study findings were completed in 2010 but the paper was published in 2016.	support group and leaflets were left in a local day centre. There were seven interviews. One carer had cared for two relatives with dementia and so the data relates to eight patients.	and carers' needs not being acknowledged. Five participants described incidents in which their relative came to actual or potential harm while in hospital.	more use of carers' knowledge. A recommendation is made that: "Work also needs to be done to develop ways of capturing feedback from patients with dementia – a task that would require time and creativity. "	that it is essential to offer more opportunities for the voices of carers – and, where possible, the patients themselves – to be heard, but includes only interviews with carers in this study.
Recommendations:	The study highlights the importance of not losing patient belongings, not making assumptions about patients' ability to function, and the importance of supporting carers who may also need care themselves.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; strategies for optimising communication with people with dementia and their carers; carer partnerships.					

Article summary:

Simpson states that people with dementia are more likely than the general hospital population to experience decline in function, fall or fracture when admitted to hospital. Again, lost property was mentioned as a cause for concern by carers, in common with a number of other studies. Three participants described how property went missing during their relative's stay. Dentures, spectacles and slippers were lost, which affected patients' ability to eat and mobilise safely. Such incidents were directly linked with ward moves, and left participants with the impression that their relative was not being cared for adequately. The participants also felt that staff made assumptions that their loved one would not be able to walk, eat or get to the toilet unaided and therefore they were not encouraged to do so. Three participants stated that staff did not speak to them to discover what their relative could do and had low expectations about people with dementia. Participants described how their relative's behaviour affected other patients on the ward. They felt such actions could be stressful for other patients, many of whom may never have had experience of dementia. Staff did not have adequate skills or knowledge to manage the care of patients with dementia on the wards. Some staff treated them in the same way as other patients and did not seem to recognise that they have different needs and vulnerabilities. Despite criticisms of nursing care and management of the patient's behaviour, 85% of participants were quick to acknowledge pressures such as staff shortages and the needs of other, acutely ill patients.

The paper includes quotes from carers that provide powerful perspectives into care. For example, participants were not asked about their relatives' individual needs and capabilities and, in some cases, nursing staff chose to ask the patient, which led to inaccurate information being given. For example, 'Carer 6' explained: "She had told them that she couldn't walk and used a wheelchair, and it was three days before a nurse asked me and I told her that she can walk and has never used a wheelchair." Two participants mentioned care that went 'deeper' than essential care and could be viewed as nurses' attempts to provide a more person-centred approach. It was acknowledged that carers can require support and care themselves at such a stressful time, and in one interview, a participant expressed how much it meant to her when a doctor made her a cup of tea. Although a small-scale piece of research, the results of this study have much in common with other studies in the review, adding to the validity of the findings.

Reference:	Surr, C., Smith, S., Robins, J. and Crossland, J. 2016. Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: A repeated measures study.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
International Journal of Nursing Studies. 53: 144–51.	This study aimed to evaluate the efficacy of a specialist training programme for acute hospital staff regarding the improvement of attitudes, satisfaction and feelings of caring efficacy in provision of care to people with dementia.	A repeated measures design, with measures completed immediately prior to commencing training (T1), after completion of foundation level training (T2: 4–6 weeks post baseline), and following intermediate level training (T3: 3–4 months post baseline).	One NHS trust in the north of England. 40 acute hospital staff working in clinical roles, the majority of whom (90%) were nurses.	All participants received a 3.5 day person-centred care training for acute hospitals (PCTAH) programme, comprised of two levels, foundation (half-day) and intermediate (three days), delivered over a three to four month period. Staff demographics and previous exposure to dementia training were collected via a questionnaire. Staff	The training programme was effective in producing a significant positive change on all three outcome measures following intermediate training compared to baseline. A significant positive effect was found on the ADQ between baseline and after completion of foundation level training, but not for either of the other measures.	Limitations of the study included the sample size and representativeness, which was limited in comparison to the wider workforce – for example, allied health professionals and the ancillary workforce. The authors suggested that follow-up over a longer period after completion of the training programme would help to establish if and what the impact of time on efficacy of dementia training was

				attitudes were measured using an approaches to dementia questionnaire (ADQ); satisfaction in caring for people with dementia was captured using a staff experiences of working with demented residents (SEWDR) questionnaire; and perceived caring efficacy was measured using the Caring Efficacy Scale (CES)	Foundation level training (half-day) was effective in changing attitudes but did not seem to be sufficient to bring about change in satisfaction or caring efficacy. Intermediate level training in person-centred dementia care is effective in producing significant improvements in attitudes towards, and satisfaction in caring for, people with dementia and feelings of caring efficacy.	within this staff population. The study did not measure impact on participants' practice; no conclusions could be drawn about whether changes in attitudes, satisfaction with working with people with dementia, or perceptions of caring efficacy also impacted on care delivered and the patient experience.
Recommendations:		More in-depth knowledge of dementia care appears to be required, as gained through intermediate level training, in order for staff to feel greater caring efficacy and satisfaction when working with people with dementia				

Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Staff skills and attitudes; the practice environment – acknowledging the need for special provision; training needs.
Article summary: The authors provide a clear explanation of methods, data collection and analysis. They found that in their study setting a half-day person-centred dementia care training was effective in producing a significant positive change in attitudes towards people with dementia but did not lead to significant positive changes in staff satisfaction in caring for people with dementia or greater feelings of caring efficacy. A more in-depth person-centred training programme led to further significant improvements in staff attitude towards people with dementia, as well as increased satisfaction and feelings of caring efficacy. Authors posited that the greater depth of knowledge achieved through completion of the intermediate training was required for staff to achieve the greatest degree of positive attitude.	

Reference:	Surr, C. and Gates, C. 2017. What works in delivering dementia education or training to hospital staff? A critical synthesis of the evidence.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

International Journal of Nursing Studies. 75: 172–88.	The purpose of the literature review was to examine published evidence on the most effective approaches to dementia training and education for hospital staff.	A systematic review was conducted using critical synthesis and included qualitative, quantitative and mixed/multi-methods studies. A four level Kirkpatrick Model for the evaluation of training interventions was adopted to structure the review.	The following databases were searched: MEDLINE, PsycINFO, CINAHL, AMED, BEI, Education Abstracts, ERIC, Cochrane Library: Cochrane Reviews, CENTRAL, HMIC, ASSIA, IBSS and CPCIndex, using a combination of keyword for the following themes: dementia/Alzheimer's, training/education, staff knowledge, and patient outcomes.	20 papers were included in the review. 16 different training programmes were evaluated in the studies, which varied in terms of duration and mode of delivery, although most employed face-to-face didactic techniques. Studies predominantly reported on reactions to training and knowledge; only one study evaluated outcomes across all of the levels of the Kirkpatrick model. Key features of training that appeared to be	Factors most likely to lead to positive outcomes were: (1) delivery via face-to-face group teaching by a skilled facilitator; (2) tailoring training to learners' roles; (3) using direct involvement, through video or written vignettes, to present the voice of people with dementia and carers; (4) duration of at least a day, with individual sessions of at least an hour; (5) providing ongoing support	The majority of papers were low or medium quality, impacting on generalisability. Only papers published in English since 2000 were included. This may have excluded non-English language and older studies that might have contributed further understanding of effective dementia training or education for hospital staff. The authors concluded that further research on the features of

				more acceptable and effective were related to training content, delivery methods, practicalities, duration and support for implementation.	via in-service experts or champions. One-off training is likely to be ineffective.	effective dementia training for hospital staff is required.
Recommendations:		Training should: be relevant to the staff's role; consider placement opportunities for staff; include the direct voice and experiences of people living with dementia and their family carers; use a facilitator who is able to role model good practice; not utilise independent study via e-learning; not include materials that are hard to understand e.g. legislation; not rely on individuals to schedule their own training; involve group learning in a classroom setting; be of at least one day's duration and delivered in not less than one hour; and consider the development and support of in-service experts.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision. Toolbox for practitioners: Ensure regular refresher training is undertaken by staff.				
Article summary: In setting out the background to this study, the authors point out that acute hospitals form a significantly different context to care homes for delivery of dementia care training, since staff work across a range of specialisms, most have limited dementia expertise and patients with dementia are usually acutely unwell during admission with another primary illness diagnosis. The authors list the aspects of training that are likely to negatively impact on learning, including difficulty accessing online material, sessions that are of						

too short duration (less than 25 minutes), and the amount of work/time involved in a programme. Interestingly, they note that where work is reliant on individuals to undertake tasks then chances of optimal uptake and impact are limited; they advocate group-based learning in classroom settings, also programmes that include practical assessment tools. Care approaches and methods to take into clinical practice were appreciated by staff. Regular refresher training may be required. The paper concludes with advice for training (see the recommendation section above).

Reference:	Surr, C., Sass, C., Burnley, N., Drury, M., Smith, S., Parveen, S., Burden, S. and Oyebode, J. 2018. Components of impactful dementia training for general hospital staff: a collective case study.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Aging & Mental Health. 24(3): 511–21.	This study aimed to understand models of dementia training most likely to lead to improved practice and better care experiences for people with dementia, and to understand barriers and facilitators to implementation.	A collective case study. Interviews with training leads, ward managers and staff who had attended training. Satisfaction surveys with patients with	Three NHS trusts in England.	Not all staff had the knowledge, attitude and skills needed to deliver good care. The authors identify the "need to be with" the patient e.g. sitting holding someone's hand to display care.	Simulation and experiential learning were distressing for some learners. An experienced and enthusiastic facilitator was important. Lack of resources, including time, was a barrier to implementing	Use of a 'positive deviance' approach to select three trusts (third ranked trust declined an offer to take part). It was not possible to collect data on staff knowledge, attitudes, behaviours or patient outcomes prior to any

		dementia and/or carers. Observations of care using dementia care mapping.		There were two primary themes related to training design: training tailored to general hospital staff; and ongoing training development and evaluation. Three themes related to training delivery and staff reactions: (1) interactive methods; (2) presenting the experience of people with dementia; and (3) skilled delivery. Two themes related to learning: (1) understanding ways to deliver better care; and	training. Supportive managers, organisational culture and strong leadership facilitate training implementation. Training should: include small group, face-to-face delivery; keep didactic aspects to a minimum and maximise creative and interactive exercises; be tailored to the general hospital setting; ensure the experiences of people with dementia and their family carers are presented through direct involvement, video or written scenarios; ensure simulation or experiential aspects are only used if there is the time and	dementia training delivery. Case studies were in-depth, but only three sites were included in the study (top performing of audit respondents). Only a relatively small sample of staff, wards and patients/relatives were included at each site. Respondents provide an in-depth picture of the impact, barriers and facilitators to training and its implementation in such settings, but they are unlikely to be representative of average training practice and impact in general hospitals across England.

				(2) development of empathy. Three themes identified in relation to staff behaviour change were: (1) improved understanding; (2) improved communication; and (3) provision of meaningful activity. Also lack of dementia-friendly spaces.	resources to provide adequate support for staff and that consideration is given to the potential for learner distress; be delivered by experienced, enthusiastic facilitators who are also good clinical role models; be supported by hospital management; be led by a designated dementia training lead who is proactive in leading change; consider mechanisms to protect agreed training time and manage this in the context of staffing shortages; urgently consider how to ensure that agency or temporary staff know the basics of person-	

					centred dementia care delivery.	
Recommendations:		Guideline recommendations at sections: Training needs; staff skills and attitudes; the practice environment – acknowledging the need for special provision. Toolbox for practitioners: Ongoing training, development and evaluation. Training tailored to staff groups.				
Article summary: The authors of this paper provided a good general overview of dementia care while considering explanations for inadequate care. They posited that: poor communication from staff and noisy, disorientating environments contribute to poor care in hospitals; staff may not be aware that a patient has dementia or, if they do, the patient's preferred methods of communication; task-focused rather than person-centred care is potentially a result of having staff who are not prepared for the potentially complex needs of the people living with dementia; staff do not value teaching dominated by didactic delivery. The authors identified a lack of engagement with training among certain professional groups (notably 'medics'). The authors considered implications for practice – when staff lacked the knowledge, attitudes and skills needed to deliver person-centred care, there were observable negative impacts on patient experiences. The authors listed a range of recommendations for the training of staff while also highlighting the importance of supportive managers, organisational culture and strong leadership. Overall, this paper raised awareness and highlighted a need to pay attention to methods of training tailored to staff groups.						

Reference:	Smythe, J., Jenkins C., Harries, M., Atkins, S., Miller, J., Wright, J., Wheeler, N., Dee, P., Bentham, P. and Oyebode J. 2014. Evaluation of dementia training for staff in acute hospital settings.

Source	Purpose	Design	Sample	Intervention/ Outcome	Findings	Limitations
Nursing Older People. 26(2): 18–24.	The study investigated the effectiveness of a brief psychosocial intervention delivered in the workplace compared with a standard teaching approach.	The development, pilot and evaluation of a brief psychosocial training intervention (BPTI) for staff working with people with dementia in an acute hospital setting. The project had two phases. Phase one involved adapting an existing competency framework and developing the BPTI using focus groups. For the pilot and evaluation, in phase two, a mixed methods approach was adopted using	30 participants from three UK wards. It was not clear what type of ward, hospital, or geographical region of the UK. The authors reported a diverse age, gender, length of experience and qualifications (presumably nurses). The authors also note that 81 staff from the wards completed questionnaires. 15 interviews were conducted.	Training was delivered on wards for one hour, for a period of five weeks (i.e. five hours).	Qualitative analysis suggested that delivering skills-based training can: develop communication, problem-solving and self-directed learning skills; benefit staff in terms of increased knowledge, skills and confidence; and be problematic in the clinical area in terms of time, organisation and the physical environment. These factors must be taken into consideration when delivering training.	Definitive conclusions could not be drawn about the efficacy of the intervention due to the contradictory outcomes between the quantitative and qualitative data. Further developments and research were required to explore how staff and organisations could be supported to deliver the best possible care. The relatively small sample size

		self-administered standardised questionnaires and qualitative interviews.			Changes due to training were not reflected in the quantitative results, and the authors reasoned that measures were not always sensitive to changes in that setting.	meant that statistical significance was unlikely to be achieved. The authors stated that a larger sample was not achievable due to resources. It was not possible to explore variation between trainers. The perspectives of people with dementia and their families were not sought.
Recommendations:		Skills-based training delivered in the clinical area can be restricted by time, organisational and environmental factors, which should be taken into account in the design of a tailored training programme.				
Aspects of the guidance document this reference can inform:		Guideline recommendations at sections: Training needs.				

Article summary:
Staff participants in this study were aware of the effect of their lack of knowledge and skills on people with dementia and their own work, expressing enthusiasm for training if it were practical, realistic and relevant. Gaps in knowledge about the aetiology of disease processes, managing behaviour, lack of time and inadequate staffing were identified as barriers to person-centred care. The authors aimed for staff to address attitudes and therefore to develop emotional competence, empathy and a non-judgemental approach. Admirable aims for a brief intervention.

Nursing staff thought that the training increased their awareness of the needs of people with dementia and gave them a better understanding of people's emotions and behaviour, and as a result the staff felt that they had increased tolerance, understanding and confidence. The authors preferred to call the programme a psychosocial intervention, but arguably in healthcare parlance it can be regarded as a training programme; despite labelling it 'brief', in total the intervention did take place over a period of five weeks (five hours).

Reference:	Tay, F., Thompson, C., Nieh, C.M., Nieh, C.C., Koh, H., Tan, J. and Yap, P. 2018. Person-centered care for older people with dementia in the acute hospital.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**

Alzheimer's & Dementia. 4(1): 19–27.	The authors examined the effect of care for acute mentally infirm elders (CAMIE) versus usual care on pre- post outcomes for people with dementia.	A prospective naturalistic cohort study whereby people with dementia in the CAMIE unit (n=170) were compared with a control group in usual care wards (n=60) over six months. Assessments included patient demographics, dementia type and stage, comorbidities (Charlson Comorbidity Index), acute illness severity, well-being, ill-being, functional status (Modified Barthel Index), agitation levels (Pittsburgh Agitation Scale),	An acute hospital in Singapore to set up a specialised unit that adopted person-centred care. The unit, known as Care for Acute Mentally Infirm Elders (CAMIE), was set within a home-like environment, which prioritised the needs of patients beyond care tasks. Patients in the conventional geriatric ward (control group) received standard medical care. A total of 230 patients (170 in CAMIE unit and 60 in conventional geriatric ward as controls) admitted to Khoo Teck Puat	CAMIE patients showed statistically significant greater gains in Modified Barthel Index (MBI) function and well-being, decreased ill-being and agitation, and greater improvement in Quality of Life (EuroQoL) index score (effect size: D 5 0.18) after adjusting for baseline differences that translated to a quality-adjusted life years gain of 0.045, assuming stability over three months. Estimating added cost of CAMIE stay	The authors examined the effectiveness of CAMIE care compared with conventional geriatric care as control. The authors hypothesised that people with dementias in the CAMIE unit would display greater improvements in general well-being and functional ability, require lower doses of psychotropic medications with greater reduction in agitated behaviours, and have a shorter length of stay (LoS).	This was a naturalistic observational study – there was little control over the comparability of patients' baseline variables between the groups. It was important to note that there were significant group differences at baseline on mini mental state examination (MMSE) and on four out of five dependent variables, specifically well-being, agitation, functional ability, and quality of life. While a fully randomised controlled trial

		and quality of life assessed on admission and discharge. Multivariate analysis of covariance examined the effect of CAMIE versus usual care on pre-post outcomes.	Hospital, Singapore, were recruited over six months. All patients received standard treatment for their respective medical conditions. Patients were admitted to the CAMIE unit if they had confusion due to dementia, with/without delirium based on the confusion assessment method criteria, and concomitant acute medical problems. The exclusion criteria for CAMIE were medically unstable patients, patients requiring high dependency care, or isolation due to infection	over usual care at SGD $1,500 (USD $1,040) for average length of stay of 15 days per patient, the incremental cost-effectiveness ratio fell within the threshold for cost-effectiveness at USD $23,111.	It is stated that the authors aimed to show that these enhanced outcomes are cost effective through an economic analysis.	may have yielded equivalence of groups at baseline, this was not possible in a naturalistic observational study. This engenders the possibility that as CAMIE patients were better off than those in the conventional geriatric ward at baseline, they may have had greater potential for improvement. The assessments of outcomes were short term and not blinded, as the individuals (doctors, nurses, and therapists) involved in administering the

			control or reverse barrier care. The control group consisted of patients who satisfied admission criteria for the CAMIE unit but were denied because of the lack of bed availability; they were representative of the multi-ethnic composition of Singapore.			measures (well-being, Pittsburgh Agitation Scale, and Modified Barthel Index) were also involved in providing the care. Patients' post intervention outcomes were assessed only upon discharge without serial assessments during the hospital stay. It would have been ideal to chart the outcomes periodically as well as conducting post-discharge assessments to derive more robust conclusions on the outcomes. As such, cost-effectiveness computation assumed stability

						of the outcomes for three months after discharge without a formal assessment being performed. Follow-up studies would be necessary to determine the long-term sustainability of the benefits gained.
Recommendations:	The findings call for wider adoption of person-centred care models of enhanced care for people with dementias in the acute hospital setting.					
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: The practice environment – acknowledging the need for special provision; building relationships with patients and carers to optimise the patient and carer experience; recommendations for future research.					
Article summary: CAMIE care was operationalised under two protocols: (1) enhanced medical care protocol, which included moderating intrusive interventions (e.g., catheters, feeding tubes), a physical restraints-free policy, appropriate and modest use of psychotropic medications, careful attention to hydration, bowel and bladder care, and encouraging mobilisation; and (2) enhanced psychosocial care protocol, which included prioritising patient needs over tasks, encouraging family members and volunteers to provide						

companionship, and engaging in daily structured activities (e.g. music therapy, recreational/group activities). A thorough description of the CAMIE unit was provided. The likely factors that contributed to better outcomes in CAMIE patients include the enhanced medical protocol that stressed: early mobilisation; restraints-free care; careful attention to hydration; and bladder and bowel care. This was the only study to consider costs, stating that better outcomes came at a modest cost of SGD $100 more per patient daily, which was further shown to be cost effective.

Overall, this evaluation of clinical and economic outcomes of the CAMIE unit demonstrated the potential benefits of implementing person-centred care in an acute care setting. By implication, this insinuated that general wards were not implementing person-centred care. The study addressed a gap in extant literature with the potential to inform hospital practice and healthcare policy. The study included multiple outcomes, used robust statistical methods, and offered a cost-effectiveness assessment that enabled the investigation of the impact of care in the CAMIE setting. The authors concluded that the findings called for wider adoption of person-centred care models of enhanced care for people with dementias in the acute hospital setting.

Reference:	Thompson, R. 2015. Transforming dementia care in acute hospitals.					
Source	**Purpose**	**Design**	**Sample**	**Intervention/ Outcome**	**Findings**	**Limitations**
Nursing Standard. 30(3): 43–8.	This article provided an overview of 2015 developments to support improvements in	The process and outcomes of a development programme carried out by the Royal College of	During December 2012, nine hospital sites across the UK were selected after submission of an initial action plan	The use of outcome measures to evaluate both the experience of care and changes in	A more systematic approach to developing practice that considered the context and	The study authors did not specifically refer to, or appear to consider, the roles of the

	dementia care in acute general hospital settings. It considered the urgent need for improvement along with the effectiveness of approaches in achieving change and delivering person-centred care.	Nursing (RCN) and evaluated by the University of Worcester were described. This programme supported clinical nurse leaders in developing dementia care in nine acute general hospitals by use of an action learning approach. The development programme was supported by facilitators from the RCN and comprised three development days and one site visit over a period of 12 months. Engagement of family carers in the programme	that identified areas for improvement. Applicants were required to demonstrate: (1) support from the trust board, including the director of nursing; (2) willingness to commit to a series of development days; (3) commitment to the principles of engagement and collaboration with patients and carers; (4) nomination of three main clinical leads with responsibility for dementia care in the organisation to	practice was encouraged. A website platform was also developed with a range of resources, including tools to measure staff confidence and patient and carer satisfaction, and monitor change and observations of care. Finally, a self-assessment scale based on the SPACE principles (see below) was developed and used to measure changes at three points throughout the programme: at the beginning, midway through, and at completion.	culture of acute hospital care for people with dementia was required. The need for investment in clinical leaders and dementia specialists who could assist improvements and support change was emphasised. Findings indicated that the programme acted as a catalyst for change, with a statistically significant increase in scores for each of the SPACE principles.	wider healthcare teams in acute hospitals, nor people with dementia or carers, although this was part of a wider programme of improvement (a series of reports were made).

		was seen as instrumental in assisting learning about partnership working with families. A range of information was provided on developments and evidence-based practice in dementia care, along with learning about clinical leadership and practice development. Participants were supported in refining local action plans and identifying actions and strategies to develop practice, using an action learning approach. Shared learning between	lead on improvements.		Outcomes varied across healthcare organisations according to the focus of local actions and measures used, and examples included improvements in staff confidence, increase in well-being of people with dementia and improved carer satisfaction. Participants considered that the involvement and support provided by the programme provided focus and structure to make changes and equipped them with the strategies	

		participants enabled reflection and learning from experience. Support was also offered via phone and email, and participants were urged to connect with each other. Evaluation by senior staff and researchers from the University of Worcester included a bespoke online questionnaire, analysis of the SPACE self-rating scores and a site visit to triangulate self-assessment data.			and confidence to change practice.	
Recommendations:		To achieve sustainable and extensive changes to the delivery of care for older people and those with dementia, investment is required to develop practice in a systematic way. However,				

	recommendations also included a need for a more focused and individualised approach to supporting change, which was difficult to achieve through a national programme.
Aspects of the guidance document this reference can inform:	Guideline recommendations at sections: Training needs; the practice environment – acknowledging the need for special provision. Toolbox for practitioners: Resources were produced to support implementation of the SPACE principles, and these are still widely accessed via the RCN dementia website (www.rcn.org.uk/dementia). A tool to support carer involvement was also developed in collaboration with the Carers Trust, based on its successful Triangle of Care model.

Article summary:

Thompson provides a useful summary that outlines the development of dementia care in the UK. Thompson describes how UK national dementia strategies and plans have targeted improvements in acute hospital care. This has resulted in an increase of, and investment in, a range of quality initiatives. Examples included increased staff education and training, changes in the hospital environment, increased assessment and identification of people with dementia, investment in specialist teams and roles, and recognition of the roles of family carers.

In line with many other authors, Thompson posits that hospitals are busy, confusing places in which care is based on assessing, treating and discharging people as quickly and efficiently as possible. This often relies on patients being able to express their wishes and to quickly understand and cooperate with their treatment. However, this was not always possible for those with dementia. Thompson recognised that the emotional effect of caring for vulnerable people, particularly those with dementia, was an important consideration. If not addressed, it could have negative outcomes for staff and patient care. Although many local initiatives have emerged with the aim of achieving improvements, these are often task focused, with little emphasis on how to support, implement and embed changes in care. Examples can be seen across the UK where care has been improved through a combination of effective leadership, facilitation and collaborative, multifaceted approaches. The RCN development programme went some way to supporting leaders in assisting change through taking a supportive, emancipatory approach to developing practice. A set of recommendations are included that support the SPACE principles:

The SPACE principles

- **S**taff who are informed, skilled and have time to care.
- **P**artnership working with carers.
- **A**ssessment and early identification of dementia.
- **C**are that is person-centred and individualised.
- **E**nvironments that are dementia friendly.

Appendix 6

Practice guideline summary themes (Word)

Appendix 6: Summary for person-centered dementia care

The Society and College of Radiographers (SCoR) undertook a review of a 2015 document, Caring for people with dementia in clinical imaging and radiotherapy: a clinical guideline. The review found that research studies published since 2015 had themes about caring for people with dementia. The themes are listed below:

The main points from the themes include the following suggestions and key messages.

Communication

- Staff must specifically ask if patients and carers have any questions or concerns.
- Staff should reassure people that there is time to listen to their concerns and to answer questions.
- People with dementia can have difficulties understanding, retaining and using cancer information. That can impact on making decisions about treatment. Staff and carers can help by adapting language to help with consent processes, patient information, and understanding the terminology used.
- Staff should communicate with people with dementia at eye level, e.g. avoid “standing over the person” when they are seated.

- Staff should reassure people that they will not be left on their own, for example, when in an MR or CT scanner or a linear accelerator (LINAC); staff will be able to see that person and to communicate with them.

- Some people with dementia might find it difficult to keep track of time during examinations, so it helps to inform them, for example, of how much time is left until the end of a scan or how long a specific sequence will go on for.

Deficiencies in person-centred care

- Staff can have difficulties recognising and addressing unmet needs of people with dementia.

- It is important for some patients and carers to feel in control in unfamiliar environments.

- Partnerships between staff, the person with dementia and their carer, relatives and friends, can result in holistic care (not focused solely on physical needs).

- Each person with dementia is unique and will need a personalised care package.

- People with dementia and carers may find it helps to bring their own music/photos/items that are comforting to them during the visit.

- Hospital organisations can help with improved identification for people with dementia within their documentation.

Receive role-specific training (clinical and non-clinical staff)

- Staff may not understand about the different types and stages of dementia or the ways that they can help people in clinical imaging and radiotherapy.

- Knowledge of the type of dementia that a person has can be used to tailor interactions.

- Each individual experience for a person can depend on the type or cause of their dementia, the stage of the illness, the person's own personality and, importantly, the way others interact with the person.

Dementia-friendly environment

- Department design and layout can make a big difference in the care of people with dementia.

- There should be a calming atmosphere.

- It is important to ensure the safe keeping of personal belongings for people with dementia. For example, lost spectacles and hearing aids affect the senses. Slippers or walking sticks left behind can affect mobility.

- Consistency of teams is important.

Time and resource pressures

- Staff need time to care (clinical and non-clinical staff).

- Staff need time to train.

- Departments do not always make effective use of volunteers who would like to help.

- People with dementia must be offered longer appointment times.

Optimisation of dementia care experience

- There needs to be collaborative working – between staff across departments and organisations, the person with dementia, their carers, relatives and friends.

- The aim should be to inform, involve and support patients and carers.

Identification of people with dementia

- There can be issues with identifying that a person has dementia. To help with clear communication when a person has a diagnosis of dementia, departments should have a question on imaging and radiotherapy referral forms or initial assessment forms that includes a request for information about a person's type of dementia and cognition.

- The staff who will be caring for a person with dementia should ideally be informed about the person's diagnosis, and the form and stage of their dementia, beforehand, to allow adequate preparation and adaptations of care. It is important to tailor care to the form of dementia the person has and their needs.

- Departments should have mechanisms for referral on to the person's general practitioner to follow up in cases of potential undiagnosed memory problems.

Appendix 7

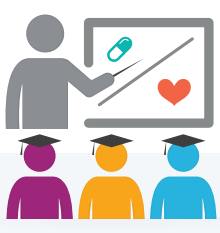
Practice guideline summary themes (infographic)

Summary for person-centered dementia care

The Society & College of Radiographers (SCoR) undertook a review of a 2015 document, Caring for People with Dementia in Clinical Imaging and Radiotherapy: A Clinical Guideline. The review found published research had **the following themes about caring for people with dementia:**

Communication

Deficiencies in person-centred care



Need for role-specific, tailored training (clinical & non-clinical staff)

Dementia-friendly environment

Time and resource pressures

Optimisation of dementia care experience

Identification of people with dementia

Main points from the themes:

Communication

Staff must specifically ask if individuals and their carers have any questions or concerns.

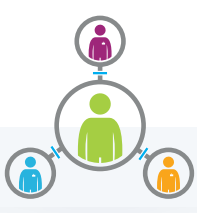
Staff should reassure people that there is **time to listen to their concerns** and to answer questions.

People with dementia can have difficulties understanding, retaining and using cancer information. Staff and carers can help **by adapting language to help.**

Some people with dementia might find it difficult to keep track of time during examinations - **inform them how much time is left until end of procedure.**

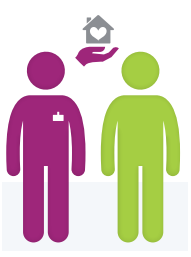
Staff should reassure people that **they will not be left on their own,** e.g. when in an MR or CT scanner or having radiotherapy treatment, staff will be able to see that person and to communicate with them.

Communicate with people at eye-level, e.g. avoid "standing over the person" when the person is seated.



Deficiencies in person-centred care

Staff can have difficulties recognising and addressing **unmet needs of people with dementia.**



It is important for some individuals and their carers to **feel in control in unfamiliar environments.**

Partnerships between staff, the person with dementia and their carer, relatives and friends **can result in holistic care** (not focused solely on physical needs).

Each person with dementia is unique and will **need a personalised care package.**

People with dementia and carers may find it helps to **bring their own music/ photos/items** that are comforting to them during the visit.

Hospital organisations can help with **improved identification for people** with dementia within their documentation.

Need for role-specific, tailored training
(clinical & non-clinical staff)

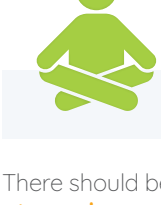
Staff may not understand about the **different types and stages of dementia** or the ways that they can help people.

Knowledge of the type of dementia that a person has can be used to tailor interactions.

Each individual experience for a person can depend on the type or cause of their dementia, the stage of the illness, the individual's personality and, importantly, **the way others interact with the individual.**

Dementia-friendly environment

Department design and layout can make a big difference for the care of people with dementia.

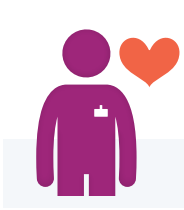


There should be a **calming atmosphere.**

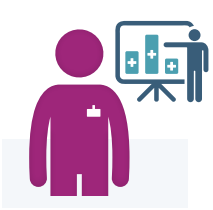
It is important to ensure the safe keeping of personal belongings for people with dementia. For example, lost **spectacles and hearing aids** affect the senses. **Slippers or walking sticks** left behind can affect mobility.

Consistency of teams. Try to arrange for **the same staff to care for people** e.g. radiotherapy appointments.

Time and resource pressures



Staff need **time to care** (clinical and non-clinical staff).



Staff need **time to train.**

Departments do not always **make effective use of volunteers** who would like to help.

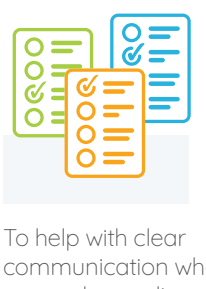
People with dementia must be **offered longer appointment times.**

Optimisation of dementia care experience

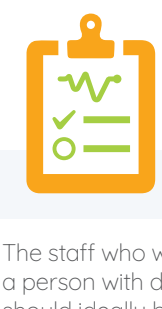
There needs to be collaborative working - between staff across departments and organisations, the person with dementia, their carers, relatives and friends.

Recognise the importance of partnerships with carers to support each person with dementia. **Remember that carers need care and support too.**

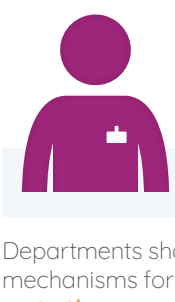
Identification of people with dementia



To help with clear communication when a person has a diagnosis of dementia, departments should have a **question on imaging and radiotherapy referral forms or initial assessment forms** to include a request for information about a person's type of dementia and cognition.



The staff who will be caring for a person with dementia should ideally be **informed about the person's diagnosis, form and stage of dementia beforehand.**



Departments should have mechanisms for **referral on to the person's General Practitioner** to follow up in cases of potential undiagnosed memory problems.

Appendix 8

A toolbox for practitioners

Guideline area	Advice	Resources
The practice environment	The Royal College of Psychiatrists provides information about the **standards** that it uses for the National Audit of Dementia.	https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/national-clinical-audits/national-audit-of-dementia/r4-resources/tools-guidance/r4-standards.pdf?sfvrsn=a44cbc5f_2
	Five SPACE principles for the care of people with dementia in hospital settings were developed in collaboration with people with dementia and carers. Royal College of Nursing resources were produced to support implementation of the SPACE principles.	https://www.rcn.org.uk/professional-development/publications/pub-007827
	Resources to support **environmental design** are available via: The King's Fund Enhancing the Healing Environment programme. The University of Stirling's Dementia Services Development Centre Virtual Environments website. Dementia Engagement and Empowerment Project (DEEP) network audit checklists. Is this inside space dementia inclusive? Is this outside space dementia inclusive?	https://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia https://dementia.stir.ac.uk/design/virtual-environments https://www.dementiavoices.org.uk/deep-resources/deep-templates/
	Find practical ways to help **personalise the examination/treatment room.** Provide and allow extra time for people to bring their familiar belongings into	

	examination and treatment rooms. This may include bags, photos, clothes, comforters, blankets, a pillow etc.	
	Apply to local funding sources, for example hospital friends, for monies to purchase **items for waiting areas** e.g. Fidget Widget Tool Kit from Alzheimer's Society.	https://shop.alzheimers.org.uk/ https://shop.alzheimers.org.uk/Sensory-stimulation
	The National Institute for Health and Care Excellence (**NICE) guideline 97 (NG97)**, Dementia: assessment, management and support for people living with dementia and their carers, provides information about best practice pathways for people with dementia.	https://www.nice.org.uk/guidance/ng97
Building relationships with patients and carers	SCoR continues to support **John's Campaign** by advocating that all clinical imaging and radiotherapy departments welcome carers and relatives of people with dementia and encourage them to stay with the person with dementia at all stages of their journey, should they so wish.	https://johnscampaign.org.uk/
	Clinical imaging and radiotherapy staff should understand and **implement the core values** of the Society and College of Radiographers' Patient, public and practitioner partnerships within clinical imaging and radiotherapy: guiding principles.	https://www.sor.org/learning/document-library/patient-public-and-practitioner-partnerships-within-imaging-and-radiotherapy-guiding-principles

	Dementia statements reflect the things that people with dementia and carers say are essential to their quality of life. The statements were developed by people with dementia and their carers; the person with dementia is at the centre of these statements.	https://nationaldementiaaction.org.uk/dementia-statements/
	Partner with the person with dementia and any carers to **plan care** – for a series of visits consider making a contract of care. A contract of care can include the person bringing a 'This is me' document. If available, staff should read this prior to meeting. A care plan can include agreeing about the use of music, occupational activities such as reminiscence resources, games and relaxation techniques, and discussing signals about the withdrawal of consent.	BBC Reminiscence Archive: https://remarc.bbcrewind.co.uk/index.html BBC Music Memories: https://musicmemories.bbcrewind.co.uk/ Playlist for Life: https://www.playlistforlife.org.uk Alzheimer's Society: Five online activity ideas for people with dementia: https://www.alzheimers.org.uk/blog/5-online-activity-ideas-people-living-dementia
	Alison Tonkin and Julia Whitaker wrote an article titled **Power play for imaging and therapy practice** (2017). They discussed how the application of play-based techniques and resources can contribute to the provision of imaging and radiotherapy services that are responsive to, and supportive of, the needs of people who have dementia and the carers who look after them. The article has three central themes, which explore the building of	https://www.sor.org/learning/library-publications/imaging-therapy-practice/january-2017/power-play

	relationships, communication as a means of connection, and the role of the environment.	
	In preparation for a hospital visit, **hospital readiness tools** can be downloaded from the Alzheimer Society of Canada website.	https://alzheimer.ca/en/Home/Living-with-dementia/Caring-for-someone/Hospital-visits
Strategies to optimise communication	Give people time and reassurance, encourage them and be specific when asking questions. Offer people with dementia **longer appointment times**.	
	Ask if people have a copy of the Alzheimer's Society and Royal College of Nursing (RCN) **'This is me'** information leaflet. Encourage people to bring this document to appointments and treatments. Take time to stop and read the information prior to commencing any examinations or treatments.	https://www.alzheimers.org.uk/get-support/publications-factsheets/this-is-me?gclid=Cj0KCQjwu6fzBRC6ARIsAJUwa2RIt5jDyhGl-E9YDccf33D7P3kgYCVuvriTUycFnXitzfEQC1Y1ZB8aAm7nEALw_wcB&gclsrc=aw.ds
	A table of advice about **approaches to communication** with a person with dementia was included in a paper by McCorkell et al.	McCorkell, G., Harkin, D., McCrory, V., Lafferty, M. and Coates, V. 2017. Care of patients with dementia in an acute trauma and orthopaedics unit. *Nursing Standard*. 31(36): 41–53.
	A need to '**slow down'** was a feature of providing better care in an article by McWilliams et al. Adjustments to support treatment it identified included not using written information leaflets for some patients, and changing the language used around radiotherapy, tailoring it to the patient; for example, the radiotherapy mask was described as a 'wet towel'.	McWilliams, L., Farrell, C., Keady, J., Swarbrick, C., Burgess, L., Grande, G., Bellhouse, S. and Yorke, J. 2017. Cancer-related information needs and treatment decision-making experiences of people with dementia in England: a multiple perspective qualitative study. *BMJ Open*. 8(4): E020250.

	The Dementia Engagement and Empowerment Project (DEEP) network offers helpful tips in **Dementia words matter: Guidelines on language about dementia**.	http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf
	Give people time and reassurance, encourage them and be specific when asking questions. Dementia UK offers **Tips for better communication.**	https://www.dementiauk.org/get-support/understanding-changes-in-behaviour/tips-for-better-communication/
Understand people's behaviour	**Emotional experience** is paramount to the perspectives of people with dementia. Staff should be aware that a person with dementia's current emotional experiences can often be represented by discussing past experiences. Wendy Mitchell describes her experiences of life with dementia for Age UK. The Royal College of Psychiatrists' 2019 report, Caring for the whole person: Physical healthcare of older adults with mental illness: integration of care, provides an overview of the **intersections of mental and physical health** that may affect behavior, for example, delirium. Members of the Beth Johnson Foundation Dementia Advocacy Peer Support Group developed **a comic called There's no bus map for dementia about living well with dementia** in collaboration with Manchester Metropolitan University and Arts Council England.	https://www.ageuk.org.uk/discover/2019/march/wendy-mitchell-on-life-with-dementia/ https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2019-college-reports/cr222 https://www.dementiavoices.org.uk/wp-content/uploads/2014/05/dementia_comic-1.pdf

Carer partnerships	Alzheimer's Society offers healthcare professionals **a direct link to refer someone to Dementia Connect**. This personalised service connects people with dementia, their carers, families and friends to free support and advice by phone, online and face to face, from practical advice about living with dementia, to someone to talk to when things get tough. The NHS England and NHS Improvement Dementia Best Practice Repository includes a Carers Trust and RCN guide for best practice in dementia adapted from the Triangle of Care project. The **triangle of care** can lead to consistent carer involvement and support across all health and social care services, irrespective of where and when a person is being treated.	https://www.alzheimers.org.uk/refer https://www.england.nhs.uk/publication/a-triangle-of-care-carers-included-a-guide-to-best-practice-for-dementia-care/
Staff skills and attitudes	**TalkWell** is a conversation training resource for mental health workers from the Star Wards project to improve the daily experiences of inpatients. It aims to help staff to become better listeners, to enjoy and feel able to manage conversations, with a greater awareness of what's happening in patients' minds and their own. **Brief Encounters** is a staff training resource from the Star Wards project and Cambridge University Hospitals NHS Foundation Trust. The underlying ethos is that it can be hard for ward staff in general and acute hospitals to know what to say to inpatients – what is the 'correct thing' – how to behave, how to help relatives and also how to help	https://www.starwards.org.uk/talkwell/ https://www.brief-encounters.org/introduction/

	themselves so they don't go home and worry about their patients. Alzheimer's Research UK provides a range of **helpful information about dementia**, including different types. Alzheimer's Society offers advice for carers in **Caring for someone with dementia: a practical guide**.	https://www.alzheimersresearchuk.org/about-dementia/ https://www.alzheimers.org.uk/get-support/publications-factsheets/caring-person-dementia-practical-guide
	Peer support and guidance is available, including from allied health professional (AHP) colleagues, such as the Alzheimer Scotland AHP Dementia Forum.	https://www.alzscot.org/our-work/transforming-health-care/allied-health-professionals-and-dementia/alzheimer-scotland-ahp-dementia-forum
Training needs	**Capacity for consent training** is required to enable radiographers to meet the mandatory requirements of the Mental Capacity Act 2005. SCoR provides some guidelines in Consent: Guidance on mental capacity decisions in diagnostic imaging and radiotherapy. The Social Care Institute for Excellence (SCIE) has developed a range of resources on **helping people with dementia to make their own decisions.** The National Institute for Health and Care Excellence (NICE) **guideline 108,** Decision making and mental capacity, covers keeping people who lack capacity at the centre of the decision-making process.	https://www.sor.org/sites/default/files/document-versions/consent_guidance_09110218.pdf https://www.scie.org.uk/dementia/supporting-people-with-dementia/decisions/helping.asp https://www.nice.org.uk/guidance/ng108

	The Skills for Health's **Person-centred approaches** core skills education and training framework is about empowering people in their lives and communities to enable an upgrade in prevention, wellbeing, health, care and support. SCoR has helped produce a handbook and training resources, **Values-based practice in diagnostic and therapeutic radiography: a training template**, which include scenarios piloted with radiographers and students. The Royal College of Nursing (RCN) intercollegiate document, **Adult safeguarding: roles and competencies for healthcare staff**, sets out minimum training requirements and education principles around personalised safeguarding.	https://www.skillsforhealth.org.uk/services/item/575-person-centred-approaches-cstf-download https://www.sor.org/sites/default/files/document-versions/2018.10.03_radiography_vbp_training_manual_-_final.pdf https://www.rcn.org.uk/professional-development/publications/pub-007069
	Ensure that regular refresher training is undertaken by staff, with ongoing training, development and evaluation, and training tailored to staff groups. The **Managing success in dementia care** dementia training standards support guide can assist with planning.	https://www.hee.nhs.uk/sites/default/files/documents/Managing%20Success%20v3.pdf
	Use the Skills for Health **Dementia training standards framework**. Radiographers should be trained to Tier 2.	https://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf

	Hospital postgraduate education centres can advise on the availability of local resources and access to e-books, such as Brooker and Kitwood's *Dementia reconsidered, revisited*, which offers insight into person-centred dementia care.	Brooker, D. and Kitwood, T. 2019. *Dementia reconsidered, revisited: The person still comes first*. Open University Press.

Appendix 9

PowerPoint presentation

The Society and College of Radiographers

Caring for people with dementia in clinical imaging and radiotherapy

Objective:

Using SCoR dementia guidance, consider practical solutions to involving people, their families and carers to co-design services.

Learning outcome:

Share and use this knowledge to review local dementia policies.

Apply the recommendations in ‘Caring for people with dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)’ to local service and develop a process for service improvement.

A definition of dementia

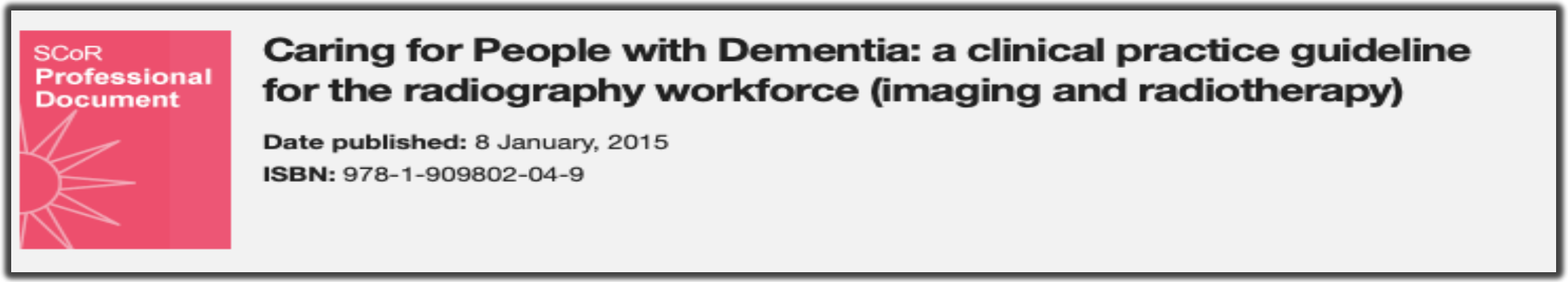
Dementia is the overarching term used for a collection of conditions that result in the brain declining progressively. There are around 100 different diseases that can affect the brain in different ways (and 200 subtypes).

Dementia is defined as a disease that is always progressive over time. It affects more than one aspect of thinking (for example, memory, language, behaviour, visual processing) and is severe enough to affect everyday life.

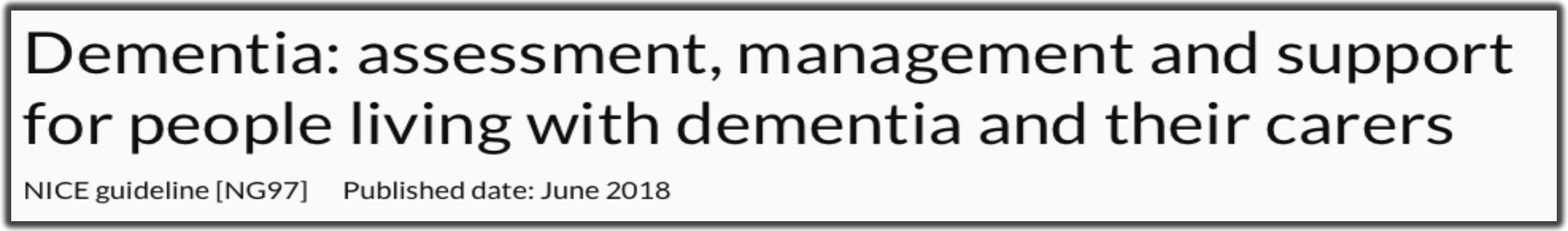
- It is estimated that there are over **850,000** people with dementia in the UK.

- Dementia doesn’t just affect the person with dementia. It affects the people around the person, their family and friends. A large proportion of people affected by dementia will **visit or work** in our imaging and radiotherapy departments.

SCoR clinical practice guideline: first edition 2015, updated 2020



NICE Guidance:



SoR 100 YEARS
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Summary for person-centered dementia care

The Society & College of Radiographers (SCoR) undertook a review of a 2015 document, Caring for People with Dementia in Clinical Imaging and Radiotherapy: A Clinical Guideline. The review found published research had **the following themes about caring for people with dementia:**

Communication

Deficiencies in person-centred care

Need for role-specific, tailored training (clinical & non-clinical staff)

Dementia-friendly environment

Time and resource pressures

Optimisation of dementia care experience

Identification of people with dementia

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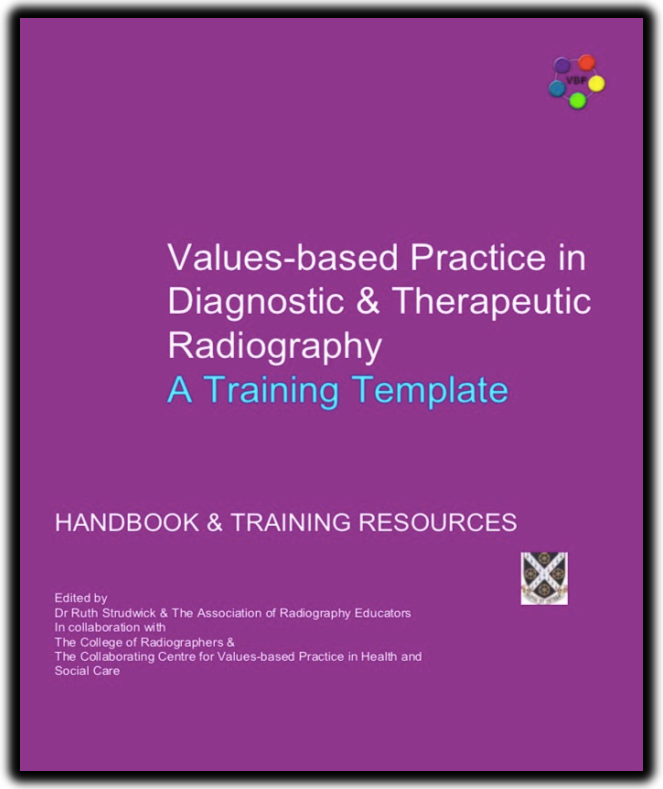
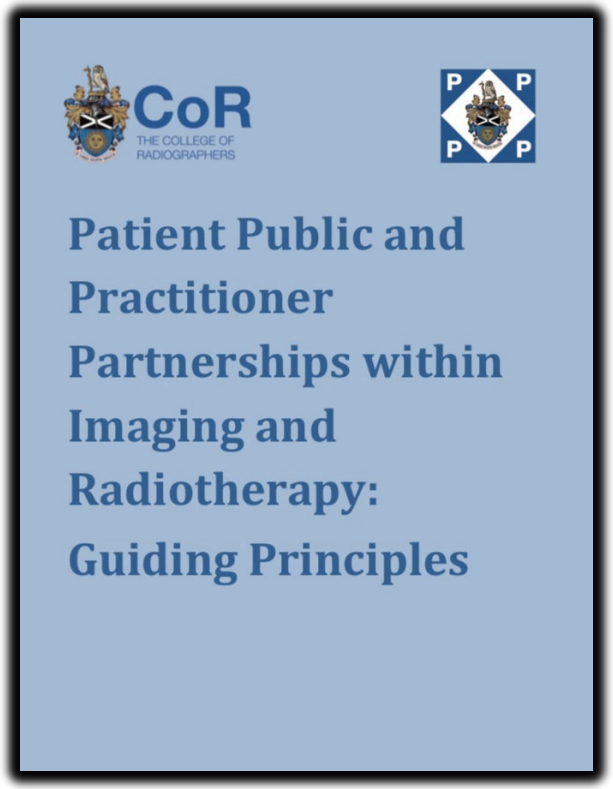
Strategies for person-centred communication

Living with dementia can result in a loss of confidence **for some people** who may be frightened and anxious in an unfamiliar environment.





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Example information from the factsheet:

Behaviours have meaning for the person with dementia. It is their attempt to stop feeling confused or distressed and to feel well again. Try to see things from the person's perspective.

A person's sense of **reality may be different** from yours and they are responding to their current needs.

Try to be aware of a **person's beliefs and thoughts**. For example, if a person believes that they need to go and collect children from school, then don't tell the person that they are wrong –reassure and ask the person to tell you more about their children.

•For example, if an examination or treatment room is too dark then the person may be confused or distressed because they can't work out where they are.

•A person may be feeling a sense of being out of control, frustration with the way others are behaving, boredom, not being listened to or understood.

•A person may be communicating unmet needs –physical, psychological and social e.g. to meet a need by removing clothes because it's too hot or communicating needs by shouting out because the person needs to use a lavatory.

Sharing of information and identification schemes:

SCoR
THE SOCIETY & COLLEGE OF RADIOGRAPHERS

‘This is me’ communication passports, produced by Alzheimer’s Society & the Royal College of Nursing: https://www.alzheimers.org.uk/download/downloads/id/3423/this_is_me.pdf

With a caveat -do not assume that a person does not have mental capacity because they have been identified by a dementia scheme or passport.

Mental capacity guidance and duties with respect to consent

Guidance on mental capacity decisions in diagnostic imaging and radiotherapy

Date published: 11 November, 2018

Topics: Advanced practitioners, Assistant practitioners, Consultants, Imaging, Managers, Patients with additional needs, Radiotherapy, Students

ISBN: 978-1-909802-29-2

An ethos of all mental capacity legislation is to empower those with impaired capacity.

A person's mental capacity is both time and decision specific; capacity to consent can fluctuate.

It may be necessary to delay procedures that are not emergencies in cases where there are any concerns.

Approaches to support in imaging and radiotherapy settings:

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John's Campaign:

Playlist for life:

PLAYLIST FOR LIFE
Personal music for dementia

https://www.dementiaaction.org.uk/dementiafriendlyhospitalscharter

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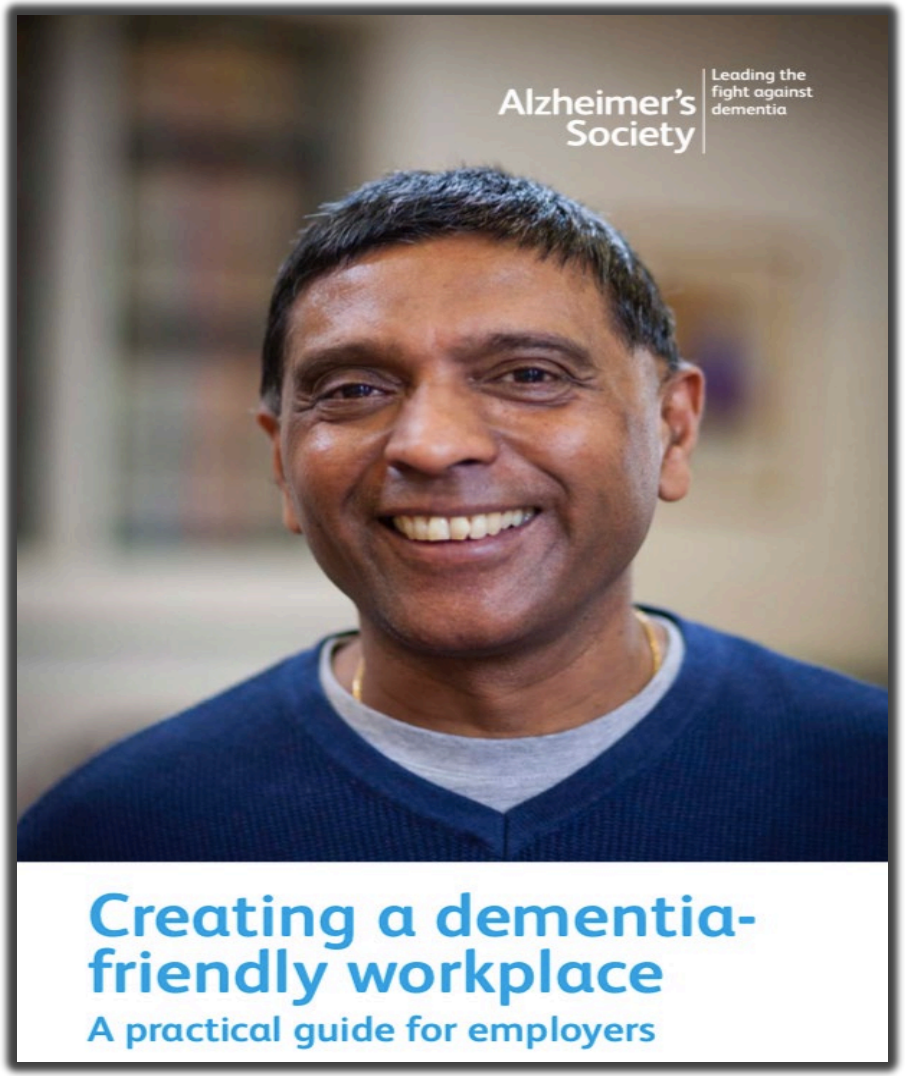
Support for managers in health and care in implementing learning outcomes

As a leader and manager, your teams not only need to have a knowledge and awareness of the key areas highlighted in Subject 10, you also need to be confident that your team are implementing guidelines effectively.

A quick checklist of things to consider:

Framework learning outcome	Things to consider
a) be aware of cultural diversity and equality issues, and how they may impact on people with dementia	Does your team have a brief understanding of some of the key things to consider around equality and diversity for people with dementia? How well do you feel your service is currently considering and managing equality and diversity issues for people living with dementia?

https://www.hee.nhs.uk/news-blogs-events/news/new-resource-launched-improve-dementia-care



Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset

NICE guideline [NG16] Published date: October 2015

1 Recommendations

Promoting healthy lifestyles
Service organisation and delivery

Promoting healthy lifestyles

1 Encouraging healthy behaviours

National organisations and local government departments that influence public health should continue to:

- Develop and support population-level initiatives to reduce the risk of dementia, disability and frailty by making it easier for people to:
  - stop smoking
  - be more physically active
  - reduce their alcohol consumption
  - adopt a healthy diet
  - achieve and/or maintain a healthy weight.
- Use the local regulatory options and legal powers available to encourage increased adoption of healthy behaviours, and risk reduction. For example, as outlined on websites such as Healthy Places.
- Make physical activity, adopting a healthy diet and achieving and maintaining a healthy weight as accessible, affordable and acceptable as possible.

DECODING DEMENTIA
Healthy ageing:
Exercise
Physical activity and exercise may improve cognition and reduce dementia risk.
World Health Organization
Western Pacific Region
www.wpro.who.int/mental_health_substance_abuse/topics/dementia

DECODING DEMENTIA
Understand and manage:
Agitation
Try to stay calm, address the trigger of the behaviour and shift to another activity
World Health Organization
Western Pacific Region
www.wpro.who.int/mental_health_substance_abuse/topics/dementia

VOLUNTEER
VOLUNTEER
DECODING DEMENTIA
Dementia-friendly community:
Social Engagement
Involve people with dementia in social activities
World Health Organization
Western Pacific Region
www.wpro.who.int/mental_health_substance_abuse/topics/dementia

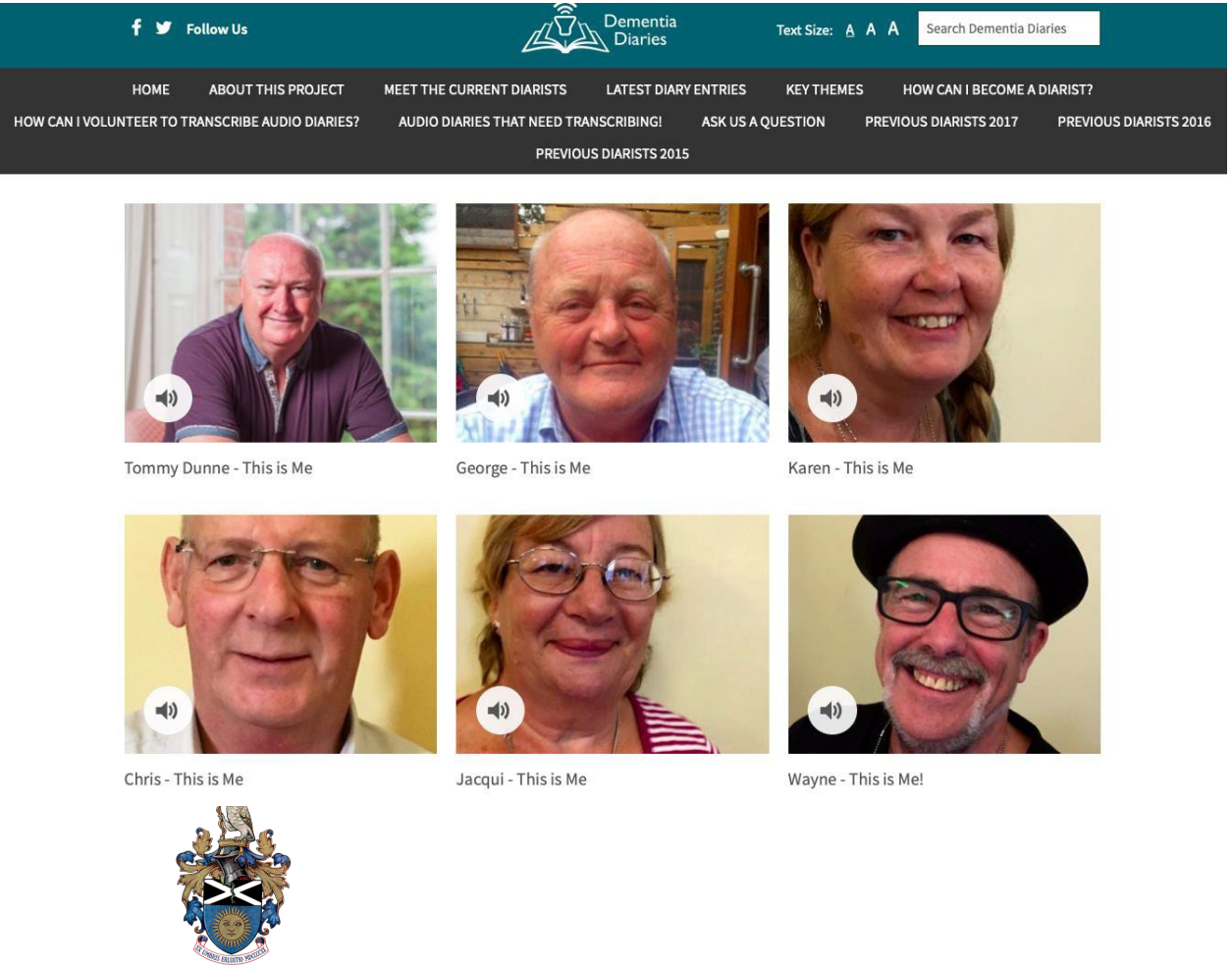
PARTNERSHIPS:

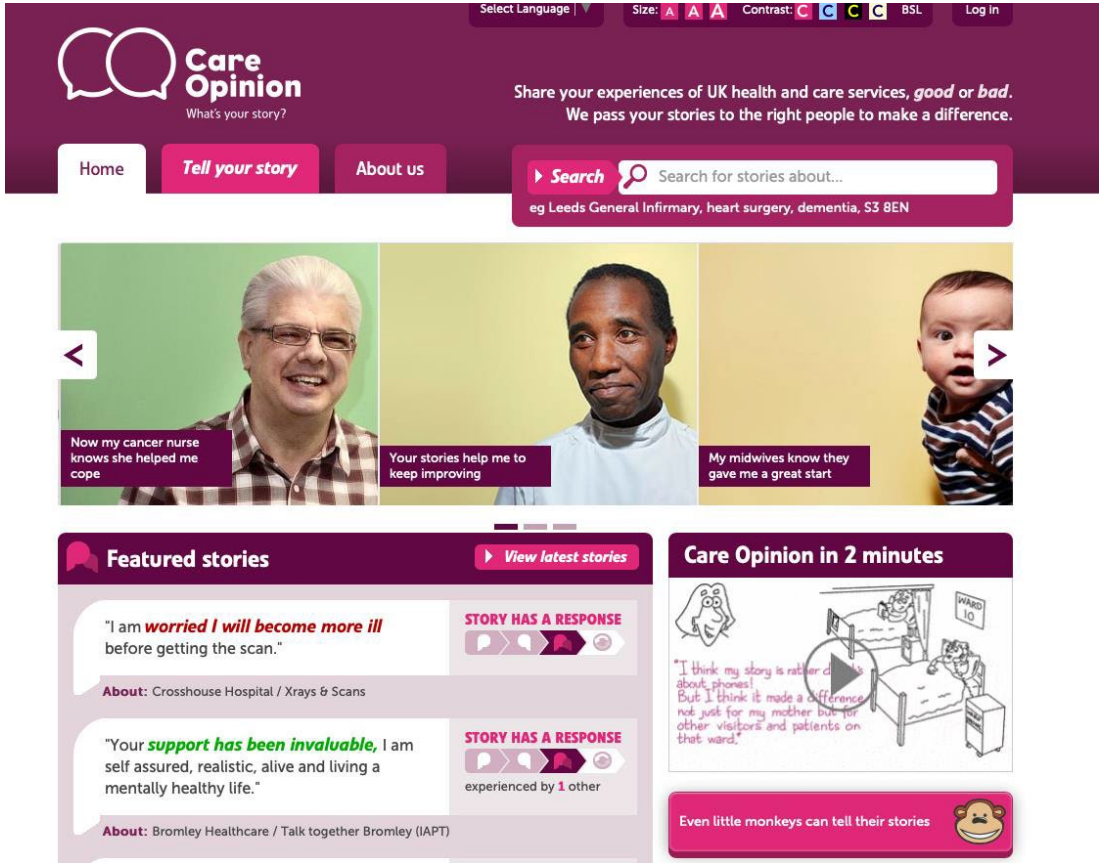
People living with dementia have a voice –this does take different forms.

Ask people how they want to be involved.

Listen to what is being said.

Ask & listen online: e.g. Care Opinion, Dementia Diaries, Alzheimers UK discussion boards.





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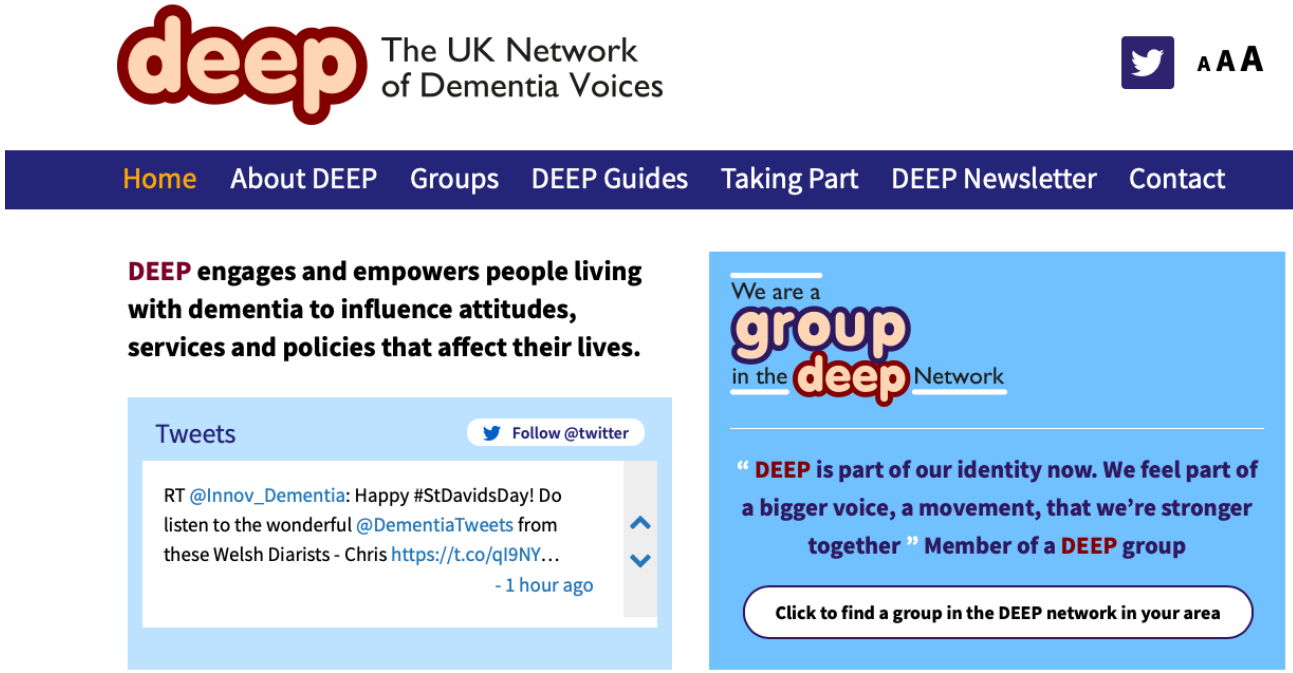
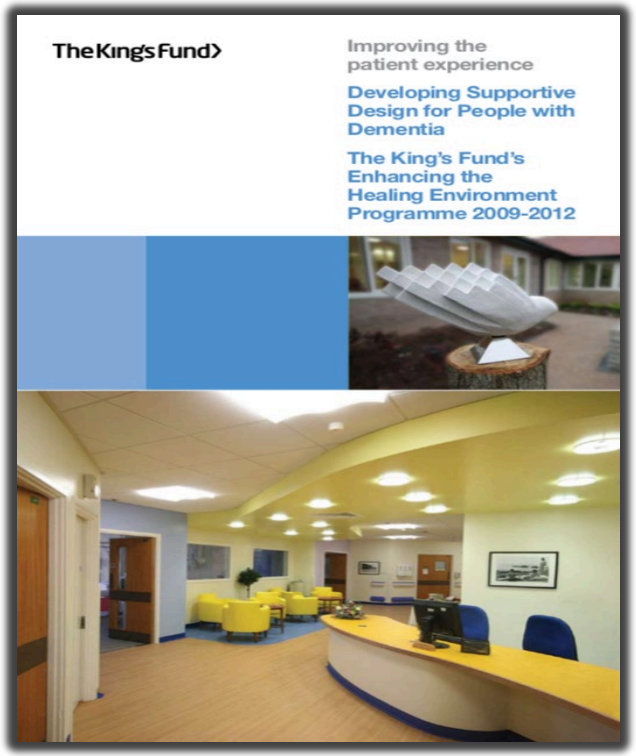
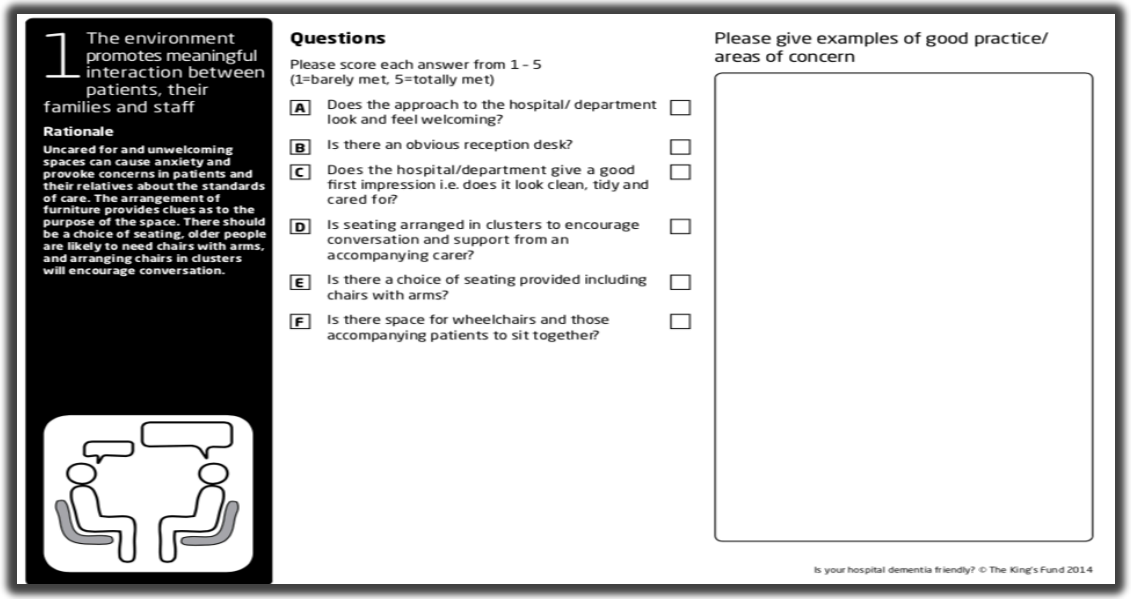
Ask & listen nationally: Dementia Engagement and Empowerment Project (DEEP), Action Groups and Charities.



Ask & listen: Local Dementia support and action groups





The person, their family and their carers are the experts in the person's condition.

Time for questions and suggestions.