



School of Psychology

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**A Systematic Literature Review of Attachment Relationships  
between Paid Caregivers and People with Dementia, and an  
Empirical Study of Staff Skill Development in Supporting  
People with Dementia**

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## CONTENTS

		Page
<b>Acknowledgements</b>		1
<b>Preface</b>		2
<b>The Role of The Paid Caregiver in Attachment Relationships with People with Dementia: A Systematic Literature Review</b>		
	Abstract	6
	Introduction	7
	Context of Dementia	7
	Effective Care Provision for People with Dementia	7
	Policy, Legislation and Guidance	8
	Attachment	9
	Attachment and Dementia	10
	Attachment and Family Caregivers	10
	Rationale	12
	Aims and Objectives	12
	Method	13
	Search Strategy	14
	Results	24
	Study Characteristics	24
	Model of Paid Caregiver Attachment Relationships	26

	Factors Influencing the Attachment Relationships of Paid Caregivers	28
	Workplace Context	28
	Professional Boundaries and Guidance	29
	Personal Factors	30
	Experience	31
	The Individual with Dementia	31
	Mechanisms by Which Factors Influence Paid Caregiver Attachment Relationships	32
	Internal Working Model of Self	32
	Internal Working Model of Others	34
	Emotional Resilience	35
	Attachment Relationships of Paid Caregivers	36
	Emotional Expression and Suppression	36
	Closeness and Distance	37
	Comfort and Discomfort	38
	Mutual Respect and Understanding	38
	Changeable	39
	Links to Family	40
	Discussion	41
	Methodological Considerations and Limitations	43
	Clinical Implications	44

	Workplace Context	45
	Professional Boundaries and Guidance	46
	Personal Factors	46
	Experience	46
	The Individual with Dementia	46
	Internal Working Models of Self and Others	47
	Opportunities for Future Research	47
	Conclusion	48
	References	51
<b>Staff Skill Development in Supporting People with Dementia: A Delphi Study</b>		
	Abstract	61
	Introduction	
	Dementia	63
	Paid Care Providers	63
	Staff Training	63
	Other Resources Required	66
	Policy, Legislation and Guidance	67
	The Good Work Framework	68
	Rationale	71
	Aim	72
	Method	73
	Procedures	73

	Participants	74
	Design	74
	Additional Measures	76
	Results	77
	Demographics	77
	Attrition Rates	81
	Round I Data Analysis	81
	Round II and III Data Analysis	88
	Key Factors	89
	Clusters	93
	Wilcoxon Matched-Pairs Signed Ranked Test	95
	Discussion	97
	Consensus Factors	97
	Methodological Considerations and Limitations	101
	Clinical Implications	103
	Opportunities for Future Research	105
	Conclusion	105
	References	108
<b>Appendices</b>		
	Appendix A – Journal Guidelines for Submission	118
	Appendix B – QATSDD Quality Appraisal Tool Rating Guidelines (taken from Sirriyeh, Lawton, Gardner & Armitage, 2012)	125
	Appendix C – QATSDD Quality Appraisal Tool Ratings	126

	Appendix D – Narrative Synthesis Process Chart	127
	Appendix E – Mapping Articles to the Theory	128
	Appendix F – Identifying Links Within and Between Articles	137
	Appendix G – Peer-Review Confirmation Email	142
	Appendix H – Cardiff University Sponsorship Confirmation Letter	143
	Appendix I – Cardiff University School of Psychology Ethical Approval Email	145
	Appendix J – Health and Care Research Wales (HCRW) Approval Letter	146
	Appendix K – Hywel Dda University Health Board (HDUHB) Research and Development Department Permissions	150
	Appendix L –Global Poster Email	151
	Appendix M – Invitation to Participate Email	152
	Appendix N – Participant Information Sheet	153
	Appendix O – Participant Consent Form	158
	Appendix P – Participant Debrief Sheet	159
	Appendix Q – Research Summary for Stakeholders	162
	Appendix R – Delphi Round I Questionnaire	166
	Appendix S – Delphi Round II Questionnaire	174
	Appendix T – Delphi Round III Questionnaire	202

## LIST OF TABLES

		Page
<b>Systematic Review</b>		
	Table 1. Search terms used in the systematic literature review of impact of paid carer attachment relationships on care provision for people with dementia	13
	Table 2. Descriptive synthesis of studies included in the systematic literature review of impact of paid carer attachment relationships on care provision for people with dementia	16
	Table 3. Clinical implications and relevant references from systematic review	45
<b>Empirical Study</b>		
	Table 1. Demographics of Expert Panel	79
	Table 2. Knowledge in Dementia (KIDe) and Culture of Care Barometer (CoCB) Data for Expert Panel (n=10)	80
	Table 3. Raw Data Quotes for 24 Key Factors	83
	Table 4. Delphi Round II and III Results for 24 Key Factors	91
	Table 5. Delphi Round II and III Results for Clusters	94
	Table 6. Wilcoxon Matched-Pairs Signed-Ranked Test for Clusters and Key Factors	96

## LIST OF FIGURES

		Page
Systematic Review		
	Figure 1. Search strategy for systematic literature review of paid caregiver role in attachment relationship with care-receiver with Dementia	25
	Figure 2. Model of the factors that influence attachment relationships of paid caregivers, the mechanisms by which they act and the nature of the attachment relationships themselves	27
Empirical Study		
	Figure 1. Attrition Rates	81
	Figure 2. Key factors and clusters identified following analysis of Round I responses	82

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## **PREFACE**

### **BACKGROUND**

The prevalence of dementia in the UK is increasing and due to its complexities, those with a diagnosis often require support from professional caregivers. It is therefore important to explore the factors related to paid caregivers, which facilitate effective care provision for people with dementia. This thesis aims to inform evidence-based practice of paid caregivers.

Attachment theory has long been applied to informal caregivers' relationships, from the perspective of the person with dementia, or that of the caregiver, but infrequently from the perspective of the dyad. Evidence shows informal caregiver attachments impact psychological, physical and social wellbeing for both caregiver and care-recipient. This review systematically appraised and synthesised the extant literature on the role of attachment in professional caregiver relationships.

Factors associated with paid caregivers' delivery of effective care for people with dementia have been researched, and policies developed to guide service provision. However, both can be criticised for lacking theoretical and methodological rigour, and making recommendations which are difficult to implement in practice. This empirical research examines factors staff perceive are important for dementia caregiving.

### **AIMS**

The aims of this thesis were to answer the following two research questions:

- *What is the role of the professional caregiver in attachment relationships with people with dementia?*

- *What are the key factors that healthcare staff perceive to be important for developing skill in working with people with dementia?*

## **METHODS**

The literature review was completed in accordance with PRISMA guidance. Search terms and inclusion/exclusion criteria were defined and articles gathered through a systematic search of databases, Google Scholar and a search of references and citation lists. The review consists of a descriptive synthesis, quality assessment and narrative synthesis.

National Health Service (NHS) staff (N=10) who had experience working with adults were recruited to participate in an expert panel for the empirical research. A three round Delphi was undertaken, commencing with an open-ended question on the factors needed to develop skill in working with people with dementia; themes were analysed and key factors identified. In Round II, participants rated the importance of each key factor. In Round III, feedback on collective ratings were provided, and the panel again rated importance.

## **FINDINGS**

The systematic review identified ten relevant articles, of varying methodology and quality. On appraisal there was significant lack of high-quality extant literature. Articles of moderate quality and methodological diversity were included to ensure a systematic, replicable approach. A model was developed, linking attachment relationships of paid caregivers, with the factors that influence them, and their mechanisms. This is advanced tentatively due to the quality issues in the literature.

The contributions of the empirical research expert panel led to the generation of 24 key factors, which grouped into four clusters. Three key factors reached consensus, and a further 12 key factors achieved at least 70% agreement. The clusters were ranked from most, to least important, with the following results: *'Training and Work Environment'*; *'Personal Characteristics'*; *'Approach to Work'*; and *'Life Experience'*. Agreement was reached on the order of importance, with consensus on the position of *'Life Experience'*. The key factors achieving consensus (*'Training'*, *'Patience'* and *'Communication'*), represented three out of the four clusters.

## **IMPLICATIONS**

The systematic review is the first of its kind, drawing together the literature on attachment relationships with people with dementia, developed by paid caregivers in their roles. The proposed model aligns with attachment theory tenets, and offers a number of theoretical, clinical and research implications. However, limitations should be considered: the evidence base is small; this review includes articles of varying vintage; quality; methodology; culture; and care giving role (e.g. nurse, manager). There are clinical implications for both staff recruitment and retention including: valuing qualities of empathy and self-awareness; meeting employee basic needs; creating a positive working culture; adequate training and supervision; knowledge of policy and guidance; and matching client and caregiver, where possible. This evidence base requires more modern, peer-reviewed studies, using robust outcome measures, assessment tools, and theoretical foundation.

The presented empirical results derive from a homogeneous expert panel of NHS staff, offering evidence-based implications to service provision in that health

board. The limitations of this study are acknowledged, with a small expert panel, high attrition rate, and the likelihood of a self-selecting bias. Findings suggest the following should be considered priorities for service provision: developing effective training programmes with a practical element; protected time for peer support and supervision; a values-based recruitment approach that is weighted towards personal qualities, rather than work experience or qualifications; fostering a work environment of continual learning, involving all relevant stakeholders; and being considerate of personal circumstance, promoting a healthy work life balance. There are opportunities for future research to apply this methodology with staff in other health and social care settings.

# THE ROLE OF THE PAID CAREGIVER IN ATTACHMENT RELATIONSHIPS WITH PEOPLE WITH DEMENTIA: A SYSTEMATIC LITERATURE REVIEW

This systematic literature review has been written for prospective submission to “Dementia: The International Journal of Social Research and Practice”, and was prepared in accordance with submission guidance (Appendix A).

## ABSTRACT

**Background:** An increasing number of people with dementia require support from paid caregivers. Literature on attachment of caregivers for people with dementia has focused on informal family caregivers, not staff.

**Method:** A systematic search was completed of the extant literature around the role of attachment in professional caregiver relationships with people with dementia, identifying ten articles for review. A descriptive synthesis and quality assessment (QATSDD) were completed, followed by a narrative synthesis.

**Results:** A model was developed, linking attachment relationships of paid caregivers, with the factors that influence them, and their mechanisms. This model is tentative due to methodological limitations of the evidence base.

**Conclusion:** Literature in this area is sparse and of variable quality. The evidence available can be represented in a model, in keeping with existing theories of attachment. This forms a basis for future research and has clinical implications for staff support, training and recruitment.

## **INTRODUCTION**

### **Context of Dementia**

Dementias are progressive diseases, impacting an individual's cognitive abilities and their skills of daily living (National Institute for Health and Care Excellence [NICE], 2018). Dementia is most common among people over the age of 65; due to the aging population in the UK, dementia is a major public health concern (Prince et al., 2014; Office for National Statistics, 2019; Gardner et al., 2013).

The impact on functional abilities, and association between dementia and physical health conditions, means people with a diagnosis of dementia frequently require care from professional caregivers (Bunn et al., 2014; Elvish et al., 2014; Prince et al., 2013). Care may be delivered in hospital settings, care homes, or recipients' homes, with disease progression making accessing paid care more likely (The Alzheimer's Society, 2009; Prince et al., 2014; The Health and Care Champion Subgroup on Homecare, 2015).

### **Effective Care Provision for People with Dementia**

It is essential to ensure care provided by paid caregivers is effective at meeting the needs of people with dementia (Alzheimer's Society, 2009; Department of Health 2015). The literature tends to focus on staff training provision, which is often below recommended levels (Hughes et al., 2008; Alzheimer's Society, 2009). Evidence-based guidance on providing effective training is available (Skills for Health, Health Education England and Skills for Care, 2015 & 2018). Findings indicate aspects of training most helpful for caregivers are practical strategies and post-training support; the barriers to effective training include difficulties engaging,

lack of confidence and inability to be released from clinical duties (Sass, et al., 2019; Smith et al., 2019; Surr & Gates, 2017; Surr et al., 2017; Surr et al., 2020a).

Factors promoting effective care provision by professional caregivers can be organisational, such as sufficient staffing and wages, a positive working culture and passionate leaders (Bimpong et al., 2020; Godfrey et al., 2018; Surr et al., 2020). Other factors are personal, such as: self-efficacy (the belief in one's own abilities), personal experience of caring for a loved one with dementia; external support from friends/family; feeling motivated and empowered, also contribute to effective caregiving (Coates & Fossey, 2019; Coogle et al., 2006; Gitlin et al., 2001; Surr et al., 2020).

Gwernan-Jones et al. (2020) present a conceptual framework based on evidence from a systematic literature review on the experiences of hospital staff providing care for people with dementia. This framework draws together staff characteristics, behaviours and emotions, characteristics of the person with dementia, and the working environment, to make sense of the factors required to improve staff experience of providing care for people with dementia.

### **Policy, Legislation and Guidance**

There is a legal obligation to offer appropriate support to people with dementia (Equality Act, Department of Health and Social Care, 2010; Carers Act, Department of Health and Social Care, 2014; Mental Capacity Act, Department of Health, 2005). It is recognised that care provision has been sub-standard and dementia care is now a priority area for the UK Government (Department of Health, 2015; Department of Health, 2016; Mental Health Taskforce Strategy, 2016).



Guidelines on the health, social support, and care management of people with dementia have been set out (NICE, 2018) and the National Health Service (NHS) has made a pledge to create Dementia-Friendly Environments (NHS England, 2017).

The Welsh Government has published guidance aiming to meet the specific needs of people with dementia in Wales, with the Dementia Action Plan and Good Work framework (Welsh Government, 2018; Care Council for Wales, 2016).

## **Attachment**

Theories of attachment, first described by Bowlby (1969), are widely accepted models of social and emotional development. The premise of attachment theory is the innate 'attachment system' of individuals, that regulates interactions with caregivers, in response to threat. Those with secure attachments will seek proximity to their caregiver as a source of safety in times of possible danger; when the threat has passed, the individual can independently explore the world, in the knowledge their caregiver is available, when necessary. If a caregiver cannot be relied upon to meet an individual's needs, the attachment is insecure; individuals may seek constant proximity to, or distance from, the caregiver, or relate in unpredictable ways. Whilst Bowlby's original theory has focused on the caregiving experiences of infants, later research has applied these models to adult attachment relationships (Shaver & Mikulincer, 2002). Individuals develop internal working models of themselves and others, based on their experiences of care-receiving, which they use to guide decision making in adult relationships (George & Solomon, 1999; Mikulincer & Shaver, 2007).

## **Attachment and Dementia**

Attachment theory predicts that attachment behaviours (e.g. seeking proximity) will be exacerbated in times of threat, such as ill health or loss (Bowlby, 1973). A systematic review of the literature on attachment theory and dementia described the uncertainty and confusion experienced at each stage of dementia, and concluded that attachment-seeking behaviours aim to restore feelings of security for the individual with dementia (Browne & Shlosberg, 2006). There is evidence that people with dementia are particularly vulnerable to decreased emotional safety (Grobosch et al., 2020) and the behaviours of people in the later stages of dementia may be attempts to create emotional security (Cheston & Christopher, 2019).

A shift from medicalising the experience of dementia, to a more person-centred approach to care, has highlighted the importance of attachment relationships, identifying them as one of the principles of good care (Kitwood, 1999). However, there can be a focus on the attachment style and care-receiving experiences of the person with dementia, and a failure to acknowledge the relational aspect of attachment, and the importance of the role of the caregivers in the attachment relationship (Kokkonen et al., 2014; Morris et al., 2020).

## **Attachment and Family Caregivers**

There are an estimated 700,000 informal caregivers for people with Dementia in the UK, with this figure likely to rise (Lewis et al., 2014). Informal caregivers are typically spouses, or adult children (Lewis et al., 2014) and in the context of attachment theory, it is logical to examine the impact of attachment relationships on all parties. Informal caregivers therefore dominate dementia care attachment research, above formal or paid carers.

There is evidence that informal caregivers with secure attachment styles report fewer psychological difficulties and negative emotions in relation to their caring role (Chen et al., 2013; Nelis et al., 2014). Morris et al. (2020) described the powerful emotions experienced in attachment relationships and the impact these emotions may have on the cognitive processes required for decision making. Outcomes for people with dementia may be better for those in secure attachment relationships with their informal caregiver, reporting fewer physical and psychological symptoms, compared to those in insecure attachment relationships (Monin et al., 2013). Individuals with dementia who have poorer attachments with their informal caregivers are more likely to move to a nursing home (Toot et al., 2017). A literature review of attachment and informal caregiving for people with dementia, described this area as “highly under-researched”, and identified issues around the measurement tools used to explore attachment (Karantzas et al., 2019).

Salmon and Young (2009) completed a critical review on the literature of dependence and caring in clinical communication. The authors describe how the attachment based mental models of self and others might impact a practitioner’s approach to communicating with patients, identifying opportunities for future research exploring how healthcare educators should approach communication training, from an attachment perspective.

The relevance of attachment theory in formal care provision for people with dementia has been considered to a limited extent, but these reflections lack an empirical evidence-base (Flannery, 2002; Miesen, 2010).

## **Rationale**

Whilst the attachment relationships between the family or informal caregiver, and the person with dementia has received some attention (Karantzas et al., 2019), fewer articles consider attachments with paid care staff (Kokkonen et al., 2014). Exploring the extant literature, via a systematic review, allowed scrutiny of the research, recommendations for clinical practice that are based in theory and evidence, and identification of areas requiring further research.

## **Aims and Objectives**

The aim of this systematic literature review was to answer the main research question: *What is the role of the professional caregiver in attachment relationships with people with dementia?* This was to be explored through several objectives:

- To explore how paid caregivers approach relationships with the people with dementia they care for;
- To identify the factors influencing the paid caregiver in building attachments with people with dementia;
- To explore the mechanisms of how these factors impact the paid caregiver attachment relationship.

## METHOD

This systematic literature review was completed following the PRISMA guidance (Moher et al., 2015). A search on PROSPERO (International prospective register of systematic reviews) on 25.09.20, indicated no ongoing, completed or published systematic literature reviews on this topic, in the English language; and this review was registered (CRD42021231080).

This review focuses on the care provision for people with dementia, therefore the search term *dement\** was used, to include variations of the word that may be relevant (e.g. dementias, dementing). The review was not limited to specific types of dementia, or to a particular age range. In order to explore the attachment styles, processes and relationships of professional caregivers, the search term *attach\** was used. This broad search term aimed to be over-inclusive, to ensure high sensitivity. Only literature pertaining to professional caregiving was of relevance to this review, rather than that of informal or family caregivers; search terms (Table 1) and inclusion criteria reflected this focus.

Initial investigative searches indicated a small number of papers relevant to the research question, therefore it was decided not to restrict the review to a specific methodological approach. The inclusion of a diverse range of methodologies has some limitations, which will be discussed later in this paper.

### Table 1

*Search terms used in the systematic literature review of impact of paid carer attachment relationships on care provision for people with dementia*

Dementia	Professional Carers	Attachment
Dement*	"formal care*" "paid care*" "professional care*" "staff"	Attach*

## **Search Strategy**

Inclusion criteria:

1. English language, or adequate English translation;
2. Focus on paid carers and health or social care professionals;
3. Care provision for people of any age with a diagnosis of dementia;
4. Exploring roles of caregiver in attachment relationships with clients, or identifying attachment as a mediating factor;
5. Empirical papers.

Exclusion criteria:

1. Full English language text unavailable;
2. Focus on unpaid carers or family carers;
3. Care provision for people without a diagnosis of dementia;
4. Articles with no reference to attachment relationships, or a sole focus on attachment relationship from perspective of the person with dementia;
5. Reflective articles, with no systematic or empirical underpinnings.

The search databases used were: AMED (Allied and Complementary Medicine), EMBASE, Ovid MEDLINE (R) ALL, APA PsycINFO, PsycArticles Full Text, Ovid Emcare and Global Health, and was supported by the Cardiff University Psychology librarian. Initial screening for eligibility used titles and abstracts for each article, where eligibility was uncertain full text articles were reviewed. Searches were completed on 25.09.20 and 26.10.20.

Additional articles were identified through Google Scholar searches (using Table 1 search terms), and through hand searching, identifying relevant articles cited by, or citing, an included reference.

Key areas of interest were identified and extracted in an initial descriptive synthesis (Table 2). A mixed methods quality assessment tool was chosen (QATSDD; Sirriyeh et al., 2012) due to the variety of methodologies of included articles. The 14 item QATSDD uses a 4-point scale to rate article quality, calculating a percentage of the maximum possible score (Appendix B). Scores above 75% were considered “high quality”, 50-75% “good”, 25-50% “moderate”, and those scoring below 25% were considered “poor quality”. The QATSDD has been shown to have good reliability (Cohen’s kappa,  $\kappa = 71.5$ ) and good face validity (Sirriyeh et al., 2012). To ensure empirical rigor, two reviewers (one independent from the study), completed the quality assessment tool, with substantial levels of agreement (Cohen’s kappa,  $\kappa = .763$ ,  $p < .000$ ); reviewers discussed ratings to reach a consensus (Appendix C). In addition, reflections on the quality of each article were made by the author (Table 2).

Due to the varied methodologies of the identified studies, a narrative synthesis approach was selected as most appropriate (Centre for Reviews and Dissemination, 2009). The narrative synthesis was completed following relevant guidance (Popay et al., 2006) and was in keeping with other systematic literature reviews in the field (Farina et al., 2017; Quinn & Toms, 2019).

**Table 2**

*Descriptive synthesis of studies included in the systematic literature review of impact of paid carer attachment relationships on care provision for people with dementia*

Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Abrams, Vandrevalla, Samsi and Manthorpe (2019)  South East England and London, UK	Qualitative: Framework analysis	Semi-structured open-ended interviews	N = 43	<ul style="list-style-type: none"> <li>- Home-care staff and managers</li> <li>- Sample demographics congruent with the typical make-up of the home-care workforce, other than the majority being employed full-time</li> </ul>	<p>Home-care staff from 10 different services. Services providing care on behalf of the local authority and privately</p> <p>Providing care for people with dementia up to end of life</p>	Exploring how professional boundaries are established and constructed by home-care staff working with people with Dementia in the last years of their lives.	<p>Four key themes identified:</p> <ul style="list-style-type: none"> <li>- Adaptability and flexibility</li> <li>- Home as site of work: vulnerability, risk and need for protection</li> <li>- Personal relationships seen as conducive to person-centred care</li> <li>- Manager as protective gatekeeper for employee safety</li> <li>- Role of ambiguity</li> <li>- Forming attachments yet remaining professional</li> <li>- Attachments as inherent to role</li> <li>- Demonstrating substantial emotional investment</li> <li>- Metaphor of parental figure</li> <li>- Relational aspects blur boundaries</li> <li>- Emotional distance needed to preserve wellbeing</li> <li>- Provide comfort and reassurance to family members</li> <li>- Juggling compassion with professionalism</li> <li>- Loss and grief at client death</li> </ul>	Good 71.4%	<ul style="list-style-type: none"> <li>- Recruitment via home-care managers, may have biased which care workers received the invite to participate</li> <li>- Participants may have tailored responses to present themselves in a desirable way</li> <li>- Alternative analysis method may have been more appropriate.</li> <li>- No evidence of service user involvement in study design</li> <li>- Limited rationale for sample size</li> </ul>



Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Berg, Hallberg, and Norberg (1998) Sweden	Qualitative: phenomenological-hermeneutic analysis	Open-ended, unstructured interviews	N=13	<ul style="list-style-type: none"> <li>- Nursing staff</li> <li>- Median age=28years</li> <li>- Median work experience=6years</li> <li>- Females N=11</li> </ul>	<p>Psychogeriatric clinic Ward of N=11</p> <p>Providing care for people with severe dementia</p>	Nurses reflection on Dementia care, in context of new ward intervention of systematic clinical supervision	<p>Two key themes identified:</p> <ul style="list-style-type: none"> <li>- Intertwined lives (caring means making and doing, caring evokes immediate emotions and reactions, caring means developing means of handling emotions, caring has an ongoing relation to the whole life)</li> <li>- Delicate interpretative work (searching for meaning and being in the hands of others)</li> </ul>	Good 61.9%	<ul style="list-style-type: none"> <li>- Lack of depth in the interviews.</li> <li>- Nursing staff not familiar with regularly reflecting on own practice, may inhibit responses.</li> <li>- Risk of interviewees narrating situations to please researcher.</li> <li>- Bias of researchers, perhaps alternative interviewers would have evoked other narratives.</li> <li>- Subjectivity of the researchers influences the analysis.</li> <li>- Results not providing definitive knowledge, rather an argument that contributes to discourse</li> <li>- Age of study, published 1998</li> <li>- No evidence of service user involvement in study design</li> <li>- No rationale for sample size</li> <li>- Acknowledge the cultural context being based outside of the UK</li> </ul>
Coates (2015, unpublished) Oxfordshire and Buckinghamshire, UK	Qualitative: interpretative phenomenological analysis (IPA)	<ul style="list-style-type: none"> <li>- Semi-structured interview schedule</li> <li>- Inventory of Geriatric Nursing Self-Efficacy (IGNSE)</li> </ul>	N = 8 (N = 19 completed initial questionnaires, N = 9 met inclusion criteria)	<ul style="list-style-type: none"> <li>- Care Assistants in care-homes accepting people with dementia</li> <li>- Worked in role for 6 months or more</li> <li>- Identified as high levels of self-efficacy on IGNSE</li> <li>- Fluent in English</li> <li>- Representative of population of UK care-assistants</li> <li>- 100% female</li> <li>- Age range from 25-67 years</li> <li>- 62.5% White British</li> </ul>	<p>Care home registered to provide services for individuals with dementia</p> <p>Stage of dementia not described</p>	To explore the experiences of care assistants providing dementia care in care home settings	<ul style="list-style-type: none"> <li>- Four superordinate themes identified</li> <li>- Feeling Torn</li> <li>- Togetherness and Connection</li> <li>- Attunement</li> <li>- "Caring as Part of Life" <ul style="list-style-type: none"> <li>- Innate abilities</li> <li>- Genuine interest in others</li> <li>- Attitude of acceptance</li> <li>- Motivation to care</li> <li>- Caring identity</li> <li>- Personal experiences of care</li> </ul> </li> </ul>	High 78.6%	<ul style="list-style-type: none"> <li>- From the grey literature, unpublished thesis</li> <li>- Possible biased recruitment strategy: managers selected staff to invite</li> <li>- Limitation to sample: only included those with high self-efficacy scores; no male participants</li> <li>- Not generalisable findings</li> <li>- Sample had higher than average levels of qualification</li> <li>- Lack of involvement of key stakeholders in study design</li> </ul>

Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Drebing, McCarty, and Lombardo (2002)  New England, USA.	Quantitative: archival study, correlational analysis	<ul style="list-style-type: none"> <li>- Boston University Alzheimer's Disease Core Centre (BU ADCC) questionnaire</li> <li>- Pruchno et al. Uplift Scale</li> <li>- Professional Caregiver Burden Index (PCBI)</li> <li>- The Grief Resolution Index (GRI)</li> </ul>	N=77 (122 invited to participate)	<ul style="list-style-type: none"> <li>- Professional caregivers</li> <li>- 34% of participants between 40-49 years old</li> <li>- 47% of participants with 11+ years' experience in the profession</li> <li>- 84% Female</li> </ul>	Residential dementia special care program  Stage of dementia not described	Exploration of the impact of extrinsic and intrinsic factors on job and career commitment.	<ul style="list-style-type: none"> <li>- Extrinsic factors (e.g. position and total hours of work) were found not to be related to job or career commitment</li> <li>- The greater percentage of work time spent with patients, the more the job or career commitment</li> <li>- Attachment to patients and family members is significantly correlated with career commitment and significantly negatively correlated to thoughts of quitting</li> <li>- Professionals who report a high degree of grief over the death of patients, are more likely to see themselves working in the field throughout their career</li> </ul>	Good 59.5%	<ul style="list-style-type: none"> <li>- Correlational study, so causation cannot be interpreted</li> <li>- No exploration of the biases that might impact those who chose to participate and those that did not</li> <li>- Limited range of intrinsic factors explored</li> <li>- Age of study, published 2002</li> <li>- No evidence of service user involvement in study design</li> <li>- No rationale for sample size</li> <li>- Acknowledge the cultural context being based outside of the UK</li> </ul>

Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Edwards (2017, unpublished)  South of England, UK	Qualitative: Thematic Analysis	- Semi-structured interview schedule	N = 7	- All participants were female - N = 1 care manager, N = 6 carers - N= 6 non-native English speakers	Two care homes providing care for people with dementia  Providing care for people with mid to later stage dementia	To consider the relevance of attachment in caregiving within residential care home settings.	- Identified three major themes: - Creating a home - Ideas of safety and security - A place of belonging - Receiving care and meeting needs - Freedom and independence - Participants reflected on their relationships with parents - Relationship with client fulfils staffs own need to 'belong' - "We are like the caring parent-figure" - Forming a relationship - Learning to trust and building bonds - Distraction - Mapped themes onto attachment theory model	Good 73.8%	- From the grey literature, unpublished thesis - Authors report some communication difficulties as English was a second language for many participants - Cultural backgrounds of participants may have influenced themes - Possibility of participant responses being influenced by what they feel is socially desirable - No comment on if the sample is representative of the target population - Recruitment and invite figures not provided - Reliability of results limited as no other researcher involved - No evidence of involvement of service users in study design

Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Gerritsen et al., (2007) Netherlands	Quantitative: exploratory questionnaire study	- Quality of life measure designed for the study based on the responses of people with dementia	N = 374 (distributed questionnaire to N = 793)	- Three groups: 24-hour care staff (N = 280), day-time activity staff (N = 76), unknown profession (N = 18) - 95% female - Mean age of 38 years (range 17-62) - Mean hours worked per week 26 (4-40)	Psychogeriatric units and day centres  Stage of dementia not described	Exploration on the degree to which professional caregivers focus on the quality-of-life domains that people with dementia consider important. Identifying any differences between the 24-hour care staff and day-centre staff.	- Some degree of similarity between the focus of staff and what is important to people with dementia - Relatively little attention to "financial situation" and "being useful/giving meaning to life" - Differences between groups on the domains that are focused on - Day-centre staff focused more than 24-hour staff on "attachment", "enjoyment of activities", "sense of aesthetics", and "being useful/giving meaning to life".	Moderate 50%	- Significantly smaller day-centre staff sample - Exploratory study with limited validity - Sample of convenience - Low response rate - Not representative of all professionals working with people with dementia (e.g. social workers and physicians etc.) - Limited statistical analysis, only reporting analysis of means - No exploration of the reliability or validity of the quality-of-life tool - Acknowledge the cultural context being based outside of the UK - Age of study, published 2007

Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Haggström and Norberg (1996) Northern Sweden	Qualitative: phenomenological-hermeneutic analysis	<ul style="list-style-type: none"> <li>- Individual interview of 1 hour</li> <li>- Carer observation of 2.5 hours</li> <li>- Reflective talk following each observation</li> <li>- Group interview following 25 completed observations</li> <li>- Final staff interview, reflecting on communicative context of ward</li> </ul>	<ul style="list-style-type: none"> <li>N = 5 (personal interviews)</li> <li>N = 13 (group interview)</li> </ul>	<ul style="list-style-type: none"> <li>- N = 4 nurses, N = 1 nursing aid</li> <li>- Identified by selves and management as good at communicating with people with dementia</li> <li>- Age range 29-55 years</li> <li>- Education range from 10 weeks to 2.5 years</li> <li>- Work experience from 10 to 27 years</li> </ul>	<ul style="list-style-type: none"> <li>Group dwelling for people with dementia</li> <li>Providing care for people with a diagnosis of dementia for more than four years</li> </ul>	<ul style="list-style-type: none"> <li>Illuminate the thinking of identified good dementia carers in an attempt to make explicit their means of understanding people with dementia</li> </ul>	<ul style="list-style-type: none"> <li>- Carers make explicit reference to the concept of mother.</li> <li>- Carer's mentioned a variety of roles of the mother.</li> <li>- Carer's drew on the experience of their own mother: someone who was always around, exercised patience, positive model.</li> <li>- They describe their caring being influenced by their own mother</li> <li>- Carer's drew on their experience as mothers: exercising patience, interpreting unspoken messages, diplomacy</li> <li>- Reflected on the care-home community as a family</li> <li>- If individual lacks clarity on her own self, it will be transferred to the child (or individual with dementia in this case).</li> </ul>	Moderate 42.9%	<ul style="list-style-type: none"> <li>- Age of the study, published 1996, outdated language</li> <li>- Study undertaken in one care-home only, very limited sample</li> <li>- Care-home had a good reputation for communication between staff and individuals with dementia, so may not generalisability</li> <li>- Carer's use of metaphor means it could be interpreted in many ways; this interpretation is therefore not the only credible one</li> <li>- No description of ensuring methodological rigor, e.g. themes being analysed by more than one researcher</li> <li>- No involvement of key stake holders in study design</li> <li>- Risk of interviewees narrating situations to please researcher.</li> <li>- No rationale for sample size</li> <li>- Acknowledge the cultural context being based outside of the UK</li> </ul>

Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Kokkonen, Cheston, Dallos, and Smart (2014) UK	Quantitative: cross-sectional survey study	<ul style="list-style-type: none"> <li>- Experiences in Close Relationships – Revised (ECR-R)</li> <li>- Approaches to Dementia Questionnaire (ADQ)</li> <li>- Inventory of Geriatric Nursing Self-Efficacy</li> <li>- Maslach Burnout Inventory 3<sup>rd</sup> Edition (MBI)</li> </ul>	N=75 (174 invited to participate)	<ul style="list-style-type: none"> <li>- Permanent member of NHS care staff</li> <li>- 31.2% of participants between 40-49 years old</li> <li>- Mean length of work experience 11.6 years</li> <li>- 79.2% Female</li> </ul>	<p>National Health Service (NHS) inpatient wards for older people</p> <p>Stage of dementia not described</p>	Examine the relationships between staff attachment style, self-efficacy, approaches to dementia, and burnout in paid caregivers for people with dementia	<ul style="list-style-type: none"> <li>- Attachment insecurity is associated with caregiver burnout</li> <li>- Adult attachment styles are significant in coping of paid caregivers working within institutional settings</li> <li>- Attachment anxiety is related to more emotional exhaustion, depersonalisation and lower ratings of personal accomplishment</li> <li>- Attachment avoidance is significantly positively correlated with emotional exhaustion and depersonalisation</li> <li>- Avoidantly attached individuals are vulnerable to experiencing burnout</li> </ul>	High 88.1%	<ul style="list-style-type: none"> <li>- Correlational cross-sectional design, therefore cannot imply causality</li> <li>- Model of adult attachment used comprised two parts (attachment anxiety and attachment avoidance), some overlap in these constructs therefore power of independent predictors may be questioned</li> <li>- Some criticism of the ECR-R, as not tapping into unconscious defences</li> <li>- Participant interpretation of questionnaire items might differ (responding in relation to close personal relationships vs. work context relationships)</li> <li>- MBI floor effect meant results violated normal distribution assumptions</li> <li>- Responses may be affected by social desirability</li> <li>- Low response rate of 44.3%</li> <li>- Recruitment may be biased, those experiencing burnout may not engaged in the study due to effects of burnout (e.g. lack of motivation, time off work etc.)</li> <li>- No evidence of service user involvement in study design</li> </ul>

Study	Design	Measures Used	Number of Participants	Participant Characteristics	Study/Service Context/Stage of Dementia	Main Focus	Key Findings	Quality Assessment (QATDSS % of Maximum Score)	Potential Bias or Study Weaknesses
Law, Patterson, and Muers (2019) UK	Qualitative: Interpretative Phenomenological Analysis (IPA)	Semi-structured interview schedule	N = 8	<ul style="list-style-type: none"> <li>- White British females</li> <li>- First language English</li> <li>- Minimum of National Vocational Qualification Level 2 in Health and Social Care</li> <li>- Average age 36 years</li> <li>- Average of 8 years 7 months experience caring for clients with dementia</li> <li>- Working an average of 31.5 hours per week</li> </ul>	Residential care homes providing 24-hour care  Stage of dementia not described	Exploring experiences of healthcare assistants working with people with dementia in UK residential care homes.	<ul style="list-style-type: none"> <li>- 3 Superordinate themes, consisting of several subordinate themes</li> <li>- Theme 1: Importance of relationships <ul style="list-style-type: none"> <li>- Attachment relationship with clients seen as pivotal to providing good care, but in contrast, less attachment to clients may be a protective mechanism against loss.</li> <li>- Relationship with colleagues also identified as important</li> </ul> </li> <li>- Theme 2: Something special about the role</li> <li>- Theme 3: The other side of caring</li> </ul>	Good 73.8%	<ul style="list-style-type: none"> <li>- Lack of diversity within the participant sample, not reflective of the profession</li> <li>- Small sample size, limiting transferability/generalisability</li> <li>- Opt-in recruitment process may have biased findings</li> <li>- Data was analysed at the end of data collection, meaning the interview schedule was not adapted/developed during the data collection phase</li> </ul>
Vandrevalla et al., (2017) South of England, UK	Qualitative: thematic analysis	Semi-structured, open-ended interview guide	N = 20	<ul style="list-style-type: none"> <li>- Care home staff, excluding trained nursing staff</li> <li>- 90% female</li> <li>- 35% over 50 years old</li> <li>- 80% British nationality</li> <li>- 75% White</li> <li>- 35% 2-5 years' experience in the role</li> <li>- 70% single marital status</li> <li>- 75% working full-time</li> </ul>	Five care homes for people with dementia  Providing care for people with dementia at the end of their lives	Job related stress experienced by care home staff working with residents with dementia	<ul style="list-style-type: none"> <li>- Attachments staff form with residents are integral to care at the end of life and, in the context of working with residents with dementia, it was felt to be particularly salient</li> <li>- Staff may find it hard to detach but to do so to protect themselves from grief.</li> <li>- Staff sought to remain professionally detached rather than recognising the impact of death on them</li> <li>- Reciprocal bonds between residents with dementia, their families and care staff have the potential to increase wellbeing for all.</li> </ul>	Good 66.7%	<ul style="list-style-type: none"> <li>- Staff who participated were mostly working full-time, which is not reflective of the general care staff population, participants may have more exposure to residents at the end of life and less free time for self-care</li> <li>- Self-selecting nature of sample may limit generalisability</li> <li>- Since study was completed mandatory training for all care staff is a requirement in the UK, meaning staff may have more extensive training on how to manage some of these issues</li> </ul>

## RESULTS

### Study Characteristics

Search strategy and results are detailed in Figure 1. In brief, 159 references were identified, of which 145 were excluded based on information from the title and abstract. A full-text English language version was not available for one of the remaining articles and two were reflective pieces with no empirical basis. Six articles were included in the final review. An additional article was sourced via Google Scholar, and three identified through hand searches. A total of ten articles were included in the study.

The QATSDD (Sirriyeh et al., 2012) was used to assess the quality of these articles, indicating large range in quality across the literature. Two papers were rated as moderate; six as good; and only two of the included articles reached a high-quality level, rating over 75% of the maximum possible score.



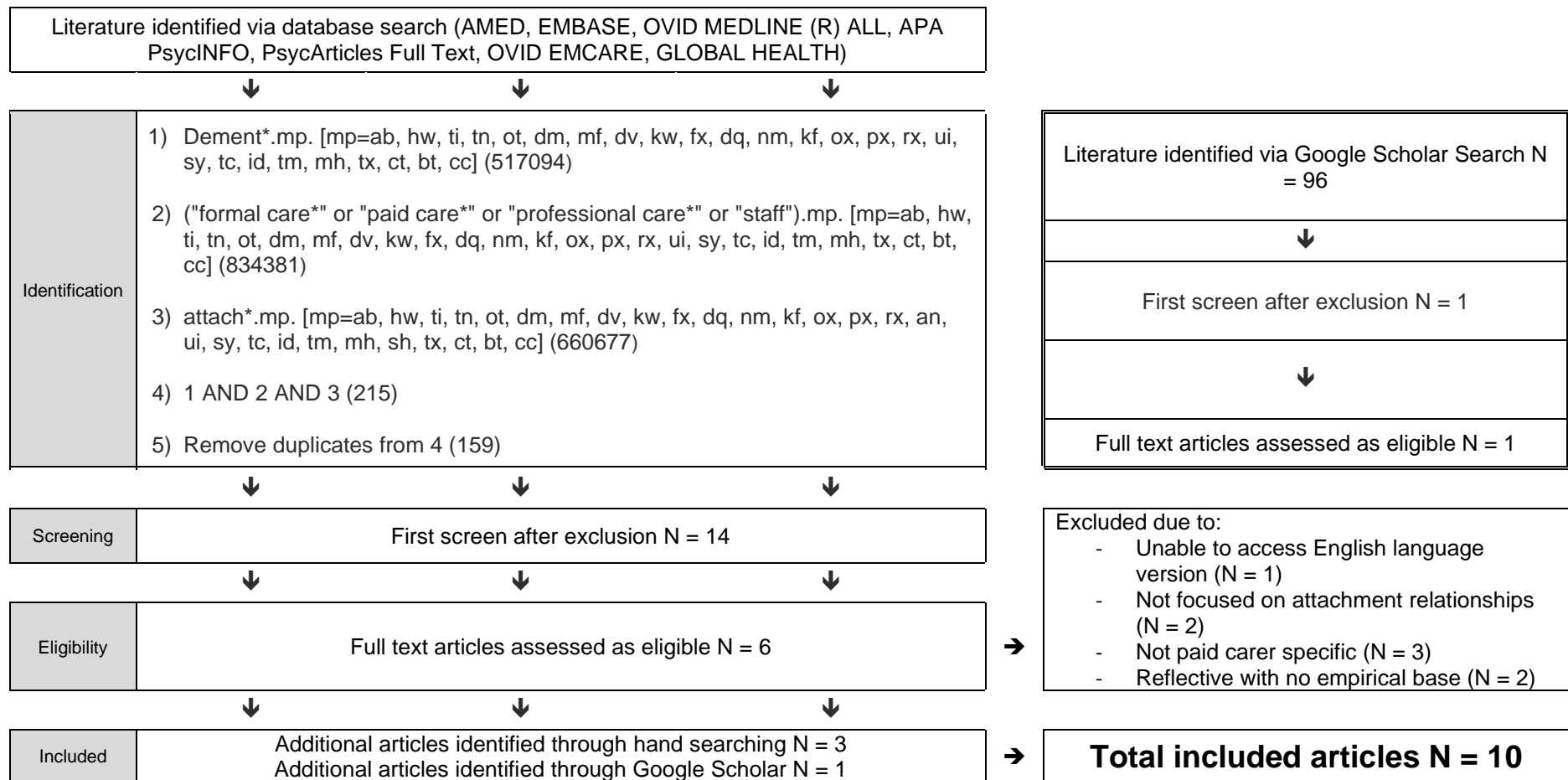


Figure 1. Search strategy for systematic literature review of paid caregiver role in attachment relationship with care-receiver with Dementia

## **Model of Paid Caregiver Attachment Relationships**

The Popay et al. (2006) guidance informed the narrative synthesis process (Appendix D). An initial theory was developed, and a table used to identify information from the literature pertaining to the three aspects of the theory: attachment relationships; influencing factors; and mechanisms (Appendix E). Links between and within articles were drawn out, leading to the identification of sub-factors and processes (Appendix F).

The final model generated through the narrative synthesis is presented in Figure 2. This model shows the three main aspects of the theory and their sub-components, overlapping circles indicate direct influence or associations between those sub-factors. Each of the sub-components includes at least one high quality paper, and at least 60% of the articles contributing evidence to each sub-component are of good or high quality.

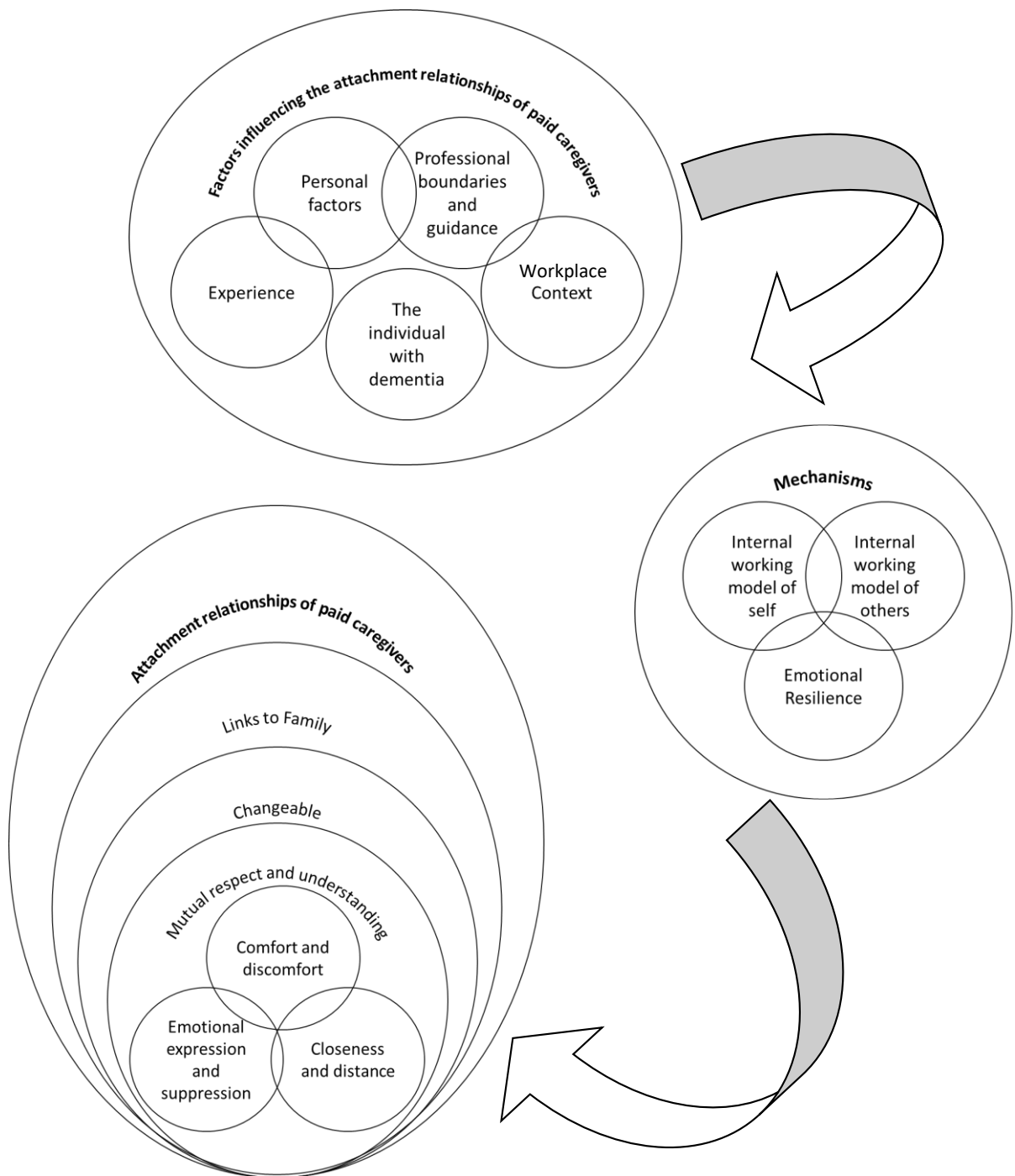


Figure 2. Model of the factors that influence attachment relationships of paid caregivers, the mechanisms by which they act and the nature of the attachment relationships themselves

## ***Factors Influencing the Attachment Relationships of Paid Caregivers***

All ten articles made reference to the factors influencing attachment relationships between paid caregivers and people with dementia. These clustered into five groups: *Workplace Context*; *Professional Boundaries and Guidance*; *Personal Factors*; *Experience*; and *The Individual with Dementia*.

### **Workplace Context**

Half of the included articles identified the context of care provision as playing a role in attachment relationships. Of those articles contributing to this sub-component, 80.0% are of good or high quality. A thematic analysis of job-related stress (Vandrevala et al., 2017) indicated attachments between care home staff and people with dementia could be disrupted by competing demands and time pressures of the role. The reflections of ward nurses presented by Berg et al. (1998) provides evidence that the number of individuals a nurse is expected to support at any one time, will influence their ability to form caring relationships. In a study on professional boundaries of home care staff (Abrams et al., 2019), participants shared that working in a client's home prompted more person-centred care, helped in getting to know the individual, and facilitated building meaningful relationships. Gerritsen et al. (2007) explored the degree to which professional caregivers focus on the aspects of quality of life important to people with dementia. The authors identified differences between two groups of staff, dependant on their role, with 24-hour care staff and day-activities staff reporting different approaches.

Another aspect of *Workplace Context* impacting attachment relationships is workplace culture. Working together as a team, and learning from influential colleagues and managers were identified as conducive to care provision in an IPA study by Coates (2015, unpublished). Support from colleagues and managers, and

positive team spirit are helpful in relationship building, but working culture can also have a negative impact, for example a culture of not talking about death can increase stress and isolation of caregivers, who then withdraw from clients (Vandrevalla et al., 2017).

In relation to this previous point, working in the context of end-of-life care was identified as a challenge to forming attachments by several studies (Abrams et al., 2019; Berg et al., 1998; Vandrevalla et al., 2017).

### **Professional Boundaries and Guidance**

Abrams et al., (2019) found building attachments whilst remaining professional, a key theme of home care staff's role. The nature of working in people's homes meant boundaries were blurred, but having robust care plans, a good knowledge of policy, and understanding expectations of the role, were all helpful in finding a balance. Adequate training was identified in this study, as in others, as helping staff to feel comfortable and confident in their role, and to build attachments with people with dementia (Coates, 2015, unpublished; Law et al., 2019; Vandrevalla et al., 2017).

Coates (2015, unpublished) describes the change in good practice participants had seen in the course of their careers (e.g. views on concealing medication in food), this overlaps *Professional Boundaries and Guidance*, and *Workplace Context*. Professional support, from managers and peers were also valued (Abrams et al., 2019), again linking to *Workplace Context*.

Of those articles contributing to this sub-component, 100.0% were of good or high quality.

## **Personal Factors**

The third factor impacting attachment relationships was the personal qualities of the paid caregiver, with 87.5% of contributing articles being of good or high quality. The work of Berg et al. (1998) and Coates (2015, unpublished) make reference to the innate abilities and intuitions of staff, with one caregiver describing caring as “in the blood”.

In a thematic analysis on the relevance of attachment in residential care home settings, Edwards (2017, unpublished) highlights the vital role of empathy in forming attachment relationships. Other authors consider the temperament and emotional abilities of paid caregivers, such as their emotional investment in the role and self-awareness (Abrams et al., 2019; Gerritsen et al., 2007).

Barriers to forming attachment relationships included the worries and fears paid caregivers have in relation to their role, including concerns about accusations, feeling vulnerable when working alone, work resulting in conflicts in personal life, and an inability to resolve the discomfort of clients (Abrams et al., 2019; Drebing et al., 2002; Law et al., 2019). Drebing’s et al. (2002) archival study linked workplace attachment relationships, with impact on personal life, and the levels of commitment staff had to their role. Another IPA study with care home staff revealed feelings of not fulfilling their role, when staff were unable to resolve the client’s discomfort and distress, often leading to staff withdrawing from the attachment relationship as a self-protective mechanism (Law et al., 2019).

Some paid caregivers report their faith and religion as having an impact on their approach to forming relationships with people with dementia, particularly during end-of-life care (Coates, 2015, unpublished).

*Personal Factors* also link to *Professional Boundaries and Guidance*, as paid caregivers must not merely be offered training, but must feel this has met their competency needs (Abrams et al., 2019; Coates, 2015).

The final aspect of *Personal Factors*, connects to the next factor, *Experience*. Whilst *Experience*, refers to the professional experience of the paid caregiver, this section considers the personal experiences that facilitate caregiver's attachment relationships with people with dementia. Personal life, both past and present will impact the caregiver's approach to work, and vice versa, with particular consideration for experiences of caring for a loved one and getting older oneself (Law et al., 2019; Berg et al., 1998; Coates, 2015). Haggström and Norberg (1996) explored how "good dementia carers" relate to people with dementia, the authors identified the theme of "the mother" and made reference to the paid caregiver's own experience of being mothered, and mothering.

### **Experience**

Alongside the personal experiences relating to caregiving, professional experience was frequently referenced in the literature as conducive to attachment relationship building. These experiences included, the length of time in the role/profession, experience supporting people at the end of life, experiencing the death of clients, and the length of time the caregiver has known the client (Abrams et al., 2019; Berg et al., 1998; Coates, 2015; Law et al., 2019). Of those articles contributing to this sub-component, 100.0% were of good or high quality.

### **The Individual with Dementia**

Outside of the caregiver's personal life, role and work environment, are factors specific to the individual with dementia; 100.0% of articles contributing to this sub-component were of good or high quality. Paid caregivers identified a number of

challenges related to the individual, which impact relationship building. These included: disease progression; level of disability; communication difficulties; unresolved discomfort or distress; aggression and abuse (e.g. racial discrimination); distrustful and suspicious attitudes; attachment seeking behaviours (e.g. seeking comfort, not wanting to be alone etc.); and difficulties expressing and managing emotions (Abrams et al., 2019; Berg et al., 1998; Edwards, 2017, unpublished; Kokkonen et al., 2014; Law et al., 2019; Vandrevalla et al., 2017).

### ***Mechanisms by which Factors Influence Paid Caregiver Attachment***

#### ***Relationships***

Having acknowledged the factors that influence the attachment relationships of paid caregivers, an exploration of potential mechanisms by which they act is now made.

The attachment literature describes the formation of mental representations referred to as Internal Working Models (IWM; Bowlby, 1973). When applying the theory of IWM to this literature review, two key mechanisms were identified, *IWM of Self*, and *IWM of Others*. A third mechanism, *Emotional Resilience*, was added alongside the IWMs; this is also in keeping with attachment theory which states an individual with secure attachments will be better able to regulation their emotions, preventing them from being overwhelmed at witnessing the distress or suffering of others (Mikulincer & Shaver, 2007).

#### **Internal Working Model of Self**

The *IWM of Self*, refers to the individual's perceptions of themselves and has an impact on their approach to relationships and how to cope with adversity; 80.0% of the articles contributing to this sub-component were good or high quality.



Supporting people with dementia and forming attachment relationships will inevitably bring its challenges. The literature identified a range of attitudes and approaches to responding to these challenges which could be conceptualised as the individual differences in the IWM of self. When faced with adversity in working relationships, some caregivers may make negative evaluations of themselves, their knowledge and expertise; resulting in feelings of powerlessness, reduced confidence, feeling overwhelmed, unmotivated and struggling to cope (Abrams et al., 2019; Berg et al., 1998; Coates, 2015, unpublished; Kokkonen et al., 2014; Vandrevalla et al., 2017). Other individuals will make positive evaluations of themselves; feeling confident in their skills, empowered, knowledgeable, motivated and equipped for their role, taking a more light-hearted approach to their work, and seeing challenges as learning opportunities (Abrams et al., 2019; Coates, 2015, unpublished; Drebing et al., 2002; Edwards, 2017, unpublished).

Understanding one's own actions and motivations is important in forming attachment relationships (Berg et al, 1998), these motives and actions will be influenced by the individual's IWM of self. Some caregivers view their role as an important one, in which they have superior knowledge and expertise (Law et al., 2019), and are relied upon by others (Vandrevalla et al., 2017). Others may view this responsibility as a pressure to perform and "get it right", particularly during end-of-life care (Law et al., 2019). Coates (2015, unpublished) found some caregivers experienced a need to care, as if it were a "drug or a duty". This example represents two IWMs of self, one using caregiving for personal reward, whilst another feeling responsible for others. Haggström and Norberg (1996) identify a possible driver for pursuing a career in caregiving as making up for care that the individual did not provide for their own family member; this would represent a self-deprecating IWM of

self, where negative appraisals of past decisions shape caregiving. For others, the role of caregiver may provide a sense of belonging (Edwards, 2017, unpublished), which can be diminished when other professionals become involved in care provision (Abrams et al., 2019).

In summary, paid caregivers view their roles in a variety of ways (Gerritsen et al., 2007), possibly as a result of their individual IWM of self. An individual's experience of caregiving, how they manage the challenges of the role and how situational factors influence their attachment relationships with people with dementia, will be shaped by their IWM of self.

### **Internal Working Model of Others**

The *IWM of Others*, refers to the individual's perceptions of the needs and motives of others; 87.5% of the articles contributing to this sub-component are good or high quality.

When considering the mechanisms for developing attachment relationships, a common theme in the literature was around caregivers being invested in their clients (Abrams et al., 2019; Berg et al., 1998; Drebing et al., 2002; Edwards, 2017, unpublished). In order to invest in others, the caregiver must hold an IWM that values others, seeing them as worthy of care and support. Caregivers may invest more in understanding the relational patterns of the individual with dementia, and appropriately adapt their own approach to relationship building.

The literature also refers to feeling supported by others, such as managers and colleagues (Berg et al., 1998; Coates, 2015, unpublished; Law et al, 2019). In order for paid caregivers to feel able to rely on the team around them, their IWM must consider others as reliable, as invested in the caregiver's wellbeing, and must also judge the support offered as helpful.

Kokkonen et al. (2014) examined the relationship between staff attachment style, self-efficacy, burnout and approach to care provision. The authors identified when staff view others as unworthy of help, they show less empathy, display less positive attitudes to others, and increased depersonalisation (holding cynical and negative views of the people they work with). The importance of experiencing empathy for others, and caring for people in the way they wish to be cared for, is commented by several authors (Edwards, 2017, unpublished; Haggström & Norberg, 1996)

An IWM holding others in high esteem may support caregiver's satisfaction in their role. Law et al. (2019) describes the feelings of privilege a healthcare assistant experienced at being able to support an individual with dementia to the end of their life.

In summary, an IWM of others that views people with dementia as worthy of care, and sees colleagues as reliable and supportive, may facilitate the development of positive caregiving attachment relationships.

### **Emotional Resilience**

Providing care for a person with dementia comes with a number of challenges, from communication difficulties, to decisions around end of life. The quality of care and the caregiver's role in the attachment relationship, will be shaped by the ways in which the caregiver manages these challenges. Of those articles contributing to this sub-component, 100.0% were good or high quality.

Some caregivers may respond to adversity in the job with negative emotions, pessimism and emotional exhaustion (Kokkonen et al., 2014), particularly if the adversity is caused by a difficulty in the relationship with the client (Abrams et al., 2019). Reduced emotional resources, poor psychological wellbeing and low morale

can result in a cyclical process of challenging interactions with clients (Kokkonen et al., 2014).

Caregivers of people with dementia experience repeated loss as the disease progresses, reducing individuals' abilities, making meaningful connections more challenging, and resulting in the death of an individual that they have built attachments with. The literature frequently makes reference to the emotional toll of repeated loss and grief, and the range of responses caregivers may have to this (Abrams et al., 2019; Drebing et al., 2002).

In summary, how paid caregivers cope with the emotional demands of their role will impact the type of relationships they are able to build with the people with dementia they support.

### ***Attachment Relationships of Paid Caregivers***

As the factors influencing attachments, and their mechanisms, have been identified, an exploration of the nature of the attachment relationships themselves can be made.

#### **Emotional Expression and Suppression**

The demands of a caregiving role may be considered great, with evidence of the impact on carers psychological wellbeing (Law et al., 2019). The literature describes a spectrum of emotional responses, from expression to suppression; 87.5% of articles contributing to this sub-component were good or high quality.

Some paid caregivers view emotional attachments as a key part of their work (Abrams et al., 2019). These individuals approach attachment relationships with clients with empathy, consideration and patience (Berg et al., 1998; Haggström & Norberg, 1996). They express the profound loss, grief and sadness they feel

(Abrams et al., 2019; Law et al., 2019; Vandrevalla et al., 2017) and gain satisfaction from interactions with clients (Coates, 2015, unpublished). Caregivers can find moments of pleasure and happiness, sharing emotional experiences and using these positive connections to regulate their own emotions (Berg et al., 1998; Coates, 2015, unpublished; Haggström & Norberg, 1996).

In contrast, caregivers may create an emotional distance from the client, or a numbness, in order to protect themselves (Coates, 2015, unpublished; Kokkonen et al., 2014; Law et al., 2019). An emergent theme in qualitative studies has been, “it breaks you” and that caregivers require a “mask to hide emotions” in order to continue their work (Abrams et al., 2019). Some paid caregivers may suppress their emotions as they feel it is important to remain professional (Vandrevalla et al., 2017), particularly with emotions such as impatience with clients (Edwards, 2017, unpublished). Law et al. (2019) found around 50% of participants in their study felt they should carry on work despite their emotions, as this is the expectation of a caregiving role. This type of emotional suppression may be associated with high attachment related anxiety within the caregiver (Kokkonen et al., 2014).

### **Closeness and Distance**

Closeness can be seen as inherent in the caregiving role (Abrams et al., 2019), and close contact with clients as the central reason many paid caregivers do their job (Drebing et al., 2002). Closeness helps caregivers and people with dementia enter a shared world of positive physical contact and psychological connection (Berg et al., 1998).

Closeness to clients opens caregivers up to vulnerability of experiencing loss, with some individuals creating distance as a form of protection (Coates, 2015, unpublished; Kokkonen et al., 2014; Vandrevalla et al., 2017). Too close a

relationship can also be stifling, and distance may be needed to support the autonomy, independence and freedom of clients (Edwards, 2017, unpublished; Gerritsen et al., 2017); Haggström and Norberg (1996) summarise this as choosing “when to mother, and when not to”.

Of those articles contributing to this sub-component, 77.8% were good or high quality.

### **Comfort and Discomfort**

Central to the attachment relationship is the sense of comfort, with caregivers needing to create a “home”, a place of belonging and nourishment, radiating security (Edwards, 2017, unpublished; Haggström & Norberg, 1996). This may spread to the wider network, with paid caregivers offering comfort to the family of the person with dementia (Abrams et al., 2019).

Berg et al., (1998) share the reflections of one nurse, who acknowledged the need for tenderness, warmth and closeness in the relationship with patients, but experienced discomfort with this, considering how “terrible” it must be to be at the “nurses’ mercy”. Meeting the emotional needs of the client can be more demanding than meeting their physical needs (Vandrevala et al., 2017), and best interests dilemmas in the role can lead caregivers to feel uncomfortable with tasks they are required to do (Coates, 2015, unpublished).

Of those articles contributing to this sub-component, 83.3% were good or high quality.

### **Mutual Respect and Understanding**

Emotional expression, comfort and closeness, sit within the context of *Mutual Respect and Understanding*. Many of the articles included in the review make reference to the importance of mutual respect and understanding in the attachment

relationship (Berg et al., 1998; Gerritsen et al., 2007; Haggström & Norberg, 1996, Kokkonen et al., 2014); 75.0% of the contributing articles were good or high quality.

Making the effort to build knowledge of the individual with dementia and attempting to take their perspective, contributes to understanding their behaviours and actions, leading caregivers to be more responsive to the client's needs and unspoken cues (Berg et al., 1998; Coates, 2015, unpublished; Edwards, 2017, unpublished; Haggström & Norberg, 1996).

Other aspects of respect and understanding include: connecting in a human way (Law et al., 2019); trust (Edwards, 2017, unpublished), open communication (Abrams et al., 2019), valuing small interactions and feedback, and showing a genuine interest (Coates, 2015, unpublished).

### **Changeable**

Underlying each of the previous four aspects is the changeable nature of the attachment relationship; 83.3% of articles contributing to this sub-component were good or high quality. Haggström & Norberg (1996) described the “important and varying roles of the mother”; the relationship is flexible, adaptable and creative, balancing compassion and professionalism (Abrams et al., 2019; Law et al., 2019). The caregiver's boundaries must fluctuate between rigid and fluid, to balance the competing needs of the client, their family, other residents and staff (Coates, 2015, unpublished). A number of articles make reference to circularity or reciprocity of emotion between client and caregiver (Abrams et al., 2019; Berg et al., 1998; Coates, 2015, unpublished). It has been proposed that the role of the caregiver is to build trust from the mistrust of the client, and to move from an insecure to a secure position of attachment (Edwards, 2017, unpublished).

## **Links to Family**

The majority of the articles included in this review make some reference to the caregiver's own family; with 85.7% of those contributing to this sub-component being good or high quality. Kokkonen et al. (2014) directly explored the influential role of caregiver's prior attachments and impact on caregiving behaviours. Individuals may compare a client to a member of their own family, to help guide their caregiving decisions (Coates, 2015; Vandrevalla et al., 2017). Other authors refer to caregivers as attempting to create a "home", or seeing the work setting as a "family" (Edwards, 2017, unpublished; Haggström & Norberg, 1996). Caregivers can see their role as filling the attachment gap created when contact between the person with dementia and their family is disrupted (Haggström & Norberg, 1996; Vandrevalla et al., 2017). Several articles offer evidence of transference, that caregivers view their clients as family members, likening their interactions to a parent, child, close relative, or friend (Abrams et al., 2019; Edwards, 2017; Haggström & Norberg, 1996; Law et al., 2019).



## DISCUSSION

To summarise the results described in detail above; the narrative synthesis gave rise to a model representation of the data (Figure 2). This model identifies five factors that are evidenced to influence attachment relationships, four of these are interlinked (*Workplace Context, Profession Boundaries and Guidance, Personal Factors, Experience*), and the remaining factor of *The Individual with Dementia*. These factors, emergent from the data, act on the attachment relationship by way of three mechanisms (*Internal Working Model of Self, Internal Working Model of Others, and Emotional Resilience*). The nature of the attachment relationships themselves can be broken into six parts; *Emotional Expression and Suppression, Closeness and Distance, Comfort and Discomfort*, all sit within a context of *Mutual Respect and Understanding*, and are *Changeable*. The final aspect of the relationship, that influences all other aspects, is the *Links to Family*, encompassing the caregiver's own attachment relationships, past and present.

This is the first review of its kind, drawing together the literature on paid caregivers' attachment relationships with people with dementia and how they influence caring roles. Searches were completed systematically, with quality appraisal, reflection and critical appraisal conducted throughout. The model developed here is broadly in keeping with attachment theory, linking attachment-based internal working models, to emotional experiences and behaviours within adult relationships (Browne, & Shlosberg, 2006; Chen et al., 2013; Nelis et al., 2014; Monin et al., 2013). These results offer some empirical support for the reflections shared by professionals working in this area, on the importance of attachment theory in providing effective care for people with dementia (Flannery, 2002; Miesen, 2010). This review presents a model which builds on existing theories connecting

practitioner's approach to clinical relationships with patients with their mental models of self and others (Salmon & Young, 2009). This model also leads to a number of clinical and service development recommendations, to be discussed in more detail below.

Having considered the strengths of this review, its various limitations must also be explored. All articles included in this review make reference to attachment relationships, however, for only a limited number of papers was this the central focus. Nearly half (N=4) of the articles included were completed more than 10 years ago, and whilst important to include these papers, their relevance to current practice may be questioned; a further two papers were unpublished theses. The research included in this review is international, and there may be cultural differences, the complexity of which are not fully captured in the synthesis process.

The overall quality of the articles included was variable. The quality assessment tool shows only two articles reached the highest level of empirical rigor, with a further six rated as "good", and two as 'moderate' quality. Critical evaluation also indicated that much of the research used a qualitative methodology with small sample sizes, limiting generalisability. The 'opt in' nature of these studies leave them vulnerable to a self-selecting bias, so the full range of attachment experiences is unlikely to be represented in this literature.

Whilst some authors may comment on the attachment styles of caregivers, very few supported these claims with the use of robust tools for assessing caregiver attachment style. This review also fails to distinguish between the different types of paid caregivers, for example, pooling together the results of studies with in-home care staff (Vandrevalla et al., 2017), alongside those with ward nurses (Berg et al., 1998). Factors constraining or promoting attachment relationships within these

varied job roles and work settings are likely to be very different, and there is insufficient evidence to account for these differences.

Finally, the factors included in this model are derived from the perspective of the paid caregiver, not the individual with dementia, as per the research question. However, attachment processes are relational and evidencing the role of the person with dementia is also vital in understanding relationship building and maintenance.

### **Methodological Considerations and Limitations**

In addition to the limitations of the findings described above, there are some methodological considerations to be acknowledged. During initial searches, it was clear the extant literature would be limited; however, continuance with this review was felt beneficial to draw the existing literature together and to ensure recommendations for future research were based on evidence, or lack thereof.

On reflection, the use of the search term 'attachment' may have been reconsidered. Publications relevant to this review derived from nursing, social work or medical journals; the term 'attachment' was sometimes used to refer to a one-sided process, rather than relational interactions that are theoretically informed and defined. These professionals may not frame 'attachment' in the same way as intended in this review, with attachment theory in mind (Bowlby, 1969, 1973). Few papers made explicit the theoretical models and predictions guiding their research questions. A broader set of search terms including words such as 'relational', may have elicited further relevant literature, however preliminary searches produced a plethora of results and introduced complexity in regard to definitions and theoretical assumptions.

Due to the limited number of articles in this field, a decision was made to include all papers meeting the inclusion criteria, regardless of the methodology used. This decision may be criticised for restricting potential methods of quality evaluation and synthesis. However, mixed-methods reviews are argued to have more utility and impact (Harden, 2010), which is important for the implementation of theory to practice in complex systems such as health and social care settings.

An independent researcher was involved for only the quality appraisal aspect of this review, and the narrative synthesis did not receive input from any other researchers. Personal motives, assumptions and unconscious biases were explored through a reflective/reflexive diary informed by bracketing strategies described by Ahern (1999). However, this synthesis is at risk of being influenced by interpretive biases of the researcher.

The variable quality and limited quantity of literature made the synthesis process challenging, however it felt valuable to appraise these findings, as it evidences the need for further research in this field.

### **Clinical Implications**

Attachment styles of staff cannot be directly altered, however, there are independent means to influence attachment security when working with people with dementia. This model offers opportunities for interventions, based on reviewed evidence, and understanding of possible operating mechanisms. The following recommendations are prompts for reflection, rather than strict criteria to adhere to, due to the limitations of this research. A table mapping the clinical implications to the model and the relevant articles included in the literature review can be found in Table 3.

**Table 3***Clinical implications and relevant references from systematic review*

Model Area	Clinical Implication	Relevant Reference from Systematic Review
Workplace Context	Meeting staff's basic needs	Abrams et al., 2019; Berg et al., 1998; Gerritsen et al., 2007; Vandrevalla et al., 2017
	Positive culture of care	Vandrevalla et al., 2017
	Communicating about challenges of the role	Abrams et al., 2019; Berg et al., 1998; Vandrevalla et al., 2017
Professional Boundaries and Guidance	Clear professional guidance and policies	Abrams et al., 2019; Coates, 2015, unpublished
	Adequate training to meet staff needs	Coates, 2015, unpublished; Law et al., 2019; Vandrevalla et al., 2017
Personal Factors	Values based recruitment	Abrams et al., 2019; Edwards, 2017, unpublished; Gerritsen et al., 2007
Experience	Valuing personal experience of caregiving	Abrams et al., 2019; Berg et al., 1998; Coates, 2015; Law et al., 2019
The Individual with Dementia	Matching care-giver and care-recipient	Abrams et al., 2019; Berg et al., 1998; Edwards, 2017, unpublished; Kokkonen et al., 2014; Law et al., 2019; Vandrevalla et al., 2017

The following service level recommendations are in keeping with Gwernan-Jones et al. (2020) systematic review findings, on the experience of staff in providing care for people with dementia in hospital. Those authors identified the responsibility of the institution in fostering a culture of person-centred care, in order to improve experiences of care provision for both staff and people with dementia.

### ***Workplace Context***

Service providers and senior managers should ensure the basic needs of paid caregivers are met, including adequate salaries, staffing levels, resources and time.

Efforts should be made to maintain a positive culture of care, with colleagues supporting each other in a cohesive team. Staff should be prompted to communicate openly about the challenges of their role, in particular end of life care.

### ***Professional Boundaries and Guidance***

These review findings imply professional guidance should be clear, with every client having a robust care plan, with explicit description of the expectations on staff. All staff should feel confident in their knowledge of relevant policies; provision should be made to ensure all paid caregivers are up to date with the latest best practice guidance. Each member of staff should receive training that feels adequate for their personal competency needs.

### ***Personal Factors***

In addition to those recommendations that can be applied to current employees, there are some factors services should consider at recruitment. Values of empathy and emotional investment in the role, along with a reflective, self-awareness, should be prioritised and protected to ensure retention.

### ***Experience***

Whilst extensive experience of working with people with dementia, particularly at end of life, might be desirable when recruiting new staff, personal experience of caregiving roles should also be valued.

### ***The Individual with Dementia***

Service providers should remain mindful of factors around the individual with dementia, matching caregiver and client, where possible, is likely to be beneficial for the development of a positive attachment relationship.

### ***Internal Working Models of Self and Others***

Whilst IWM's are developed through experiences in early life, they will adapt and update to incorporate relational experiences from adulthood (Bowlby, 1973). Service providers are not able to influence the early experiences of their employees, but through implementing the clinical recommendations described above, they can foster an environment supporting positive IWM's of self and others.

### **Opportunities for Future Research**

The limitations of this review are consistent with those in the informal caregiver literature (Karantzas et al., 2019), and present opportunities for future research. This evidence base requires more modern, peer-reviewed studies, applying theory to practice, using robust outcome measures and assessment tools. Research should be completed with paid caregivers, systematically exploring their attachment styles, the impact on care provision, and on efficacy of care for people with dementia.

Future research could take a quantitative approach to exploring this tentative model. The factors influencing the attachment relationship of paid caregivers, could be explored through questionnaires such as the Culture of Care Barometer (Rafferty et al., 2017), the Knowledge in Dementia Scale (Elvish et al., 2014) and explorations of the basic needs of staff at work (e.g. staffing levels, salary etc.). The attachment styles and IWM's of staff could be assessed using the Experiences in Close Relationships – Revised (Fraley et al., 2000). Finally, interactions between professional caregivers and people with dementia could be observed using the Quality of Interactions Schedule (Dean et al., 1993). A correlational analysis could identify links between these areas of the tentative model.

It may be helpful to compare and contrast the attachment relationships of paid caregivers in differing roles (e.g. at home care staff versus ward nurses), and to consider the nature of the relationship required in these differing settings. Research with dyads of caregiver and client may also provide insightful evidence on the reciprocity of attachment relationships. In a society ever more reliant on paid caregivers to maintain the quality of life for people with dementia, these areas of research are essential.

Further analysis on patterns within attachment relationships could be explored, for example how attachments between people with dementia and their paid caregivers adapt to times of change. Knobloch et al. (2020) have explored the impact of change on the relationship between informal adult caregivers, and developed a framework informed by Relational Turbulence Theory, future research could consider the application of this framework to the paid caregiver context.

There is also an opportunity to explore the impact of factors such as cultural difference and ethnic diversity, on the formation of attachment relationships between paid caregivers and people with dementia. Whilst there is some research considering the experience of migrant care workers, the relational and interactional aspect requires further evidence (Adebayo et al., 2020).

## **CONCLUSION**

Attachment theory has been applied to the context of dementia for some time, however this tends to simplify the relational by focussing on the perspective of the person with dementia, or informal caregivers, such as friends and family (Browne, & Shlosberg, 2006; Chen et al., 2013; Nelis et al., 2014; Moninet al., 2013). Due to the significant number of people with dementia requiring support from paid care



professionals (Bunn et al., 2014; Elvish et al., 2014; Prince et al., 2013), further investigation into their role in attachment relationships was required. This systematic literature review presents the findings of 12 articles, on the role of paid caregivers in attachment relationships with people with dementia, the factors influencing the attachment, and the mechanisms behind this.

A systematic search, quality appraisal, and narrative synthesis were completed, inclusive of studies using a range of methodologies. A model presenting the literature findings was developed (Figure 2.), identifying the factors influencing attachment relationships (*Workplace Context, Profession Boundaries and Guidance, Personal Factors, Experience, and The Individual with Dementia*), the mechanisms by which they act (*Internal Working Model of Self, Internal Working Model of Others, and Emotional Resilience*), and the nature of the attachment relationships themselves (*Emotional Expression and Suppression, Closeness and Distance, Comfort and Discomfort, Mutual Respect and Understanding, Changeable, and Links to Family*).

There are however, limitations to these findings. The articles identified are of variable quality, with only two reaching the highest standard. The studies use a range of methodologies, making direct comparisons more challenging. The type of paid caregiver recruited for each of the studies is different, working in various settings. The literature is also sourced from multiple cultural backgrounds, which should be considered when making comparisons between articles.

Despite its limitations, this model may be useful to health and social care services in recruitment planning, staff training, and provision of staff support and supervision. This literature review has identified a number of opportunities for further

research with paid caregivers, in order to ensure future policy and service provision is based on robust evidence.

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## **STAFF SKILL DEVELOPMENT IN SUPPORTING PEOPLE WITH DEMENTIA: A DELPHI STUDY**

This research project is written for prospective submission to “Dementia: The International Journal of Social Research and Practice”, and is prepared accordingly (Appendix A).

### **ABSTRACT**

**Background:** The Good Work Framework is designed to support healthcare staff to provide good care for people with dementia. Application of this policy has been criticised, with services needing further guidance on how staff can develop relevant skills.

**Method:** A three round Delphi was performed with an expert panel of NHS staff (N=10). An open-ended question in Round I, generated themes that were rated by importance in subsequent rounds, with feedback on collective ratings provided in Round III.

**Results:** Twenty-four key factors were grouped into four clusters in order of importance to the panel: ‘Training and Work Environment’; ‘Personal Characteristics’; ‘Approach to Work’ and ‘Life Experience’. Three key factors reached consensus, ‘Training’, ‘Patience’ and ‘Communication’. Twelve key factors reached agreement.

**Conclusion:** Findings contribute to operationalising the Good Work Framework.

Methodological limitations are considered, including sample size and definition of 'expert panel'.

## INTRODUCTION

### **Dementia**

Dementia is a group of conditions affecting cognitive processes and adaptive functioning (National Institute for Health and Care Excellence [NICE], 2018). The risk of developing dementia increases with age, with 7.1% of people over the age of 65 having dementia (Prince et al., 2014). Due to ageing populations, dementia has been identified as a major public health issue globally (Office for National Statistics, 2019; Gardner et al., 2013).

People with dementia are more likely to have comorbid physical health conditions (Bunn et al., 2014) which need support and treatment in general hospitals (Elvish et al., 2014). The Alzheimer's Society (2009) estimates 25% of hospital beds are occupied by a person with dementia. Individuals with a diagnosis of dementia make up 69% of the care home population (Prince et al., 2014). Approximately a third of people with dementia receive care at home, making up 60% of service users of homecare providers (The Health and Care Champion Subgroup on Homecare, 2015). When compared to people with other chronic health conditions, people with dementia are more likely to depend on the support of paid carers (Prince et al., 2013).

### **Paid Care Providers**

Paid carers constitute a broad range of professionals, from both health and social care sectors. In Wales, around 9.5% of economically active adults were employed in the healthcare sector (Health Education Improvement Wales [HEIW], 2019). Adult social care services in Wales employ over 53,000 people (Social Care Wales, 2019). Both sectors have predominantly female employees, between with 77-

83% (HEIW, 2019; Social Care Wales, 2019). Employees in health and social care tend to be older than in other industries (Social Care Wales, 2019; HEIW, 2019). Between 5-6% of employees in this sector are from Black, Asian, or Minority Ethnic (BAME) groups (HEIW, 2019), with 5% not having English or Welsh as their first language (Social Care Wales, 2019).

Issues with staff turnover are well reported in adult social care; employees in direct care-providing roles are most likely to leave their post, with approximately 40% turnover rates (Skills for Care, 2019). Healthcare services experience similar retention difficulties, and values-based recruiting (an approach aiming to attract and recruit employees whose values align with that of the organisation) has been associated with improved staff satisfaction and lower turnover (Bimpong et al., 2020; Figgett, 2017; Consilium Research and Consultancy Ltd., 2016; HEIW, 2019a).

## **Staff Training**

Levels of training vary greatly across professionals who work with people with dementia, with estimates that as few as 8% of care home staff have received adequate training (Hughes et al., 2008). In 2009, the Alzheimer's Society reported that 54% of nurses they surveyed had no dementia training at all, and 34% felt they did not have enough training (Alzheimer's Society, 2009).

Studies have evaluated the effectiveness of dementia training programmes, finding some benefits in staff knowledge, communication and prescribing practices (Sass et al., 2019; Surr et al., 2017), but there is a lack of robust evidence that training impacts staff care behaviours (Scerri et al., 2017). The UK government have acknowledged nationwide deficits in dementia education and training (Department of Health, 2015).



Guidance supporting provision of effective staff training and education have been set out (Skills for Health, Health Education England and Skills for Care, 2015 & 2018). Smith et al. (2019) audited services against this gold standard dementia training framework, finding adequate provision of general “Dementia Awareness” programmes, but poorer support for staff in regular contact with people with dementia, who needed more extensive knowledge and skill. The most complex and challenging components of this work were often those addressed least in training (Smith et al., 2019).

Surr and Gates (2017) reviewed the literature on the effective aspects of training, reporting that staff found practical strategies and tools helpful, as well as post-training support. Learner interaction and translating theory to practice have been identified as especially important for web-based dementia training programmes (Moehead et al., 2020). Barriers to effective training are often logistical, such as the ability to be released from clinical work, difficulties with staff engagement and confidence (Surr & Gates, 2017; Surr et al., 2019).

Alongside their literature review, Surr et al., (2020a) reported on case studies, drawing together the experience of staff, service users and carers and observations of staff behaviours. Staff reported an interactive, face-to-face training session, facilitated by enthusiastic individuals, created a helpful learning environment. However, improvements in practice were not observed in all cases, and feedback from service users and carers showing mixed levels of satisfaction corroborated this evidence (Surr et al., 2020a).

## **Other Resources Required**

The literature tends to focus on training interventions, and whilst the importance of adequate training is acknowledged, it is not the only factor fundamental to care provision for people with dementia. Practical considerations, such as sufficient staffing and adequate wages, have been associated with more effective care (Bimpong et al., 2020; Godfrey et al., 2018).

Surr et al (2020) used the COM-B (Capability, Opportunity, Motivation, Behaviour) model to explore the barriers and facilitators of dementia education and training; finding that effective care is provided by staff working in organisations with a positive culture around dementia (Surr et al., 2020). Services require leaders who are passionate, and organisations which harness the energy and creativity of front-line staff (Godfrey et al., 2018). Blood and Guthrie (2018) describe the benefits of a strengths-based leadership approach, supporting employees and service users to identify resources in themselves and the environment.

There is some evidence that the personal experiences and qualities of paid caregivers play a role in effective care. Burnout rates may be higher for staff with insecure attachment styles (Kokkonen et al., 2014). Effective care is facilitated by those staff with external support from their friends/family (Surr et. al., 2020). Professional caregivers with personal experience of providing care for a person with dementia may present with lower levels of resilience, but higher levels of job satisfaction (Coates, & Fossey, 2019; Coogle et al., 2006;).

The professional attitudes of staff are influential in providing effective care for people with dementia. Staff need to feel motivated and empowered to engage in change within a service (Surr et al., 2020). The belief a professional caregiver has in their ability to manage the demands of the role (self-efficacy), is associated with

reduced staff burnout, and increases in the daily functioning of the individuals they support (Gitlin et al., 2001). There is evidence that interventions such as training can improve caregiver self-efficacy, contributing to increased effectiveness of care provision (Mackenzie, & Peragine, 2003; Pleasant et al., 2020).

## **Policy, Legislation and Guidance**

In recognition of the difficulties faced by people with dementia in accessing adequate care, support and treatment, the UK Government identified improving support for people with dementia as a key priority area with the Prime Minister's Challenge on Dementia 2020 (Department of Health, 2015). The Challenge on Dementia was followed by an Implementation Plan, with measurable targets around prevention, diagnosis, living well, supporting carers, and end of life care (Department of Health, 2016). The Implementation Plan promised to increase dementia awareness training provision for health and social care staff, and to create "Dementia Friends Champions" within these services, with particular focus on the role of nurses (Department of Health, 2016).

Supporting people with dementia was a key feature of The Five Year Forward View for Mental Health (Mental Health Taskforce Strategy, 2016). When this document was reviewed, a further pledge was made to create NHS Dementia-Friendly Environments (NHS England, 2017).

To highlight the legal obligation to support the independence of people with dementia, the Dementia Action Alliance reviewed their Dementia Statements; of particular relevance to this study is the right to receive treatment "*from trained people who understand us and how dementia affects us*" (Dementia Action Alliance, 2017). These statements link dementia care with the Equality Act (Department of Health

and Social Care, 2010), Carers Act (Department of Health and Social Care, 2014) and Mental Capacity Act (Department of Health, 2005).

The National Institute for Health and Care Excellence published guidelines on the support and management of care for people with dementia; with a dedicated section to staff training and education (NICE, 2018).

Whilst documents such as those described above acknowledged the need for change, and set out what effective services might look like, they made no specific recommendations on how to implement this in practice, stating that services will need to develop based on the individual needs of the population in that area (Older People's Mental Health and Dementia, 2017).

In 2018, the Welsh Government published the Dementia Action Plan, a much-awaited document that set these previous reports and guidance within the local Welsh context. However, as with the English guidance, this document offered recommendations to services, rather than enforceable targets that would hold care providers accountable. The Action Plan described aims for staff to be adequately trained and to feel confident and competent to support the care needs of people with dementia (Welsh Government, 2018). The Action Plan makes reference to the "Good Work", a framework guiding the training of any individuals that may support a person with dementia (Care Council for Wales, 2016). The Good Work Framework forms the focus of this empirical study.

### **The Good Work Framework**

Alongside the Dementia Action Plan (Welsh Government, 2018), the foundational policies of the Good Work are: The Social Services and Well-being (Wales) Act (Welsh Government, 2014); Prudent Healthcare (Bradley et al., 2014);

The National Dementia Vision for Wales (Welsh Assembly Government, 2011); and Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales (Welsh Government, 2012).

The vision for the Good Work Framework is to support what matters most to the people of Wales, guiding the learning and development of all dementia care stakeholders in a person-centred way, rather than being prescriptive. The main target audience for the framework is health and social care professionals, however it is written to be accessible to anyone interested in developing their knowledge and skills in supporting people with dementia.

The Good Work is influenced by positive psychology and appreciative inquiry; approaches which focus on affirming and building on the strengths within individuals and organisations. The Good Work consists of three core elements; compassionate, competent and wise practice. The framework specifies, compassionate practice is the inherent link between individual and group wellbeing; competent practice is achieved when an individual has the knowledge and skills required for their particular role; and wise practice involves reflective, responsive working with a focus on wellbeing. This is in keeping with the values-based approach to care, which has been associated with improvements in staff retention and “stronger care values” of staff (Consilium Research and Consultancy Ltd., 2016; HEIW, 2019a).

The framework identified the intrinsic link between the wellbeing of health and social care staff and the service users and communities they serve. The authors acknowledge the need for training that resonates with staff values in order for them to feel engaged. The framework gives weight to the lived experience of all individuals and suggests a values-based recruitment strategy is used for care professionals, rather than a hierarchical approach focusing on qualifications or formal work

experience. Given this person-centred approach, the framework suggests staff training should be tailored to the needs of the individual. The Good Work identifies three broad groups of people: *Informed*, *Skilled* and *Influencers*, and sets out learning and development topics and outcomes for each of the three groups.

*Informed* people will have an understanding of dementia, the impact it has and how to communicate effectively with people with dementia. *Skilled* people will have more extensive knowledge and training than *Informed* individuals, and are likely to be in a position where they spend longer periods of time supporting people with dementia. *Influencers* can be *Informed* or *Skilled*, and will also have a management, leadership or strategic role.

The Good Work describes a number of different routes to learning for care professionals: formal qualifications, non-formal (e.g. supervision, mentoring) and informal (e.g. observation, experience). However, the framework does not describe how these different types of learning may be harnessed within care settings to ensure staff are able to work at the Good Work level that is required for their role. Surr et al., (2017) completed a systematic review of the literature on dementia workforce education and training, identifying most success is seen when a structured tool or guideline is provided to guide care practice. Clarity on the non-formal and informal routes of learning could be found through examples and guidance on evaluating these types of learning methods.

Whilst the Good Work makes reference to several theoretical influences, it does not appear to be guided by any theory of learning or behaviour change; this is a common critique of policy and intervention in this field (Surr et al., 2020).

The person-centred approach of the Good Work creates challenges in implementing its recommendations in practice, given the scale of health and social

care services. The Good Work does not specify which roles fall into which group, how to assess if staff are working at that level, or practical steps for supporting staff to develop skill in required areas.

The Good Work does not transfer easily onto a mapped care model, which acknowledges the changing needs of people with dementia as the disease progresses. Whilst this may be by design to facilitate adaptation to the needs of individual staff members' roles, it creates barriers for implementation at scale.

Another critique of the framework may be the lack of auditable standards by which services could be scrutinised, this is not an uncommon issue for dementia care policies (Older People's Mental Health and Dementia, 2017). Researchers across the world have considered the role of professional caregivers in improving the quality of life of people with dementia and their families (Martin et al., 2020; de Vries et al., 2019; Jensen et al., 2018; Young et al., 2019). The UK could learn from policies elsewhere; the Aged Care Act in Australia, takes a holistic approach to older people's wellbeing, enshrining rights in law, with specific, auditable standards of care and dementia training, and commitments to implement (Royal Commission into Aged Care Quality and Safety, 2021).

## **Rationale**

The Good Work Framework can be commended for its values base and person-centred approach, however there are challenges with implementation of the framework. It is not sufficient to provide education opportunities for those supporting people with dementia, direct links to clinical practice must be made (Jackson & Tolson, 2019).

This research will explore staff perspectives on the key factors needed to develop skill in working with people with dementia. The process of staff consultation used in this research is in keeping with the spirit of the Good Work, using empirical methods to examine perspectives, and contribute to the evidence base.

The aims of this study were to identify factors staff perceive as important for effective training, building on the work of Surr & Gates (2017), Moehead et al. (2020), and Surr et al. (2020a); and to inform training programmes provided by health boards in Wales.

This study also aimed to identify other key factors, such as workplace culture, personal experience and attitudes, to inform the extant literature (Blood & Guthrie, 2018; Gitlin et al., 2001; Kokkonen et al., 2014); local health board staff recruitment and appraisal strategies; and potential international dementia care practices.

Whilst this study aimed to operationalise the Good Work framework, a Welsh policy document, the results also have implications for service provision beyond Wales. The framework has been used here as a vehicle for exploration, but the identified key factors are relevant more broadly in understanding effective dementia care provision.

## **Aim**

The aim of this study is to use Delphi methodology to answer the research question: *what are the key factors that healthcare staff perceive to be important for developing skill in working with people with dementia?* This methodology will enable exploration of consensus, and lack of agreement within in the expert panel, and identify how these factors should be prioritised.



## METHOD

### Procedures

The proposal for this research was peer-reviewed by South Wales Clinical Psychology Training Programme staff who were independent of the project (Appendix G) and was sponsored by Cardiff University (SPON- 1721-19; Appendix H). Ethical Approval was granted by Cardiff University School of Psychology, (EC.19.03.12.5615; Appendix I). Health and Care Research Wales (HCRW) gave approval (IRAS Project ID: 255921, Appendix J) and Hywel Dda University Health Board (HDUHB) Research and Development Department gave consent for health board staff to be recruited (Appendix K). All procedures and documentation used in the study were approved through these processes.

Participants were recruited either in response to a global email sent by the health board media team (Appendix L), or through direct contact by the Dementia Coordinator (Appendix M). Individuals who expressed an interest were sent a participant information sheet (Appendix N) and invited to complete the questionnaires. All questionnaires were constructed using Qualtrics software package; for those who wished to participate via post, paper copies were available. Individuals were asked to complete a consent form prior to participating (Appendix O). Participants who completed all questionnaires were sent debrief sheets (Appendix P) and were invited to enter a prize draw to win a £50 voucher. A lay person summary of results was offered to participants and stakeholders (Appendix Q).

## **Participants**

The Delphi method requires an expert panel, the definition of an 'expert' for this study was an individual working in a health care setting within the National Health Service (NHS). It was not a requirement that participants work frequently with people with dementia (e.g. older adult services), however it was necessary that engagement with individuals with dementia could be anticipated in their practice (i.e. not working exclusively in children's services). The study was open to all health care staff within HDUHB via a global email.

Originally the project aimed to make comparisons between two expert panels, one with general level of dementia training, and one with more extensive training. However, recruitment difficulties precluded this, and one group of mixed training experience was formed. There are no specific recommendations for the number of participants required for meaningful data using Delphi (Jorm, 2015). It is acknowledged that the larger the size, and more homogenous the panel, the more reliable the results; similar studies have used around 10 participants (Keeney et al., 2011). Twenty-five individuals responded to the advertising emails expressing an interest in participating, with 10 completing all Delphi rounds; attrition rates are discussed in '*Results*'.

## **Design**

This research used a classical Delphi method, in which an open first round is used to generate ideas, which are rated in terms of agreement or rank in subsequent rounds (Sumsion, 1998). Although originally developed for technological purposes (Custer et al., 1999); Delphi method has long been applied across settings including health care (Woodcock et al., 2020), play therapy (Turner et al., 2020) and clinical

psychology (Mitchell et al., 2020). The aim of the Delphi process is to use an expert panel to reach a consensus of opinion (Keeney, 2009).

During Round I participants were asked to complete some basic demographic information; this was followed by a brief summary of the Good Work Framework, with wording taken directly from the policy document to explain the three level of skill in working with people with dementia (Appendix R). The Delphi component was then presented to the expert panel, in the form of an open-ended question: *“In your opinion, how can a healthcare professional become INFORMED and then develop to a SKILLED level when working with people with dementia?”* This main Delphi question was reviewed by two supervisors, both with experience working with people with dementia, healthcare staff teams and in psychological research. The data from Round I was reviewed for themes, leading to the identification of 24 key factors, grouping into four clusters. These key factors and clusters formed the basis for Delphi Round II.

In Round II the expert panel were presented with each of the 24 key factors, with a brief description, and were asked to rate the level of importance of each factor on a 5-point Likert rating (*Very Important to Not at all Important*). Participants were asked to rank order the four clusters that these key factors represented, from most to least important. These data were analysed, with percentages of agreement calculated for each Likert point of each key factor, and for each rank level of each cluster.

In the third and final round, the expert panel were presented with their individual responses for each key factor and cluster, alongside overall percentages for each Likert point, as advised by Iqbal and Pison-Young (2009). Participants were asked to consider their Round II response in this new context and were given the

opportunity to change their rating for the key factors and clusters, if they wished. This aimed to identify consensus for the level of importance of the key factors, and the order of priority for skill development of the clusters.

Bracketing (Ahern, 1999) informed a reflective/reflexive diary, to explore personal motives, assumptions and unconscious biases throughout the project.

### **Additional Measures**

Included in Round III, following the Delphi questions, participants completed three additional questionnaires, which explored the homogeneity of the expert panel and the similarities and differences between participants.

The Confidence in Dementia Scale (CoDe) is a nine item, 5-point Likert, self-report measure of confidence in working with people with dementia; it has been shown to have good internal consistency and content validity ( $\alpha = 0.91$ ,  $n = 115$ ,  $KMO = 0.90$ ; Elvish et al., 2014).

The Knowledge in Dementia Scale (KIDe) is a 16-item questionnaire, assessing the level of knowledge an individual has on dementia; it has been shown to have good internal consistency and content validity ( $\alpha = 0.72$ ,  $n = 115$ ,  $KMO = 0.70$ ; Elvish et al., 2014).

The Culture of Care Barometer (CoCB) was used to explore if the expert panel shared similar views on the culture of their organisation; this a 30 item, 5-point Likert scale questionnaire, with good validity and reliability ( $\alpha = 0.7-0.93$ ,  $n = 1557-1617$ ,  $M = 3.2-4.0$ ; Rafferty et al., 2017).

## RESULTS

### Demographics

Table 1 presents detailed participant demographics for all three rounds. Of those completing Rounds I-III, the majority were female (90%), with one male participant (10%). All participants were under 65, with consistent age spread across the rounds. The expert panel represented a cross section of professionals, including Registered Nursing and Health Visiting (40%), Healthcare Assistant/Support Worker (20%), Allied Health Professionals (20%) and those in 'Other' roles, such as Administrators in patient facing roles (20%). Of note, no medical doctors or dental staff participated. Most participants worked full time (80%).

In Round III, 20% of participants had been in role for less than one year, 40% had spent between 1 and 4 years in role and 40% 5-9 years. There were no participants in Round II who had more than ten years' experience in role, this is significantly different to the cohort of Round I (29%), a factor to be considered when interpreting these data. The majority of participants came into contact with people with dementia on a daily basis (90%), had received dementia specific training within the last year (70%) and felt this training met their needs (90%).

Those who completed all three rounds scored similarly in measures of confidence (90% very confident) and knowledge in dementia ( $M = 14.6$ ,  $SD = 1.56$ ). There was a broader range of experiences in work place culture, as reflected by the CoCB ( $M = 116.6$ ,  $SD = 22.89$ ; Table 2).

When asked to consider the Good Work Framework in relation to their role, 70% perceived themselves as working at the *Skilled* level. Half the panel (50%) felt they were *Influencers*, with a leadership role in advocating for the needs of people with dementia. Most participants felt they were working at the Good Work level

required for their role (60%), some felt they were at a level lower (20%) or higher (20%) than required.

**Table 1***Demographics of Expert Panel*

Demographic Characteristics		Delphi 1		Delphi 2		Delphi 3	
		N=17	%	N=11	%	N=10	%
Gender	Female	14	82.35	10	90.91	9	90.00
	Male	3	17.65	1	9.09	1	10.00
Age	21-29	3	17.65	3	27.27	2	20.00
	30-39	2	11.76	2	18.18	2	20.00
	40-49	6	35.00	2	18.18	2	20.00
	50-59	5	29.41	3	27.27	3	30.00
	60-64	1	5.88	1	9.09	1	10.00
	65+	0	-	0	-	0	-
Occupation	Registered nursing and health visiting staff	8	47.06	4	36.36	4	40.00
	Healthcare assistant/support worker	3	17.65	2	18.18	2	20.00
	Allied health professional	4	23.53	3	27.27	2	20.00
	Medical, including Dental	0	-	0	-	0	-
	Other	2	11.76	2	18.18	2	20.00
Length in role	Less than 1 year	2	11.76	2	18.18	2	20.00
	1-4 years	6	35.00	5	45.45	4	40.00
	5-9 years	4	23.53	4	36.36	4	40.00
	10+ years	5	29.41	0	-	0	-
Hours of work	Full time	12	70.59	9	81.82	8	80.00
	Part time	5	29.41	2	18.18	2	20.00
Frequency of working with people with dementia	Daily	16	94.12	10	90.91	9	90.00
	Weekly	1	5.88	1	9.09	1	10.00
	Less than weekly	0	-	0	-	0	-
Date of most recent dementia training	Within the last year	11	64.71	7	63.64	7	70.00
	Between 1 and 3 years ago	5	29.41	3	27.27	2	20.00
	Over 3 years ago	1	5.88	1	9.09	1	10.00

Demographic Characteristics		Delphi 1		Delphi 2		Delphi 3	
		N=17	%	N=11	%	N=10	%
Training perceived as adequate	Yes	15	88.24	10	90.91	9	90.00
	No	2	11.76	1	9.09	1	10.00
Perceived Good Work level	Informed	2	11.76	2	18.18	2	20.00
	Skilled	14	82.35	8	72.73	7	70.00
	Neither	1	5.88	1	9.09	1	10.00
Perceived as an Influencer	Yes	6	35.00	5	45.45	5	50.00
	No	11	64.71	6	54.55	5	50.00
Perceived Good Work Level in line with what you feel is required for the role	Working at a higher level than required	3	17.65	2	18.18	2	20.00
	Working at the same level as required	12	70.59	7	63.64	6	60.00
	Working at a lower level than required	2	11.76	2	18.18	2	20.00
Confidence in Dementia Scale (CoDe)	Not confident (0-18)	-	-	-	-	0	-
	Somewhat confident (19-35)	-	-	-	-	1	10.00
	Very confident (36-45)	-	-	-	-	9	90.00

**Table 2**

*Knowledge in Dementia (KIDe) and Culture of Care Barometer (CoCB) Data for Expert Panel (n=10)*

	Mean	Median	Interquartile Range	Standard Deviation
Knowledge in Dementia Scale (KIDe)	14.6	15	2	1.56
Culture of Care Barometer (CoCB)	116.6	117	35	22.89



## Attrition Rates

Of those contacted directly, 25 expressed an interest in participating, with 17 completing Round I, and ten completing all three rounds (Figure 1.). The literature recommends attrition rates not exceeding 30% (Sumsion, 1998), here the rate between Rounds I and II was 35.29%, but remained low between Rounds II and III at 9.09%. Issues of bias must be considered given this level of dropout (Keeney et al., 2011).

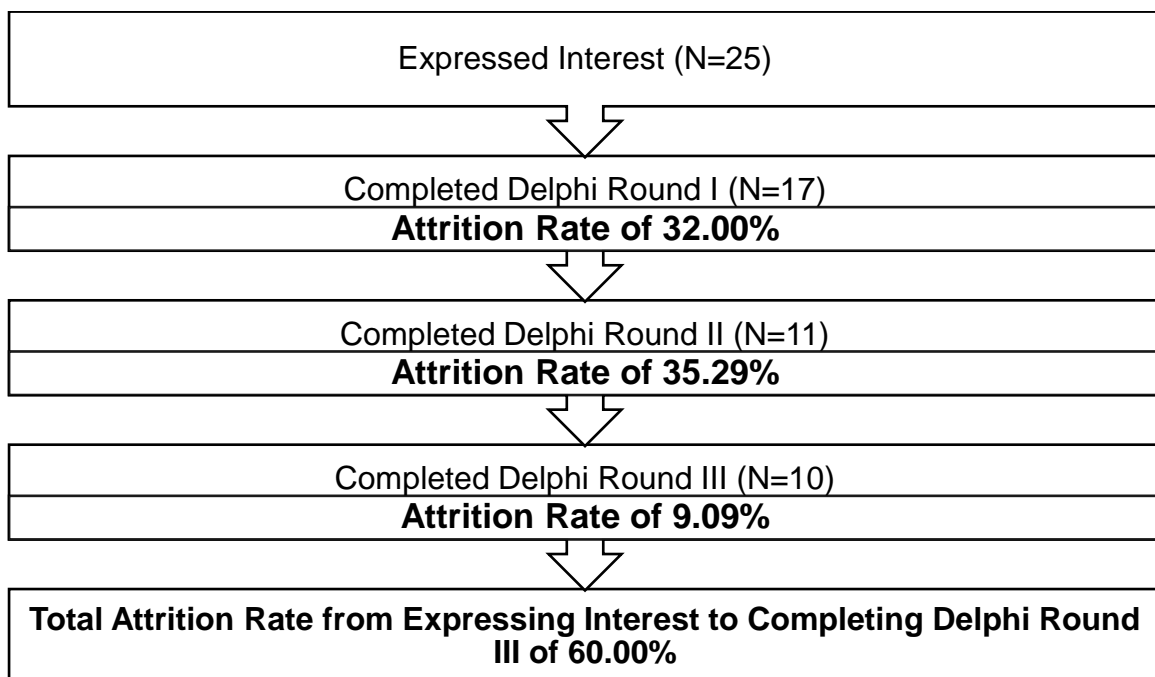


Figure 1. *Attrition Rates*

## Round I Data Analysis

Responses to the open-ended question posed in Round I were thematically analysed; identifying 24 key factors, grouping into four clusters (Figure 2.). Eight of the 24 key factors were identified by only one participant, but these were included as per Delphi research guidelines (Keeney et al., 2011). Quotes representative of each key factor are presented in Table 3, alongside the item included for Likert rating in Round II.

Cluster 1 - Training and Work Environment	Cluster 2 - Personal Characteristics	Cluster 3 - Approach to Work	Cluster 4 - Life Experience
<ul style="list-style-type: none"> <li>• Training</li> <li>• Practical Workshops</li> <li>• Peer Support</li> <li>• Supervision and Management Support</li> <li>• Coordinated Services</li> <li>• Challenging Experiences in Work</li> <li>• Skills Assessment*</li> </ul>	<ul style="list-style-type: none"> <li>• Resilience*</li> <li>• Sense of Humour*</li> <li>• Empathy</li> <li>• Compassion</li> <li>• Patience</li> <li>• Confidence*</li> </ul>	<ul style="list-style-type: none"> <li>• Person-Centred Care</li> <li>• Reflective and Willing to Learn</li> <li>• Learning from Care Partners</li> <li>• Enjoying the Work*</li> <li>• Sense of Responsibility for Work*</li> <li>• Communication</li> <li>• Awareness of Latest Research and Service Developments</li> </ul>	<ul style="list-style-type: none"> <li>• Level of Work Experience</li> <li>• Support of Friends and Family</li> <li>• Work Life Balance and Coping Strategies*</li> <li>• Personal Experience Supporting a Person with Dementia</li> </ul>

\* = Identified by one participant only

Figure 2. Key factors and clusters identified following analysis of Round 1 responses

**Table 3**

*Raw Data Quotes for 24 Key Factors*

Key Factor	Raw Data Quote	Round II Item
Cluster 1 – Training and Work Environment		
Training	<i>“Training on dementia awareness as a basic is needed for more people to become informed” – Participant 1022</i>	In order to develop skill in working with people with dementia, staff need <b>regular training opportunities</b> . Training should include information about types of dementia, the impact of dementia, supporting individuals and their families and end of life care.
Practical Workshops	<i>“REAL-LIFE EXAMPLES Workshops - to demonstrate the importance of "minor" skills, e.g. talking to someone at their own level, introducing yourself, explaining a task as you go” – Participant 1007</i>	In order to develop skill in working with people with dementia, staff need <b>practical workshops</b> . Training delivered in a face-to-face way, based on real life examples, with opportunities to practice skills.
Peer Support	<i>“A close staff network helps and able to off load any problems we come across. Sharing a problem with other staff sometimes helps as we all have different ideas of how to deal with people with dementia.” – Participant 1004</i>	In order to develop skill in working with people with dementia, staff need <b>peer support</b> . A coordinated network of colleagues with a range of skills, approaches and experience, to share difficulties with, get support, learn from and problem solve with.
Supervision and Management Support	<i>“Supervision with someone who is of a skilled or influencer role to discuss complex cases and wanting to learn more.” – Participant 1025</i>  <i>“support of the team and manager” – Participant 1008</i>	In order to develop skill in working with people with dementia, staff need <b>supervision and management support</b> . Regular supervision to reflect on current practice and consider ways to develop skills and knowledge. Support from senior management to access training when needed and to implement learning in practice.

Key Factor	Raw Data Quote	Round II Item
Coordinated Services	<i>“Visiting various places (hospitals/care homes) who care for people suffering from dementia to network and share ideas”</i> – Participant 1009	In order to develop skill in working with people with dementia, staff need <b>coordinated services</b> . Multi-disciplinary working, regular reviews or case discussions, links between relevant services, with appropriate information sharing.
Challenging Experiences in Work	<i>“They might be motivated to develop their skills if there is a person with a rare form of dementia or if there is an incident and they need to learn more about why it happened.”</i> – Participant 1022	In order to develop skill in working with people with dementia, staff need <b>to have experienced challenging situations in work</b> . Learning from difficult experiences within their role to develop practice.
Skills Assessment	<i>“It would be beneficial for all staff to undergo a period of assessment following their training to ensure that what has been learnt is being appropriately applied to practice.”</i> – Participant 1023	In order to develop skill in working with people with dementia, staff need <b>to have their skills assessed</b> . A period of assessment following their training to ensure that what has been learnt is being appropriately applied to practice.
<b>Cluster 2 – Personal Characteristics</b>		
Resilience	<i>“I like to think that every member of staff who works with people with dementia should have the personal qualities to become a skilled professional. In particular ... resilience”</i> – Participant 1025	In order to develop skill in working with people with dementia, staff need <b>resilience</b> . The ability to recover from or adapt to challenging circumstances.
Sense of Humour	<i>“To work with someone with dementia you need ... a sense of humour”</i> – Participant 1022	In order to develop skill in working with people with dementia, staff need <b>a sense of humour</b> . Ability to see the funny or enjoyable side of situations that might be difficult.
Empathy	<i>“You need to be empathetic”</i> – Participant 1002	In order to develop skill in working with people with dementia, staff need <b>empathy</b> . The ability to understand and share in the emotional experience of others.
Compassion	<i>“Interest in individuals and a desire to help make life easier are the most important traits.”</i> – Participant 1015	In order to develop skill in working with people with dementia, staff need <b>compassion</b> . Understanding the challenges of others and working to alleviate suffering.

Key Factor	Raw Data Quote	Round II Item
Patience	<i>“Personal qualities that are needed are naturally caring, diligent and patient”</i> – Participant 1001	In order to develop skill in working with people with dementia, staff need <b>patience</b> . The ability to wait, or to continue doing something despite difficulties.
Confidence	<i>“I like to think that every member of staff who works with people with dementia should have the personal qualities to become a skilled professional. In particular ... confidence”</i> – Participant 1025	In order to develop skill in working with people with dementia, staff need <b>confidence</b> . Trusting in their abilities to support people with dementia.
Cluster 3 – Approach to Work		
Person-Centred Care	<i>“willing to take time to understand the patient. [Not] judgemental and accepting the patient.”</i> – Participant 1017	In order to develop skill in working with people with dementia, staff need <b>to work in a person-centred way</b> . Respecting individuality rather than focusing on deficits, supporting people with dementia to live a life meaningful to them, investing time in the person with dementia.
Reflective and Willing to Learn	<i>“there is still a lot to learn about Dementia and would like to learn more so I can help my patients and families in the community.”</i> – Participant 1005	In order to develop skill in working with people with dementia, staff need <b>to reflect on their practice and be willing to learn</b> . Recognising there are always opportunities to develop practice, showing interest in learning from others, flexibility with approach to work, engaging in training opportunities.
Learning from Care Partners	<i>“Speaking to family members also has helped me get a clearer insight in dementia, on a more personal/individual level.”</i> – Participant 1020	In order to develop skill in working with people with dementia, staff need <b>to learn from the care partners of people with dementia</b> . Talking to the loved ones of the person with dementia, understanding their experience and learning about the individual from those close to them.
Enjoying the Work	<i>“enjoying working with people with dementia and find it rewarding they might want to learn more.”</i> – Participant 1022	In order to develop skill in working with people with dementia, staff need to <b>enjoy the work</b> . Finding working with people with dementia and their care partners rewarding.

Key Factor	Raw Data Quote	Round II Item
Sense of Responsibility for Work	<i>"people responsible for their own work"</i> – Participant 1025	In order to develop skill in working with people with dementia, staff need <b>a sense of responsibility for their work</b> . Seeking out learning and development opportunities, with a diligent approach to work.
Communication	<i>"Good communication skills are vital"</i> – Participant 1006	In order to develop skill in working with people with dementia, staff need <b>to communicate well</b> . Being thoughtful about how you say something, about language, and non-verbal communication, both with the person with dementia, their loved ones and other professionals involved.
Awareness of Latest Research and Service Developments	<i>"Regular updates as ideas are changing in how we deal with and treat dementia is always improving"</i> – Participant 1004	In order to develop skill in working with people with dementia, staff need <b>to be aware of the latest research and updates within services</b> . Staff need to feel informed about developments and changes in good practice.
<b>Cluster 4 – Life Experience</b>		
Level of Work Experience	<i>"I think that "skilled" is only achievable with time, exposure to the patient group and with exposure to staff that are well trained in managing the dementia patients."</i> – Participant 1011	In order to develop skill in working with people with dementia, staff need <b>experience in the job</b> . To have worked with people with dementia for some time, learning "on the job".
Support of Friends and Family	<i>"An understanding husband is helpful as sometimes if there is problems in the community and we can get home late due to the support you need to give at the time to our client when there is a crises"</i> – Participant 1004	In order to develop skill in working with people with dementia, staff need <b>the support of their family and friends</b> . A supportive home environment, with family and friends that are understanding of the demands of the role.
Work Life Balance and Coping Strategies	<i>"work/life balance"</i> – Participant 1002  <i>"established de-stressing techniques so they don't take work home [with] them."</i> – Participant 1025	In order to develop skill in working with people with dementia, staff need <b>effective coping strategies</b> . Ways the staff member can cope with the challenges of the role e.g. good work life balance, de-stressing techniques.

Key Factor	Raw Data Quote	Round II Item
Personal Experience Supporting a Person with Dementia	<i>“it is usually a personal experience, e.g. a family member or close friend that has either got an organic or functional mental health problem.”</i> – Participant 1025	In order to develop skill in working with people with dementia, staff need <b>personal experience supporting a person with dementia</b> . Experience of a close friend or family member who has/had a dementia diagnosis.

## Round II and III Data Analysis

Each of the 24 key factors were presented alongside brief descriptions in Round II (Appendix S). Participants were asked to rate the level of importance of each key factor on a 5-point Likert scale from *Not at all Important* to *Very Important*. The four clusters were also presented, and participants asked to rank them in order of importance.

In Round III, percentages were given, informing participants on the level of importance for each key factor and cluster, as voted on by the panel (Iqbal & Pipon-Young, 2009; Appendix T). Alongside the response of the panel as a whole, participants were shown their response from Round II and given the opportunity to amend this.

Participants from Round I who did not respond to Round II (N=6), were prompted via email on two occasions to participate, if they did not participate in Round II within two weeks of the final email prompt, they were not included in the Round III invitation to participate. One participant completed Rounds I and II, but did not participate in Round III, they were given two follow up email prompts, and two weeks after the final prompt the Delphi was closed to allow data analysis.

As recommended, the cut offs for consensus and agreement levels were fixed prior to the commencement of data collection (Keeney et al., 2011); with consensus requiring the same response across all participants, and agreement requiring the same response from 70% or more (Morgan & Jorm, 2009).

It was decided to present all key factors in Round III, even those already reaching consensus and agreement, to maximise the opportunity for agreement and to observe any variability in panel response across the rounds.



Although it is recommended Delphi rounds continue until stability of response (Linstone & Turoff, 2001), this study was stopped after the third round due to several factors: time limitations; participant numbers; attrition rates; and demands on healthcare staff at that time of data collection, due to the global pandemic. Whilst it is acknowledged that this is a limitation of the study, the areas not reaching consensus have value in their own right.

### **Key Factors**

Table 4 shows at the end of Round III, three key factors reached consensus (*Training, Communication, Patience*), 12 reached agreement (*Practical Workshops, Person-Centred Care, Reflective and Willing to Learn, Empathy, Compassion, Support of Friends and Family, Learning from Care Partners, Enjoying the Work, Resilience, Peer Support, Supervision and Management Support, Work Life Balance and Coping Strategies*) and nine did not meet the criterion for agreement (*Awareness of Latest Research and Service Developments, Coordinated Services, Level of Work Experience, Challenging Experiences in Work, Sense of Humour, Skills Assessment, Confidence, Personal Experience Supporting a Person with Dementia, Sense of Responsibility for Work*).

Of the 15 factors that reached agreement or consensus, all were identified as *Very Important*, bar one, *Support of Friends and Family*, which was identified as *Important*.

The three key factors that reached consensus had reached it by Round II. Nine of the agreed upon factors were reached in Round II, with an additional three key factors becoming agreed upon in Round III (*Peer Support, Supervision and*

*Management Support, Work Life Balance and Coping Strategies*). No factors moved out of consensus or agreement between rounds.

The level of agreement increased between rounds for six of the 12 factors that were agreed upon (*Peer Support, Supervision and Management Support, Resilience, Person-Centred Care, Learning from Care Partners, Work Life Balance and Coping Strategies*). Six key factors reaching agreement in Round II decreased in percentage agreement by Round III, but remained above the 70% cut off (*Practical Workshops, Empathy, Compassion, Reflective and Willing to Learn, Enjoying the Work, Support of Friends and Family*).

In Round III, five key factors that did not reach agreement, increased their level of agreement slightly, but not above the cut off (*Coordinated Services, Skills Assessment, Sense of Humour, Awareness of Latest Research and Service Developments, Personal Experience Supporting a Person with Dementia*). There were further reductions in agreement for the remaining four factors which did not meet the criterion for agreement at Round III (*Experiences in Work, Confidence, Responsibility for Work, Level of Work Experience*).

The biggest spread, and least agreement, in Round II was observed in *Skills Assessment* and *Personal Experience Supporting a Person with Dementia*, the latter remaining most widely spread factor at Round III. Higher levels of spread were also seen in *Skills Assessment, Sense of Humour* and *Level of Work Experience*, in Round III.

**Table 4***Delphi Round II and III Results for 24 Key Factors*

Key Factors identified during Round I	Round II					Round III					Round Agreement Achieved	Level of Importance Agreed
	Mean	Median <sup>a</sup>	Interquartile Range	Standard Deviation	Percentage of Agreement (%)	Mean	Median <sup>a</sup>	Interquartile Range	Standard Deviation	Percentage of Agreement (%)		
<b>Cluster 1 – Training and Work Environment</b>												
Training	5	5	0	0.00	100**	5	5	0	0.00	100	II	VI
Practical Workshops	4.70	5	1	0.48	72.73*	4.70	5	1	0.48	70	II	VI
Peer Support	4.60	5	1	0.52	63.64	4.80	5	0	0.42	80*	III	VI
Supervision and Management Support	4.70	5	1	0.48	63.64	4.70	5	1	0.48	70*	III	VI
Coordinated Services	4.30	4	1	0.68	45.45	4.50	4.50	1	0.53	50	-	-
Challenging Experiences in Work	4.40	4.50	1	0.70	54.56	4.40	4.50	1	0.70	50	-	-
Skills Assessment	3.90	4	2	0.876	36.36	3.80	4	1	0.789	40	-	-
<b>Cluster 2 – Personal Characteristics</b>												
Resilience	4.70	5	1	0.483	72.73*	4.80	5	0	0.422	80	II	VI
Sense of Humour	4.50	5	1	0.707	54.56	4.50	5	1	0.707	60	-	-
Empathy	4.90	5	0	0.316	90.91*	4.90	5	0	0.316	90	II	VI
Compassion	4.90	5	0	0.316	90.91*	4.90	5	0	0.316	90	II	VI
Patience	5	5	0	0.000	100**	5	5	0	0.000	100	II	VI
Confidence	4.40	4	1	0.516	63.64	4.40	4	1	0.516	60	-	-

Key Factors identified during Round I	Round II					Round III					Round Agreement Achieved	Level of Importance Agreed
	Mean	Median <sup>a</sup>	Interquartile Range	Standard Deviation	Percentage of Agreement (%)	Mean	Median <sup>a</sup>	Interquartile Range	Standard Deviation	Percentage of Agreement (%)		
<b>Cluster 3 – Approach to Work</b>												
Person-Centred Care	4.60	5	1	0.699	72.73*	4.80	5	0	0.422	80	II	VI
Reflective and Willing to Learn	4.80	5	0	0.422	81.82*	4.80	5	0	0.422	80	II	VI
Learning from Care Partners	4.70	5	1	0.483	72.72*	4.90	5	0	0.316	90	II	VI
Enjoying the Work	4.70	5	1	0.483	72.73*	4.70	5	1	0.483	70	II	VI
Sense of Responsibility for Work	4.40	4	1	0.516	63.64	4.40	4	1	0.516	60	-	-
Communication	5	5	0	0.000	100**	5	5	0	0.000	100	II	VI
Awareness of Latest Research and Service Developments	4.60	5	1	0.516	54.56	4.40	4	1	0.516	60	-	-
<b>Cluster 4 – Life Experience</b>												
Level of Work Experience	4.40	4.50	1	0.699	54.56	4.10	4	1	0.738	50	-	-
Support of Friends and Family	3.90	4	0	0.568	72.73*	3.90	4	0	0.568	70	II	I
Work Life Balance and Coping Strategies	4.40	4	1	0.516	54.56	4.30	4	1	0.483	70*	III	VI
Personal Experience Supporting a Person with Dementia	3.10	3	2	0.994	36.36	3.00	3	1	0.943	50	-	-

Note:

<sup>a</sup> = 1-5 Likert scale; \* = Agreement reached in this round; \*\* = Consensus reached in this round; II = Agreement/consensus reached in Round II;

III = Agreement/consensus reached in Round III; - = Agreement/consensus not reached; VI = Very Important; I = Important

## Clusters

Participants rank ordered the four clusters from most to least important, results are presented in Table 5. *Life Experience* reached consensus in Round II and maintained this at Round III, being identified as the least important cluster. *Training and Work Environment* reached agreement in Round II as the most important cluster, this was also maintained at Round III. The second and third most important key factors did not reach agreement at Round II; however, agreement was reached during Round III, identifying *Personal Characteristics* as second most important and *Approach to Work* as third most important.

**Table 5***Delphi Round II and III Results for Clusters*

Cluster	Round II					Round III					Round Agreement Achieved	Agreed Level of Importance
	Mean	Median <sup>a</sup>	Interquartile Range	Standard Deviation	Percentage of Agreement (%)	Mean	Median <sup>a</sup>	Interquartile Range	Standard Deviation	Percentage of Agreement (%)		
Training and Work Environment	1.50	1	1	0.85	72.73*	1.40	1	1	0.70	70	II	Most Important
Personal Characteristics	2	2	1	0.67	63.64	1.90	2	0	0.57	70*	III	Second Most Important
Approach to Work	2.50	3	1	0.71	63.64	2.70	3	0	0.68	80*	III	Third Most Important
Life Experience	4	4	0	0.00	100**	4	4	0	0.00	100	II	Least Important

Note:

<sup>a</sup> = 1-5 Likert scale; \* = Agreement reached in this round; \*\* = Consensus reached in this round; II = Agreement/consensus reached in Round II; III = Agreement/consensus reached in Round III

### **Wilcoxon Matched-Pairs Signed Ranked Test**

Thus far, only descriptive statistics and percentage agreement have been reported, due to the limitations of inferential statistics in studies of small participant numbers (Keeney et al., 2011). However, the stability of responses between Round II and III was scrutinised with a non-parametric Wilcoxon Matched-Pairs Signed Ranked Test. The Wilcoxon Matched-Pairs is the most appropriate statistic as the data is ordinal, has two related data points, small sample size and has been used in Delphi studies previously (von der Gracht, 2012). At a 95% confidence level there were no statistically significant differences between the responses in Round II to Round III (Table 6).

There were three key factors that moved into agreement in Round III, despite moving to agreement, all three had limited evidence for change across rounds: *Peer Support* ( $Z = -1.414$ ,  $p = 0.157$ ); *Supervision and Management Support* ( $Z = 0.000$ ,  $p = 1.000$ ); and *Work Life Balance and Coping Strategies* ( $Z = -1.000$ ,  $p = 0.317$ ). The raw data shows two participants changed their responses for *Peer Support*, from *Important* to *Very Important*, and one participant changed their response from *Very Important* to *Important* for *Work Life Balance and Coping Strategies*. These key factors appear to have been most effected by participant attrition between Round II and III.

Of interest, most instability across rounds, although not statistically significant, was seen in *Level of Work Experience* ( $Z = -1.732$ ,  $p = 0.083$ ). This key factor did not reach agreement; however, three participants changed their responses between rounds, reducing their rating of the level of importance.

**Table 6***Wilcoxon Matched-Pairs Signed-Ranked Test for Clusters and Key Factors*

Key Factors identified during Round I	Z Score	p Score
<b>Cluster 1 – Training and Work Environment</b>	<b>-0.378</b>	<b>0.705</b>
Training	0.000	1.000
Practical Workshops	0.000	1.000
Peer Support	-1.414	0.157
Supervision and Management Support	0.000	1.000
Coordinated Services	-1.414	0.157
Challenging Experiences in Work	0.000	1.000
Skills Assessment	-1.000	0.317
<b>Cluster 2 – Personal Characteristics</b>	<b>-0.447</b>	<b>0.655</b>
Resilience		
Sense of Humour	0.000	1.000
Empathy	0.000	1.000
Compassion	0.000	1.000
Patience	0.000	1.000
Confidence	0.000	1.000
<b>Cluster 3 – Approach to Work</b>	<b>-0.557</b>	<b>0.577</b>
Person-Centred Care	-1.414	0.157
Reflective and Willing to Learn	0.000	1.000
Learning from Care Partners	-1.414	0.157
Enjoying the Work	0.000	1.000
Sense of Responsibility for Work	0.000	1.000
Communication	0.000	1.000
Awareness of Latest Research and Service Developments	-1.414	0.157
<b>Cluster 4 – Life Experience</b>	<b>0.000</b>	<b>1.000</b>
Level of Work Experience	-1.732	0.083
Support of Friends and Family	0.000	1.000
Work Life Balance and Coping Strategies	-1.000	0.317
Personal Experience Supporting a Person with Dementia	-1.000	0.317



## DISCUSSION

### Consensus Factors

The three round Delphi produced 24 key factors; three reached consensus, 12 reached agreement, and the expert panel did not agree on ratings for nine factors. Key factors grouped into four themed clusters: *Training and Work Environment*; *Personal Characteristics*; *Approach to Work*; and *Life Experience*. The three key factors reaching consensus (*Training*, *Patience*, *Communication*) fitted in each of the first three clusters respectively. All key factors that reached agreement or consensus were identified as *Very Important*, with the exception of *Support of Friends and Family* which was agreed to be *Important*. The cluster with least agreed-upon key factors was *Life Experience*, which reached consensus as the least important cluster in Round II. Nine factors did not meet the criterion for agreement, evenly representing aspects of each of the four clusters. These results give evidence to address the study questions: what do healthcare staff perceive to be important in developing skill in working with people with dementia; which factors reach consensus; which factors are not agreed upon; and which areas are of priority for staff?

These results provide expert panel agreement on the four clusters relevant for developing skill in working with people with dementia and how they should be prioritised. They are consistent with literature giving evidence that adequate practical training is important for effective care provision (Sass et al., 2019; Smith et al., 2019; Surr & Gates, 2017; Surr et al., 2020a) and give additional detail around the value of peer support, supervision and management support. The personal characteristics that support skill development identified in this study (*Resilience*, *Empathy*, *Compassion* and *Patience*) are in keeping with the traditional notions on the caring

professional and the evidence base (Surr et al., 2020; Gitlin et al., 2001). The key factors the expert panel identified as *Very Important* in *Approach to Work (Person-Centred Care, Reflective and Willing to Learn, Learning from Care Partners, Enjoying the Work and Communication)* reflect values highlighted in the literature around enthusiasm, reflective practice and fostering creativity in the workplace (Godfrey et al., 2018; Blood & Guthrie, 2018; Surr et al., 2020). The aspects of Life Experience the expert panel valued most were *Support of Friends and Family*, and *Work Life Balance and Coping Strategies*, the factors in this cluster relating to personal experience of supporting a person with dementia had least agreement, this finding is again consistent with the literature (Coates, & Fossey, 2019; Coogler et al., 2006; Surr et al., 2020). Whilst findings regarding staff perceptions of the importance of various key factors are consistent with previous research, this study builds on the extant literature by drawing together these key factors and by application of the Delphi ranking method, makes a novel contribution to the field.

The focus of national policy on training staff to better support those with dementia (Care Council for Wales, 2016; NICE, 2018 Welsh Government, 2018) is understandable in the context of these results, where *Training and Work Environment* was rated most important. However, to focus so heavily on training, will neglect a wide range of other factors that are vital in supporting staff to feel skilled and be enabled to demonstrate competence.

The strengths of these results are in the consistency of the ratings over time, the Wilcoxon Matched-Pairs Signed Ranked Test measures the stability of ratings across the rounds, indicating no significant differences between the responses in Round II to Round III. The speed and stability of the agreement on the most and least important clusters provides decisive evidence on the priorities of the expert

panel. Another strength is how use of a local base enhanced ecological validity. The philosophy behind the *Good Work* emphasised flexibility was required to adapt to the needs of local services and during research development engagement with stakeholders corroborated this. These results are from a homogeneous expert panel of health board staff, and any local policy/service development can be shaped based on evidence directly from health board employees. The Good Work was used here to provide a language and context of the study; however, the findings may generalise outside of the framework, influencing care provision for people with dementia more widely. Up-skilling the health and social care workforce and ensuring policies meet the needs of people with dementia, are areas identified as requiring improvement internationally (Martin et al, 2020; de Vries et al., 2019). The findings of this study on the key factors important for skill development offer a new contribution to the evidence-base and inform recommendations for service delivery and policy implementation.

There are weaknesses however in this research. The participant numbers are very small, and although there is no lower limit required for this methodology (Jorm, 2015), it is acknowledged that the larger the expert panel the more reliable the results (Keeney et al., 2011).

The demographics of this expert panel vary somewhat to that of the professional carer population. At Round III, 90% of participants were female, in comparison to approximately 80% of the paid carers in general (Social Care Wales, 2019; HEIW, 2019). The age of this sample is also lower than the population, which tends to have a higher proportion of over 55's (Social Care Wales, 2019; HEIW, 2019). A survey by the Alzheimer's Society (2009), reported 54% of nurses had no dementia training and 34% felt they had inadequate training. All participants here

had some form of training and approximately 10% felt their training was inadequate; this may be due to a self-selecting bias. Seventy percent of participants identified as *Skilled*, and the expert panel was consistent in measures of confidence and knowledge in dementia; again, possible evidence of self-selecting bias.

Further inspection of the demographics of participants shows nearly 30% of participants at Round I had 10 years' experience or more, interestingly by Round II, none of these individuals were participating, and therefore their views are not represented in the consensus figures.

The attrition rates show high levels of drop out between expression of interest and Round I completion and between Rounds I and II. The attrition rate was low between Rounds II and III (Sumsion, 1998; Keeney et al., 2011), again this may indicate a self-selecting bias. With this significant evidence of self-selecting bias, it is unlikely the views of individuals with less experience or confidence in working with people with dementia are represented here.

Three Delphi rounds was the maximum achievable given the time constraints of this project, however this is the minimum number of rounds recommended in the literature and it is advised to continue with rounds to consensus or prolonged stability of results (Iqbal & Pison-Young, 2009; Keeney, 2009). This research used a classical Delphi method, completed through questionnaires; whilst some responses to the Round I open-ended question were detailed and rich, others were very brief. This could be overcome with an adapted Delphi method, focusing more on eliciting rich data from which to draw themes for subsequent rounds (Sumsion, 1998). A further consideration has been the timing of this research, Round I was completed prior to the COVID-19 pandemic, with Rounds II and III completed during initial phases of UK lockdown. Not only might this have impacted attrition rates, due to

increase demands on staff time, but potentially participant views on dementia care provision, and the NHS as a whole, might have been influenced under the strain of such unprecedented care requirements.

### **Methodological Considerations and Limitations**

As described above, there are some weaknesses in the implementation of this Delphi study, however, general critiques of the method should also be acknowledged. It is argued that the definition of an “expert panel” is not clear, and criteria for panel selection can be broad (Sumsion, 1998). The absence of face-to-face interaction in the method has been linked to a lack of depth and richness in the data (Linstone, & Turoff, 2011). When compared to methods involving in person contact, Delphi studies may see higher rates of attrition, as the social support and approval of the group is not present (Ven & Delbecq, 1974). Indeed, the entire premise of using a consensus method to identify “truth” has been questioned (Landeta, 2006) and to condense a range of views into one narrow description is also criticised (Sumison, 1998).

Having described the limitations of the Delphi technique, there are several benefits which apply directly to this study. The lack of face-to-face contact required in this approach addresses the difficulty of engaging staff from a wide geographical area, such as the rural location of this health board (Sumsion, 1998). The anonymous questionnaire format also allows participants to reconsider their responses at Rounds II and III, without the pressure of “losing face” in front of other panel members, increasing the honesty of responses (Boulkedid et al., 2011). The questionnaire format gives opportunity for participants to take time to consider their responses, without time pressures related to a focus group (Jorm, 2015). Bringing

diverse views together, and eliciting statements of shared interest or opinion, can help in making unwieldy topics manageable (Hohmann et al., 2018), such is the case in issues of health and social care policy implementation. Some statements the panel are asked to rate do not reach consensus, so far from diluting diverse opinions, it can highlight the key aspects lacking agreement.

The expert panel used in this study consisted of healthcare workers working in any setting in which they may have contact with a person with dementia. An alternative approach would be to form an expert panel of health care staff involved in staff education and continual professional development. However, this would have resulted in identification of factors *trainers* perceive are important for skill development, which may be different to the views of staff delivering clinical interventions.

A different method that may have met the research aims is nominal group technique (NGT). NGT has similarities to Delphi as a means of identifying group consensus, however NGT identifies themes through face-to-face focus groups, with several rounds to classify statement and rate consensus (McMillan et al., 2016). The benefits of NGT are the direct contact between group members, which can elicit richer content, and data gathering can be completed in one session (Humphrey-Murto et al., 2017). However, the issues with meeting in person described above would apply to this methodology (Cantrill et al., 1996).

Another alternative to the Delphi method would be a thematic analysis (TA; Braun & Clarke, 2006). TA could have been applied to the responses of the initial open-ended question, these results then fed back to participants, who could be re-interviewed to explore the mechanisms of skill development in more detail. However, this methodology is susceptible to the same difficulties of attrition as the Delphi and

likely to be impacted more significantly by the unprecedented demands on the health services.

The arguments in support and opposition to the Delphi method are of equal value and it remains to the researcher to evaluate the suitability of their chosen method (Hohmann et al., 2018). In this case, the benefits of anonymous, electronic data collection, across a wide rural catchment, during a global pandemic, outweighed the Delphi's disadvantages, and alternative methodologies were not considered practicable, or suited to the research question.

### **Clinical Implications**

The identification of key factors important in enabling staff to develop skills in working with people with dementia might inform service development in the health board, with the possibility of wider applicability and up-scaling. The consensus that training and work environment is most important to staff, puts an onus on services to ensure their provision addresses these needs. Based on these results, services should prioritise review of their training programmes, ensuring a practical workshop element is included. Space for peer support and reflection should be ring fenced, as should clinical supervision. Managers should be equipped to provide a safe, supportive environment for their teams.

Teams should be encouraged to take a curious approach, open to continual learning and development. Opportunities to learn from the experience of all stakeholders, especially people with dementia and their care partners, should be sought, with effective communication between these stakeholders.

When recruiting staff, a values-based approach was endorsed. Individuals with limited work experience, but the personal characteristics that facilitate skill

development, may be better suited to the role than someone without these qualities, but with extensive work experience.

Whilst there is obviously some value in extensive work experience, and attributed to personal experience of caring for a loved one with dementia, these factors do not appear as important to staff for skill development, as the support of friends and family, and a good work life balance. Employers should be facilitative of this and, where possible, adapt to ensure personal needs of the workforce are considered and balance maintained.

These recommendations offer opportunities to develop care provision for people with dementia, in line with the *Good Work* framework (Care Council for Wales, 2016) and other national policies (Welsh Government, 2018; NICE, 2018; Older People's Mental Health and Dementia, 2017). It maintains the flexibility valued in these policies to respond to the needs of the local community, whilst setting-out practical strategies for service development. National initiatives that mandate and audit care provision for older people and those with dementia, as seen in Australia (Royal Commission into Aged Care Quality and Safety, 2021), may be required in order to ensure robust and equitable service provision across the country.

These findings also have implications for care provision for people with dementia outside of Wales. Whilst this research aimed to operationalise the Good Work framework, which is specific to Wales, its holistic approach to considering the factors required for skill development has not previously been explored in the literature, and could inform dementia care provision internationally.



## **Opportunities for Future Research**

These recommendations are developed out of the consensus reached by a local expert panel; the needs of staff in other areas may be different, so the Plan-Do-Study-Act (PDSA) cycle (ACT Academy, 2018) could be used to replicate this study in other nations. With adequate stakeholder buy in, the Delphi could be scaled up to a national approach, given the ability of the method to be conducted remotely.

This study used the Confidence in Dementia Scale (CoDe; Elvish et al., 2014), the Knowledge in Dementia Scale (KIDe; Elvish et al., 2014), and the Culture of Care Barometer (CoCB; Rafferty et al., 2017) to explore the characteristics of the expert panel and seek homogeneity. A quantitative method with a larger sample of paid caregivers would offer opportunity to explore the relationship between confidence, knowledge, working culture, and perceptions of the important key factors for skill development.

The staff involved in this study identified the key factors facilitating skill development; it may be helpful to consider what clinical practice looks like without these key factors. In order to explore this question further, a root cause analysis (ACT Academy, 2018a) could be made of the relevant factors in examples of poor dementia care, when complaints and concerns are raised. Put together, standards for skill development, maintenance and improvement, could be applied to promote a more evidence-based dementia culture.

## **CONCLUSION**

A number of policies and guidance documents have been published to guide service provision for people with dementia (Care Council for Wales, 2016; Welsh Government, 2018; NICE, 2018; Older People's Mental Health and Dementia, 2017),

however, these reports are rarely shaped by theoretical models and are often lacking in concrete recommendations and plans for implementing theory to practice.

This Delphi method study aimed to establish the key factors healthcare staff felt are important in developing skill in working with people with dementia; identifying factors reaching consensus, factors not agreed upon, and how the expert panel prioritised these factors.

The expert panel of healthcare professionals identified 24 key themes, three of which reached consensus and a further 12 reached at least 70% agreement. The key themes divided into four clusters; *Training and Work Environment*; *Personal Characteristics*; *Approach to Work*; and *Life Experience*. These clusters were rank ordered by importance to developing skill. The expert panel agreed that *Training and Work Environment* was top priority, followed by *Personal Characteristics*, then *Approach to Work*, reaching a consensus that *Life Experience* is the least important. Each of the three key factors that reached consensus (*Training*, *Patience*, and *Communication*) mapped onto the three clusters rated most important.

The limitations and methodological weaknesses of this study are acknowledged, with low participant numbers, high attrition rates and the likelihood of a self-selecting bias. However, the value of this study is in its structured approach to informing the way services implement policy, based on the consensus opinion of the staff within that service.

The following areas should be considered priorities for service provision: developing effective training programmes with a practical element; protected time for peer support and supervision; a values-based recruitment approach that is weighted towards personal characteristics, rather than work experience or qualifications per se; fostering a work environment of continual learning, involving all relevant

stakeholders; and being considerate of personal circumstance, promoting a healthy work life balance.

Given the potential to upscale the Delphi methodology and the improvements in access to digital technology for the health and social care workforce, further research could apply this methodology in other nations.

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## APPENDICES

### APPENDIX A – JOURNAL GUIDELINES FOR SUBMISSION

# Dementia

Manuscript Submission Guidelines:

This Journal is a member of the [Committee on Publication Ethics](#).

**Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/dementia> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.**

Only manuscripts of sufficient quality that meet the aims and scope of Dementia will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere. Please see our guidelines on prior publication and note that **Dementia may accept submissions of papers that have been posted on pre-print servers**; please alert the Editorial Office when submitting (contact details are at the end of these guidelines) and include the DOI for the preprint in the designated field in the manuscript submission system. Authors should not post an updated version of their paper on the preprint server while it is being peer reviewed for possible publication in the journal. If the article is accepted for publication, the author may re-use their work according to the journal's author archiving policy. If your paper is accepted, you must include a link on your preprint to the final version of your paper.

If you have any questions about publishing with SAGE, please visit the [SAGE Journal Solutions Portal](#)

#### 1. What do we publish?

##### 1.1 Aims & Scope

Before submitting your manuscript to Dementia, please ensure you have read the [Aims & Scope](#).

##### 1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at [Sarah.Campbell@MMU.ac.uk](mailto:Sarah.Campbell@MMU.ac.uk) and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

### **1.3 Writing your paper**

The SAGE Author Gateway has some general advice and on [how to get published](#), plus links to further resources.

#### **1.3.1 Make your article discoverable**

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

## **2. Editorial policies**

### **2.1 Peer review policy**

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

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For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

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Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

*Abbreviations.* As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

*Useful websites to refer to for guidance*

We recommend that authors refer to the [Dementia Engagement and Empowerment Project \(DEEP\) guidance](#) which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

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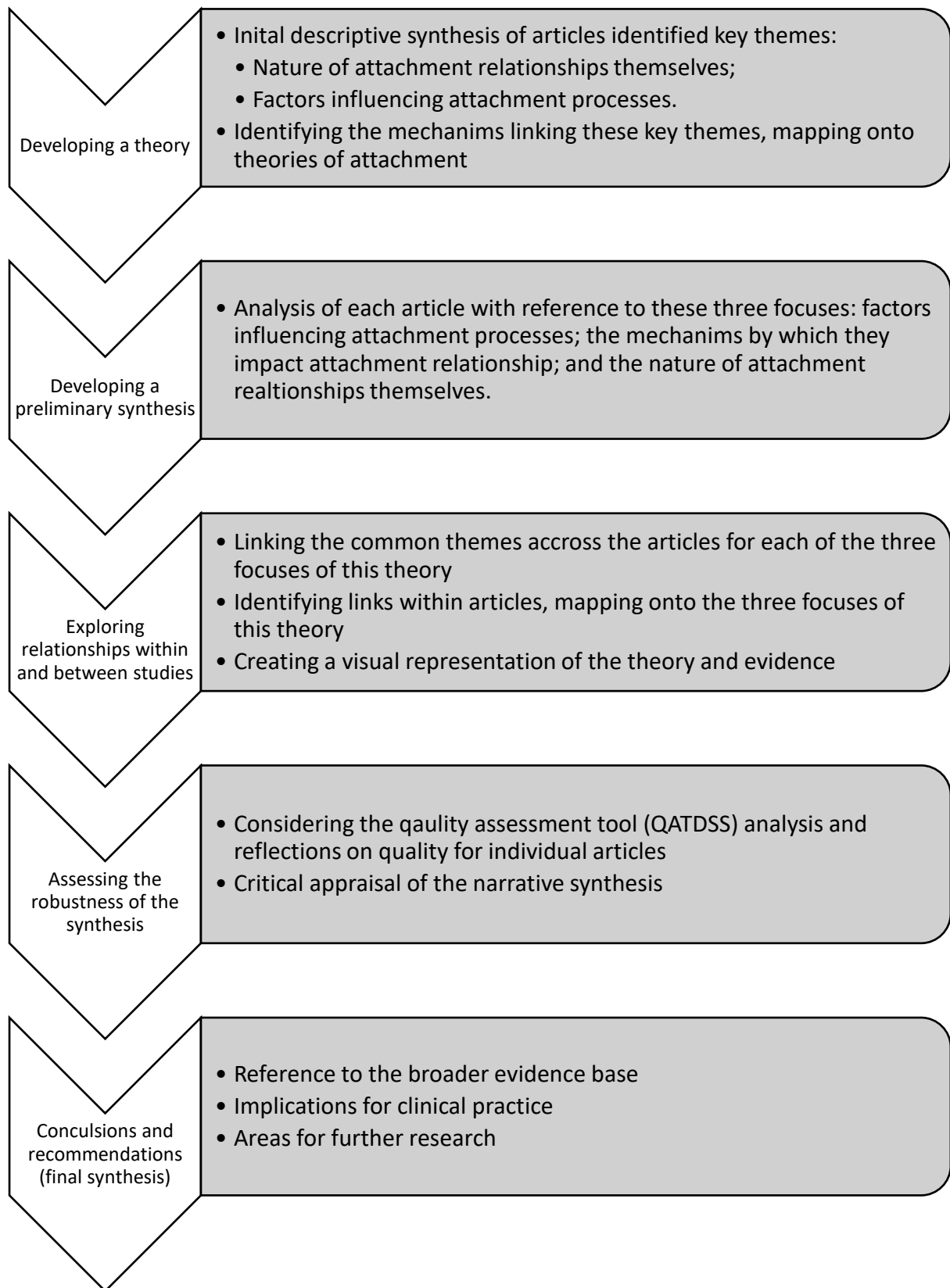
## APPENDIX B – QATSDD QUALITY APPRAISAL TOOL RATING GUIDELINES (TAKEN FROM SIRRIYEH ET AL., 2012)

Criteria	0 = Not at all	1 = Very slightly	2 = Moderately	3 = Complete
Explicit theoretical framework	No mention at all.	Reference to broad theoretical basis.	Reference to a specific theoretical basis.	Explicit statement of theoretical framework and/or constructs applied to the research.
Statement of aims/objectives in main body of report	No mention at all.	General reference to aim/objective at some point in the report including abstract.	Reference to broad aims/objectives in main body of report.	Explicit statement of aims/objectives in main body of report.
Clear description of research setting	No mention at all.	General description of research area and background, e.g. 'in primary care'.	General description of research problem in the target population, e.g. 'among GPs in primary care'.	Specific description of the research problem and target population in the context of the study, e.g. nurses and doctors from GP practices in the east midlands.
Evidence of sample size considered in terms of analysis	No mention at all.	Basic explanation for choice of sample size. Evidence that size of the sample has been considered in study design.	Evidence of consideration of sample size in terms of saturation/information redundancy or to fit generic analytical requirements.	Explicit statement of data being gathered until information redundancy/saturation was reached or to fit exact calculations for analytical requirements.
Representative sample of target group of a reasonable size	No statement of target group.	Sample is limited but represents some of the target group or representative but very small.	Sample is somewhat diverse but not entirely representative, e.g. inclusive of all age groups, experience but only one workplace. Requires discussion of target population to determine what sample is required to be representative.	Sample includes individuals to represent a cross section of the target population, considering factors such as experience, age and workplace.
Description of procedure for data collection	No mention at all.	Very basic and brief outline of data collection procedure, e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail, or states some stages in details but omits others.	Detailed description of each stage of the data collection procedure, including when, where and how data were gathered.
Rationale for choice of data collection tool(s)	No mention at all.	Very limited explanation for choice of data collection tool(s).	Basic explanation of rationale for choice of data collection tool(s), e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool(s), e.g. relevance to the study aims and assessments of tool quality either statistically, e.g. for reliability & validity, or relevant qualitative assessment.
Detailed recruitment data	No mention at all.	Minimal recruitment data, e.g. no. of questionnaire sent and no. returned.	Some recruitment information but not complete account of the recruitment process, e.g. recruitment figures but no information on strategy used.	Complete data regarding no. approached, no. recruited, attrition data where relevant, method of recruitment.
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	No mention at all.	Reliability and validity of measurement tool(s) discussed, but not statistically assessed.	Some attempt to assess reliability and validity of measurement tool(s) but insufficient, e.g. attempt to establish test-retest reliability is unsuccessful but no action is taken.	Suitable and thorough statistical assessment of reliability and validity of measurement tool(s) with reference to the quality of evidence as a result of the measures used.
Fit between stated research question and method of data collection (Quantitative)	No research question stated.	Method of data collection can only address some aspects of the research question.	Method of data collection can address the research question but there is a more suitable alternative that could have been used or used in addition.	Method of data collection selected is the most suitable approach to attempt answer the research question
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative)	No research question stated.	Structure and/or content only suitable to address the research question in some aspects or superficially.	Structure & content allows for data to be gathered broadly addressing the stated research question(s) but could benefit from greater detail.	Structure & content allows for detailed data to be gathered around all relevant issues required to address the stated research question(s).
Fit between research question and method of analysis	No mention at all.	Method of analysis can only address the research question basically or broadly.	Method of analysis can address the research question but there is a more suitable alternative that could have been used or used in addition to offer greater detail.	Method of analysis selected is the most suitable approach to attempt answer the research question in detail, e.g. for qualitative IPA preferable for experiences vs. content analysis to elicit frequency of occurrence of events, etc.
Good justification for analytical method selected	No mention at all.	Basic explanation for choice of analytical method	Fairly detailed explanation of choice of analytical method.	Detailed explanation for choice of analytical method based on nature of research question(s).
Assessment of reliability of analytical process (Qualitative only)	No mention at all.	More than one researcher involved in the analytical process but no further reliability assessment.	Limited attempt to assess reliability, e.g. reliance on one method.	Use of a range of methods to assess reliability, e.g. triangulation, multiple researchers, varying research backgrounds.
Evidence of user involvement in design	No mention at all.	Use of pilot study but no involvement in planning stages of study design.	Pilot study with feedback from users informing changes to the design.	Explicit consultation with steering group or statement or formal consultation with users in planning of study design.
Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues.	Discussion of some of the key strengths and weaknesses of the study but not complete.	Discussion of strengths and limitations of all aspects of study including design, measures, procedure, sample & analysis.

## APPENDIX C – QATSDD QUALITY APPRAISAL TOOL RATINGS

Criteria	Paper: Abrams et al. (2019)	Paper: Berg et al. (1998)	Paper: Coates (2015)	Paper: Drebing et al. (2002)	Paper: Edwards (2017)	Paper: Gerritsen et al. (2007)	Paper: Haggstóm and Norberg (1996)	Paper: Kokkonen et al. (2014)	Paper: Law et al. (2019)	Paper: Vandrevalla et al. (2017)
Explicit theoretical framework	2	2	3	2	3	2	1	3	2	3
Statement of aims/objectives in main body of report	3	2	3	3	3	3	3	3	3	3
Clear description of research setting	3	3	3	3	3	3	3	3	3	3
Evidence of sample size considered in terms of analysis	1	0	1	0	2	1	0	3	1	1
Representative sample of target group of a reasonable size	2	3	2	2	2	1	1	2	1	2
Description of procedure for data collection	3	2	3	2	3	1	2	3	2	3
Rationale for choice of data collection tool(s)	2	0	2	2	3	2	1	3	2	2
Detailed recruitment data	2	2	3	2	2	1	1	3	2	1
Statistical assessment of reliability and validity of measurement tool(s) (Quantitative only)	-	-	-	2	-	0	-	3	-	-
Fit between stated research question and method of data collection (Quantitative only)	-	-	-	3	-	2	-	2	-	-
Fit between stated research question and format and content of data collection tool e.g. interview schedule (Qualitative only)	3	2	3	-	3	-	2	-	3	3
Fit between research question and method of analysis	2	2	3	2	3	1	2	3	3	2
Good justification for analytic method selected	2	3	3	1	2	0	1	3	3	1
Assessment of reliability of analytic process (Qualitative only)	3	3	1	-	0	-	0	-	3	2
Evidence of user involvement in design	0	0	0	0	0	2	0	0	1	0
Strengths and limitations critically discussed	2	2	3	1	2	2	1	3	2	2
<b>TOTAL SCORE</b>	<b>30</b>	<b>26</b>	<b>33</b>	<b>25</b>	<b>31</b>	<b>21</b>	<b>18</b>	<b>37</b>	<b>31</b>	<b>28</b>
<b>PERCENTAGE SCORE</b>	<b>71.4%</b>	<b>61.9%</b>	<b>78.6%</b>	<b>59.5%</b>	<b>73.8%</b>	<b>50%</b>	<b>42.9%</b>	<b>88.1%</b>	<b>73.8%</b>	<b>66.7%</b>
<b>QUALITY LEVEL</b>	<b>Good</b>	<b>Good</b>	<b>High</b>	<b>Good</b>	<b>Good</b>	<b>Moderate</b>	<b>Moderate</b>	<b>High</b>	<b>Good</b>	<b>Good</b>

## APPENDIX D – NARRATIVE SYNTHESIS PROCESS CHART



## APPENDIX E – MAPPING ARTICLES TO THE THEORY

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Abrams, Vandrevalla, Samsi and Manthorpe (2019)	<ul style="list-style-type: none"> <li>Role of care work – blurred boundaries</li> <li>Context (end of life, individuals own home)</li> <li>Racial discrimination and inappropriate behaviour from clients (regardless of if it is attributable to dementia or not)</li> <li>Length of time known to client</li> <li>Wearing a uniform</li> <li>Professional boundaries and guidance</li> <li>Clear care plans, understanding what is expected e.g. personal care, housework, companionship</li> <li>Having rules and procedures</li> <li>Views on the importance of emotional investment for the role</li> <li>Changes at end of life</li> <li>Death of clients</li> <li>Concerns about accusations and feeling vulnerable</li> <li>Feeling adequately trained, knowing policy and talking to managers</li> </ul>	<ul style="list-style-type: none"> <li>Impact of difficult relationship on confidence, work motivation and emotional state</li> <li>Feeling equipped to deal with emotions of family members at end of life</li> <li>Working in client’s home – facilitated getting to know the person more easily and highlights their character and personality, drives you to put them first</li> <li>Ambiguity of role – need clear care plans, understanding what is expected e.g. personal care, housework, companionship</li> <li>Changes at end of life – feeling relationship diminished as more professionals become involved</li> <li>Repeated loss and death of clients</li> </ul>	<ul style="list-style-type: none"> <li>“Maintaining boundaries was not always straightforward and discussed the blurring or erosion”</li> <li>Fluctuate between rigid and fluid</li> <li>Flexibility and adaptability (very important) needed when working with people with dementia – creativity</li> <li>Emotional attachments as part of the work, including with families</li> <li>Managers take the “role of protective gatekeepers”, mindful of risks staff face</li> <li>“quite close” – “attachments as an inherent part of their role”</li> <li>Substantial emotional investment, seen as blurred boundaries, viewed as parental figure, close relative or “friend” (note: the differences in boundaries)</li> <li>Emotional distance to preserve own wellbeing</li> <li>Offering comfort and reassurance to family</li> <li>Compassion and professionalism</li> <li>Feelings of loss and grief after client’s death – emotional toll “it breaks you”, “mask” to hide emotions</li> <li>Open communication</li> </ul>



	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Berg, Hallberg, and Norberg (1998)	<p>Stage of dementia when attempting to build relationship</p> <p>“Intertwined life world” – shaped by the nurses’ response in the moment, the nurse’s life outside of caring (past and present)</p> <p>Patients behaviour – suspicious/distrustful, unable to manage emotions, not wanting to be alone, aggression</p> <p>Number of patients the nurse is supporting at any one time</p> <p>Time and experience in role, know what to expect, easier to form close relationships</p> <p>Feeling powerless</p> <p>Effected by personal life history and present life situation outside of work</p> <p>In turn, work impacts everyday life and life outside of work</p> <p>Always liked being with humans or animals, natural contact with elderly people in childhood</p> <p>Disease progression</p> <p>Perception of patient as abandoned by society</p>	<p>Understanding own and patients’ actions through talking with colleagues – supports patient outcomes</p>	<p>About <i>being</i> together as well as <i>doing</i> together</p> <p>Interactions between nurse and patient effect each other in range of positive and negative ways through feelings, thoughts and actions</p> <p>“Intertwined life world” – the experience of the shared world of the patient and nurse.</p> <p>“close physical contact, personal closeness, tenderness, warmth and feeling of give and take”</p> <p>Empathy and consideration – reciprocity of emotion and feeling</p> <p>Setting up barriers’ vs seeking support – going between the two</p> <p>Internal dialogue to explore what happened when things go wrong</p> <p>Becoming more respectful understanding and patient and finding moments of happiness</p> <p>Mature approach to relationships and expectations</p> <p>Using knowledge of patient to make sense of current behaviours and actions</p> <p>Striving for mutual understanding</p> <p>Dependency – patient at the “nurses mercy” – empathy for how “terrible” this must be</p> <p>Sharing emotional experiences</p> <p>Tenderness and closeness</p>

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Coates (2015)	<p>Change in clinical practice over years (e.g. hiding medication in food)</p> <p>Feeling powerless</p> <p>Perceived lack of experience or feeling ill-equipped</p> <p>Feeling supported</p> <p>Working as part of a team</p> <p>Innate ability to care – “in the blood”, intuitive</p> <p>Training and experience</p> <p>Personal experience of caring</p> <p>Life experience – getting older</p> <p>Faith and religion</p> <p>Influence of colleagues (inspiring manager or staff member)</p>	<p>Motivation to care</p> <p>Knowledge is empowering (training)</p>	<p>Experiencing dilemmas</p> <p>“Feeling Torn” – short term distress for long term benefit in providing care in line with best interests.</p> <p>Fear of causing harm, - abuse or force</p> <p>Balancing competing needs of other – individual with dementia, families, other residents, staff</p> <p>Inevitability and unconditionality to the attachment – regardless of abuse from clients</p> <p>Comparisons “like having a child”</p> <p>Maintain distance to protect yourself from distress</p> <p>Numb, else it will emotionally drain you</p> <p>Wanting to connect with residents</p> <p>Taking value in small interactions and feedback</p> <p>Reciprocal relationships – gaining pleasure from interactions and using them to regulate emotions (you relax more if you have a conversation with someone), circularity of emotion (they’re happy I’m happy, they’re distressed, I’m distressed)</p> <p>Empathy with residents’ guide care decision making</p> <p>Giving support and care – compassion</p> <p>Perspective-taking – compare to own family members to guide decision making</p> <p>In times of fear – need to put own emotions to the back and focus on the individual’s distress</p> <p>Attempt to gain residents perspective and understand behaviour</p> <p>Innate abilities, genuine interest in others, attitude of acceptance and motivation to care</p> <p>Internal standard of good and bad</p> <p>“need” to care – like a drug, and a duty</p> <p>Personal satisfaction</p> <p>Accepting attitude</p>

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Drebing, McCarty, and Lombardo (2002)	<p>Those who feel work results in family conflict are more likely to be thinking of quitting</p>	<p>Extrinsic factors (position and total hours worked, income) are not related to job or career commitment</p> <p>The more time spent with patients the more committed to the job and profession</p> <p>77% of participants did the job because they were learning</p> <p>Attachment to patients and families is significantly correlated with career commitment – people committed to the career will form attachments with patients and families</p> <p>Attachment to patients and families was negatively correlated to thoughts of quitting</p> <p>Professionals reporting a high degree of grief at the death of a client are more likely to see themselves in dementia care for the rest of their career</p> <p>Fostering attachments with patients and families is one way to enhance intrinsic rewards and therefore job and career commitment</p>	<p>72% of participants did the role because of the contact with patients.</p>

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Edwards (2017)	<p>Feeling empathy with residents            Connection grows as residents display affection or recognise staff member as familiar            Difficulties with communication</p>	<p>Personal experience of being away from family (empathy)            Fulfilling own needs to “belong”            Humour – light hearted, fun, jovial, entertaining            Trust built as residents get more familiar with staff</p> <p>(Observed Themes: feeling invested in a person, feeling appreciated, feeling special and acknowledged)</p>	<p>“creating a home” – home is a place of safety and security, a place of belonging where you would be cared for and your needs would be met as if you were part of a family, and where you would have a sense of freedom and independence in order to pursue lifestyle choices            Supporting residence to have space to make choices even when they are reluctant to            Making effort to know and understand the residents as individuals            Caring parent-figure – likening residents to their own children for whom they care for – checking they are safe, starting activities and giving resident space to continue by independently            Trust            Ability to suppress feelings of impatience            Role of defusing distress and keeping residents pre-occupied            Entertaining to residents            Being a secure base – creating an environment with features of a secure attachment, sense of belonging            Moving from insecure to secure – building trust from mistrust</p>
Gerritsen et al., (2007)	<p>Self-awareness of limitations            Role with the client, 24-hour care vs day activities</p>	<p>(Observed Themes: What do you see as your role)</p>	<p>Daytime activities group focused more on domains of quality of life – attachment, enjoyment of activities, sense of aesthetics, being useful/giving meaning to life            24-hour care focus less on the different domains of quality of life than day activities staff            Focus of all staff is on affect and self-esteem            Less emphasis on self-determination and giving meaning to life (the exploration aspects of attachment, perhaps staff are stuck in the parent role of a young child, not looking to future to promote independence?)</p>

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Haggstróm and Norberg (1996)	<p>Drawing on experience of own mother</p> <p>Drawing on experience as a mother</p> <p>Feeling comfortable in work environment</p>	<p>Caring for others in the way they wish they had been cared for</p> <p>Caring for others to make up for the care they did not provide to their own mother</p> <p>If a mother lacks clarity about her own self it will be transferred to the child, with negative consequences for the child's experience of the home</p>	<p>The important role of the mother – the variety of roles</p> <p>Patience, always there</p> <p>Source of skills, patience, interpreting unspoken messages and being diplomatic</p> <p>Choosing when to be a mother, or not</p> <p>Responding to cues for comfort</p> <p>Filling the attachment gap left when family cannot or do not visit</p> <p>Carer taking the role of daughter</p> <p>Radiating security</p> <p>Satisfaction of being involved in a close, important and satisfying relationship</p> <p>Mutual understanding</p> <p>The ward as a family expressed a relatedness between the people there, a foundation for security, nourishment, and a belonging to a historical place</p> <p>Role of home and carers as an incubator, caring for residents when their own mother is not able to</p>

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Kokkonen, Cheston, Dallos, and Smart (2014)	<p>Burnout</p> <p>Emotional exhaustion</p> <p>Reduced emotional resources</p> <p>Depersonalisation – holding cynical and negative views of the people we work with</p> <p>Negative evaluation of ones' self and reduced sense of achievement</p> <p>Reduced staff wellbeing, personal dysfunction, absenteeism, low morale, and deterioration in the quality of care provided</p> <p>Struggling to cope with demands at work and stresses</p> <p>Increased attachment-seeking behaviours of people with dementia</p>	<p>Cycles of negative interactions – high levels of burnout is associated with behavioural and Psychological symptoms of dementia – strong relationship between distress in staff and aggression from residents</p> <p>Staff with high burnout rates behave differently to patients, less willing to help, low optimism, negative emotional responses, lower empathy, less positive attitudes, reduced interactions</p>	<p>A person's caregiving behaviour is influenced by his or her own prior attachment experiences, as the internal working models of attachment are likely to be closely related to the internal working models of caregiving</p> <p>Secure attachment orientation = positive perception of self as effective caregivers and positive perception of others and deserving respect and support. Good emotional regulation skills prevent feeling overwhelmed by own distress at the suffering of others</p> <p>People with high attachment related anxiety focus on their own distress and adopt emotion-focused coping strategies – negative appraisal of self and coping</p> <p>People with high attachment related avoidance distance themselves cognitively and emotionally from the source of distress – blocking awareness of distress and devaluing the need of others – chronic stress results in negative emotion and burnout</p> <p>Higher levels of attachment related anxiety associated with higher levels of emotional exhaustion and lower levels of personal accomplishment, and less self-efficacy, less person-centred attitudes</p> <p>Higher levels of attachment related avoidance related to higher levels of emotional exhaustion</p> <p>Higher levels of attachment insecurity were associated with higher levels of depersonalisation</p> <p>Attachment is a significant predictor of emotional exhaustion and personal accomplishment</p> <p>Insecure attachment is associated with burnout</p> <p>Attachment anxiety relation to more emotional exhaustion and depersonalisation and lower personal accomplishment, lower levels of self-efficacy and higher burnout</p> <p>Attachment avoidance related to more emotional exhaustion and depersonalisation</p>

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Law, Patterson, and Muers (2019)	<p>Knowing your client – life history</p> <p>Feeling supported in role and relationships with colleagues</p> <p>Discomfort of clients (unable to resolve e.g. end of life)</p> <p>Training</p> <p>Length of experience in role</p> <p>Experience of end-of-life care</p>	<p>Knowing client enables adapting of approach to meet their needs</p> <p>Feeling supported – able to seek advice and support</p> <p>Feeling important in role with superior knowledge and expertise</p> <p>Feeling privileged to provide end of life care – comes with pressure to get it right</p> <p>Experience of being with older people changes preconceived perceptions</p> <p>Thoughts about own mortality and that of friends and family</p>	<p>Connecting in a human way</p> <p>Viewing clients as family members</p> <p>Experiencing the loss when a client dies</p> <p>Others not experiencing loss – being more matter of fact – less attachment = less affected when client dies – protective mechanism</p> <p>Emphasis on positive aspects of role, minimising the negative – give positive impression</p> <p>Going the extra mile vs feel responsible but reluctant to step in</p> <p>Being unable to help brings assumption they have not been able to fulfil their role (e.g. not able to make someone comfortable = bad carer)</p> <p>Seeking reassurance to help to cope with emotional demands of role – comfort in positive feedback from others</p> <p>50% felt they should carry on despite emotions – that is what you have to expect in this role therefore need to just carry one</p>

	<b>Influencing Factors</b> (Factors influencing attachment relationship)	<b>Mechanisms</b> (Mechanisms of how these factors attachment influence relationship)	<b>Attachment relationships</b>
Vandrevala et al., (2017)	Complexity of the work – especially end of life competing demands, time pressures, significant resident disability communication difficulties Limited training opportunities Support from colleagues and managers – team spirit work place culture – don't talk about death = limited emotional outlets for distress = suppressing stress and feeling isolated and as a burden	Competing demands, time pressures, significant resident disability = feeling stressed and overwhelmed, feeling relied upon, feeling out of control Mismatch between expectations and reality of role – anticipating stress levels would reduce with experience but not the case	Feeling helpless when time and work demands impact relationship with resident Integral to role is responding to emotional needs of residents – for some this is more stressful than the physical aspects of work Growing close to residents increases anxieties around bearing witness to decline and death Attachment increases feelings of helplessness to reduce suffering Taking on the role of the family for residents Connecting with vulnerability and causing reflection on own mortality and that of their own family Expressing profound sadness and loss at end-of-life stages Feeling it is important to remain professional, detached and not to express this sadness Needing 'space' to grieve for loss of client



## APPENDIX F – IDENTIFYING LINKS WITHIN AND BETWEEN ARTICLES

### Factors influencing attachment relationship

- Professional boundaries and guidance – Nature of care work mean boundaries are blurred, clear care plans, understanding what is expected (e.g. personal care, housework, companionship, having rules and procedures, wearing a uniform, training, knowing policy, managers support (Abrams et al., 2019), change in acceptable clinical practice over the years (e.g. hiding medication in food), training (Coates, 2015), adequate training (self-defence, restraint procedures, alternatives to restraint, monitoring and incident reporting), training (Law et al., 2019), training opportunities (Vandrevala et al., 2017)
- Workplace Context – end of life, working in individuals own home (Abrams et al., 2019), number of patient's nurse is supporting at any one time, perception of patient as abandoned by society (Berg et al., 1998), working as part of a team, influential colleagues and managers (Coates, 2015), role with the client (24 hour care or day activities) (Gerritsen et al., 2007), complexity of the work (especially end of life), competing demands, time pressures, support from colleagues and managers, team spirit), work place culture (e.g. don't talk about death = limited emotional outlets for distress – suppressed stress and feeling isolated) (Vandrevala et al., 2017)
- The individual with dementia – racial discrimination, inappropriate behaviour, disease progression, end of life (Abrams et al., 2019), stage of dementia when attempting to build a relationship, patients' behaviour suspicious/distrustful, unable to manage emotions, not wanting to be alone, aggression, disease progression (Berg et al., 1998), displays of affection, recognising staff as familiar, communication difficulties (Edwards, 2017), increasing attachment seeking behaviours (Kokkonen et al., 2014), unresolvable discomfort and distress (E.g. end of life) (Law et al., 2019), significant disability (Vandrevala et al., 2017)
- Experience – length of time known to person with dementia, death of clients (Abrams et al., 2019), length of time and experience in role (knowing what to expect) (Berg et al., 1998), experience, personal experience of caring, life experience (Coates, 2015), knowing your client (life history), length of experience in role, experience of end of life care (Law et al., 2019).
- Personal factors – view on importance of emotional investment for the role, concerns about accusations and feeling vulnerable, feeling adequately trained (Abrams et al., 2019), response in the moment, life outside of caring (past and present), personal life history and present life situation outside of work, impact of work on life, always liked working with

humans and animals, natural contact with elderly people in childhood (Berg et al., 1998), perceived lack of experience or feeling ill equipped, innate ability to care “in the blood”, intuitive, getting older (life experience), faith and religion (Coates, 2015), feeling work is resulting in family conflict (Drebing et al., 2002), feeling empathy with residents (Edwards, 2017), self-awareness of limitations (Gerritsen et al., 2007), relationships with colleagues, unable to resolve the discomfort of clients (Law et al., 2019), experience of own mother and of mothering (Haggstrom et al., 1996)

#### **Mechanisms by which these factors influence attachment relationship**

- Internal Working Model of Self: feeling powerless (Berg et al., 1998) (Coates, 2015), Impact of difficult relationship on confidence, work motivation feeling equipped to deal with emotions of family members at end of life, ambiguity of role, role in relationship changes (feeling diminished as other professionals are involved) (Abrams et al., 2019), understanding own actions (Berg et al., 1998), motivation to care, feeling knowledgeable and empowered, Innate abilities - internal standard of good and bad, needing to care – like a drug or duty (Coates, 2015), role as a continual learning opportunity (Drebing et al., 2002), need to ‘belong’, light hearted, jovial entertaining approach (Edwards, 2017), what do you see as your role (Gerritsen et al, 2007), need to make up for care I did not provide to my mother, lack of clarity of self will reflect in the child (Haggstrom et al., 1996), struggling to cope with demands and stresses at work, negative evaluation of one’s self and reduced sense of achievement, personal dysfunction, (Kokkonen et al., 2014), my role is important and I have superior knowledge and expertise, I must get it right (its important and a privilege to provide end of life care), thoughts of own mortality and that of friends and family (Law et al., 2019), feeling overwhelmed by competing demands, feeling relied upon and out of control, mismatch of expectations and reality (Vandrevala et al., 2017)
- Internal Working Model of Other: feeling supported (Coates, 2015), feeling supported in role (Law et al., 2019), getting to know the person (working in their own home facilitates this) (Abrams et al., 2019), understanding clients actions, valuing the support of colleagues (Berg et al., 1998), time invested in others, commitment to clients and their families (Drebing et al., 2002), empathy for the experience of others (related to own experience), others are worth investing time in (Edwards, 2017), others should be cared for in the way they wish (Haggstrom et al., 1996), others not worthy on help, lower empathy, less positive attitudes to others, depersonalisation (holding cynical and negative views of the people we work with), (Kokkonen et al., 2014), approach needs to be adapted for the individual, others support me, it is a privilege to provide end of life care (Law et al., 2019)
- Emotional resilience: Impact of difficult relationship on emotional state (Abrams et al., 2019), coping with repeated loss and death (Abrams et al., 2019), coping with grief (Drebing et al., 2002), negative emotional responses, unoptimistic, emotional exhaustion, reduced emotional resources, reduced staff wellbeing, low morale (Kokkonen et al., 2014),

- Cyclical process, negative interactions undermine sense of self being effective at work, leading to further challenging interaction, undermines sense of other being worthy of care, leading to further challenging interactions (Kokkonen et al., 2014)

### **Attachment relationships of paid caregivers**

- Changeable – Flexibility and adaptability is important, creativity, Fluctuating between ridged and fluid, boundaries blur and erode, balancing compassion and professionalism (Abrams et al., 2019), interactions with patient impact thoughts, feelings and actions and vice versa (Berg et al., 1998), reciprocity of emotion and feeling, setting up barriers vs. seeking support – going between the two (Berg et al., 1998), balancing competing needs of others (individual, families, other residents, staff), circularity of emotion (they happy I happy, they distressed I distressed) (Coates, 2015), moving from insecure to secure - building trust from mistrust (Edwards, 2017), the variety of roles as the mother and its importance, (Haggstrom et al., 1996), going the extra mile vs reluctant to step in (Law et al., 2019)
- Emotional expression and suppression – emotional attachment as part of the work, including with families, too much emotional investment seen as blurred boundaries, emotional distance to preserve own wellbeing, emotional toll “it breaks you”, “mask to hide emotions”, feelings of loss and grief after clients death (Abrams et al., 2019), empathy and consideration, finding moments of happiness, sharing emotional experiences (Berg et al., 1998), feeling numb (else it will emotionally drain you), gaining pleasure from interactions and using them to regulate emotions, empathy influences action and decision making, in times of fear need to put emotions to the back and focus on the individuals distress, satisfaction (Coates, 2015), suppress feelings of impatience (Edwards, 2017), ), satisfying to be involved in a close important satisfying relationship, patience (Haggstrom et al., 1996), good emotional regulation skills prevent feeling overwhelmed by own distress at the suffering other others, people with high attachment anxiety tend to focus on their own distress and adopt emotion-focused coping strategies – making negative appraisals of self and coping strategies, people with high attachment related anxiety tend to distance themselves emotionally from the source of the distress, attachment insecurity results in high levels of emotional exhaustion (Kokkonen et al, 2014), experiencing loss when a client dies or not (being matter of fact, perhaps a protective mechanism), giving a positive impression, seeking reassurance to cope with the emotional demands of the role (seeking positive feedback), 50% felt they should carry on despite emotions – that is what you have to expect in this role therefore you need to just carry on, being unable to help (e.g end of life) leads to feeling unable to fulfil their role = bad carer (Law et al., 2019), feeling helpless when work demands impact relationship with client, expressing profound loss and sadness at end of life stages, feeling it is important to remain professional, detached and not express this sadness (Vandrevala et al., 2017)

- Closeness and distance – “quite close”, attachments as inherent part of role (Abrams et al., 2019), about *being* together as well as *doing* together, experience of the shared world with the patient (intertwined life world), close physical contact, personal closeness (Berg et al., 1998), inevitability and unconditionality to attachment (regardless of abuse), maintaining distress to protect yourself from distress, wanting to connect with residents (Coates, 2015), 72% of participants did the role because of the contact with patients (Drebing et al., 2002), foster a sense of freedom and independence, supporting residents to have space to make choices, starting activities and giving resident the space to continue independently, sense of belonging (Edwards, 2017), staff may get stuck in the caring aspects of attachment and not move onto promoting independence (the exploration aspects of attachment) (Gerritsen et al., 2007), always there, choosing when to mother and when not to, (Haggstrom et al., 1996), people with high attachment related anxiety tend to distance themselves cognitively from the source of the distress (Kokkonen et al., 2014), work and time demands impact relationship with client, closeness to client means vulnerability to experiencing loss when client declines and dies, attachment increases feelings of helplessness to reduce suffering, needing “space” to grieve for loss of client (Vandrevala et al., 2017)
- Comfort and Discomfort – offering comfort and reassurance to families (Abrams et al., 2019), tenderness, warmth, dependency – patient at the “nurses mercy” – empathy for how “terrible” this must be, tenderness and closeness (Berg et al., 1998), experiencing dilemmas, “feeling torn” (short term distress for long term gain), fear of causing harm, force or abuse, giving care and support - compassion (Coates, 2015), creating a “home”, a place of safety and security, a place of belonging where you would be cared for and your needs would be met, checking they are safe, defusing distress, sense of belonging, (Edwards, 2017), radiating security, foundation for security nourishment and belonging (Haggstrom et al., 1996), responding to emotional needs of clients is more stressful than physical demands of role for some (Vandrevala et al., 2017)

Mutual Respect and Understanding - Open communication (Abrams et al., 2019), Feeling of give and take, using knowledge of patient to make sense of behaviours and actions, striving for mutual understanding, (Berg et al., 1998), valuing small interactions and feedback, attempts to gain individual perspective and understand behaviour, genuine interest in others, accepting attitude (Coates, 2015), making effort to know and understand each individual resident, trust (Edwards, 2017), understanding attachment relationships are key to quality of life (daytime activities staff prioritised this more than 24hour care staff) (Gerritsen et al., 2007), source of skills, interpreting unspoken messages and being diplomatic, responsive to cues, mutual understanding (Haggstrom et al., 1996), positive perceptions of others deserving support and respect, people with high attachment related anxiety tend to distance themselves emotionally and cognitively withdrawing from the source of distress and devaluing the needs of others, higher levels of attachment insecurity associated with higher levels of depersonalisation (Kokkonen et al., 2014), connecting in a human way (Law et al., 2019).

- Links to own family – viewed as parental figure, close relative or “friend” (Abrams et al., 2019), “like having a child”, compare to own family members to guide decision making (Coates, 2015), “creating a home” as if you were part of a family, caring parent-figure, likening residents to their own children for whom they care for (Edwards, 2017), the role of the mother, filling the attachment gap when families cannot or do not visit, taking the role of daughter to the resident, the ward as a family (relatedness between people there), role of the ward as an incubator – caring for the resident when their own mother is not able to (Haggstrom et al., 1996), caregiving behaviour influenced by own prior attachment experiences – internal working models of attachment are closely linked to internal working models of caregiving (Kokkonen et al, 2014), viewing clients as family members (Law et al., 2019), taking the role of family for residents, connecting mean reflecting on own mortality and that of own family, (Vandrevala et al., 2017)

## APPENDIX G – PEER-REVIEW CONFIRMATION EMAIL

### RE: LSRP Proposal Review

Christopher Hobson (Cardiff and Vale UHB - Dclinpsy)

<Christopher.Hobson@wales.nhs.uk>

Fri 12/10, 11:27

Katie Veale; Reginald Morris

Dear Katie

Thank you for your revised proposal which we consider to be better articulated than the original version. You do not need to submit another proposal so that you can get on with modifying the proposal further so that you can apply for the relevant permissions to carry out the study.

However we do have some further comments/advice:

- 1) In the rationale section you state that the project is “to inform the development of the Good Work ..Framework”. This needs to be expanded to indicate how this approach could do this **and** what useful information may emerge. (There is some information about this in the easy to understand section, but none in the rationale section).
- 2) At its core, this is a study of knowledge translation **and** implementation issues in services , but the knowledge translation literature isn’t referenced. It would greatly strengthen the proposal if this were to be incorporated.
- 3) You propose to measure confidence **and** knowledge in working with dementia. But the literature cited in the rationale indicates that these things don’t affect practice. (There is plenty more evidence of this from other fields as well). The question is ‘why measure this?’. The knowledge translation literature tells us that it is service factors (support from the top, time to undertake new procedures, access to materials, monitoring of performance, etc) that primarily affect practice change: It could therefore make better sense to measure these aspects as well as knowledge **and** confidence.

If you have further questions about this or previous feedback do not hesitate to contact us. If there are any problems regarding feasibility of the research along the way please inform myself or other members of the research team.

Good luck in the future research!

Best wishes

Chris

**Dr Chris Hobson, PhD DCLinPsy**

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**Dr Chris Hobson, PhD DCLinPsy**

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*Usual working days:*

*Tuesday, Wednesday (South Wales Clinical Psychology Programme)*

*Friday (Neurodevelopmental Assessment Unit)*

# APPENDIX H – CARDIFF UNIVERSITY SPONSORSHIP CONFIRMATION LETTER



Research and  
Innovation Services

Gwasanaethau Ymchwil  
ac Arloesi

#### Cardiff University

McKenzie House, 7<sup>th</sup> Floor  
30-36 Newport Road, Cardiff  
CF24 0DE, Wales, UK  
Tel +44(0)29 2087 5834  
[www.cardiff.ac.uk](http://www.cardiff.ac.uk)

#### Prifysgol Caerdydd

Tŷ McKenzie, 7<sup>fed</sup> Llawr  
30-36 Heol Casnewydd, Caerdydd  
CF24 0DE, Cymru, DU  
Ffôn +44(0)29 2087 5834  
[www.caerdydd.ac.uk](http://www.caerdydd.ac.uk)

27<sup>th</sup> February 2019

Dr Jenny Moses  
School of Psychology  
Cardiff University  
Floor 11, Tower Building  
70 Park Place  
Cardiff  
CF10 3AT

Dear Dr Moses,

#### Staff skill development in supporting people with dementia: a Delphi Study

I understand that you are acting as Chief Investigator and Academic Supervisor for the above DCLinPsy project to be conducted by Katie Veale.

I confirm that Cardiff University agrees in principle to act as Sponsor for the above project, as required by the UK Policy Framework for Health and Social Care Research.

#### Scientific Review

I can also confirm that Scientific Review has been obtained from: the DCLinPsy supervisors.

#### Insurance

The necessary insurance provisions will be in place prior to the project commencement. Cardiff University is insured with UMAL. Copies of the insurance certificate are attached to this letter.

#### Approvals

On completion of your IRAS form (required for NHS REC and HRA/HCRW/NHS R&D permission), you will be required to obtain signature from the Research Governance team for the 'Declaration by the Sponsor Representative'. Please note that you are also required to provide the Statement of Activities and Schedule of Events to the Research Governance team for review prior to submission to HRA/HCRW.

Please then submit the project to the following bodies for approval:

- Health & Care Research Wales (HCRW)- to arrange HCRW Approval for Welsh NHS sites.
- Cardiff University School of Psychology Research Ethics Committee (SREC)

The University is considered to have accepted Sponsorship when Research and Innovation Services has received evidence of the above approvals. **Once an NHS organisation has confirmed capacity and capability, responsibility lies with the Chief Investigator (or their appropriate delegate) to follow an appropriate 'green light' procedure to open the study at that Site.**

#### Roles and Responsibilities

As Chief Investigator you have signed a Declaration with the Sponsor to confirm that you will adhere to the standard responsibilities as set out by the UK Policy Framework for Health and Social Care Research. In accordance with the University's Research Integrity & Governance Code of Practice, the Chief Investigator is also responsible for ensuring that each research team member is qualified and experienced to fulfil their delegated roles including ensuring adequate supervision, support and training.



Registered Charity, no. 1136855  
Elusen Gofrestredig, rhif 1136855

If your study is adopted onto Health & Care Research Wales Clinical Research Portfolio you are required to upload recruitment data onto the portfolio database.

**Contracts**

- No research specific tasks delegated to NHS Host Organisation staff (staff acting as participants) – no contract required. The HRA/HCRW Statement of Activities will act as the agreement between the sponsor and participating NHS organisations.

May I take this opportunity to remind you that, as Chief Investigator, you are required to:

- register clinical trials in a publicly accessible database before recruitment of the first participant and ensure that the information is kept up to date
- ensure you are familiar with your responsibilities under the UK Policy Framework for Health and Social Care Research;
- undertake the study in accordance with Cardiff University's Research Integrity & Governance Code of Practice (available on the Cardiff University Staff and Student Intranet) and the principles of Good Clinical Practice;
- ensure the research complies with the General Data Protection Regulation 2016/679;
- where the study involves human tissue, ensure the research complies with the Human Tissue Act and the Cardiff University Code of Practice for Research involving Human Tissue (available on the Cardiff University Staff and Student Intranet);
- inform Research and Innovation Services of any amendments to the protocol or study design, (including changes to start /end dates) and submit amendments to the relevant approval bodies;
- respond to correspondence from the REC and NHS organisation R&D offices within the required timeframes;
- co-operate with any audit, monitoring visit or inspection of the project files or any requests from Research and Innovation Services for further information.

You should quote the following unique reference number in any correspondence relating to Sponsorship for the above project:

**SPON 1721-19**

This reference number should be quoted on all documentation associated with this project.

Yours sincerely



**Dr K J Pittard Davies**  
**Head of Research Governance and Contracts**  
Direct line: +44 (0) 29208 79274  
Email: [resgov@cardiff.ac.uk](mailto:resgov@cardiff.ac.uk)

Cc Katie Veale.



# APPENDIX I – CARDIFF UNIVERSITY SCHOOL OF PSYCHOLOGY ETHICAL APPROVAL EMAIL

**From:** psychethics

**Sent:** 09 April 2019 11:32

**To:** Katie Veale

**Cc:** Jennifer Moses

**Subject:** Ethics Feedback - EC.19.03.12.5615

Dear Katie,

The Ethics Committee has considered your PG project proposal: Staff Skill Development in Supporting People with Dementia: A Delphi Study (EC.19.03.12.5615).

The project has been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,

Adam Hammond

## School of Psychology Research Ethics Committee

Cardiff University

Tower Building

70 Park Place

Cardiff

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E-bost: [psychethics@caerdydd.ac.uk](mailto:psychethics@caerdydd.ac.uk)

## APPENDIX J – HEALTH AND CARE RESEARCH WALES (HCRW) APPROVAL LETTER



Ymchwil Iechyd  
a Gofal Cymru  
Health and Care  
Research Wales



Miss Katie E H Veale  
Trainee Clinical Psychologist  
Cardiff and Vale University Health Board  
Doctoral Programme in Clinical Psychology,  
11th Floor, Tower Building, 70 Park Place,  
Cardiff  
CF10 3AT

Email:  
[Research-permissions@wales.nhs.uk](mailto:Research-permissions@wales.nhs.uk)

31 May 2019

Dear Miss Veale

**HRA and Health and Care  
Research Wales (HCRW)  
Approval Letter**

Study title:	Staff Skill Development in Supporting People with Dementia: A Delphi Study
IRAS project ID:	255921
Protocol number:	SPON 1721-19
REC reference:	19/HCRW/0009
Sponsor	Cardiff University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, [in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.](#)

### **How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

**What are my notification responsibilities during the study?**

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 255921. Please quote this on all correspondence.

Yours sincerely,  
Ann Parry

Email: [Research-permissions@wales.nhs.uk](mailto:Research-permissions@wales.nhs.uk)

Copy to: *Ms Helen Falconer*

## List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Cardiff University Ethical Approval Confirmation]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Cardiff University School of Psychology Ethic Application]		
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Cardiff University School of Psychology Risk Assessment]		
Copies of advertisement materials for research participants [Poster Advert]	1	26 February 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Insurance from Cardiff University]		27 February 2019
HRA Schedule of Events	1	31 May 2019
HRA Statement of Activities		31 May 2019
IRAS Application Form [IRAS_Form_12042019]		12 April 2019
Letter from sponsor [Cardiff University Sponsorship Confirmation]		27 February 2019
Letters of invitation to participant [Group 1]	1	26 February 2019
Letters of invitation to participant [Group 2]	1	26 February 2019
Non-validated questionnaire [Questionnaires]	1	26 February 2019
Other [Personal Data Ethics GDPR]		
Participant consent form [Participant Consent Form Paper Copy]	1	26 February 2019
Participant information sheet (PIS) [Participant Information Sheet]	1	26 February 2019
Participant information sheet (PIS) [Debrief Sheet]	1	26 February 2019
Participant information sheet (PIS)	1.1	29 April 2019
Referee's report or other scientific critique report [Peer Review Email Confirmation]		26 February 2019
Research protocol or project proposal [Protocol]	1	26 February 2019
Response to Request for Further Information		29 May 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV (KV)]		26 February 2019

**Information to support study set up**

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
All participating organisations will undertake the same activities, as detailed in the protocol and supporting documents.	Organisations will not be required to formally confirm capacity and capability, and research procedures may begin after provision of the local information pack, provided the following conditions are met. You have contacted participating NHS organisations (see below for details) HRA and HCRW Approval has been issued You should now provide the local information pack for your study to	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.		It is expected that a principal investigator is in place at all participating organisations	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access

	your participating NHS organisations. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose. The password to access the R&D contact list is Redhouse1.				
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**Other information to aid study set-up and delivery**

<i>This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.</i>

## APPENDIX K – HYWEL DDA UNIVERSITY HEALTH BOARD (H DUHB) RESEARCH AND DEVELOPMENT DEPARTMENT PERMISSIONS

### IRAS:255921 Confirmation

Chris Tattersall (Hywel Dda UHB - R&D Manager) <Chris.Tattersall@wales.nhs.uk>

Tue 27/08/2019 11:12

To:

- Katie Veale;
- Sally Corlett (Hywel Dda UHB - Dementia Coordinator) <Sally.Corlett@wales.nhs.uk>

### Full Study Title: Staff Skill Development in Supporting People with Dementia: A Delphi Study

This email confirms that Hywel Dda University Health Board has the capacity and capability to deliver the above referenced study. Fully executed SoA and HCRW/HRA approval letter attached. Please pass on to the sponsor/contact. If relevant, any visiting researchers need to be in possession of their Letter of Access or Research Contract from our HR dept.

- Please ensure all recruitment / data uploads are made as appropriate (Please let me know if you want recruitment data to be uploaded by us).
- Please ensure that all SAEs relevant to this Health Board are reported to R&D.
- Please wait for sponsor confirmation to begin recruitment.

If you wish to discuss further, please do not hesitate to contact me.

Good luck and kind regards

Chris

***Important changes: A UK Local Information Pack will be introduced on the 5 June 2019. Researchers working with NHS / HSC organisations across the UK will benefit from a consistent package to support study set-up and delivery. More information is given in the [Local Information Pack section of IRAS Help](#).***

**Chris Tattersall**

**Research & Development Manager / Rheolwr Ymchwil a Datblygu  
Hywel Dda University Health Board / Bwrdd Iechyd Prifysgol Hywel Dda  
2nd Floor, Sealyham Block / Ail Llawr, Adeilad Sealyham  
Withybush Hospital / Ysbyty Cyffredinol Llwynhelyg  
Fishguard Road / Heol Abergwaun  
Haverfordwest / Hwlfordd  
Pembrokeshire / Sir Benfro  
SA61 2PZ**

**Email / e-bost:** [chris.tattersall@wales.nhs.uk](mailto:chris.tattersall@wales.nhs.uk)

**Tel / Rhiff ffôn:** 01437 773813 (EXT 3813) or 01437 773823 (EXT 3823)

**Mobile:** 07772642770

## APPENDIX L – GLOBAL POSTER EMAIL



Staff Skill Development  
Poster version 1.0 (26/02/19)  
IRAS Project ID: 255921



Bwrdd Iechyd Prifysgol  
Hywel Dda  
University Health Board

# RESEARCH OPPORTUNITY

If you are a **healthcare professional** working with adults, we would like to invite you to participate in our research.

Our study looks at the factors healthcare professionals think are important when working with people with dementia.

We are interested in hearing the views of staff with a range of experience working with people with dementia, from very little experience to those working with people with dementia on a daily basis.

Our study involves a number of surveys, where you will have the opportunity to share your thoughts and find out what other healthcare professionals think is important too.

Those who complete the surveys will be entered into a **prize draw for £50** vouchers.

If you would like more information, please contact us on:

[vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk)

Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>	Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>	Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>	Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>	Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>	Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>	Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>	Research: Working with people with Dementia <a href="mailto:vealek@cardiff.ac.uk">vealek@cardiff.ac.uk</a>
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## APPENDIX M – INVITATION TO PARTICIPATE EMAIL



Staff Skill Development  
Invitation Email Group 2 version 1.0 (26/02/19)  
IRAS Project ID: 255921



GIG  
CYMRU  
NHS  
WALES  
Bwrdd Iechyd Prifysgol  
Hywel Dda  
University Health Board

### INVITATION TO PARTICIPATE IN RESEARCH

Project: Staff Skill Development in Supporting People with Dementia: A Delphi Study.

My name is Katie Veale, I am a Trainee Clinical Psychologist. I am working on a research project exploring about how to put into practice a framework called the Good Work. This framework aims to ensure people with dementia who access healthcare services receive the care and support they need. I am interested in what healthcare staff feel they need to help them put this framework into practice.

You are invited to be part of this research as you are currently working in healthcare services.

The study will consist of a series of questionnaires, which can be completed online or in paper format.

It is hoped the results of this research will help healthcare services to support its staff in ways they find most effective.

If you are interested in participating, would like more information and/or have any questions about the study please contact me via email: [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk).

If you do not wish to participate, you do not need to do anything.

If you require this information in an alternative format (e.g. Welsh language, large font), please contact me.

Thank you for your time in considering participation.

Best wishes

Katie Veale  
Trainee Clinical Psychologist

Doctorate of Clinical Psychology,  
Floor 11,  
Tower Building,  
70 Park Place,  
Cardiff,  
CF10 3AT

Tel: 029 208 70582  
Email: [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk)



## APPENDIX N – PARTICIPANT INFORMATION SHEET



Staff Skill Development  
Participant Information Sheet version 1.1 (29/04/19)  
IRAS Project ID: 255921



GIG  
CYMRU  
NHS  
WALES

Bwrdd Iechyd Prifysgol  
Hywel Dda  
University Health Board

### PARTICIPANT INFORMATION SHEET

**Project:** Staff Skill Development in Supporting People with Dementia: A Delphi Study.

**Researcher:** Katie Veale (Trainee Clinical Psychologist)

You are being invited to take part in a research project that is being undertaken as part of a Doctorate in Clinical Psychology. Please read the information below carefully before deciding whether to take part. If you have any questions, please contact the researcher. Contact details are at the end of this document.

#### Why is the study being done?

The Good Work is a staff training and development framework that has been developed by health and social care services in Wales. The framework describes the level of skill expected for staff when working with people with dementia. It is hoped this framework will ensure people with dementia will receive the best possible care and support when accessing health and social care services. Welsh Government aims to audit services to ensure they are complying with the Good Work Framework.

Here is a brief description of the levels of skill identified in the Good Work:

1. **INFORMED:** INFORMED people understand what dementia is and how it affects a person with dementia and those around them (e.g. family, friends, carers). They also understand how to communicate effectively with the people with dementia and those around them.
2. **SKILLED:** SKILLED people are INFORMED but have also developed more detailed and comprehensive knowledge and skills across a range of key learning and development topics. For example:
  - They have an understanding of factors that can prevent or delay dementia onset
  - They are aware of the local services to support people with dementia and those around them
  - They know about different kinds of dementia and their impact
  - They are able to identify the skills and strengths of individuals with dementia
  - They understand the sensory needs that a person with dementia may have
  - They are able to interpret what may be seen as "behaviour that challenges"
3. **INFLUENCER:** INFLUENCERS are people who are INFORMED, possibly SKILLED and who also have a management, leadership and/or strategic role. This leadership role is in relation to dementia and the services, policies and practices which are relevant to people with dementia. It is not just managers who can be leaders, this can apply to anyone who is able to inspire, lead or influence others.

This project hopes to explore staff views about the key factors needed to meet the level of skill set out in the framework. The views will be analysed and any key themes will be shared with senior staff that work across Wales to explore if these factors could be relevant for all healthcare services. This will generate some clear recommendations and guidelines for services to ensure they are complying with the framework, providing a more consistent approach across services in Wales.

#### **Do I have to take part?**

No, it is your choice whether to participate or not. If you do decide to take part you are free to change your mind and discontinue with the study at any time without giving a reason, but we will need to keep any questionnaire and survey responses you have provided up until the point you left for inclusion in the final report.

#### **What will happen if I decide to take part?**

If you want to participate in this study, you will be invited to ask the researcher any questions you may have and will be asked to sign a consent form.

You will be asked to complete an initial questionnaire about your experience, role and level of training in working with people with dementia. You will then be reminded about the levels of skill in the Good Work Framework and will be invited to participate in a further survey about your opinions on what might help implement the framework. This is likely to take approximately 20 minutes.

Once all participants have completed this survey, the responses will be analysed and key themes identified. These themes will be shared with you so you can provide feedback and indicate whether you agree with the statements or not. Again, these responses will be analysed and results shared with all participants for further feedback. Depending on the information received, there may be up to 4 rounds of the questionnaire, with each round taking approximately 15 minutes to complete and around 2 weeks between each round.

You will also be asked to complete some further short questionnaires which will focus on your level of confidence in working with people with dementia, your knowledge of dementia and a measure of the culture in your working environment. These will be sent to you following completion of all other surveys in the project and this will take approximately 20 minutes.

All questionnaires will be available in online format, you can choose which email address (personal or work) the links are sent to. Online questionnaires can be accessed via mobile devices. If you wish to complete paper copies of the questionnaires, you will be asked to provide a postal address so paper copies can be sent to you, along with a stamped addressed [envelope](#) so you can return completed questionnaires.

If you choose to take part, you can expect to be involved in the study for up to ten weeks.

#### **What are the possible disadvantages of taking part?**

There are minimal anticipated disadvantages to participating in the study. Some individuals may find completing the measures about knowledge and confidence in working with people with dementia difficult, if this area of work is challenging for them. Unlike the themes from the main survey, these individual questionnaires will not be shared with other participants and will remain anonymous.

During the main survey, key themes from the responses will be shared and participants will see the number of other participants agreeing with that theme. We understand some participants may feel uncomfortable if their answers vary significantly from the majority, again all responses will remain anonymous and no one will be able to identify you from your responses.

The researcher is available to discuss any concerns you may have and can offer signposting to further support. You are also free to withdraw from the study at any time.

#### **What are the possible benefits of taking part?**

Participants that complete all stages of the study will be entered into a prize draw, with a chance to receive a £50 voucher. Although you may not benefit personally from the study, your participation will contribute to our understanding of the support healthcare staff require when working with people with dementia. It is hoped this can lead to service developments that benefit both staff and patients.

#### **What will happen to the information I provide?**

Cardiff University is the Sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the Data Controller for this study. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished. The legal basis we will rely upon to collect and store your information is 'public interest'.

The NHS will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Cardiff University and regulatory organisations may look at your research records to check the accuracy of the research study. The NHS will pass these details to Cardiff University along with the information collected from you. The only people in Cardiff University who will have access to information that identifies you will be people who need to contact you with information about the study or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details.

The NHS and Cardiff University will keep identifiable information about you from this study for 15 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you change your mind, you are free to withdraw from the research at any time. If you choose to leave the study, we will need to keep any data you have provided up until the point you chose to leave the study and it may be included in the final analysis. As is the case for all participants, you will not be identified in any publications or presentations about the study.

You can find out more about how we use your information at

<https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

The University's Data Protection Officer can be contacted at:

[inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)

#### What will happen when the study ends?

The results of the study will be written up and submitted as part of the Doctorate in Clinical Psychology qualification. It is hoped the study will also be published in a peer-reviewed journal. You will not be identified in any report or publication related to this study. You will only be contacted after the end of the study if you win the voucher prize draw. A summary of the findings of this research will also be available if you would like to request this.

#### Who has approved this study?

This study has been approved by both the Cardiff University School of Psychology Research Ethics Committee, Health and Care Research Wales and Hywel Dda University Health Board.

#### Contact Details

If you would like any further information or have any queries please contact:

Researcher: Katie Veale (Trainee Clinical Psychologist)

Email: [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk)

Tel: 029 208 70582

Research Supervisor: Andrea Evans (Consultant Clinical Psychologist)

Email: [andrea.evans@wales.nhs.uk](mailto:andrea.evans@wales.nhs.uk)

Tel: 01437 773096

Research Supervisor: Jenny Moses (Academic Director/Clinical Psychologist)

Email: [jenny.moses@wales.nhs.uk](mailto:jenny.moses@wales.nhs.uk)

Tel: 029 208 70582

Thank you for taking the time to read this information sheet.

## APPENDIX O – PARTICIPANT CONSENT FORM



Staff Skill Development  
Participant Consent Form version 1.0 (28/02/19)  
IRAS Project ID: 255921



GIG  
CYMRU  
NHS  
WALES  
Bwrdd Iechyd Prifysgol  
Hywel Dda  
University Health Board

### PARTICIPANT CONSENT FORM

Project:	Staff Skill Development in Supporting People with Dementia: A Delphi Study
Researcher:	Katie Veale (Trainee Clinical Psychologist)
Participant Identification Number:	

This research project explores the views of healthcare staff on putting into practice a framework called the Good Work. This framework aims to ensure people with dementia who access healthcare services receive the care and support they need.

You have been invited to participate as you are currently working in healthcare services and we are interested in your thoughts about this.

You should have received a copy of the participant information sheet, which contains more detailed information about this study, see enclosed.

If you have any questions about the study please contact [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk).

If you consent to participate in the study and have read the information sheet, please consider the statements below. If you agree with the statements, please put your initials in each box.

		Please Initial:
1.	I confirm that I have read and understood the participant information sheet (Version X) for the above-named study.	
2.	I have had the opportunity to consider the information provided, ask questions and have had these answered satisfactorily.	
3.	I understand that my participation in this study is entirely voluntary and that I am free to withdraw from the study at any time without giving reason. If I choose to withdraw from the study there will be no adverse consequences.	
4.	I understand that my participation is anonymous and my responses will be recorded without any identifiable information.	
5.	I agreed to take part in the above study	

Name of Participant	Date	Signature

## APPENDIX P – PARTICIPANT DEBRIEF SHEET



Staff Skill Development  
Debrief Sheet version 1.0 (28/02/19)  
IRAS Project ID: 255921



Bwrdd Iechyd Prifysgol  
Hywel Dda  
University Health Board

### DEBRIEF SHEET

Project: Staff Skill Development in Supporting People with Dementia: A Delphi Study

Researcher: Katie Veale (Trainee Clinical Psychologist)

Thank you for taking part in this study. This debriefing sheet will give you an overview of the purpose of the study. Please take time to read this information and ask the researcher any questions you may have.

#### What were the aims of the study?

This research aimed to identify key factors that healthcare staff identified as helpful in developing skills, knowledge and confidence in working with people with dementia. It also explored any differences between those staff who have received more comprehensive dementia training compared to those that received only the basic mandatory training on dementia.

#### Why were there different questionnaires?

The first questionnaire was very broad to ensure participants could include any opinions or thoughts they had, without being restricted by the researcher. The responses to the first questionnaire were analysed and key themes drawn out. The second questionnaire asked participants to give more specific views on each factor. By analysing the results of the second questionnaire, participants were able to receive feedback about how their answers compared to other participants. The purpose of this method was to try to find a consensus between participants, key themes that the majority agreed upon.

#### What are the details about the other tasks completed?

1. Basic information about staff role, experience and training was gathered to explore if different professional experiences were related to any specific opinions.
2. The Knowledge in Dementia Scale (KIDE) measures levels of understanding in key aspects of Dementia.
3. The Confidence in Dementia Scale (CODE) explores how confident an individual is in working with people with Dementia.
4. The Culture of Care Barometer' (CoCB) is a measure of the organisational culture of your service.

### What are the research hypotheses?

This research hypothesized that there would be a range of factors, both personal (e.g. good communication skills) and professional (e.g. training) that healthcare staff would identify as important in putting the good work framework into practice.

It was hypothesized that the factors identified may be different depending on the level of experience a staff member had in working with people with Dementia.

### Data Protection

Cardiff University is the Sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the Data Controller for this study. This means that we are responsible for looking after your information and using it properly. Cardiff University will keep identifiable information about you for 15 years after the study has finished. The legal basis we will rely upon to collect and store your information is:

The NHS will collect information from you for this research study in accordance with our instructions. The NHS will keep your name, and contact details confidential and will not pass this information to Cardiff University. The NHS will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Cardiff University and regulatory organisations may look at your research records to check the accuracy of the research study. Cardiff University will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. The NHS will keep identifiable information about you from this study for 15 years after the end of the study.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you change your mind, you are free to withdraw from the research at any time. If you choose to leave the study, we will need to keep any data you have provided up until the point you chose to leave the study and it may be included in the final analysis. As is the case for all participants, you will not be identified in any publications or presentations about the study.

You can find out more about how we use your information at

<https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>

The University's Data Protection Officer can be contacted at:

[inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk)



### Relevant Reading

Here is a link to the Good Work Framework document:

[https://socialcare.wales/cms\\_assets/file-uploads/Good-Work-Dementia-Learning-And-Development-Framework.pdf](https://socialcare.wales/cms_assets/file-uploads/Good-Work-Dementia-Learning-And-Development-Framework.pdf)

### Research Findings

If you would like to be contacted with a summary of the research findings when completed, please email your request to Katie Veale ([vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk)).

### Prize Draw

If you entered the prize draw for £50 vouchers you will be contacted via the email address you provided if you win.

### Contact Details

If you would like any further information or have any queries please contact:

Researcher: Katie Veale (Trainee Clinical Psychologist)

Email: [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk)

Tel: 029 208 70582

Research Supervisor: Andrea Evans (Consultant Clinical Psychologist)

Email: [andrea.evans@wales.nhs.uk](mailto:andrea.evans@wales.nhs.uk)

Tel: 01437 773098

Research Supervisor: Jenny Moses (Academic Director/Clinical Psychologist)

Email: [jenny.moses@wales.nhs.uk](mailto:jenny.moses@wales.nhs.uk)

Tel: 029 208 70582

If you have any questions or queries relating to ethical issues and this study, please contact Cardiff University School or Psychology Ethic Committee:

School of Psychology Research Ethics Committee

Email: [psychethics@cardiff.ac.uk](mailto:psychethics@cardiff.ac.uk)

Tel: 029 2987 0360

**Thank you for taking the time to read this debrief sheet and to take part in this research.**

## APPENDIX Q – RESEARCH SUMMARY FOR STAKEHOLDERS



### RESEARCH SUMMARY

Project: Staff Skill Development in Supporting People with Dementia: A Delphi Study

Researcher: Katie Veale (Trainee Clinical Psychologist), [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk)

**Thank you for your interest in this study. This summary describes the study findings and rationale, research context, critical appraisal, clinical and theoretical implications, and opportunities for future research.**

#### STUDY RATIONALE AND FINDINGS

The prevalence of dementia in the UK is increasing and due to its complexity, those with a diagnosis often require support from paid caregivers. It is therefore important to explore how paid caregivers perceive their role in providing that care. This research used a systematic literature review and an empirical study to inform evidence-based practice of paid caregivers.

Informal caregiver attachments impact psychological, physical and social wellbeing for both caregiver and care-recipient. It is important to consider the role of attachment in paid caregiver relationships. The systematic literature search identified 12 articles for review. Narrative synthesis allowed a model to be developed of the factors and mechanisms influencing attachment relationships displayed by paid caregivers. This model is in keeping with existing theories of attachment, but remains tentative due to quality issues in the extant literature.

Policies guiding service provision for people with dementia are often lacking in theoretical and methodological rigour, and can be challenging to operationalise. Policy implementation, service development and staff training should be based in a robust evidence base. This empirical study aimed to inform practice by examining factors an expert panel perceive are important for dementia caregiving using a three round Delphi. An open-ended question generated themes that were rated by importance in subsequent rounds. Twenty-four key factors were grouped into four clusters in order of importance to the panel: 'Training and Work Environment'; 'Personal Characteristics'; 'Approach to Work' and 'Life Experience'. Three key factors reached consensus, 'Training', 'Patience' and 'Communication', and 12 reached agreement. The study has methodological limitations, including small sample size and definition of 'expert panel'.

#### RESEARCH CONTEXT

##### Service Provision and Direction

Scrutiny of current policy around dementia caregiving, highlights a lack of theoretical underpinnings and vague implementation recommendations, resulting in varying service provision across Welsh health boards. This research provided opportunity for health board specific recommendations to be made, drawing on empirical data provided by staff working in that region.

##### Research Governance

This project required coordination between university ethical approval systems, Health and Care Research Wales (HCRW) research processes and National Health Service research and development teams. Covid-19 and the resources and time required to navigate the rigorous ethical process, limited roll out of the project in other health boards and sectors, such as care homes.

### **Stakeholder Involvement**

This project arose from reflection on service needs during clinical placement within a community older people's psychology service. Older people's community mental health team colleagues, including senior managers, were consulted informally throughout project development. An author of the Good Work Framework, the policy at the heart of this research, was consulted to gain further understanding of the guidance and how best to focus research efforts. Consultation with the health board Dementia Training Coordinator also informed project development and aided recruitment. A criticism of this project is the lack of engagement with people with dementia and informal caregivers. Future research could explore service user perceptions of factors important for staff skill development.

## **CRITICAL APPRAISAL**

### **Strengths of Project and Methodology**

This systematic review is the first of its kind, filling a gap in the evidence-base. Whilst the literature is sparse, it has informed a tentative model, and has drawn attention to areas requiring more robust research.

The empirical study presents the views of front-line healthcare staff who are unlikely to have been directly involved in policy and training development, and whose perceptions would otherwise remain unknown. The Delphi method identified key consensus themes, with practical applications for service development, training provision, and recruitment. The local nature of the expert panel allows for health board specific recommendations.

### **Weakness of Project and Methodology**

The systematic literature review is limited by the lack of empirical research in this area, papers are scarce and of variable quality. The inclusion of papers using a range of methodologies may be criticised, but enabled a comprehensive synthesis, and ensured recommendations for future research were informed by critical appraisal of the evidence.

The empirical study encountered recruitment difficulties, with small sample size and relatively high attrition rates. Participants who remained engaged for the duration of the study may be subject to a self-selecting bias. Whilst the consensus of the expert panel is representative of their perceptions, it may not generalise to the wider service, other health boards in Wales, or other health and social care settings.

## **CLINICAL IMPLICATIONS**

Whilst acknowledging these caveats, the systematic review and empirical study results suggest the following areas are priorities for service provision: prioritising basic staffing conditions; developing effective training programmes with a practical element, tailored to individual needs of staff, protected time for peer support and supervision; a values-based recruitment approach that is weighted towards personal characteristics, rather than work experience or qualifications; maintaining a positive culture of care; fostering a work environment of continual learning, involving all relevant stakeholders; and being considerate of personal circumstance, promoting a healthy work life balance.

### THEORETICAL IMPLICATIONS

The systematic review described here exposed the lack of empirical research considering the dyad in attachment relationships between paid caregivers and people with dementia. Attachment theory is relational by nature, and this omission in the literature limits the application of theory to practice. Some consideration has been given to the informal caregiver and person with dementia dyads (Nelis, Clare, & Whitaker, 2012), which sets a precedent on which to build. In addition to developing an understanding of these attachment relationships, it is necessary to identify avenues for intervention, if we are to mitigate any challenges to effective care provision that arise from difficulties in attachment relationships. Such interventions have already been evaluated in other care sectors, including intellectual disabilities (Schuengel, Kef, Damen, & Worm, 2010).

The systematic literature review and empirical papers both make reference to the importance of meeting basic human needs, if positive working relationships between care-giver and care-recipient are to be formed. Maslow's hierarchy of needs model (Maslow, 1958) suggests needs at the foundation of the hierarchy (such as shelter and safety) must be satisfied in order for more complex human processes (such as relationships and creativity) to occur. This model lends itself to relational applications in considering the needs of people with dementia and their caregivers. For example, unmet needs for security by a person with dementia experiencing confusion, or of a care home employee working long shifts without breaks, have implications for reciprocity in caregiver and recipient relationships. Maslow's hierarchy would predict that both these individuals will struggle to enter a meaningful relationship, to feel a sense of belonging, self-esteem or achievement, until their basic needs are met. These basic needs, of staff and service users, should therefore be a priority for service provision.

The empirical results showed paid caregivers' openness to forming attachments with people with dementia. The premise of the theory of planned behaviour (TPB) are that actions are derived from intentions and attitudes, and are influenced by perceived behavioural control (PBC) and subjective norms (or social pressures; Azjen, 1991). Whilst this empirical study identified individual factors relevant for skill development, such as various personal characteristics and work/life experiences; there are systemic factors that will need to be in place for these perceptions to be translated into action of healthcare staff. At an organisational level, staff will need to have resources made available to them in order to hold some perceived behavioural control and the working cultural must also reward the desired behaviours. Moreover, for development of skill in working with people with dementia, people with dementia need to be valued within society and responsibility for their care, support and wellbeing, held at a community level. This societal level action is in keeping with theories of community psychology (Dalton, Hill, Thomas, & Kloos, 2013); which would also highlight the role of the community in meeting Maslow's basic human needs and addressing inequalities, rather than placing responsibility on individuals to meet their own needs.

### OPPORTUNITIES FOR FUTURE RESEARCH

Research should be completed with paid caregivers, systematically exploring their attachment styles, the impact on care provision, and on efficacy of care for people with dementia. Research with dyads of caregiver and client may provide insightful evidence on the reciprocity of attachment relationships. In a society ever

more reliant on paid caregivers to maintain the quality of life for people with dementia, these areas of research are essential.

To build on the findings of the empirical study, further research could involve replication in other health boards, or taking an "All Wales" approach given the potential to upscale Delphi methodology and as the workforce moves online.

**Thank you for taking the time to read this research summary and for expressing an interest in this research.**

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## Part 1: Staff Skill Development

### Welcome to this study!

This research project explores the views of healthcare staff on putting into practice a framework called the Good Work. This framework aims to ensure people with dementia who access healthcare services receive the care and support they need.

You have been invited to participate as you are currently working in healthcare services and we are interested in your thoughts about this.

You should have received a copy of the participant information sheet, which contains more detailed information about this study. If you have not read the participant information sheet please click the link below to access this.

[Participant information sheet v1.1](#)

If you have any questions about the study please contact **vealek@cardiff.ac.uk**.

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If you consent to participate in the study and have read the information sheet, please consider the statements below. If you agree with the statements, please place a tick next to each statement.

	If you agree, please tick.
I confirm that I have read and understood the participant information sheet (Version 1.1) for the above-named study. (1)	<input type="checkbox"/>
I have had the opportunity to consider the information provided, ask questions and have had these answered satisfactorily. (2)	<input type="checkbox"/>
I understand that my participation in this study is entirely voluntary and that I am free to withdraw from the study at any time without giving reason. If I chose to withdraw from the study there will be no adverse consequences. (3)	<input type="checkbox"/>
I understand that my participation is anonymous and my responses will be recorded without any identifiable information. (4)	<input type="checkbox"/>
I agreed to take part in the above study. (5)	<input type="checkbox"/>

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Please enter the email address you prefer to be contacted on:

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If you give your consent to participate please move on to the next page to access the questionnaires.

You will now have access to four questionnaires, this may take 30 minutes to complete.

How do you identify your gender?

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What is your age group?

- 18-20 (1)
- 21-29 (2)
- 30-39 (3)
- 40-49 (4)
- 50-59 (5)
- 60-64 (6)
- 65+ (7)

Which of the following best describes your staff group?

- Registered nursing and health visiting staff (1)
- Healthcare assistant/support worker (2)
- Allied health professional including Occupational Therapist, Physiotherapist, Speech and Language Therapist, Dietician etc. (3)
- Medical, including dental (4)
- Other (5)



How many years' experience do you have in this role?

- Less than 1 year (1)
- 1-4 years (2)
- 5-9 years (3)
- 10+ years (4)

What are your working hours?

- Full-time (1)
- Part-time (2)

In your current role, how frequently do you work with people with dementia?

- Daily (1)
- Weekly (2)
- Monthly (3)
- Less than monthly (4)
- Never (5)

When did you complete your most recent training in working with people with dementia?

- Within the last year (1)
- Between 1 and 3 years ago (2)
- Over 3 years ago (3)

What training have you received in working with people with dementia?

Please describe and include estimated year the training was completed.

*e.g. mandatory e-learning, classroom-based training etc.*

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Do you feel you have received adequate training for your needs and the demands of your role?

- Yes (1)
- No (2)

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The Good Work Framework is a document aiming to support health and social care professionals to meet the needs of people with dementia. It identifies 3 levels of competence when working with people with dementia:

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1. **INFORMED:** INFORMED people understand what dementia is and how it affects a person with dementia and those around them (e.g. family, friends, carers). They also understand how to communicate effectively with the people with dementia and those around them.

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2. **SKILLED:** SKILLED people are INFORMED but have also developed more detailed and comprehensive knowledge and skills across a range of key learning and development topics. For example: They have an understanding of factors that can prevent or delay dementia onset They are aware of the local services to support people with dementia and those around them They know about different kinds of dementia and their impact They are able to identify the skills and strengths of individuals with dementia They understand the sensory needs that a person with dementia may have They are able to interpret what may be seen as “behaviour that challenges”

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3. **INFLUENCER:** INFLUENCERS are people who are INFORMED, possibly SKILLED and who also have a management, leadership and/or strategic role. This leadership role is in relation to dementia and the services, policies and practices which are relevant to people with dementia. It is not just managers who can be leaders, this can apply to anyone who is able to inspire, lead or influence others.

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Do you feel you are currently working at and INFORMED or SKILLED level when working with people with dementia?

- INFORMED (1)
  - SKILLED (2)
  - Neither (3)
- 

Do you feel you are working at an INFLUENCER level?

- YES (1)
  - NO (2)
- 

Which of these 3 levels do you think is required for your role?

- INFORMED (1)
  - SKILLED (2)
  - INFLUENCER (3)
- 

In your opinion, how can a healthcare profession become **INFORMED** and then develop to a **SKILLED** level when working with people with dementia?

Please include as much detail and as many examples as possible.

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Thank you for completing these questionnaires about your role and for sharing your views on supporting healthcare staff to work in line with the Good Work Framework.

**You have completed the first part of the study.  
Please click the button below to submit your answers.**

The information gathered in this part will now be analysed and any key themes identified. In the second part of this study these themes will be shared with you and you will be asked how much you agree or disagree with each identified theme.

A link to the next questionnaire will be emailed to you when all the participants have been completed this first part.

Once all parts of the study are complete, you will be invited to enter a prize draw for the chance to **win £50** of vouchers.

If you have any queries or concerns please contact [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk). Contact details for other researchers involved in this project are also available in the participant information sheet.

**Thank you for taking the time to take part in this study, your participation is really valued.**

End of Block: Default Question Block

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## APPENDIX S – DELPHI ROUND II QUESTIONNAIRE

# Part 2: Staff Skill Development

**Thank you for returning to participate in the second part of this study.**

During the first part you provided some information about your role and were given some brief information about the Good Work Framework. You were invited to share your views about how staff could be supported to implement this.

The data from the first part has now been analysed and key themes have been identified. In this second part of the study you will be asked how much you agree or disagree with each of the key themes.

Please refer to the participant information sheet for a more detailed description of the study.

[Participant information sheet v1.1](#)

**If you have read the information sheet and consent to continue participating in the study please move on to the next page to access the questionnaire.**

Please enter the email address you prefer to be contacted on:

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In the last online survey, we asked:

In your opinion, how can a healthcare profession become **INFORMED** and then develop to a **SKILLED** level when working with people with dementia?

A summary of the Good Work Framework levels are below:

The Good Work Framework is a document aiming to support health and social care professionals to meet the needs of people with dementia. It identifies 3 levels of competence when working with people with dementia:

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**1. INFORMED:** INFORMED people understand what dementia is and how it affects a person with dementia and those around them (e.g. family, friends, carers). They also understand how to communicate effectively with the people with dementia and those around them.

---

**2. SKILLED:** SKILLED people are INFORMED but have also developed more detailed and comprehensive knowledge and skills across a range of key learning and development topics. For example: They have an understanding of factors that can prevent or delay dementia onset They are aware of the local services to support people with dementia and those around them They know about different kinds of dementia and their impact They are able to identify the skills and strengths of individuals with dementia They understand the sensory needs that a person with dementia may have They are able to interpret what may be seen as “behaviour that challenges”

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**3. INFLUENCER:** INFLUENCERS are people who are INFORMED, possibly SKILLED and who also have a management, leadership and/or strategic role. This leadership role is in relation to dementia and the services, policies and practices which are relevant to people with dementia. It is not just managers who can be leaders, this can apply to anyone who is able to inspire, lead or influence others.

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The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia.

Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Training - In order to develop skill in working with people with dementia, staff need regular training opportunities. Training should include information about types of dementia, the impact of dementia, supporting individuals and their families and end of life care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Practical Workshops - In order to develop skill in working with people with dementia, staff need practical workshops. Training delivered in a face-to-face way, based on real life examples, with opportunities to practice skills.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Awareness of Latest Research and Service Developments - In order to develop skill in working with people with dementia, staff need to be aware of the latest research and updates within services. Staff need to feel informed about developments and changes in good practice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Peer Support - In order to develop skill in working with people with dementia, staff need peer support. A coordinated network of colleagues with a range of skills, approaches and experience, to share difficulties with, get support, learn from and problem solve with.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Supervision and Management Support-In order to develop skill in working with people with dementia, staff need supervision and management support. Regular supervision to reflect on current practice and consider ways to develop skills and knowledge. Support from senior management to access training when needed and to implement learning in practice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Coordinated Services - In order to develop skill in working with people with dementia, staff need coordinated services. Multi-disciplinary working, regular reviews or case discussions, links between relevant services, with appropriate information sharing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Person-Centred Care - In order to develop skill in working with people with dementia, staff need to work in a person-centred way. Respecting individuality rather than focusing on deficits, supporting people with dementia to live a life meaningful to them, investing time in the person with dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Communication - In order to develop skill in working with people with dementia, staff need to communicate well. Being thoughtful about how you say something, about language, and non-verbal communication, both with the person with dementia, their loved ones and other professionals involved. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Reflective and Willing to Learn - In order to develop skill in working with people with dementia, staff need to reflect on their practice and be willing to learn. Recognising there are always opportunities to develop practice, showing interest in learning from others, flexibility with approach to work, engaging in training opportunities. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break



The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Empathy - In order to develop skill in working with people with dementia, staff need empathy. The ability to understand and share in the emotional experience of others. (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

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The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Compassion - In order to develop skill in working with people with dementia, staff need compassion. Understanding the challenges of others and working to alleviate suffering.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Patience - In order to develop skill in working with people with dementia, staff need patience. The ability to wait, or to continue doing something despite difficulties.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 Page Break \_\_\_\_\_

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Level of Work Experience - In order to develop skill in working with people with dementia, staff need experience in the job. To have worked with people with dementia for some time, learning "on the job".	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Support of Friends and Family - In order to develop skill in working with people with dementia, staff need the support of their family and friends. A supportive home environment, with family and friends that are understanding of the demands of the role.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Learning from Care Partners - In order to develop skill in working with people with dementia, staff need to learn from the care partners of people with dementia. Talking to the loved ones of the person with dementia, understanding their experience and learning about the individual from those close to them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Challenging Experiences in Work - In order to develop skill in working with people with dementia, staff need to have experienced challenging situations in work. Learning from difficult experiences within their role to develop practice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Work Life Balance and Coping Strategies-In order to develop skill in working with people with dementia, staff need effective coping strategies. Ways the staff member can cope with the challenges of the role e.g. good work life balance, de-stressing techniques.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break



The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Sense of Humour - In order to develop skill in working with people with dementia, staff need a sense of humour. Ability to see the funny or enjoyable side of situations that might be difficult.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Enjoying the Work - In order to develop skill in working with people with dementia, staff need to enjoy the work. Finding working with people with dementia and their care partners rewarding.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Skills Assessment - In order to develop skill in working with people with dementia, staff need to have their skills assessed. A period of assessment following their training to ensure that what has been learnt is being appropriately applied to practice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Resilience - In order to develop skill in working with people with dementia, staff need resilience. The ability to recover from or adapt to challenging circumstances.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Confidence - In order to develop skill in working with people with dementia, staff need confidence. Trusting in their abilities to support people with dementia.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Personal Experience Supporting a Person with Dementia - In order to develop skill in working with people with dementia, staff need personal experience supporting a person with dementia. Experience of a close friend or family member who has/had a dementia diagnosis.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Page Break

The responses from the first survey identified some key factors. These are the factors that participants felt are important for developing skill in working with people with dementia. Please tick the option you feel best describes your views on the level of importance of each statement.

	Very Important (1)	Important (2)	Neutral (3)	Low Importance (4)	Not at all Important (5)
Sense of Responsibility for Work-In order to develop skill in working with people with dementia, staff need a sense of responsibility for their work. Seeking out learning and development opportunities, with a diligent approach to work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Page Break

The key factors you have just rated have been grouped into 4 clusters:

**Training and Work Environment**

- Including: Training; Practical Workshops; Peer Support; Supervision and Management Support; Coordinated Services; Challenging Experiences in Work; and Skills Assessment.

**Personal Characteristics**

- Including: Resilience; Sense of Humour; Empathy; Compassion; Patience; Confidence.

**Approach to Work**

- Including: Respect and Person-Centred Care; Reflective and Willing to Learn; Learning from Care Partners; Enjoying the Work; Sense of Responsibility for Work and Diligence; Communication; and Awareness of Latest Research and Service Developments.

**Life Experience**

- Including: Level of Work Experience; Support of Friends and Family; Work Life Balance and Coping Strategies; and Personal Experience Supporting a Person with Dementia.

Please can you rank order the clusters from most to least important. Drag and drop each of the statements to put them in order, with the most important cluster ranked as 1 and the least important ranked as 4.

- \_\_\_\_\_ Training and Work Environment
- \_\_\_\_\_ Personal Characteristics
- \_\_\_\_\_ Approach to Work
- \_\_\_\_\_ Life Experience

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Page Break \_\_\_\_\_



Thank you for completing this questionnaire and sharing your views about the Good Work Framework.

**You have now completed the second part of the study.**

Please click the button below to submit your answers.

The information gathered in this part will now be analysed and in the third part of the study you will see a summary of how much other participants agreed or disagreed with each statement.

A link to the next questionnaire will be emailed to you when the data from this second part has been analysed.

After you complete the next part of the study you will be invited to enter a prize draw for the chance to **win £50** of vouchers.

If you have any queries or concerns please contact [vealek@cardiff.ac.uk](mailto:vealek@cardiff.ac.uk). Contact details for other researchers involved in this project are also available in the participant information sheet.

**Thank you for taking the time to take part in this study, your participation is really valued.**

End of Block: Default Question Block

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## Part 3: Staff Skill Development

**Thank you for returning to participate in the third and final part of this study.**

During the second part you were asked to rate the importance of each of the key factors identified from the first round. The key factors were grouped into clusters and we also asked you to rank order the clusters from most important to least important

The data from the second part has been analysed; we now have figures for how important each key factor was for participants and how participants rank ordered the clusters.

In this final part of the study you will be given the feedback on how participants, in general, felt about each theme. Given this new information about how other participants responded, you will have the opportunity to change your own responses, or keep them the same.

You will also be asked to complete some other questionnaires about your confidence in working with people with dementia, your understanding of dementia and information about the culture of the environment you are working in.

Please refer to the participant information sheet for a more detailed description of the study.

[Participant information sheet v1.1](#)

**If you have read the information sheet and consent to continue participating in the study please move on to the next page to access the questionnaire.**

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Page Break

Please enter the email address you prefer to be contacted on:

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In the first online survey, we asked:

In your opinion, how can a healthcare profession become **INFORMED** and then develop to a **SKILLED** level when working with people with dementia?

You might want to consider the following questions to help you answer:

- What training might a member of staff require?
- What personal qualities might a member of staff have?
- What support in the environment (work or home) might they need?
- What might motivate or trigger a member of staff to develop their skills?

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A summary of the Good Work Framework levels are below:

The Good Work Framework is a document aiming to support health and social care professionals to meet the needs of people with dementia. It identifies 3 levels of competence when working with people with dementia:

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1. **INFORMED:** INFORMED people understand what dementia is and how it affects a person with dementia and those around them (e.g. family, friends, carers). They also understand how to communicate effectively with the people with dementia and those around them.

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2. **SKILLED:** SKILLED people are INFORMED but have also developed more detailed and comprehensive knowledge and skills across a range of key learning and development topics. For example: They have an understanding of factors that can prevent or delay dementia onset They are aware of the local services to support people with dementia and those around them They know about different kinds of dementia and their impact They are able to identify the skills and strengths of individuals with dementia They understand the sensory needs that a person with dementia may have They are able to interpret what may be seen as “behaviour that challenges”

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3. **INFLUENCER:** INFLUENCERS are people who are INFORMED, possibly SKILLED and who also have a management, leadership and/or strategic role. This leadership role is in relation to dementia and the services, policies and practices which are relevant to people with dementia. It is not just managers who can be leaders, this can apply to anyone who is able to inspire, lead or influence others.

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The responses from the first survey identified some key factors for developing skill in working with people with dementia. In the second survey you gave your views on the importance of each factor.

Thank you for sharing your views, below is a reminder of you answers from the last survey. We have also included a summary of the responses of the other participants.

You may want to think about your answer now you are aware of the views of others. If you wish to change your response, please select your new response below. Changing your answer is optional, if you wish to keep your answer the same, leave the new response option blank.

**Key Factor 1: Training**

In order to develop skill in working with people with dementia, staff need regular training opportunities. Training should include information about types of dementia, the impact of dementia, supporting individual and their families and end of life care.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	100%	0%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 1: Training

In order to develop skill in working with people with dementia, staff need regular training opportunities. Training should include information about types of dementia, the impact of dementia, supporting individual and their families and end of life care.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

**Key Factor 2: Practical Workshops**

In order to develop skill in working with people with dementia, staff need practical workshops. Training delivered in a face-to-face way, based on real life examples, with opportunities to practice skills.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	72.73%	27.27%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 2: Practical Workshops**

In order to develop skill in working with people with dementia, staff need practical workshops. Training delivered in a face-to-face way, based on real life examples, with opportunities to practice skills.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 3: Awareness of Latest Research and Service Developments**

In order to develop skill in working with people with dementia, staff need to be aware of the latest research and updates within services. Staff need to feel informed about developments and changes in good practice.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	54.56%	45.45%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 3: Awareness of Latest Research and Service Developments**

In order to develop skill in working with people with dementia, staff need to be aware of the latest research and updates within services. Staff need to feel informed about developments and changes in good practice.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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**Key Factor 4: Peer Support**

In order to develop skill in working with people with dementia, staff need peer support. A coordinated network of colleagues with a range of skills, approaches and experience, to share difficulties with, get support and learn from and problem solve with.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	63.64%	36.36%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 4: Peer Support**

In order to develop skill in working with people with dementia, staff need peer support. A coordinated network of colleagues with a range of skills, approaches and experience, to share difficulties with, get support and learn from and problem solve with.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

### Key Factor 5: Supervision and Management Support

In order to develop skill in working with people with dementia, staff need supervision and management support. Regular supervision to reflect on current practice and consider ways to develop skills and knowledge. Support from senior management to access training when needed and to implement learning in practice.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	63.64%	36.36%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 5: Supervision and Management Support

In order to develop skill in working with people with dementia, staff need supervision and management support. Regular supervision to reflect on current practice and consider ways to develop skills and knowledge. Support from senior management to access training when needed and to implement learning in practice.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break



**Key Factor 6: Coordinated Services**

In order to develop skill in working with people with dementia, staff need coordinated services. Multi-disciplinary working, regular reviews or case discussions, links between relevant services, with appropriate information sharing.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	45.45%	45.45%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 6: Coordinated Services

In order to develop skill in working with people with dementia, staff need coordinated services. Multi-disciplinary working, regular reviews or case discussions, links between relevant services, with appropriate information sharing.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 7: Person-Centred Care**

In order to develop skill in working with people with dementia, staff need to work in a person-centred way. Respecting individuality rather than focusing on deficits, supporting people with dementia to live a life meaningful to them, investing time in the person with dementia.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	72.73%	18.18%	9.09%	0%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 7: Person-Centred Care**

In order to develop skill in working with people with dementia, staff need to work in a person-centred way. Respecting individuality rather than focusing on deficits, supporting people with dementia to live a life meaningful to them, investing time in the person with dementia.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 8: Communication**

In order to develop skill in working with people with dementia, staff need to communicate well. Being thoughtful about how you say something, about language, and non-verbal communication, both with the person with dementia, their loved ones and other professionals involved.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	100%	0%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 8: Communication

In order to develop skill in working with people with dementia, staff need to communicate well. Being thoughtful about how you say something, about language, and non-verbal communication, both with the person with dementia, their loved ones and other professionals involved.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break \_\_\_\_\_

**Key Factor 9: Reflective and Willing to Learn**

In order to develop skill in working with people with dementia, staff need to reflect on their practice and be willing to learn. Recognising there are always opportunities to develop practice, showing interest in learning from others, flexibility with approach to work, engaging in training opportunities.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	81.82%	18.18%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 9: Reflective and Willing to Learn

In order to develop skill in working with people with dementia, staff need to reflect on their practice and be willing to learn. Recognising there are always opportunities to develop practice, showing interest in learning from others, flexibility with approach to work, engaging in training opportunities.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 10: Empathy**

In order to develop skill in working with people with dementia, staff need empathy. The ability to understand and share in the emotional experience of others.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	90.91%	9.09%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 10: Empathy

In order to develop skill in working with people with dementia, staff need empathy. The ability to understand and share in the emotional experience of others.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 11: Compassion**

In order to develop skill in working with people with dementia, staff need compassion.  
Understanding the challenges of others and working to alleviate suffering.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	90.91%	9.09%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 11: Compassion

In order to develop skill in working with people with dementia, staff need compassion.  
Understanding the challenges of others and working to alleviate suffering.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 12: Patience**

In order to develop skill in working with people with dementia, staff need patience. The ability to wait, or to continue doing something despite difficulties.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	100%	0%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 12: Patience

In order to develop skill in working with people with dementia, staff need patience. The ability to wait, or to continue doing something despite difficulties.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 13: Level of Work Experience**

In order to develop skill in working with people with dementia, staff need experience in the job. To have worked with people with dementia for some time, learning "on the job".

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	54.56%	36.36%	9.09%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 13: Level of Work Experience

In order to develop skill in working with people with dementia, staff need experience in the job. To have worked with people with dementia for some time, learning "on the job".

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break



**Key Factor 14: Support of Friends and Family**

In order to develop skill in working with people with dementia, staff need the support of their family and friends. A supportive home environment, with family and friends that are understanding of the demands of the role.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	9.09%	72.73%	18.18%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 14: Support of Friends and Family

In order to develop skill in working with people with dementia, staff need the support of their family and friends. A supportive home environment, with family and friends that are understanding of the demands of the role.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 15: Learning from Care Partners**

In order to develop skill in working with people with dementia, staff need to learn from the care partners of people with dementia. Talking to the loved ones of the person with dementia, understanding their experience and learning about the individual from those close to them.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	72.73%	27.27%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 15: Learning from Care Partners**

In order to develop skill in working with people with dementia, staff need to learn from the care partners of people with dementia. Talking to the loved ones of the person with dementia, understanding their experience and learning about the individual from those close to them.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break \_\_\_\_\_

**Key Factor 16: Challenging Experiences in Work**

In order to develop skill in working with people with dementia, staff need to have experienced challenging situations in work. Learning from difficult experiences within their role to develop practice.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	54.56%	36.36%	9.09%	0%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 16: Challenging Experiences in Work**

In order to develop skill in working with people with dementia, staff need to have experienced challenging situations in work. Learning from difficult experiences within their role to develop practice.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 17: Work Life Balance and Coping Strategies**

In order to develop skill in working with people with dementia, staff need effective coping strategies. Ways the staff member can cope with the challenges of the role e.g. good work life balance, de-stressing techniques.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	45.45%	54.56%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 17: Work Life Balance and Coping Strategies**

In order to develop skill in working with people with dementia, staff need effective coping strategies. Ways the staff member can cope with the challenges of the role e.g. good work life balance, de-stressing techniques.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break \_\_\_\_\_

**Key Factor 18: Sense of Humour**

In order to develop skill in working with people with dementia, staff need a sense of humour. Ability to see the funny or enjoyable side of situations that might be difficult.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	54.56%	36.36%	9.09%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 18: Sense of Humour

In order to develop skill in working with people with dementia, staff need a sense of humour. Ability to see the funny or enjoyable side of situations that might be difficult.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 19: Enjoying the Work**

In order to develop skill in working with people with dementia, staff need to enjoy the work. Finding working with people with dementia and their care partners rewarding.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	72.73%	27.27%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 19: Enjoying the Work

In order to develop skill in working with people with dementia, staff need to enjoy the work. Finding working with people with dementia and their care partners rewarding.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

### Key Factor 20: Skills Assessment

In order to develop skill in working with people with dementia, staff need to have their skills assessed. A period of assessment following their training to ensure that what has been learnt is being appropriately applied to practice.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	27.27%	36.36%	36.36%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 20: Skills Assessment

In order to develop skill in working with people with dementia, staff need to have their skills assessed. A period of assessment following their training to ensure that what has been learnt is being appropriately applied to practice.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 21: Resilience**

In order to develop skill in working with people with dementia, staff need resilience. The ability to recover from or adapt to challenging circumstances.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	72.73%	27.27%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 21: Resilience

In order to develop skill in working with people with dementia, staff need resilience. The ability to recover from or adapt to challenging circumstances.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break



**Key Factor 22: Confidence**

In order to develop skill in working with people with dementia, staff need confidence. Trusting in their abilities to support people with dementia.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	36.36%	63.64%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 22: Confidence

In order to develop skill in working with people with dementia, staff need confidence. Trusting in their abilities to support people with dementia.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 23: Personal Experience Supporting a Person with Dementia**

In order to develop skill in working with people with dementia, staff need personal experience supporting a person with dementia. Experience of a close friend or family member who has/had a dementia diagnosis.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	9.09%	18.18%	36.36%	36.36%	0%
<b>Your Response</b>					

New response (optional):

**Key Factor 23: Personal Experience Supporting a Person with Dementia**

In order to develop skill in working with people with dementia, staff need personal experience supporting a person with dementia. Experience of a close friend or family member who has/had a dementia diagnosis.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

**Key Factor 24: Sense of Responsibility for Work**

In order to develop skill in working with people with dementia, staff need a sense of responsibility for their work. Seeking out learning opportunities, with a diligent approach to work.

	<b>Very Important</b>	<b>Important</b>	<b>Neutral</b>	<b>Low Importance</b>	<b>Not at all Important</b>
<b>Overall Group Response (%)</b>	36.36%	62.64%	0%	0%	0%
<b>Your Response</b>					

New response (optional):

Key Factor 24: Sense of Responsibility for Work

In order to develop skill in working with people with dementia, staff need a sense of responsibility for their work. Seeking out learning opportunities, with a diligent approach to work.

- Very Important
- Important
- Neutral
- Low Importance
- Not at all Important

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Page Break

Thank you for reviewing your responses to the key factors identified in round two.

These key factors were grouped into 4 clusters:

**Training and Work Environment**

- Including: Training; Practical Workshops; Peer Support; Supervision and Management Support; Coordinated Services; Challenging Experiences in Work; and Skills Assessment.

**Personal Characteristics**

- Including: Resilience; Sense of Humour; Empathy; Compassion; Patience; and Confidence

**Approach to Work**

- Including: Person Centred Care; Reflective and Willing to Learn; Learning from Care Partners; Enjoying the Work; Sense of Responsibility for Work; Communication; and Awareness of Latest Research and Service Developments.

**Life Experience**

- Including: Level of Work Experience; Support of Friends and Family; Coping Strategies; and Personal Experience of Supporting a Person with Dementia.

You ranked these clusters from most to least important, with the most important cluster ranked as 1 and the least important ranked as 4.

Here are the figures for how participants in this study ranked the clusters. You may want to think about your answer now you are aware of the views of others. If you wish to change your response, please drag and drop each of the statements to put them in order. Changing your answer is optional, if you wish to keep your answer the same, please move on to the next page.

**Cluster Ranking**

	<b>Percentage of Participants that Ranked Most Important</b>	<b>Percentage of Participants that Ranked Second Most Important</b>	<b>Percentage of Participants that Ranked Third Most Important</b>	<b>Percentage of Participants that Ranked Forth Most Important</b>	<b>Your Response</b>
<b>Training and Work Environment</b>	72.73%	9.09%	18.18%	0%	
<b>Personal Characteristics</b>	18.18%	63.64%	18.18%	0%	
<b>Approach to Work</b>	9.09%	27.27%	63.64%	0%	
<b>Life Experience</b>	0%	0%	0%	100%	

New Response (optional):

Please can you rank order the clusters from most to least important. Drag and drop each of the statements to put them in order, with the most important cluster ranked as 1 and the least important ranked as 4.

\_\_\_\_\_ Training and Work Environment

\_\_\_\_\_ Personal Characteristics

\_\_\_\_\_ Approach to Work

\_\_\_\_\_ Life Experience

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Page Break

Thank you for reviewing the ranked order of the clusters.

There are now three short questionnaires about your confidence in working with people with dementia, your understanding of dementia and information about the culture of the environment you are working in.

**Confidence in Dementia Scale (CODE)**

Please rate each of the following statements:	Not able	Slightly able	Somewhat able	Able	Very able
I feel able to understand the needs of a person with dementia when they cannot communicate well verbally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to interact with a person with dementia when they cannot communicate well verbally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to manage situations when a person with dementia becomes agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to identify when a person may have a dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to gather relevant information to understand the needs of a person with dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to help a person with dementia feel safe during their stay in hospital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to work with people who have a diagnosis of dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to understand the needs of a person with dementia when they can communicate well verbally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel able to interact with a person with dementia when they can communicate well verbally	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Knowledge in Dementia Scale (KIDE)

Please state if you agree or disagree with each of the following statements:

	Agree	Disagree
Anger and hostility occur in dementia mostly because the "aggression" part of the brain has been affected	<input type="radio"/>	<input type="radio"/>
Dementia is a general term which refers to a number of different diseases	<input type="radio"/>	<input type="radio"/>
Dementia can be caused by a number of small strokes	<input type="radio"/>	<input type="radio"/>
People with dementia will eventually lose all their ability to communicate	<input type="radio"/>	<input type="radio"/>
A person with dementia's history and background play a significant part in their behaviour	<input type="radio"/>	<input type="radio"/>
A person with dementia is less likely to receive pain relief than a person without dementia when they are in hospital	<input type="radio"/>	<input type="radio"/>
People with dementia who are verbally aggressive nearly always become physically aggressive	<input type="radio"/>	<input type="radio"/>
When people with dementia walk around it is usually aimless	<input type="radio"/>	<input type="radio"/>
Permanent changes to the brain occur in most types of dementia	<input type="radio"/>	<input type="radio"/>
Brain damage is the only factor that is responsible for the way people with dementia behave	<input type="radio"/>	<input type="radio"/>
Physical pain may result in a person with dementia becoming aggressive or withdrawn	<input type="radio"/>	<input type="radio"/>
People who have dementia will usually show the same symptoms	<input type="radio"/>	<input type="radio"/>
Currently, most types of dementia cannot be cured	<input type="radio"/>	<input type="radio"/>
People with dementia never get depressed	<input type="radio"/>	<input type="radio"/>
My perception of reality may be different from that of a person with dementia	<input type="radio"/>	<input type="radio"/>
It is possible to catch dementia from other people	<input type="radio"/>	<input type="radio"/>

Culture of Care Barometer (CoCB)					
Please indicate the extent you agree with each of the following statements by ticking one box in each row:	Strongly disagree	Disagree	Neither	Agree	Strongly agree
I have the resources I need to do a good job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel respected by my co-workers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have sufficient time to do my job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am proud to work in this health board	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My line manager treats me with respect	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The health board values the service we provide	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I would recommend this health board as a good place to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel well supported by my line manager	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to influence the way things are done in my team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel part of a well-managed team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know who my line manager is	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unacceptable behaviour is consistently tackled	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is strong leadership at the highest level in the health board	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When things get difficult, I can rely on my colleagues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health board managers know how things really are	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



I feel able to ask for help when I need it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know exactly what is expected of me in my job	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel supported to develop my potential	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A positive culture is visible where I work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The people I work with are friendly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My line manager gives me constructive feedback	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staff successes are celebrated by the health board	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The health board listens to staff views	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get the training and development I need	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am able to influence how things are done in the health board	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The health board has a positive culture	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am kept well informed about what is going on in our team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have positive role models where I work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel well informed about what is happening in the health board	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My concerns are taken seriously by my line manager	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you for sharing your views about the Good Work Framework and for completing the questionnaires on your confidence and understanding of dementia, and the culture of your working environment.

**You have now completed all parts of the study.  
Please click the button below to submit your answers.**

As you have completed all parts of the study you are eligible to enter the prize draw to **win £50** of vouchers. If you wish to enter the draw, please leave your email address below and you will be contacted if you win.

If you have any queries or concerns, or would like to receive a summary of the findings of this research when complete, please contact **vealek@cardiff.ac.uk**. Contact details for other researchers involved in this project are also available in the participant information sheet.

**Thank you for taking the time to take part in this study, your participation is really valued.**

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To enter the prize draw for £50 vouchers, please leave your preferred email address below:

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End of Block: Default Question Block

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