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The Mental Health Nurse Experience of Providing Care for People with Delirium Superimposed on Dementia: Influences in an Activity System

Northumbria University
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The Mental Health Nurse Experience of Providing Care for People with Delirium Superimposed on Dementia: Influences in an Activity System

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fulfilment of
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Abstract

Background

People with severe dementia are frequently cared for by registered mental health nurses due to their often complex cognitive or psychological care needs. This may present challenges in practice due to the inter-relatedness of physical and mental health that accompanies dementia, not least the presentation of delirium superimposed on dementia (DSD).

This study aimed to explore and describe the experiences of mental health nurses who provide care for people with DSD. This will support better understanding of what influences or impacts their work.

Methodology and Methods

Using Activity Theory to guide the study throughout, a mixed methods exploratory sequential design was constructed. Semi structured interviews were undertaken to collect qualitative data, before a quantitative exploration through questionnaire development and completion. Data analysis was undertaken utilising framework analysis in the qualitative phase, and descriptive statistics in the quantitative phase. Integration of data was undertaken, and findings presented in an activity system graphic.

Participants were registered mental health nurses working in 24-hour care settings for people with dementia.

Findings

Five key themes emerged from the data: 1. For RNMHs to use tools (such as scores or guidelines), they need to see them as useful and contextually relevant. Whilst they are aware of tools, they may choose not to use them if they do not see the value in them. 2. Knowing the person for whom they provide care is central and personal. The RNMHs favour aesthetic ways of knowing and use this to guide their care provision. 3. Hierarchy within the multidisciplinary team remains, however this is not seen as a negative. The RNMHs feel supported and secure within their wider MDT. 4. Burdens of care felt by the RNMHs is driven by the care environment and care context. 6. There remains a disconnection of mental and physical health in both care environments and how the RNMHs see their role.

Conclusion

This study is the first to explore the complexities of specifically the mental health nurse context in relation to DSD. The novel application of Activity Theory as a lens offered a unique frame to support exploration of the mental health nurses working environments and experiences.

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Lastly, but no means least, I wish to thank Betty, I know you like to tell people what I am up to. You have driven me forward to completion: this is for you

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee on 22 March 2016

I declare that the Word Count of this Thesis is 75,619 words

Name: Claire Anne Pryor

Signature: C. Pryor

Date: 26/02/2021

1. Introduction and Background to the Study

This first chapter introduces the study and details its origins stemming from my own experience in practice as a registered nurse. The different fields of nursing within the UK, and the nature of delirium, dementia and delirium superimposed on dementia (DSD) are discussed as these are key to understanding the unique experience of the participants in this study. Following this, the research problem is presented alongside the research aims and objectives.

The chapter concludes with an overview of both the study and the thesis structure to offer signposting and direction to the reader.

1.1 Origins of the Study and Researcher Involvement

This study developed from my considerations of practice as a registered adult nurse (RNA), and nurse practitioner when working with older people in an inpatient organic[1] mental health assessment setting. My professional knowledge surrounding delirium, dementia and, latterly DSD, largely stemmed from my previous work in medical areas of nursing. These were predominantly medical assessment units, critical care, and intermediate care nursing services. Focussing more often on the physical elements of nursing, for me, my daily work revolved around the appropriate identification of underlying physical conditions and treatment provision. Whilst care was person centred, concerns regarding escalating mental or cognitive health needs were referred on to specialist services such as psychiatry or other mental health teams. Taking an older

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[1] The term 'organic' relates to conditions where there is a physical cause for an altered mental or cognitive state, such as dementia or brain injury. This term (alongside 'functional' mental health) has been the topic of much debate as classification of mental health disorders articulated by their physical or psychological precipitant perpetuates and intensifies the mind/body duality that practice is striving to move away from. The terms have been used here to most reflect the contextual boundaries and organisational structures at play at the time of this studies inception (and that persist in practice).

people's nurse practitioner post within a mental health National Health Service (NHS) Trust highlighted a different focus of care, one in which mental health and psychological considerations were the mainstay, and I was a supportive resource working to achieve balance in care provision.

During this time, I was involved in a study developing and evaluating a delirium early monitoring system (DEMS) (Rippon *et al.*, 2016). Through this work, there appeared variance between my own experiences and expectations of caring for someone with DSD, and that of the registered mental health nurses (RNMH)s. Whilst I focussed on exploring and unearthing physical reasons for delirium, such as exacerbations of medical conditions, constipation, and metabolic considerations, I was interested in the focus of RNMH care. It was apparent that they focussed on the psychological care of the patients, such as care planning for distressed behaviour, communication strategies and psychological support to a greater extent than myself; however, they frequently requested reviews for potential physical health concerns. It appeared that we could experience caring for someone with DSD in very different ways. I wondered what their experience was as a group of registrants and what impacted or influenced this experience.

Reviewing the guidance and literature available surrounding DSD such as the National Institute for Health and Care Excellence guidelines for dementia, and delirium (National Institute for Health and Care Excellence, 2010; 2018), it became apparent there was a disconnect between the two separate conditions of dementia and delirium. Being discussed as isolated subjects, I perceived a dominance of an acute care premise in the literature, rather than mental health or cognitive care. In addition, a combined focus or discussion of DSD as a simultaneous presentation appeared absent in terms of policy and guidance. This was concerning since in the clinical area where we worked, we often cared for people experiencing DSD. Adding to this, the mental health care setting, and the mental health nurse's voice appeared absent from both the scholarly and practice-based discourse. The above considerations of my own practice, that of the RNMHs around me, and the seemingly apparent dearth of literature pertaining to DSD as a combined presentation in the mental health setting, led me to question the RNMH experience when caring for people with such a complex condition.

1.2 Dementia, Delirium and Delirium Superimposed on Dementia

To understand the complex condition of DSD, it is paramount that the singular and combined conditions and care ethos' are presented to ensure clarity.

1.2.1 Dementia

In 2019, Whittenburg *et al.* (2019) in association with the Alzheimer's Society estimated that there were 885,000 older people[2] living with a diagnosed dementia in the UK. Of these 511,00 are classed as having severe dementia[3]. They predict that if current trends continued, there will be an increase of 80% in total cases of dementia (approximately 1.6 million people) by 2040, with an increase of 108% of severe cases of dementia in older people (approximately 1,066,000 cases) within the same time frame. This population represents a significant consideration in terms of health and social care provision; with cost projections increasing by 155% and 190% respectively.

Whilst dementia has many manifestations and clinical sub types depending on patient presentation, area of brain affected and underlying pathology, there is a

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[2] In this report 'older people' were over the age of 65

[3] Severe Dementia in this report is categorised by a Mini-Mental State Examination score of 0-10. The maximum score is 30.

consensus that dementia is on ongoing condition, caused by injury or disease to the brain that progresses over time (National Institute for Health and Care Excellence, 2006; World Health Organisation, 2016; National Institute for Health and Care Excellence, 2018).

Despite dementia being recognised and identified in terms of cognitive changes such as declining memory, reasoning ability and communication skills, dementia care has traditionally been situated within mental health services. This allocation of a cognitive disorder into the remit of psychiatry is due to a pervasive medicalised view of treatment: as the brain is seen to be the main organ associated with dementia, the treatment is categorised as psychological (Regan, 2016). It is recognised that only a few people living with dementia will require inpatient hospital care specifically for their dementia, with one third of people with dementia living in care homes (including residential care. and nursing homes with adult nurse provision). Hence older people with dementia requiring specialised care, for example for behavioural and psychological symptoms of dementia (BPSD[4]) or distressed behaviours[5], are often cared for by RNMHs in specialised mental health services. Inpatient services include mental health hospitals or care homes (previously called Elderly Mentally Infirm (EMI) care homes).

Whilst terms, and phrases used in relation to care delivery have evolved alongside the conceptual premise behind them, specifically for care provided to people with dementia the terminology and underpinning focus of care is of paramount importance. The traditional phrase *patient-centred care* holds

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[4] BPSD are noted to be non-cognitive symptoms of dementia, and a neuropsychiatric presentation which indicated the level of impairment and may include agitation, hallucinations, anxiety, irritability, delusions and hallucinations (to name a few)

[5] 'Distressed behaviours' have previously been termed challenging behaviour, or behaviours that challenge. However, these terms potentially convey negative connotations, and perpetuate an idea that the person presenting them is at fault (Perry, 2018).

connotations of making the life of a patient functional, whereas person-*centred care* is seen as the work of supporting a person to have a meaningful life (Eklund *et al.*, 2019). Grounded in the work of Kitwood (1990) who recognised that people with dementia were at risk of malignant social psychology; in which neurological and psychosocial elements of dementia impact upon and reduce their personhood, care for people with dementia should recognise that the person receiving care is more than the disease (Kitwood, 1997) and should encompass the person's experience of dementia, their neurological condition, personal health, their biography or life history, their personality and the manner in which they cope with adversity, the environment in which they are cared for and the social psychology of that environment (Kitwood, 1993; 1997; Clissette *et al.*, 2013).

Continuing in this vein, McCormack and McCance (2006) found prerequisites of person-centred care to include the attributes of the nursing staff themselves, the environment in which care occurs, the range of activities and the expected outcome.

Whilst well received, and placing emphasis on the creation of positive care environments, there is now concern that the term "person-centred care" has become a political tag line or buzz word (Dewing, 2004), losing the true engagement and validation behind its practice; becoming disjointed from its original vision.

An alternative to person-centred care is proposed by Nolan *et al.* (2004): shifting the focus of care provision, not away from the person for whom care is being provided, but outward, around them to include those who provide care and the relationships built here. Nolan *et al.* (2004) explored what drove care provision and gave sense and therapeutic direction to staff working in long term care provision. Formulating a route towards enhanced care environments for older people, the SENSES framework was devised (Nolan *et al.*, 2004). This not only considered the person in receipt of care, but included the staff and family carers, and held central the notion that all should be involved in relationships that offer them a sense of security, belonging, continuity, purpose, achievement and significance. Fostering positive relationship orientated care is proposed to positively impact across the care system and ultimately improve care outcomes.

As demonstrated above, person centred care (as demonstrated by McCormack and McCance (2006), and relationship-centred care as advocated for by Nolan *et al.* (2004) have similar focus on the positive interactions between the person for whom care is being provided, the person providing care, and the environment in which it takes place. More recently Brooker and Latham (2016) suggested a framework to be applied in practice settings to maintain a true person-centred approach. This framework: VIPS, supports organisations and care arenas to: *Value* all people irrespective of age or cognitive impairment, take an *Individualised* approach, offer a *Personalised* perspective and see the world of the person receiving care, and finally support appropriate *social* and environmental provision to attend to the persons psychological needs.

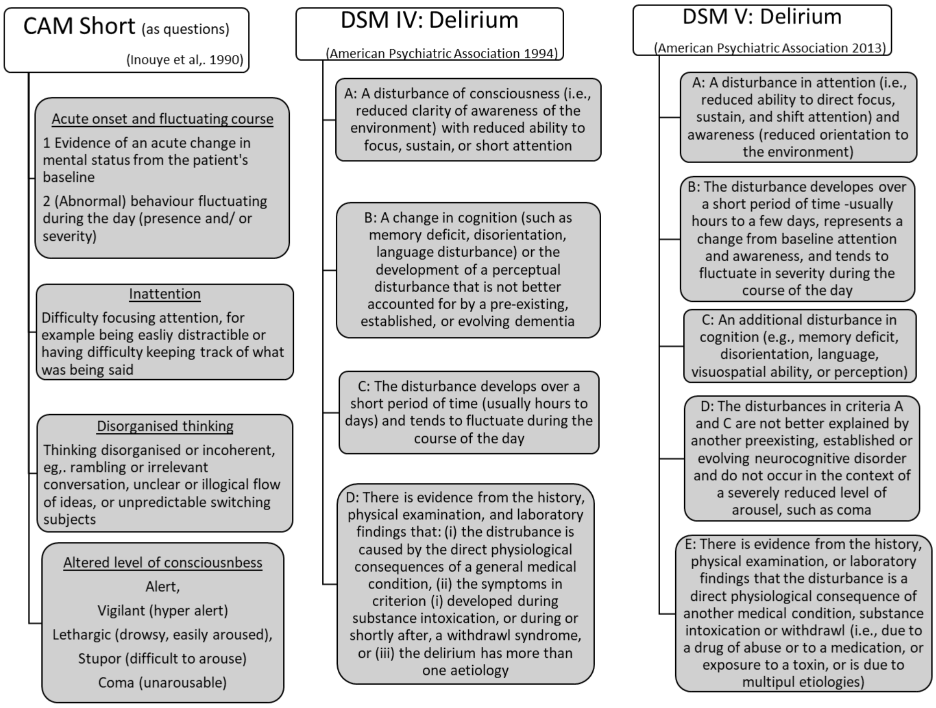
This demonstrates, that for people with dementia, practice is driving towards seeing the individual as a person interwoven in their care setting and as a social and valuable component of it, irrespective of terminology used.

1.2.2 **Delirium**

In contrast to dementia, delirium is often referred to as an acute confusional state and is not a disease. This presentation-based description highlights the episodes of fluctuating altered consciousness, perception and cognition which are seen with delirium. It is rapid in onset, represents global cognitive dysfunction, and as a syndrome, delirium demonstrates great complexity due to its generalised neural dysfunction in the absence of pathogonomic signs (National Institute for Health and Care Excellence, 2010; FitzGerald and Price, 2020; Francis and Young, 2020; Huang, 2020).

Current UK delirium guidance recommends formal diagnosis using the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM V) criteria (American Psychiatric Association, 2013), the short Confusional Assessment Method (CAM) (Inouye *et al.*, 1990) or CAM-ICU for people in a critical care or recovery setting (National Institute for Health and Care Excellence, 2010). The CAM recommendation highlights potentially limited terminology and conceptualisation of delirium referring to ‘consciousness’ as a singular entity, which has resulted with the European Delirium Association (2014) advocating the more recent definition and diagnostic criteria provided in DSM V which operationalises consciousness into components of awareness and attention (American Psychiatric Association, 2013).

Whilst the diagnostic criteria of CAM appear specific to mental health, and delirium is a mental disorder in terms of the Mental Health Act (Beales, 2002) which is indeed categorised as a mental disorder by the nature of its inclusion in the DSM, the DSM V offers a clear articulation that the change in mental state is directly attributed to a medical condition, medication, intoxication or withdrawal (American Psychiatric Association, 2013). Thus, delirium holds diagnostic components and presentations that straddle the traditional fields of practice. For people with delirium, their mental and physical health needs are inextricably linked, and should be cared for as such (Pryor and Clarke, 2017). The variance and evolution of historical diagnostic criteria for delirium are shown in Figure 1 page 8.



CAM Short (as questions)
(Inouye et al,. 1990)

Acute onset and fluctuating course
1 Evidence of an acute change in mental status from the patient's baseline
2 (Abnormal) behaviour fluctuating during the day (presence and/ or severity)

Inattention
Difficulty focusing attention, for example being easliy distractible or having difficulty keeping track of what was being said

Disorganised thinking
Thinking disorganised or incoherent, eg,. rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching subjects

Altered level of consciousnbess
Alert,
Vigilant (hyper alert)
Lethargic (drowsy, easily aroused),
Stupor (difficult to arouse)
Coma (unarousable)

DSM IV: Delirium
(American Psychiatric Association 1994)

A: A disturbance of consciousness (i.e., reduced clarity of awareness of the environment) with reduced ability to focus, sustain, or short attention

B: A change in cognition (such as memory deficit, disorientation, language disturbance) or the development of a perceptual disturbance that is not better accounted for by a pre-existing, established, or evolving dementia

C: The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day

D: There is evidence from the history, physical examination, and laboratory findings that: (i) the distrubance is caused by the direct physiological consequences of a general medical condition, (ii) the symptoms in criterion (i) developed during substance intoxication, or during or shortly after, a withdrawl syndrome, or (iii) the delirium has more than one aetiology

DSM V: Delirium
(American Psychiatric Association 2013)

A: A disturbance in attention (i.e., reduced ability to direct focus, sustain, and shift attention) and awareness (reduced orientation to the environment)

B: The disturbance developes over a short period of time -usually hours to a few days, represents a change from baseline attention and awareness, and tends to fluctuate in severity during the course of the day

C: An additional disturbance in cognition (e.g., memory deficit, disorientation, language, visuospatial ability, or perception)

D: The disturbances in criteria A and C are not better explained by another preexisting, established or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousel, such as coma

E: There is evidence from the history, physical examination, or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawl (i.e., due to a drug of abuse or to a medication, or exposure to a toxin, or is due to multipul etiologies)

Figure 1 Delirium Diagnostic Criteria Evolution

Beales (2002) discusses the dual nature of delirium in his rapid response to Brown and Boyle (2002) in which he raises the legal aspects of detaining people who have delirium, noting the complexity of this process in the absence of a psychiatrist and the use of the Mental Health Act. Beales concludes that *‘delirium is also the disorder that illustrates the folly of those who wish to create clear distinctions between physical and mental disorders: it is clearly both’* (Beales 2002: para. 5).

Unfortunately, delirium is prevalent in the older population, accounting for 96% of all cases (Royal College of Nursing, 2020). It is associated with poor prognosis (National Institute for Health and Care Excellence, 2010), and is considered to be potentially fatal (Kolanowski *et al.*, 2011a:b). It is, however, both preventable and treatable (National Institute for Health and Care Excellence, 2010). The precipitating and predisposing factors of delirium span all age groups, but become more common, and often more challenging in older adults. And whilst delirium is categorised as a mental health condition, it requires a significant amount of physical health assessment, treatment, and review as often complex physical processes underpin its manifestation. As such, in the older adult specifically, any acute change in, or fluctuation in cognition should be treated as a medical emergency and not attributed to dementia which it so often is (Wick and Zanni, 2010; Steis and Fick, 2012). Concerningly, there is recognition that an episode of delirium may increase the risk of subsequent dementia by up to 10% (Rockwood *et al.*, 1999; Davis *et al.*, 2012; Caplan *et al.*, 2020). With this in mind, if uncertainty is present regarding the nature of the presenting confusion, first line management and diagnostic considerations should be for potential delirium (National Institute for Health and Care Excellence, 2010; 2018).

1.2.3 **Delirium Superimposed on Dementia**

DSD occurs when a person with pre-existing dementia simultaneously has an episode of delirium (Fick *et al.*, 2007; Kolanowski *et al.*, 2011a;b, Morandi *et al.*, 2012; Morandi and Bellelli, 2020). DSD is often misdiagnosed or missed as both delirium and dementia present with global cognitive impairment, hindering an accurate diagnosis (Boettger, Passik and Breitbart, 2011). Concerningly, DSD is not unusual; its prevalence in community dwelling or hospitalised patients ranges from between 22-89% (Fick, Agostini and Inouye, 2002) and can persist for 3-6 months following initial presentation and, in some instances, up to one year (Jackson *et al.*, 2016; Apold, 2018).

The complexity for practice lies initially in that delirium and dementia (specifically Alzheimer’s dementia) are known to have similar pathological elements; including, decreased cerebral metabolism, presence of inflammatory response and reduction in cholinergic transmission (Eikelenboom and Hoogendijk, 1999). Sharing some metabolic, clinical and cellular processes (Inouye, 2006; Fong *et* *al.*, 2015), it is important to note that the exact etiology of DSD is, as yet not fully understood (Kolanowski *et al.*, 2011a). Often in those with dementia, the acute presentation of changes to cognition signifying delirium (and as such DSD) are overlooked (Fick and Foreman, 2000; Inouye *et al.*, 2001; Fick *et al.*, 2007; Morandi and Bellelli, 2020).

Delirium may be an early indicator or signal that there is a change in clinical condition, especially in people with dementia (Morandi *et al.*, 2012). Paramount to DSD care is early identification and recognition that delirium is a harbinger of deteriorating physical health. It is essential that once recognised, immediate comprehensive medical reviews are undertaken and appropriate supportive care is commenced (Fick and Foreman, 2000; Fick, Agostini and Inouye, 2002). The intertwining of DSD has started to gain recognition in recent years; however, key healthcare policy maintains a separation of the two conditions. This increased awareness, but failure to move past discussing the conditions in rigid silos is evidenced by the NHS Long term plan (NHS England, 2019). Here, an articulation of better support for people with dementia and delirium is given; however, the context of this discussion focusses solely on dementia and does not mention delirium past the initial headline title.

As with delirium in general, predominant underlying causes for DSD include dehydration, faecal impaction, pain, infection (Fick and Mion, 2008; Landreville, Voyer and Carmichael, 2013) malnutrition, medication or other acute illness (Landreville, Voyer and Carmichael, 2013). Nurses, irrespective of registration, play a central role in assessment, treatment, monitoring and review of such conditions and all nurses are in a privileged position to begin conversations with carers and relatives to establish a person's usual cognitive level, recognise signs of delirium and commence appropriate nursing interventions (Pryor and Clarke, 2017). However, what components of care are focussed on may stem from the nurse’s initial education and registration.

1.2.4 The History, Education and Registration of UK Nurses

The history and evolution of nurse education and registration is complex and cyclic, moving back and forth between favouring general and field specific approaches. Currently, in the UK there are four legally protected nursing titles which identify nurses’ field of practice. Each of these fields has a specific pathway of education and entry to the Nursing and Midwifery Council (NMC) register. The fields are: Adult (RNA)[6], Mental Health (RNMH), Learning Disability (RNLD) and Children’s Nurse (RNC) (Nursing and Midwifery Council, 2015; 2020). General nurse training (RGN) and registration ceased in the 1980s.

Nursing employment, post qualification education and clinical practice is guided by the registration of the nurse. As this study explores the RNMH experience, an understanding of mental health nursing evolution and professional place as a distinct field helps contextualise the study outside that of my own RNA background. As such, a brief history of mental health nursing is presented before focussing on the contemporary grounding of RNMHs in practice today.

The origins of mental health nursing are seen in the work of ‘keepers’, and ‘attendants’ in the often-overcrowded workhouses of the 19th century. The role of the keeper was to provide emotional and physical care for patients, but also to undertake heavy domestic duties (Smith, 1988). Following the introduction of the General Medical Council certificate of Psychological Medicine for doctors, training for attendants commenced, (Nolan, 1991). This training was overseen by

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[6] Registered Nurse is denoted by RN

the Medico-Psychological Association (MPA) and, in 1891, the ‘certificate of proficiency in nursing the insane’ was published and was established. Whilst training was favourable, its completion was not formally recognised or celebrated with reward for those undertaking it (Nolan, 1991).

Running in tandem to the changes in mental health training, the Royal British Nursing Association (RBNA) were considering state recognition for trained nurses. Tensions were high as general nursing representatives did not believe that those holding the MPA examination could be registered or called ‘nurses’, arguing that MPA education was not equivalent to general nurse training; specifically, as it focused on care of the ‘insane’ in asylums (Nolan, 1991).

In 1919, the Nurse Registration Act was passed along with the formation of General Nursing Council (GNC). Mental health nurses were admitted to a sub register only. The separation of mental health nursing from other registrations reflected a negative social evaluation of mental health nursing as an occupation; categorising both them, and their identify as flawed or inferior and amounted to the stigmatisation of mental health nurses (Grandy, 2008; Hudson and Okhuysen, 2014). This fostered a view of mental nurses as ‘second class nurses’; stigmatised themselves due to the nature of, and association of their work with mentally unwell people[7]. As such, they were perceived as morally and socially tainted by the nature of their profession (Ashforth and Kreiner, 1999).

In 1948, the isolation of mental health services was perpetuated in the creation of the NHS, with uncertainty around mental hospitals being included in the

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[7] Stigma, as described by Goffman (1963) as the discreditation of an individual or group due to an attribute. This leads them to be disqualified from being fully accepted in society.

service. In the event they were, albeit at a fairly latter stage of planning (Chatterton, 2012), but separated once again from acute general hospitals. In 1983, the then UK Central Council for Nursing, Midwifery and Health Visiting (UKCC), aligned formal fields of nursing registration with education provision which persists today (Thomas, 2016) (Figure 2). This balanced the nursing fields to allow all nurses to be registered at the same level whatever field of practice.

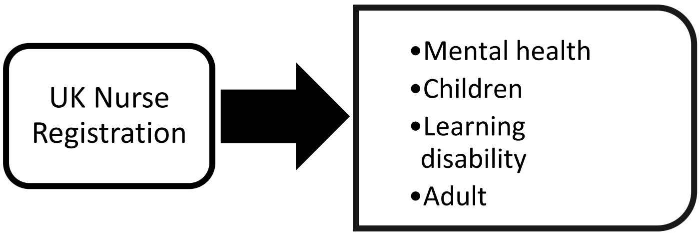


Figure 2 UK Nurse Registration Fields

Contemporary nurse education has evolved through a variety of common foundation components followed by field specific competence and proficiency assessment before nurses are admitted to the register (Nursing and Midwifery Council, 2004; 2010). The 2014 Standards for Competence for Registered Nurses (Nursing and Midwifery Council, 2014) maintained core facets of competence across all fields, in addition to field specific components. For adult nurses (for example) there were requirements to use diagnostics and technology for assessment, undertake invasive and non-invasive procedures, use medical devises, pharmaceutical interventions and assess and manage the acutely ill person at risk of clinical deterioration (or request emergency care). For mental health nurses, competence focussed upon; promoting, using, and building relationships that promoted social inclusion and recovery, supporting a meaningful and engaged life, facilitating therapeutic groups, and using interpersonal skills to support therapeutic disclosure and facilitate discussion of experience. The different components that each field could bring professionally to the patient were explicit.

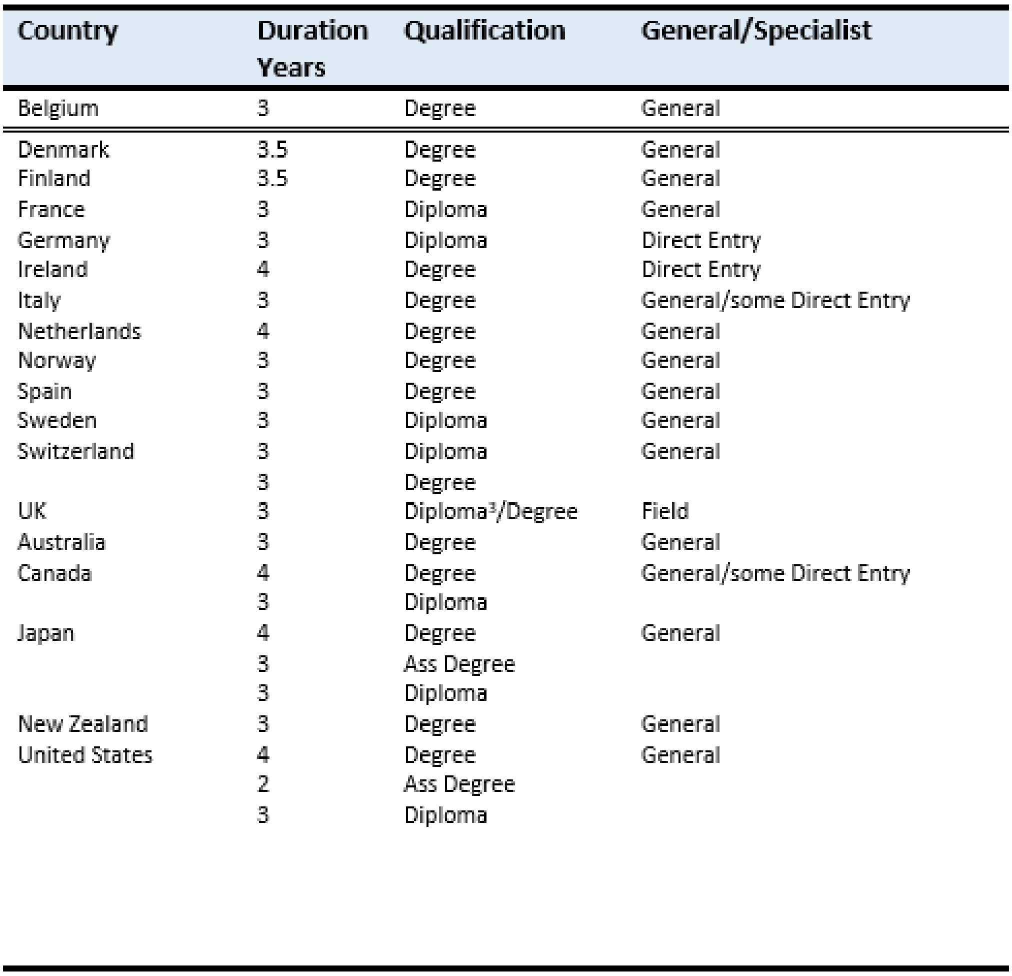
Currently, whilst registration of nurses in field specialities continues, the publication of the NMC Future Nurse: Standards of Proficiency for Registered Nurses (Nursing and Midwifery Council, 2018a) contain the same proficiencies for all fields. This approach aligns with Kings Fund (2016) assertion that healthcare professionals education needed to provide an adequate grounding in both mental and physical health, and is reported to allow for all nurses, irrespective of field, to be able to provide person centred, appropriate care across the life span, and include mental, physical, cognitive and behavioural health challenges (Nursing and Midwifery Council, 2018a). What forms the field specific education, is the depth that each proficiency is attended to by the educating organisation, leading to its attainment at a level appropriate to the field of registration.

Despite the changes in Pre-registration education, mental health nurse education maintains a focus on self-determination and recovery orientated care advocated by the (Nursing and Midwifery Council, 2010). This is now coupled with a more overt focus on RNMH’s being able to recognise and respond to physical health needs and long-term conditions (e.g. cognitive impairment) (Nursing and Midwifery Council, 2010). Today’s contemporary mental health practise utilises theories such as the Tidal model to achieve this. The Tidal model seeks to focus on personal recovery and reclamation of a person’s story (Barker and Buchanan-Barker, 2004). The onus of care is not placed on a ridged or defined process, but an adaptive one to build meaning socially, culturally, and personally. Such compassion-based care practises require intelligent kindness which centres on the relationship of empathy, sympathy, dignity and respect (Ramage, Ellis and

Marks-Maran, 2020) and form the mainstay of the RNMH care premise.

Situating this education and registration principle in a global context, it is apparent that the UK is unique in educating and registering nurses in single fields from the outset (see Table 1). Whilst most countries register nurses as general nurses, a few countries (e.g. Germany and Ireland) permit direct entry to specialism (such as general, paediatric or geriatric nursing) (Robinson and Griffiths, 2007). This places the UK health care system, and the RNMH in a unique, but possibly isolated, position.

Table 1 Nurse Registration by Country



Country	Duration Years	Qualification	General/Specialist
Belgium	3	Degree	General
Denmark	3.5	Degree	General
Finland	3.5	Degree	General
France	3	Diploma	General
Germany	3	Diploma	Direct Entry
Ireland	4	Degree	Direct Entry
Italy	3	Degree	General/some Direct Entry
Netherlands	4	Degree	General
Norway	3	Degree	General
Spain	3	Degree	General
Sweden	3	Diploma	General
Switzerland	3	Diploma	General
	3	Degree	
UK	3	Diploma[3]/Degree	Field
Australia	3	Degree	General
Canada	4	Degree	General/some Direct Entry
	3	Diploma	
Japan	4	Degree	General
	3	Ass Degree	
	3	Diploma	
New Zealand	3	Degree	General
United States	4	Degree	General
	2	Ass Degree	
	3	Diploma	

Table adapted from Robinson and Griffiths (2007)

1.2.4.1 **Parity of Esteem:**

As seen in the discussion of DSD and nurse registration, there is a complex intertwining of mental, physical, and cognitive health needs which often appear isolated. A key driver in contemporary healthcare is *parity of esteem*. This is defined by the Mental Health Foundation (2020) as valuing mental health equally with physical health. The concept of parity has become increasingly visible in policy and practice over the past decade. In 2011, the Department of Health placed the notion of whole person care once more at the centre of healthcare provision in their strategy entitled 'No health without mental health' (Department of Health, 2011). This aimed to mainstream mental health, started the parity drive across the lifespan and was followed by the inclusion of parity in The Health and Social Care Act (2012). Health Education England (2015) stipulated that all Pre-registration fields of nursing would provide parity; however, the parity drive is often situated in, and aligned to care provision for those people with the most serious mental health conditions (Royal College of Nursing, 2018). These are defined now as severe and enduring mental illness (SMI) and include bipolar disorder and schizophrenia (psychosis) (Public Health England, 2018), which excludes delirium and dementia. Nevertheless, if dementia is thought of in terms of mental health (as noted previously) it fits the definition of SMI as a psychological disorder; i.e. it is so debilitating that the persons' ability to engage in functional and occupational activities is severely impaired (Public Health England, 2018). Progressing the notion of parity of esteem, the Five-Year Forward View for Mental Health (Mental Health Taskforce, 2016) pays particular reference to care of older people; however, this is focussed on functional mental health needs such as depression and psychiatric liaison services in acute medical settings. More recently, the parity movement has broadened to be more inclusive of all mental health needs, although the focus on SMIs continues and, when considering specifically RNMHs and physical health care provision, they are found to be most confident in areas such as diet and exercise recommendations, and performing common physical health monitoring such as blood pressure monitoring, height and weight recording and smoking cessation advice (Robson *et al.*, 2013). Thus, these comfort levels and practice expectations bond SMIs to long-term physical health conditions (LTC) management and care. This physical LTC care assumption is perpetuated by the Royal College of Nursing (2019) who outlined 10 areas for physical health training and skills for mental health nurses: vital signs, infection prevention and control, pressure area care and venous thromboembolism, cardio-metabolic risk factors, motivational interviewing, nutrition and weight management, diabetes, smoking cessation, alcohol and substance misuse and health improvement and wellbeing.

Delirium or DSD may not manifest because of a stable LTC (diabetes, COPD etc) but more often as an acute exacerbation or new physical health need, requiring timely assessment, treatment, and intervention rather than ongoing monitoring. As such, whilst the parity drive has placed physical and mental healthcare provision at the fore of establishing a workforce equipped to care for physical and mental health per se, the onus on SMI and long-term conditions may not prepare mental health nurses for the acute presentation and care premise of DSD. Within the UK, there is an awareness that acute general hospital staff (predominantly focussing on physical health) are ill prepared to manage patients with confusion (most commonly associated with dementia or delirium, or DSD) (Department of Health, 2007a,b; Alzheimer's Society, 2009; Department of Health, 2009; National Audit Office, 2010), and often seek support from mental health colleagues or request transfers to mental health settings. This though, in the case of DSD, may leave the physical healthcare required at odds with the care setting's resources and basis of care. Equally, the reverse may also be true; treating DSD within a physical health setting may not allow for robust attention to be paid to the mental health or cognitive needs of the patient.

1.3 The Problem to Address

With such variance in education, registration, and practice priorities, I became interested in how the RNMH's experienced caring for someone with DSD, and what influenced their experiences. The UK field registration system means that there is often a lack of clarity in the literature in what is meant by the term 'nurse'. As a protected title, readers can assume that it pertains to registered nurses, however the field of nursing and registration is often left unclarified. Preliminary explorations identified a considerable amount of literature specifying 'registered nurse' participants and intended audiences; however, internationally, this typically denotes general nurses (as per their countries education and registration system) and makes assumptions about education and knowledge base. The mental health care setting or mental health nurses are missing in the literature in relation to DSD care (as demonstrated in Chapter three). Instead, there is a more generic or non-specialist care premise discussed. Therefore, this study was born out of what Booth *et al.,* (2008) identify as 'incomplete knowledge or flawed understanding' (Booth, Colomb and Williams, 2008 p.59).

Reflecting on the above history of nurse registration, current care provision and diagnostic classifications, it could be suggested that the UK health and social care system relies on a population of nurses who are specifically educated and registered within the mental health field, yet are charged with providing care for a patient group who present with often complex coexisting physical, mental and cognitive health needs. In a world of increasing focus on evidence-based practice, rationales for care options and standardisation, in the apparent absence of, or minimal formal guidance which pays reference to DSD as a combined presentation, the question became; what is the RNMH's experience of caring for someone with DSD and what shapes that experience?

1.3.1 **The Research Aims**

The purpose of this mixed methods study was to explore the experiences of RNMHs in 24-hour care settings who provided care for people with DSD. An exploratory sequential mixed methods approach was chosen with a focus upon what guides, impacts or influences their experience. This was in light of the unique contexts of both the RNMHs and DSD; to primarily expose and illuminate the unknown RNMH experience and, subsequently, further explore and describe this. The mixed methods approach and study design is discussed and justified in Chapter four.

This study aimed to:

1. Illuminate the experiences, views, and perceptions of RNMHs caring for people with DSD within the 24-hour healthcare setting[8]
2. Identify and describe the experience in terms of influencing and impacting factors within the workplace
3. Generate new understanding pertaining to the RNMHs care provision for DSD and explore how this could be used to support the unique care context in terms of understanding influencing factors impacting on care.

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[8] This includes organic assessment units, and specialist dementia care homes

To operationalise this, the research was organised into three objectives to:

1. Identify key influencing or impacting themes that make up the RNMHs experience of DSD care through individual semi-structured interviews.
2. Develop and test a new questionnaire based on the identified themes to facilitate wider data collection, and further the exploration of identified themes.
3. Integrate the data to describe the RNMH experience and factors which influence and impact upon it as a whole.

The intended outcome of this study was to gain a new understanding of the RNMH experience of DSD care provision, specifically in 24-hour inpatient mental health settings. Additionally, this study intended to be the first exploration of RNMHs experiences in the workplace utilising a novel application of Activity Theory as a guiding and sensitising lens.

1.4 **Thesis Structure**

The thesis structure is provided to help orientate the reader to the thesis and support navigation through this mixed methods study. Commencing with the origins of the study, the introductory chapter provides a summary of the complex interplay between delirium and dementia, RNMH registration, and contemporary health drivers. Chapter two examines Activity Theory (AT) and its use as a sensitising lens which guides all elements of the study including the literature review. Chapter three explores the literature, leading to the identification of pertinent topics that may influence the RNMH experience for further investigation. The themes identified in the literature are presented as an evolving conceptual framework supported by activity theory and become a fundamental part of the study and its evolution.

Chapter four outlines why a pragmatic mixed methods approach was chosen for this study, followed by ethical considerations. The participants and their settings are also described here. Chapter five details the research methods for data collection and analysis undertaken in sequence. This process commences with qualitative semi structured interviews leading to questionnaire development, testing and data analysis prior to integration of the data sets.

Chapter six presents the qualitative findings of the study and situates them within an activity system. This is followed by the quantitative and integrated results in Chapter seven. A discussion of the study's findings is presented in Chapter eight and illuminates how this study adds to the body of knowledge relating to RNMHs experiences of DSD care provision. The strengths and limitations of the study are considered before offering final conclusions of the study. A summary the literature, the study's findings and how these advance the understanding of the complex tensions influencing the RNMH experience is presented in Table 18 on page 288. Finally, recommendations for both practice and research are made followed by a reflection on my personal and professional journey throughout the PhD experience.

1.5 **Chapter Summary**

This chapter has shown that dementia, delirium, and delirium superimposed on dementia are complex conditions that are frequently confused and misidentified. Whilst dementia is an ongoing condition, delirium is potentially reversible and should be treated as a medical emergency. Confounding the differentiation of the conditions is the presentation of DSD; when delirium presents in a person with dementia. With delirium classed as a mental health condition, and dementia (whilst cognitive in nature) often cared for in a mental health context when complexity of care needs presents, DSD may seem to achieve a fit with the RNMH practice expertise, but delirium is known to stem from a physical underpinning cause. Mental health nursing has evolved from the work of keepers in asylums, growing in professional recognition into a distinct and professional field of nursing. Education and training for RNMHs has been in a state of flux, and currently holds central the same core proficiencies as all other fields of nursing, albeit at different levels of competence. For the contemporary RNMH, care focusses on partnership and therapeutic relationships, and whilst the parity of esteem agenda has raised the importance of physical health (and vice versa) this is situated in relation to SMIs and seemingly long-term physical health conditions. As such, the complex nature of DSD does not achieve a natural fit in practice or policy.

With such a challenging presentation both in terms of clinical condition and the nature of mental health nursing, this study aims to explore the mental health nurses' experiences of DSD, and what influences or impacts on their care provision.

Chapter two presents the theoretical underpinnings of the study and introduces Activity Theory as the lens through which the study is viewed.

2. Framing the Study: Activity Theory

This chapter discusses activity theory and its use as a sensitising lens to guide the study. Theoretical frameworks help guide exploration and frame analysis; offering an intellectual structure which shapes the view of data (Troudi, 2014). Activity theory is applied overtly throughout the study supporting integration of literature and data in all stages of investigation and analysis. This resulted in a new conceptual framework of the RNMHs experience of providing DSD care.

The history and evolution of activity theory is presented leading to the selection of second-generation activity theory based on the work of Engeström (Engeström, 2001; 2003) and its focus on tensions across components of tools, rules, division of labour, community and the object of activity. Whilst several theoretical frameworks were considered (such as realism and a practice development approach), these approaches held a prerequisite that there was a level of “known” experience or action. Preliminary explorations of the literature had suggested that the unique context of the RNMH and DSD combined was relatively unknown, and so therefore, was their experience. The use of Activity Theory was interrogated with data being applied to it. I remained open to its applicability; however it achieved a fit with the research aims to explore and illuminate the experiences, views and perceptions of RNMH caring for people with DSD with the 24-hour healthcare setting whilst describing these experiences in terms of influences and factors that impact.

2.1 **Activity Theory**

Activity theory (AT) in all its forms is often attributed to Marx (1945) and offers an expansive base for exploration and investigation (Engeström, Miettinen and Punamäki, 1999). Originating in the field of psychology in Russia, Activity Theory can be used to study and explore complex learning environments and human interactions within systems (Yamagata-Lynch, 2010). It holds the potential to have a transformative and positive effect on local systems (Peim, 2009) as well as individuals (Roth, 2004). Whilst transformative processes are possible with AT, the application here was to offer structure and clarity to a broad-based exploration of the RNMH experience.

Central to AT is its ability to support visualisation of complex situations and present this as a clear graphic to the audience (Yamagata-Lynch, 2010). This helps to illuminate not only the experience, but how different factors of the experience influence and impact upon each other and the complex practices that are at play (Orland-Barak and Becher, 2011). This resonated with the study aims to explore the RNMH experience as a collective, but also the individual and situational factors which may underpin and have influence upon the experience.

AT has two dominant manifestations, Cultural Historical Activity Theory (CHAT) (Vygotsky, 1978; Cole, 1996; Daniels, 2001) emphasising cultural and historical elements, and Engeströmian Activity Theory (EAT) which evolved from CHAT (Engeström, 2001).

Vygotsky's initial AT is often discussed as first-generation AT, with Engeströmian Activity Theory including second and third generation AT. Whilst other several versions of AT are present, all hold central the aim of exploring tasks or activity within their own context (Nussbaumer, 2012).

2.1.1 **First Generation Activity Theory**

The most basic in presentation, first generation AT was devised and popularised by Vygotsky in the 1970s (Figure 3). Drawing focus to the individuals within activity, Vygotsky considered there to be an interplay between a stimulus, the individual response and a driving mediating artefact generating that response

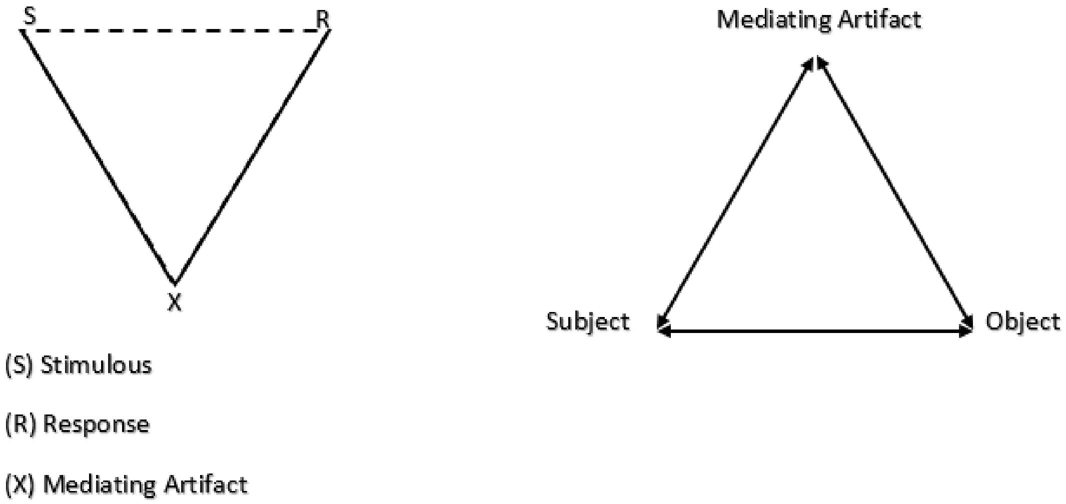

Figure 3 First Generation AT: Vygotsky's Triangles

(Engeström, 2001 p134)

Revolutionary in its inception, Vygotsky promoted the interlinking of cultural artefact and the human action/reactions removed the perceived separation of individuals from the sociocultural world in which they operate (Engeström, 2001). Activity is separated into analytical components of *Subject* representing the individual and *Object* being the motivating factor, purpose or intended activity (Hasan, 1998; Kaptelinin, 2005; Almalki, Gray and Martin-Sanchez, 2016). Whilst seen as forward thinking, a limitation of first-generation AT was its individual focus. Leont’ev advanced this notion of AT, expanding the system and introducing the context of collective activity (Leont'ev, 1981). This was subsequently furthered by Engeström (2001).

2.1.2 **Second Generation Activity Theory**

With a broader inclusion of influences on the individual, second generation AT identified the core elements of *Subject* (the individuals), *Objects* (the intended activity) and *Tools* (developed from mediating artefacts) which can be both liberating or restrictive (Hasan, 1998; Wilson, 2008). Engeström added further influencing elements of *Rules* as the conditions of the society influencing actions, *Division of Labour* highlighting the distribution of actions within a community (Engeström, 2001) and the mediating effect of division of labour and rules on a community (Hettinga, 1998). These additions significantly changed the Vygotskian first-generation AT and forms an analysis structure which can expose systemic implications and support a better understanding of the contradictions or tensions within the activity context. In addition, these can be communicated in a clear graphical form (Yamagata-Lynch, 2010) as seen in Figure 4.

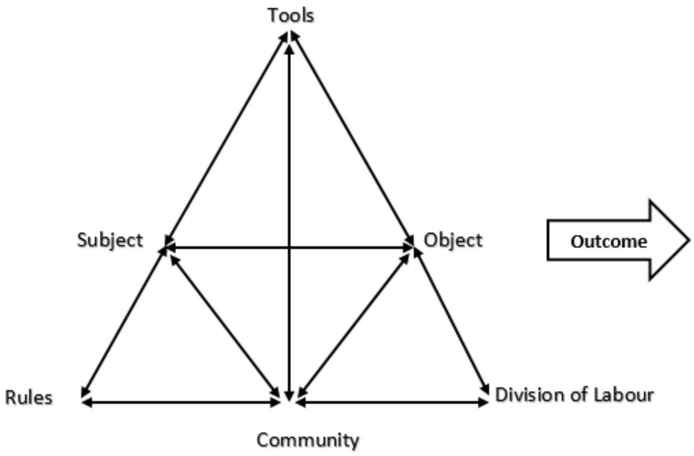

Figure 4 Second Generation AT

(Engeström, 2001)

Central to second generation AT, is the notion that the human experience is influenced and subsequently mediated by components of the society or community to which they belong or operate in, thus both the individual and the community are continually changing (Parker, 1998; Kaptelinin, 2005; Bedny and

Karwowski, 2007). The interaction between the composite parts of an activity system cannot be isolated, and all elements are integral in influencing experiences and actions. This understanding of influence can be used to promote wide scoping explorations (Engeström, Miettinen and Punamäki, 1999).

From the initial first-generation AT, Leont’ev (1978), presented additional elements of motive, conscious goals, conditions and influencing factors applied to act as facilitators within the resource of AT. These help to unearth and illuminate tensions or compounding drivers, taking into account not only historical or cultural elements, but the cognisant process involved rather than the physical in isolation (Figure 5). Leont’ev noted that all activity was driven by motive whether it is known or not (Leont'ev, 1978)

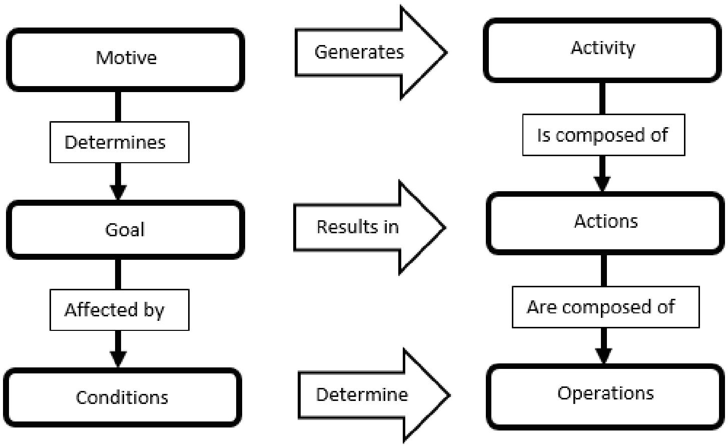

Figure 5 Activity, Actions and Operations

Adapted from Wilson (2006)

This structure for exploration resonated with the aims of the study, exploring the RNMH experience of providing care, in line with impacting and influencing factors. Practically, researchers can draft and redraft the activity system as the data evolves through analysis in a dynamic process. In relation to this study, working within organisations, RNMHs are subject to wider tensions and influences other than at an individual level. Commencing with a literature review, the complexity and interplay of tensions found can be initially demonstrated, and then expanded upon or refined throughout the study using the AT frame. This supported the study to describe interactions between individuals and their situational environment, the rules that guide them and any mediating influences (Yamagata-Lynch, 2010).

One criticism of second-generation AT is its use in local systems; not attempting to widen scope to broader social structures or fields that may overarch or encompass the activity (Peim, 2009). This is defended by Engeström who suggests there is risk in analysing larger systems due to potential variance in culture or history and advocates ‘local radicalisation’ over wider world views (Engeström, 2003). Utilising the frame of AT served to help guide and inform all phases of the study, illuminating, reviewing and applying potential influences on the RNMHs experience. This was important, as having worked in the clinical field, I needed to ensure that data collection and analysis was grounded not in my assumptions based on my own experiences (and would represent an RNA stance or judgements but from an external, more etic stance).

Whilst my prior interactions and experiences were valuable, it was paramount that the research was trustworthy, authentic and had appropriate rigour. This mechanism served to increase transparency as the activity system components evolved whilst allowing the application of new insights, findings and literature to the system throughout the study. In addition, whilst this thesis uses second generation AT as its guiding frame, it is important to recognise the progressive and ongoing developments in third generation AT which seek to address the culturally isolated factors of second-generation AT. Attempts to explore cultural diversity with AT have been made with a collective focus on objects and their interplay across activity systems (Engeström, 2001). Third generation AT situates the researcher as a participant, and interventionist to facilitate change (Yamagata-Lynch, 2010). Whilst an attractive prospect, returning to the core aims of the study, AT is used here as a frame, and a sensitising lens (rather than a complete research methodology) to explore and illuminate the experience of the RNMH within their activity system. As such, interventions toward change would be premature and would not facilitate the understanding needed of this unique contextual area first.

2.2 **Chapter Summary**

This chapter has discussed the use of second-generation activity theory as a framework to assist in identification, visualisation and analysis when exploring the RNMH experience of providing care for people with DSD. Moving on from Vygotsky’s first-generation AT (Vygotsky, 1978) in which a stimulus, response and mediating artefact model is presented, this study centred on Engeström’s second generation activity theory (Engeström, 2003) to expose components of tools, objects, divisions of labour, community, rules, subject and outcomes. Applying this framework to the mental health nurses’ experiences gives clarity about how a uniquely (and singularly) educated and registered nursing group experience DSD care provision. Chapter three presents a literature review exploring the RNMH experience with DSD as it stands in the literature today

3. Literature Review Informing a Conceptual Framework

This chapter discusses the literature review purpose and strategy before presenting the current literature. This helps to orientate the reader to what is already known about the topic, and identifies gaps in knowledge. The goal of the literature review was to achieve a comprehensive awareness of what is already known; to explore and integrate this whilst paying particular focus to elements which may impact upon or influence the study. The literature selected was reviewed for its contribution to knowledge of DSD and applied to an activity system framework.

This study focussed on the RNMHs experience of providing care, but this experience is linked specifically to the clinical condition of DSD. Considering this, it was necessary to include both aspects in the literature search. The chapter provides a first graphical representation of suggested components in the RNMHs activity system in relation to the experience of DSD care provision and discusses each component in turn. This is presented in Figure seven, page 40.

3.1 Purpose of the Literature Review

The purpose of the literature review was to appraise the corpus of literature, to become aware of the diversity and range of literature, and to provide a comprehensive overview from which themes or pertinent topics for exploration could be drawn. Boote and Beile (2005) articulate the main function of a literature review is to ‘advance our collective understanding’ (Boote and Beile, 2005 p3) and, by providing a robust exploration and synthesis of the work already undertaken, a space is identified in which this study can position itself. By placing the literature within initial groupings using activity theory, a first understanding of tentative influences on the RNMH experience can be drawn.

Bloomberg and Volp (2012 p79) provide what they term a *roadmap for conducting the literature review* comprising four key stages:

1: Identifying and retrieving literature

2: Reviewing and analysing literature

3: Synthesising: writing the review

4: Developing the conceptual framework

Creswell and Creswell (2018) advocate that, for each individual piece of literature found, a summary should be produced inclusive of the identified problem, the purpose statement, sample population, methods and results. From this information, a critique should be made regarding methods or any influencing factors noted alongside the associated recommendations from the material reviewed. By completing this, the papers can be grouped thematically and ordered by importance (Creswell and Creswell, 2018). Whilst tailored to empirical literature, the process of producing summaries highlighting relevant areas for consideration was utilised for the retrieved literature. This proved invaluable when reviewing and adding subsequent literature to the review.

3.1.1 **Positioning of the Literature Review**

Literature reviews can be conducted and positioned in several different places within a study and thesis (Bloomberg and Volp, 2012; Moule, Aveyard and Goodman, 2017; Creswell and Creswell, 2018). The positioning is dependent on the methodology, methods and purpose of the study. As an exploratory mixed methods study (discussed further in Chapter four), the literature review was commenced prior to data collection to allow for exploration of themes and concepts. These first themes formed a vital part of the study, acting as a foundation for both sets of data collection, but also as an evolving conceptual map in which to appraise the RNMHs experiences. Stylistically, mixed methods reviews can take the form of either qualitative or quantitative traditions, usually guided by a dominant methodological position. In this study, neither qualitative or quantitative data was determined to be dominant; however, commencing with qualitative data collection, an inductive approach to the literature and its subsequent presentation was undertaken to explore and frame the context and literature available.

3.1.2 **Mental Health Nursing and DSD Through an AT Lens**

In order to undertake a comprehensive and appropriately targeted literature review, the construct of the RNMHs DSD care was applied to activity system components. This application was based initially on my own knowledge of the wider practice setting and my initial ideas regarding what could be potential influencing factors. These components were reviewed, the associated literature appraised and, if found to be pertinent, included into an emerging conceptual framework. Bloomberg and Volpe (2012) support this approach, discussing that conceptual frameworks are used both to develop and support analysis born from literature, but which may be based on personal hunches for exploration.

Systems of activity hold central four key facets:

1. The individuals (including those with whom they work)
2. Conceptual models (formed by tools and equipment available)
3. Governing rules
4. The purpose of the activity (Engeström, 1996)

Applying this to the RNMH context a notational format included:

1. The RNMH, multidisciplinary team members, patients, and carers
2. Clinical guidance and known facts pertaining to DSD
3. Local and national governance (Nursing and Midwifery Council registration, organisational policy, clinical policy)
4. The focus of care and perceptions of role

Derived from consideration of what was already known from working in environments and organisational structures in the study context, key foci were applied to the second generation AT model to show and develop a representation of influencing forces in each area. The outcome is seen as an initial approximation of the impacting factors on the RNMH experience, formed from the tensions and interplay between elements of the activity system (Figure 6, page 34). Important here, is to note that at this early stage, the *object* represented the premise of DSD care; understanding what is already known about DSD, and care provision. This helped to inform and guide explorations of the nursing experience within the literature. Without this wider understanding of DSD, and DSD care provision, the ability to explore the RNMHs experience would be limited.

Tools as discussed in Chapter two are system resources and others that act as mediating artifacts within the activity system (Yamagata-Lynch, 2010). Broadly speaking, these can be any component that provides or influences an action. Applying this to a nursing context all facets of the system could be classified as tools. To account for this, tools were considered in light of what formally guides care, externally to the other components of the system.

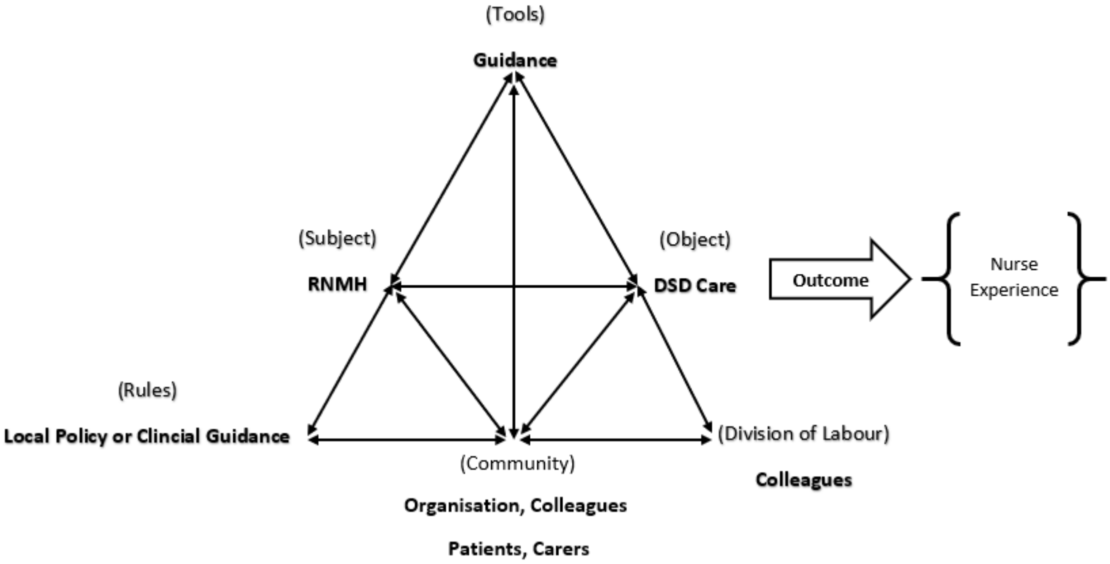

Figure 6 Initial AT Frame for RNMH Experience

Conducting an early and preliminary literature review allowed for the most current matters pertaining to the study to be addressed. The search was undertaken to be purposefully comprehensive, to explore what is currently known, and expose any areas of uncertainty or absence of information. The initial search strategy is depicted in Table 2, page 36.

Search terms were selected to capture all available literature and provided multiple relevant types of information including research, expert opinion, clinical practice, and guidance literature. These terms included *Delirium Superimposed Dementia* with refinement of terms undertaken to include *Nurs** and *Care* to focus the search. No initial limitations on types of document were specified to facilitate the inclusion of narrative discussions and non-empirical research texts. This allowed for historical and advancing studies to be identified and give an understanding regarding the history of the topic of DSD within the literature, and as a healthcare priority.

The health database initially searched was the Web of Knowledge which encompasses the Web of Science collection, BIOSIS Citation Index, KCI-Korean

Journal Database, MEDLINE and SciELO Citation Index to give a comprehensive global searching platform. The initial search generated 53 pieces of literature for review. An additional term of *Acute Confusion* was added to utilise the historical terminology used for delirium and a common synonym still found in practice today. This addition generated only two new studies relevant to the DSD nurse experience. Time considerations were appraised as there appeared to be an overall dearth of literature pertaining specifically to DSD within the last five years, broadening the inclusion criteria of located studies to 10 years did increase the literature base but still excluded key studies and texts. To maintain a comprehensive base on which to build the study and in keeping with the historical underpinnings of activity theory, selected key older pieces of literature were included in the review.

Refinement of texts was undertaken via abstract and/or introduction appraisal to ensure a clear articulation that any terms such as ‘cognitive impairment’, ‘chronic confusion’ or ‘cognitive function loss’ related to dementia. This was due to terms being used interchangeably or, on occasion, without clarity, potentially representing different conditions not applicable to this study. Texts not translated to English were excluded based on a lack of translation resources.

To ensure total resource capture, and considering the emerging dearth of literature, the search terms were input into further databases. PubMed searching produced one additional text, CINAHL offered only duplicate texts already located from previous searches, Cochrane databases offered one new text for review, the Royal College of Nursing Publishing Journals data base added no new texts; neither did a search of the Open Thesis resources and ProQuest dissertation and thesis bank.

Recognising the unique history and context surrounding RNMHs care, specific searches were undertaken of journals with a focus on mental health nursing. These searches used the same terms and exclusions presented above. These specific journals included: The British Journal of Mental Health Nursing, Mental Health Practice, Issues in Mental Health and The International Journal of Mental Health Nursing, all returning no new additional texts for review.

Table 2 Search Terms

Search no	**Search terms**	**Data Bases/search locations**	**Results**
S1	*Delirium Superimposed* *Dementia* *Nurs** *Care*	Web of Knowledge Inc. Web of science BIOSIS Citation Index KCL-Korean Journal Database MEDLINE SciELO Citation Index	53
S2	As above +	As above +	
	Acute Confusion	PubMed	1
		CINAHL	0
		Cochrane	1
		Royal College of Nursing Publishing Journals	0
		Open Thesis	0
		ProQuest dissertation+ thesis	0
		The British Journal of Mental Health Nursing, Mental Health Practice, Issues in Mental Health and The International Journal of Mental Health Nursing	0

Hand searching from reference lists and bibliographies was performed on retrieved articles to ensure thorough capture of all relevant literature. Internet searching using Google Scholar alert feed was commenced for continual updating using the terms [‘Delirium Superimposed on Dementia’ Nurs*] to ensure all works in progress were identified. Twitter formed an interesting component in the search strategy as individual professionals, professional groups and organisations with a specialist interest in delirium posted links to associated new publications in press alongside information feeds from a delirium research specialist link.

The manual formal search strategy was replicated at timed intervals to ensure all contemporary papers were reviewed. During this, it was noted that some texts reported on the same research project. In such instances, the most comprehensive report was included in the literature review process unless a different facet of the study was explored in greater detail.

3.1.3 **Literature Management**

Each individual article was retrieved, reviewed as above to ensure appropriate focus, and entered a grouping section of Endnote X9™. Each piece was allocated a category title: R+N (research inclusive of, or specifically about nursing), R+N (Wider) (research including nursing and wider participant groups), R-N (research, not nursing) T-N (theory or commentary, not nursing focussed) and T+N (theory or commentary, nursing focussed). The core selected papers were then re-read, and pertinent discussion topics, themes or statements were noted. This allowed for grouping of papers to expose key themes running through the literature. The papers often informed multiple themes and are represented in the review as such. (The literature management system is shown in Appendix one).

A smaller sub-search was undertaken to explore further what could be influencing RNMHs experiences; what are the helps, hinders or drivers at play. A variety of different terminology or foci could be applied here, but with the study being exploratory in nature and working within a comprehensive and complex activity system, the focus of this search was to review material that pertained to different forms of 'guidance' or things that were seen to 'guide' care in practice. Search terms included *Barrier*, Nurs*, Guid*, Practice, Evidence, Research.* The choice of search terms was directed by the interchangeable terminology found in the initial considerations of wider literature. 'Research' and research-based practice was pointed to by numerous synonyms: evidence-based practice, evidence informed decision making, and research-based care. The language used in literature reflects the historical and contextual development of the premise of care based on 'research' or 'evidence'. It was important to include terms that would capture, not exclude literature that may be pertinent to the area of nurses using a variety of forms of guidance. To highlight this variety of guidance forms, the terminology used in this review mirrors the language used by the authors. This was not to leave the search unrefined, but purposefully maintain authenticity and validity of the reporting, and highlight the complexity of the field of 'guidance'. In congruence with the DSD focussed search, no date, language, or types of document filters were applied, but as with search one, non-English language papers were excluded due to translation complexities.

Emerging themes were appraised using the activity system model, being categorised based on the potential influences in the activity system. This resulted in a series of subheadings for discreet themes evolving, and their associated AT group. Consideration was given to themes where the natural fit into the AT groups was not overtly clear, this represented the tensions and influences that each section of AT has on the others and as such represents the AT system in its working state. Elements of the literature shift through the dynamic system and inform multiple other components. Figure 7 page 40 depicts the first emerging themes applied to the activity system.

Whilst this review highlights there is a paucity of literature pertaining to DSD, and an absence of the mental healthcare context, there does appear to be an increasing recognition of the assessment and complexity involved. In addition, most of the literature articulated registered nurses as their participant group. As such it was often not possible to identify if these nurses had specific mental health training. Another consideration of the DSD literature was found in the presence of a few recurring authors who appear to be driving the enquiry into, and awareness of DSD forward (e.g. Donna Fick). Whilst of great importance and contribution to practice, a critical awareness of the minimal variance of authors and perspectives needs to be highlighted prior to discussing the literature.

3.1.4 An Evolving Conceptual Framework

Combining the two outputs of the literature search provided a robust and clear first iteration of potential influences within RNMH activity system out with my own personal experience. The identification and combination of these outputs can be seen in Figure 7 page 40, and represents the evolution of the activity system conceptual framework beyond my initial hunches.

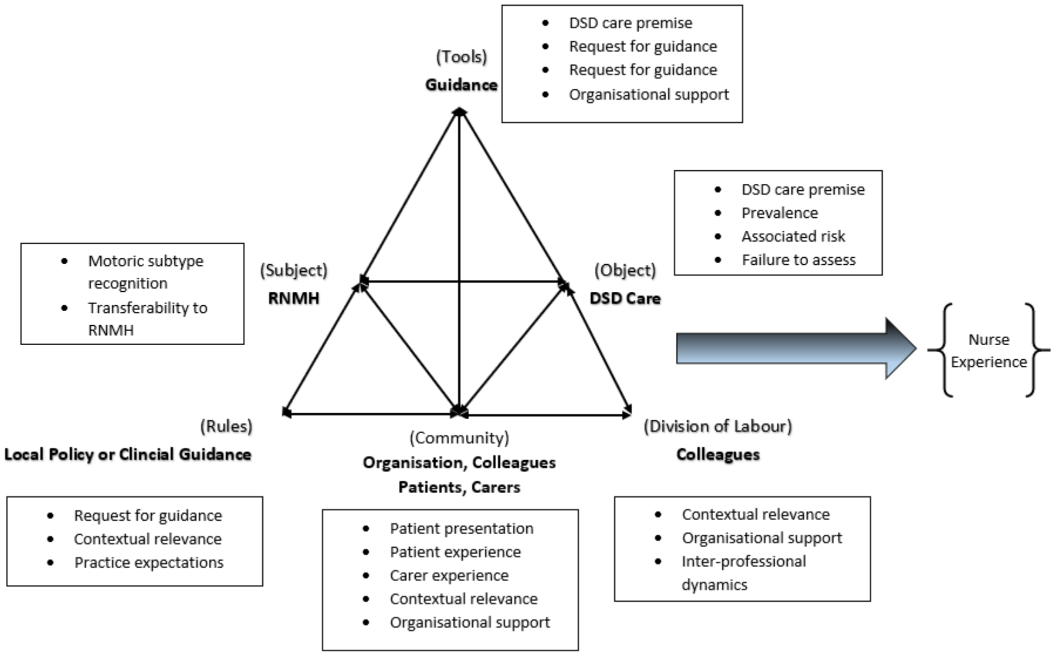

Figure 7 Combined AT representing Nurse Experiences

Bloomberg and Volp (2012) discuss a conceptual framework as a map, born out of the literature reviewed that is grouped thematically (Miles and Huberman, 1994; Bloomberg and Volp, 2012). It supports the growing and evolving areas being investigated and interrelated ideas. Relationships are exposed between individual concepts and new theory may be based upon this. The subheadings in the literature review have presented the themes emerging from the literature; whilst in keeping with the style of literature review, and initially directed by my own personal hunches, these have been borne from, evolved, formalised or refuted by empirical and theoretical literature. The framework has evolved over the duration of the thesis and what is presented above is one part of the conceptual framework's development.

3.2 **Key Considerations of the Literature**

Below is presented the key discourse found when reviewing the corpus of literature pertaining to DSD and nursing care. The literature is presented in sections supporting its position in activity theory as a frame; however, due to multiple themes influencing potentially multiple facets of the activity system (and indeed the very nature of activity theory is to expose these tensions) it was not realistic to group them into the defined headings of tools, rules, object etc as this would sit them in isolation from other factors. Figure 7, page 40 clearly displays the perceived dynamics of the activity system at this stage in the study. As the included literature stemmed from both expert opinion and research findings, the following review takes into account critique applied to both forms of literature including methodological consideration of research, contemporaneous debate and practice variance; including country of practice and the impact this may have on any expert opinion pieces, practice recommendation articles and clinical opinion. The literature review was encompassed of all types of literature, and as such, the discussions are presented together. This serves to give an inclusive overview of the literature as it stands currently.

3.2.1 **The DSD Care Premise**

The literature suggests that whilst it is recognised that there is a dearth of knowledge regarding DSD pathology, clinical treatment and outcomes, there are some articulations of robust thinking which offer clear guidance on DSD presentation and options for investigation, treatment and management.

Starting at a basic, historical, and attainable level, Fick and Foreman (2000) discuss a need for delirium to be routinely screened for inpatients with dementia to help facilitate recognition. Flanagan and Fick (2010) address this further, in their practice discussion, articulating that screening of cognition should occur on admission in partnership with families to establish a baseline, and at any changes of cognition. Cognitive state should be communicated clearly between professionals and be reassessed using consistent tools (Flanagan and Fick 2010) in order to have a benchmark from which to compare presentation changes. Recommendations for structure and content of assessment can be found in the literature; Shapiro and Mervis (2007) detail that assessments for DSD should encompass elements of presentation time frame, clinical history, physical and neurological factors, laboratory tests, medication review, potential toxins, vital signs and any injuries/trauma. Furthering the discussion, Flanagan and Fick (2010) explore DSD nursing interventions, surmising that care should focus on detection, exploration of treatable causes, safety maintenance, risk reduction (of injury) severity minimisation and prevention of reoccurrence. Fick and Mion (2008) offer a comprehensive and clear assessment and management algorithm, taking the patient from admission screening, through identification of potential delirium, potential physical causes, actions to take and follow up. These core principles form the basis for a care premise in which nurses can format care. Whilst the algorithm may be beneficial in practice, there is uncertainty here about its origins. Fick and Mion (2008) highlight that it is based on a combination of clinical experience and randomised clinical trials with people with delirium in hospital, but do not detail these studies or if they involved nursing staff. This highlights the potential complexity of the nurse experience, if the guidance offered is applicable and based on their practice, or potentially medical practice and physiology of disease process in isolation from nursing care.

3.2.2 **Prevalence and Associated Risk**

Fick *et al*., (2002) conducted a systematic review investigating the medical literature pertaining to DSD. Their search strategy utilised the MEDLINE database to search from January 1966 to February 2002. The review aimed to locate primary research studies. Some limitations exist in the review regarding language considerations, i.e. papers translated into English or any geographical limitations set. Published in 2002, the review was comprehensive and contemporary, but advances in practice and research need to be considered at this stage in relation to how the review may have driven the DSD agenda forward.

Fick *et al*., (2002) reported that DSD is not an uncommon presentation and can have serious implications for those affected, but comment that formal reporting of DSD and prevalence statistics appear to vary widely. In their systematic review, they found that prevalence of DSD in community living and hospitalised people over the age of 65 ranged from 22%-89%. This, they noted, may be attributed to different populations explored and variance in diagnostic criteria and measurements. Interestingly, higher rates of prevalence were reported in the majority of studies including hospitalised patients in comparison to those reporting on community or psychiatric/neuropsychiatric care settings. Therefore, questions should be asked regarding the driving force behind this variance; is it the clinical setting, patient need determining clinical setting, or staff recognition skills in the different clinical settings? Whilst published in 2002, this review remains heavily cited in contemporary literature, with no equivocal appraisal of the literature being undertaken as yet. Avelino-Silva *et al*., (2017) reviewed mortality rates in association with DSD in a general hospital ward for acutely unwell patients over the age of 60. Their prospective cohort study showed variation between in-hospital mortality for people with dementia alone (12%), delirium alone (29%) and DSD was reported at 32%. The study recruited 1409 participants over a 6-year period and indicates that both delirium and DSD have a poorer in-hospital prognosis and predictor of in-hospital mortality.

With prevalence rates concerningly, and consistently high, understanding the impact or consequences of DSD is paramount. To fully understand the condition and nurse people with DSD, not only the condition itself but the potential associated risks need to be known. These risks or adjuncts to care may have direct influences on the nursing experience and AT system as they experience it.

Fick and Foreman (2000) discuss clearly that failing to recognise or treat DSD appropriately may have detrimental social, financial and personal implications. Their descriptive exploratory design allowed for both statistical data gathering to measure variables in presentation (such as urinary incontinence, re-admission and cognitive function scores), alongside qualitative data derived from observation and interviews. A sample of 20 patients, 13 family members and 11 staff members (6 nurses: 5 physicians) was obtained. Specific measures of medical, physiological, and functional states were undertaken to assess the impact of DSD, and outcome measures noted to be cognitive status (as assessed using the Mini-Mental State Examination (MMSE).

The MMSE is a well-known widely used tool devised by Folstein *et al*., (1975) and remains contemporary in use. It is advocated by the National Institute for Health and Care Excellence (2016) as an instrument to use in dementia diagnosis; however, it is not specifically aligned with delirium. The confusional assessment method (CAM) tool devised by Inouye *et al*., (1990), based upon DSM-IIIR (American Psychiatric Association, 1987) was used for delirium assessment alongside other clinical assessment and diagnostic tools specifically used with family members to assess different elements of health or function. Importantly, the CAM (discussed briefly in Chapter one) is based upon the historical third revised DSM criteria from 1987, whilst the study was undertaken in 2000 and subsequent DSM diagnostic criteria have evolved to place onus on physical driving forces behind delirium (such as DSM IV in 1994).

The CAM, however, remains unchanged and focusses on issues of presentation onset, inattention, disorganised thinking, and consciousness, in the absence of considerations of physical illness. That noted, Fick and Foreman (2000) found that in comparison to patients with delirium alone, patients with DSD have increased use of restraint, lower MMSE scores on both admission and discharge, and be more likely to have new urinary incontinence. In addition, length of stay in hospital was shorter in patients with DSD but associated with a higher rate of readmission to hospital (within 30 days). In this study, 68 % of patients with DSD during their admission were readmitted; no patients with delirium without dementia were readmitted. The authors found that the DSD patients were discharged before delirium resolution. These findings clearly identify the risk of DSD influencing ongoing care needs and cognitive decline.

Whilst adding to the body of knowledge, some questions pertaining to full recruitment and selection of participants remain unanswered in Fick and Foreman's (2000) study. Clarification regarding how staff members were recruited, and any consideration of proportion of family members recruited in association to patients is not addressed. There is potential that an unregulated number of family members describing one patient's presentation, may result in over representation of a theme or effect reporting of prevalence in relation to participants with less or no family members to be interviewed.

Another consideration here was consent. Informed consent was gained for all participants, and people with dementia or a pre-existing delirium were not excluded. Notable is the inclusion of, or reported non-exclusion of people with delirium or dementia, central to the study's objectives. However, what must be considered are the principles of informed consent. Underpinned by the need for the participant to be able to: understand information regarding what the study encompasses, the benefits or risks of involvement, have capacity to consent and do so voluntarily (Royal College of Nursing, 2011), the study offers no articulation of processes undertaken to gather proxy consent if required. This may have inadvertently excluded those with advanced dementia or delirium if only those with the capacity to consent for themselves were approached; thus, contradicting the stated inclusion and exclusion criteria.

More recently, Chong, Tay and Chong (2015) echo Fick and Forman's findings (2002), reiterating that people with dementia have lessened cognitive reserves and that there is a considerable probability of a marked deterioration in cognition if delirium occurs. Fong *et al.* (2009) support this statement, reporting that within a 12-month period, participants with Alzheimer's dementia who experienced delirium, experienced a cognitive decline equivalent to 18 months; representing a rapidly changing or accelerating the progression of cognitive function loss in comparison to participants without delirium.

Torpilliesi, Bellelli and Trabucchi (2010) offer clarity, summarising that DSD may trigger a series of negatively impacting factors that influence levels of vulnerability, ability and care support requirements. Rates of rehospitalisation post discharge increase with DSD diagnosis (Fick and Foreman 2000), along with decrease in expected clinical outcome, increased rate of cognitive and functional decline, increased care needs and risk of death (Fick and Foreman 2000). Bellelli *et al*., (2007) found at 12 months post discharge from a rehabilitation setting, of participants who had a diagnosed DSD, 26% had died, in comparison to 10% for participants with a diagnosis of dementia and 8% for those with neither delirium or dementia. These associated risks place heavy onus on nursing staff to be skilled in recognition, forms of assessment appropriate to their role and able to carry out appropriate nursing interventions to improve patient outcome.

3.2.3 **Failure to Recognise or Assess**

Widely recognised as prevalent and, despite efforts made to raise awareness of delirium in dementia, the literature concurs that DSD remains poorly recognised in clinical practice (Fick, Agostini and Inouye, 2002; Voyer *et al.*, 2008; Flanagan and Fick, 2010). Fick *et al.*, (2002) indicate in their systematic review that recognition of delirium is lacking. Limiting this initial statement though, is an understanding that, at the time of review, they found only one study specifically pertained to differences of delirium recognition in those with and without dementia which further highlights a gap in knowledge, not only in a clinical sense, but in research upon which to base clinical guidance.

Exploring medical and nursing staff's recognition of DSD, Fick and Foreman (2000) through observation and interview found that both physicians and nurses demonstrated poor recognition of DSD. Statistically, failure to recognise DSD by nursing and medical staff was 88% of identified cases, despite clear articulations of sudden changes in mental state by family members in their interviews with researchers (Fick and Foreman 2000). Following this, at interview, Fick and Forman (2000) found that despite 75% of the nurses reporting they had received education on confusion in older people, 75% self-reported not knowing the difference between delirium and dementia. During the study, it was observed that no formal mental state examinations were carried out by either physicians or nursing staff. This was confirmed by an absence of assessment information in documentation; the authors observed both professions spending only a short amount of time with patients. Important here is not only the absence of formal assessments conducted or documented, but also the time frames of interactions with patients: minimal time spent with patients, reduced the opportunity to gather informal information which could assist in recognising DSD. In one interview, the authors report questioning a member of the nursing team if they changed their assessments if they knew the patient had a diagnosis of Alzheimer’s disease; the nurse responded:

‘If they are known to have Alzheimer’s then I don’t even try to ask them questions’

Participant response in: Fick and Foreman (2000) p35

This highlights both understanding and the amount of time spent with patients as important influential elements in nursing care provision. Following this, Voyer *et al.* (2006) noted that there is often a failure to recognise DSD if memory capacity is seen as an indicator, rearticulating previous findings that nursing staff may attribute cognitive changes in delirium to dementia despite memory capacity not being an indicative screening component in delirium assessment. This calls attention to potential knowledge deficits or attitudinal components that may influence the nursing experience and care delivery.

Fick *et al*., (2013) advanced the understanding of the level of nurse recognition of DSD in their second of two studies using case vignettes (the first, conducted in 2007 is presented in Chapter 3 page 55, and aligned to the paper’s main theme and discussion regarding DSD motoric subtype recognition). They aimed to evaluate recognition of delirium in people with dementia as well as dementia alone. The study was undertaken in the United States of America, and included registered nurses, licenced practical nurses, nursing assistants and certified nursing assistants. These different titles were all amalgamated in the study to represent “nurses”.

The participants completed 5 vignettes at timed intervals over a year to allow appraisal of knowledge and any changes in knowledge. Specific focus was placed on motoric subtype recognition. The study found that 60% of the nursing staff could correctly identify dementia alone, 37% recognised hyperactive DSD, 34% recognised hypoactive delirium (no dementia) but only 18% of nurses recognised hypoactive DSD. On questioning regarding the causes of delirium staff reported infection frequently alongside medication and environmental changes, but also were found to believe in some instances that acute confusion was caused by processes of normal ageing. No changes in knowledge base were found across the one-year time span. This is important as it draws attention to the lack of recognition for hypoactive DSD (discussed latterly in Chapter 3.2.6 pages 55 to 56), but also a misunderstanding that confusion is part of an ageing process. This could indicate a lack of access to professional development regarding DSD care, or indeed a lack of motivation to explore practice following the introduction of DSD at the first interview stage of the study. Additionally, it is important to clarify that several forms of nursing registration and level were included in this study.

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3.2.4 **Context, Organisational Support, and Inter-Professional Dynamics**

For mental health nurses, their role and identify is impacted upon by contextual, organisational and interprofessional dynamics. Current health and social care advocates for greater integration of services and a multidisciplinary team approach. Hercelinskyj *et al.* (2014) report a framework of professional identity specifically pertaining to mental health nurses which is founded in three core features; the value they place on mental health as a person, their motivation as a mental health nurse, and how they internalise attributes, skills and knowledge. These factors are mediated by how the RNMHs are socialised professionally. This professional socialisation may occur in the context of professional registration, organisation, and local practice environment. Hurley (2009) found that the professional identity of mental health nurses is not fixed; rather, it shifts and evolves as mental health nurses draw upon different characteristics of the other professionals that surround them, and the changing service user needs. Whilst many positives of interprofessional and multidisciplinary working are established, this may leave the RNMH role and identity poorly articulated.

In terms of interprofessional working and multidisciplinary teams, mental health nurses may feel that their specific professional role is eroded as the boundaries between professions become blurred due to erosion of their sense of *being with* the individual they provide care for is replaced by other professional roles (Brown, Crawford and Darongkamas, 2000). Hurley (2009) suggests that there is a place for recognition of a multi-skilled mental health nurse, or a ‘generic specialist’; this role would represent a construction of the role of the practitioner, the policy, location (inpatient, community practice etc.), and field of work.

Intertwined throughout the literature, the notion of organisational support as a great influence is found. Specifically, in terms of guidance in the AT system, several studies have found the organisational support (or lack of) to be a noteworthy barrier to nurses implementing evidence in practice (Retsas, 2000; McCaughan *et al.*, 2002; Carrion, Woods and Norman, 2004; French, 2005; Abrahamson, Fox and Doebbeling, 2012). Retsas (2000) conducted a study with nurses in a medical centre to look at the extent to which research was used in practice, the perceived barriers to using research and what supported them to use research. Four hundred nurses participated in the study, completing a questionnaire using the 29 item “barriers” scale (Funk *et al.*, 1991). It was found that a significant factor noted by over 50% of participants as a moderate or great barrier (identified by Likert scale) was a need for organisational support.

Composite factors of this section of the survey scored 1st 2nd and 3rd in the overall analysis of influencing factors (being 1st, insufficient time to implement new ideas, 2nd, nurses not having enough authority to change practice and 3rd facilities inadequate for implementation). In addition, they found support from others was an important influence. Over 50% of respondents reported moderate or great barriers to be physicians (doctors) not co-operating with implementation and other staff not supporting implementation. These were noted to be ranked 6th and 10th retrospectively.

McCaughan *et al*., (2002) found that cultural resistance, apathy and a lack of action played a role in non-uptake of research, but this was dichotomous with the nurses expressing opinions of both supporting research use, coupled with a lack of motivation. Those who engaged positively noted a lack of peer support from other nurses, colleagues, and medical staff (McCaughan *et al*., 2002; Bryar *et al*., 2003). This is in keeping with previous work (Nelson, 1995) noting historically an absence of positive ward culture toward research use, and more recently Bryar *et al*., (2003) who needed specifically the help of doctors to use research in practice.

Bryar *et al*., (2003) conducted a large-scale UK base study into the experiences of nurses using research to guide or change practice. Five individual NHS Trusts were sampled in one health authority. 2009 participants returned a quantitative survey regarding barriers to research use over a three- week period. The study spanned several health settings including two hospitals, three community setting, and practice nursing. Bryar *et al*., (2003) found that across all clinical areas surveyed, time to implement new ideas was rated highly by 25% of respondents, alongside a range of barriers including a lack of authority to make changes and a need for peer support.

Bryar *et al.*, (2003) commented that nurses felt there was insufficient time to explore research or implement new processes based on research. Whilst these studies were not DSD specific, they highlight that organisation support and requiring positive interprofessional dynamics (as seen here in relation to needing doctors' cooperation and other team members support) as key features which could be a direct influencing factor on RNMH experiences when trying to provide or change complex and potentially challenging elements of care.

3.2.5 **Patient Presentation, Experience and Carer Experience**

Discussing the potentially distressing presentation of DSD, Steis and Fick (2012) note the characteristics displayed by people with DSD often require additional support. They report that patients with DSD (in comparison to delirium in isolation) have worse fluctuations in presentation, slower responses to verbal stimuli and increased hallucinations, agitation, and anxiety. Both distressing for the patient and for carers, Landreville, Voyer and Carmichael (2013) summarised that a DSD presentation has an association with heightened behavioural symptoms of dementia; inclusive of wandering, irrational behaviours and sleep disturbance. These may have significant impact on the nursing care required, patient experience, experience of family and carers and thereby influence the nursing experience.

Morandi *et al.* (2015a) studied the experiences of informal carers (family members or private care givers) and health care staff (identified as formal care givers including nurses, nurse aides or health care assistants, and physical therapists) in relation to DSD. Unique as the only study found specifically aiming to articulate the experience of care providers, they found that care delivery for people with DSD represented an additional emotional toil and exposed concerns regarding ability to provide the required care; this manifested as concerns about time to provide care for both the person with DSD and both to the patient with DSD and a reduction in time for patients without DSD. Of note here is that increased distress was reported in informal care givers whilst formal care givers reported a lower level of distress.

The authors raise a pertinent association between formal care giver education in DSD and support from senior clinicians, and lower levels of distress in the workplace. Morandi *et al.* (2015a) advocate that training in delirium and DSD presentation and management is vital, as caring for people with dementia, let alone DSD, is shown to be emotionally demanding. Formal care givers reported increased distress in line with increased severity of symptoms (such as aggression) and the ability to provide required care, time provision for care and the impact on care for other patients. This points to the importance of education and support in DSD care and distress: the nurses report distress not at the patients with DSD clinical presentation, but rather in knowing the impact the required care provision will have on time management, other patients' care, and clinical risks (for example, aggression).

A potential influencing factor on the study's results pertaining to distress levels of formal care givers is identified by the authors: in this context the nursing staff were trained specifically in delirium management and had support from expert geriatricians for the majority of the week. This represents a pertinent contextual influence on the study's findings. The authors acknowledge previous studies report variance in distress levels reported by formal care givers. However, in this study, the nurses were specifically educated in delirium management and had support from expert geriatrician. The authors of the study suggest that higher levels of training and education in relation to delirium were synonymous with lower levels of distress. This strengthens the need for further exploration in keeping with the proposed research aims.

3.2.6 **Motoric Subtypes and Recognition**

Compounding the issue of DSD recognition further is the variance in presentation. Noted to have hypoactive, hyperactive and mixed forms, DSD presentation can vary dramatically. Fick *et al*., (2007) conducted a cross sectional survey using standardised case vignettes (their first study using vignettes) to assess and describe recognition of DSD by registered nurses, and their recognition of DSD in line with motoric subtypes. The study was conducted in medical-surgical units of an academic medical centre. Their recognition of DSD was paired with information regarding their geropsychiatric knowledge base. Presentation for case vignette included dementia, hypoactive delirium, hyperactive delirium, hypoactive DSD and hyperactive DSD. The case vignettes were devised from literature and reviewed by a geropsychiatrist. Feasibility, face and content validity were tested and agreed upon. Twenty-nine registered nurses completed a series of five case vignettes, each multiple choice and open-ended questions alongside the Mary Strake Harper Knowledge Exam (MSHAKE) to assess general geropsychiatric knowledge base. Fick *et al*., (2007) found that in the dementia only vignette, 83% of nurses chose the correct presentation, but had difficulty distinguishing between DSD and delirium. Hypoactive DSD appeared to be most challenging, with correct identification occurring in only 21% of reports.

This highlights a deficit in either knowledge or application of knowledge into practice and the complexity of recognising DSD across the motoric subtypes.

Whilst a deficit in recognition is shown, and clearly important, this study is an example of the wider literature having a narrow contextual focus; situated in what is seen in the UK as ‘acute care’ settings, (medical and surgical wards which would equivocally be set in acute care hospitals and staffed by RNAs). In the study, no discussion of field of nurse registration was noted. Therefore, it was not possible to explore the findings in terms of nurses potentially with (or without) mental health training and registration.

3.2.6.1 **Hypoactive Delirium**

Hypoactive delirium may present with the patient being drowsy or sedated, appearing, lethargic with slow or reduced movements and responses (Voyer *et al.*, 2006; National Institute for Health and Care Excellence, 2010; 2014b) and is more likely to occur in patients with severe cognitive impairments (dementia) (Voyer *et al.*, 2006). The absence of agitation or overt behavioural symptoms appears to present more of a challenge to identify DSD than hyperactive delirium (Inouye *et al.*, 2001; Fick *et al.*, 2007). Inouye *et al.*, (2001) found hypoactive delirium to be seven times more likely to be unrecognised by nursing staff. When coupled with dementia, over 80 years of age, visual impairment and hypoactive delirium, Inouye *et al*., (2001) found the risk of delirium being unrecognised by nurses was 20 times that of delirium without these specific features. Fick *et al*., (2007) concur, discussing that nurse participants were less likely to recognise hypoactive delirium than hyperactive delirium, leaving it, and the patient at risk of under recognised and subsequently under or inappropriate treatment.

3.2.6.2 **Hyperactive Delirium**

Hyperactive delirium in contrast may manifest with elements of increased restlessness, hallucinations, hyper-vigilance and both verbal and physical agitation (Voyer *et al.*, 2006; National Institute for Health and Care Excellence, 2010; 2014b). Fick *et al*., (2007) reported a 59% correct identification rate in hyperactive delirium presentation. Whist the increased rate of recognition appears encouraging, it would leave 41% of DSD unrecognised.

3.2.6.3 **Presentation Complexity**

In comparison to delirium in isolation, nurses' correct identification rates were found to be 52% for hyperactive delirium only, and 41% for hypoactive delirium. Fick *et al*.'s study (Fick *et al*. 2007) clearly shows that nursing staff may identify dementia correctly in the majority of case vignettes, but the complexity of delirium and additionally DSD remains a challenge. Even more so, is the finding that, when presented with hypoactive DSD vignettes, 39% of nurses attributed it solely to dementia and 21% did not identify it using the vignette options (dementia, delirium, DSD or normal ageing) reported as 'none of the above'.

Fick *et al*., (2007) discuss the study's limitations; clearly identifying the complex nature of patient presentation and the use of case vignettes as not assessing true recognition in a clinical setting. But the case vignettes' value as a resource and education tool can be seen. In addition to the author's limitations, the omission to include mixed delirium presentation in the DSD vignettes and survey may be of importance. It remains unclear if this presentation would be better recognised by nursing and medical staff, with the patient fluctuating between hyperactive and hypoactive delirium states.

Using a retrospective descriptive design, Steis and Fick (2012) reviewed clinical documentation of patients already enrolled in a prospective study pertaining to delirium and dementia. Study data gathered included demographics and CAM test results. Additional data was gathered through an electronic medical record review. Two data groups were established for comparison: DSD and no delirium (ND). Steis and Fick (2012) found that nurses did indeed recognise and document elements of both hypoactive and hyperactive DSD presentation but failed to associate them with delirium as a clinical condition; reporting consisted of terms such as *confusion, delusions, restless* that point to delirium but no overt associations were made. They comment that delirium is a medical diagnosis and question if nurses feel comfortable in using their assessments to reach a diagnosis. Steis and Fick continued, reviewing notes to ascertain what language or terms the nurses used in relation to mental state, and frequency of documentation of mental state in comparison between the DSD and ND groups. They found that for the DSD group, mental state descriptors and documentation were different to the ND group. Mental state descriptors were found to occur twice as frequently in the DSD group compared to the ND group with the term confusion also occurring twice as often. There was a noted variance in descriptors of orientation. ND group reports of '*Alert and orientated'* were frequent; DSD documentation related to terms exploring '*disorientation'* in more detail, using orientation to factors such as: place, time and person e.g. *'Patient alert to person only'* (Steis and Fick 2012 p37). Steis and Fick (2012) identify that nurses documentation substituted '*orientated'* for '*alert'*; reporting terms such as '*alert to person'* or '*not alert to person'*. Documentation did not indicate acute changes in mental state, and whilst some features pertained to elements of hypoactive or hyperactive delirium, no clear articulations of this were found.

The substitution in documentation of terms of orientation for alertness calls for further discussion. Whilst not explored in Steis and Fick's study, there needs to be a consideration, stemming from the change in, and use of terms, that with patients experiencing DSD or dementia, nursing assessment strategy or the focus of care may shift from trying to ascertain or understand the level of orientation that the patient holds, to only documenting perceived level of alertness. The use of the term “alert”, such as *alert to person,* can be ambiguous as to what *alert* represents. In addition, the level of said alertness may be left unknown if no additional information is offered. This echoes the work of Fick and Foreman (2000) where nurse participants reported not asking people with known Alzheimer’s disease questions, thus leaving detailed exploration of potential elements pertaining to DSD unrecognised.

Steis and Fick’s study is particularly interesting in their finding that nurses did not recognise delirium. Steis and Fick used documentation reviews, looking for exact phraseology of delirium or acute confusion. Nursing documentation did, however, include orientation and confusion descriptors for both DSD and ND groups. The use of terms seen as medical diagnosis (such as delirium) is mentioned by Steis and Fick (2012), but it would be valuable for future work to ask nurses directly about their willingness or confidence in using assessments or observations to diagnose delirium and about documenting delirium in their notes.

Consideration of these findings needs to take into account that, whilst a range of individuals were included in the study, it also excluded patients who were non-verbal, aphasic or unable to communicate because of advanced dementia, and the absence of a carer or family to participate in the interview. Whilst for the purpose of the study these exclusions were accepted in terms of ethical applicability to consent, it must be noted that these exclusion criteria do not leave a patient unaffected by DSD. As such a significant patient group experiencing DSD, and the nursing care of these patients is not included in this study. This could hold important information about the care for people with DSD who are non-verbal, and how their DSD is interpreted by the nurses providing care for them.

A recent survey of delirium specialists concluded that the diagnosis of DSD was particularly challenging (Richardson *et al.*, 2016). The study undertaken consisted of a self-administered web-based questionnaire. Participants self-selected following recruitment via mailing lists and web pages of a selection of international delirium associations. The study termed the participants as specialists; however, the determinants of the specialist title are not clearly articulated. The study sample consisted of 205 participants stemmed from four delirium associations (66%) and associated participants (34%). Richardson *et al.* (2016) found that only 57% of participants thought it was only possible to differentiate between DSD and dementia in some circumstances, with presentations occurring in people with severe dementia the most challenging to identify (represented by 63%). Although 63% identified that it was always possible to differentiate DSD from dementia alone, 57% indicated that it is not always possible. Contrasting with this uncertainty of differentiation of conditions, an overall high confidence in practice (76% of participants reporting ability to detect DSD as between 5-8 on a ten-point scale with 0=none and 10=excellent) was found. The study also demonstrated practice variance in diagnostic measures taken. This indicates a dissociation between confidence in ability and consistency found in practice. As the first study to explore specialists' attitudes and practice in relation to DSD the study holds valuable insight and advances the understanding of DSD assessment, however, the study does not correlate responses to professional group. Total response numbers are presented, but value would be found in the splitting of results between professional groups. Nurses are identified as 'staff nurses' which may not translate across the international setting, and it does not appear to include formally recognised nursing roles of specialist or advanced practitioner. This information may be useful to further explore the nursing care construct in relation to DSD.

One key observation in reviewing Richardson *et al.* (2016) alongside Steis and Fick (2012) is the potential correlation of specialist (either from medical or specialist nursing staff) practice variance, and the reluctance of nursing staff to document terms indicating a delirium or DSD diagnosis. It could be considered that the variance seen by nursing staff in practice pertaining to diagnosis impacts on the clinical reasoning or confidence to use appropriate terms or discuss potential DSD presentation within the clinical setting.

3.2.7 **Requests for Guidance**

Formal UK guidelines are present for delirium and dementia as separate conditions with brief reference paid to the other: dementia guidance by the National Institute for Health and Care Excellence (2018) has made recent inroads to address the complexity of delirium in dementia; however, this is brief and sits as part of a wider guidance for dementia specifically. Specific recommendations are made pertaining to a need for research into delirium superimposed on dementia and long-term recovery of people with DSD through non-pharmacological management. The paucity of recognition of the interrelation of conditions is mirrored by delirium guidance (National Institute for Health and Care Excellence, 2010) which details the increased risk of delirium in people with dementia and the complexity of differentiation and diagnosis. Whilst this guidance does articulate the need to assess for dementia if delirium does not resolve, and notes the challenge of diagnostic uncertainty, as has been seen above, contemporary research literature clearly articulates that the considerable interplay and overlapping of each individual condition to produce DSD presents a unique and challenging nursing care construct; one which is difficult to manage and understand in a robust and evidence-based manner. Complicating clinical decision making, the clinician is moved towards trying to assess which ‘individual’ condition requires assessment and treatment following the currently available specific guidance (i.e. the delirium or dementia national guidance).

Highlighting the interplay and variance found when both conditions are present, Boettger, *et al*., (2011) identified that resolution of DSD within two to three days post diagnosis was only 18.2%. This is important since patients diagnosed with delirium without dementia had a resolution rate of 53.9% in the same time frame; resolution rates were found to be in excess of 30% lower in DSD patients than those with delirium alone at 72 hours and one-week post diagnosis. The prolonged nature of delirium is highlighted in the wider literature by Rockwood (1993) and McCusker *et al*., (2003) who articulate that delirium has the ability, in the older population (including those with cognitive impairments or dementia) to persist for up to 12 months. With people with DSD experiencing more symptoms of delirium for longer than those without dementia (McCusker *et al*., 2003). Grounded in time frames, there is a clear need for specialist knowledge and guidance to facilitate ongoing management and assessment of patients with DSD as a condition in its own right.

The request to assess for dementia if delirium is unresolved (National Institute for Health and Care Excellence, 2010; 2014b) is unclear regarding what would be an expected resolution time frame, thus influencing nurses’ ability to plan for dementia assessment if ‘unresolved’ confusion persists. With slower resolution rates known, and recognition, documentation and treatment characteristics variable depending on setting and clinician knowledge, how is the suitable time for assessment known? Whilst the National Institute for Health and Care Excellence (2010) articulate that if clinical uncertainty is present regarding a diagnosis of delirium versus dementia, potential delirium should be treated first.

The complexity of DSD as a combined presentation is clearly noted by Voyer (2006) and later, Boettger *et al*., (2011), with Boettger *et al.,* (2011) highlighting the variance in treatment options and characteristics for people with DSD versus those for a person with delirium in isolation. As discussed previously, Morandi *et al.,* (2015a) comment on their individual study context, a consideration of how, potentially, high levels of education regarding delirium care and organisational support impacted greatly on care givers distress levels and ability to care effectively. Morandi *et al.,* (2015a) hypothesise that due to education and medical support of a delirium expert, nursing staff did not report high levels of distress in caring for those with DSD; this was in direct contrast to high levels of distress experienced by informal care givers. Supporting this observation of educational impact, Fick *et al*., (2002) detail research recommendations for future practice stemming from their systematic review of DSD. This is inclusive of research into replicable DSD prevention and management strategy, with specific focus on developing education for students and clinicians in practice. This call has been subsequently echoed by Voyer *et al*., (2006) and Steis and Fick (2012) and the argument is added to by Shapiro and Mervis (2007) who highlight a paucity of guidelines regarding treatment decisions on which clinicians can base their care. Voyer *et al*., (2008) advocate the need for professional support at organisational level to help nurses adopt appropriate and specific DSD protocols and procedures. As such, a systems approach inclusive of primarily understanding nurse practice, experience, education and wider organisational support is indicated by the literature.

More recently, the aforementioned survey of delirium experts was undertaken on a multinational level to review current practice (Richardson *et al.*, 2016). The study identified that the experts were confident in their ability to recognise DSD, with 60% of participants rating their confidence at 7/10 (DSD recognition). Whist initially positive, it was found that only one third of participants felt it was always possible to recognise DSD from dementia alone, and when severe dementia was noted in an individual, the complexity of diagnosis was felt to increase. This is critical to the understanding of the RNMH context since organic inpatient mental health units and specialised 24-hour dementia care homes may have a high proportion of patients with the most severe dementia presentation. As the severity of dementia increases, so does the likelihood of needing to live in a care home (Whittenburg *et al.*, 2019). Richardson *et al*., (2016) found that there was no consensus between experts in assessment and diagnostic processes. This study provides the first exploration via survey of delirium experts of practice and confidence in diagnosis, offering a valuable confirmation that even within fields of expertise, DSD remains an ongoing challenge. This challenge is compounded for RNMHs with respect to from where they seek guidance; if formal written guides are absent, and experts (spanning both nurses and doctors) have varied confidence, ability and processes for diagnosing and treating DSD, on what do RNMH base their daily care? And what influences this?

Whilst the literature is growing around DSD, it is often fragmented to the individual conditions at play, is presented predominantly in journal articles and has not translated into practice guides (as the useful products of research for RNMHs).

As such, the RNMH may wish for more precise guidance, relevant to the DSD condition as a whole. Conversely, nurses' perceptions that guidelines undermine clinical judgements and experiential knowledge are identified by Sitzia (2002). This represents a misunderstanding and belief that evidence-based guidance for practice stemming from research excludes individualisation and personalisation of guidance to the patient and does not value the clinical expertise of those providing care (Melnyk *et al.*, 2000). This may account for the realisation that whilst published guidelines are increasing as research outputs, one third of the time they are not used in practice (McCaughan *et al*., 2002).

McCaughan *et al*., (2002) used a variety of methods to explore what barriers were perceived by nurses when using research information for clinical decision making, and what is undertaken in practice. One area of specific interest and importance is their finding that the failure to use research findings or knowledge is not in itself a barrier to application, but it is an articulation that challenges are present in research information presentation and management. Participants vocalised that they found research information disappointing since it did not offer clear answers about clinical care, believing that research should provide guidance for practice. This illuminates a feeling from nurses that research fails to deliver tangible, real world guidance to them, which is sought from nursing staff. It appears that they have a need for there to be a level of certainty in clinical direction delivered to them at the end of a research piece for it to be applicable and useful for them. The absence of this may make research appear isolated or removed from clinical practice, as nursing staff favour answers and clinical direction presented to them in an easy-to-use manner (McCaughan *et al.*, 2002).

Johnston *et al.* (2016) found that community nurses (no field identified) identified four main categories of barriers and facilitators of research evidence utilisation: Keeping up to date with evidence, using a clinical tool, education/training, and implementation. Interestingly, clinical tools seemed to be viewed as being put in place to theoretically support good practice, but the nurses in this study articulated that they could be perceived as restricting nursing practice. They reported a loss of autonomy regarding choice of tool; it was mandated by the organisational systems. This appeared to incite frustration as in the context of the study, the nurses perceived the time taken to complete the tools to be an issue. Whilst they found that tools could support confidence in practice specifically relating to junior staff, in contrast, the over-reliance on tools was reported; tools were felt to restrict practice and be irrelevant to the clinical decisions required.

3.2.8 **Context**

It is clear from the literature that the RNMH context in which DSD care is situated is not overtly represented; hence the RNMHs may draw on guidance, policy and clinical debates from a wider range of different healthcare contexts. However different care settings may require different approaches and play host to unique interactions exerting influence each other (Angus, Hodnett and O'Brien-Pallas, 2003; Bryar *et al.*, 2003).

French (2005) conducted a comprehensive study to explore contextual influences on the formation of evidence-based guidance for use in nursing practice. Constructionist in nature, the study aimed to understand nurses’ perspectives regarding how context influenced their perception of what could be ‘reasonably’ done in a practical setting, exploring reasoning, timing and manner in which research was implemented in practice. The study used transcriptions from discussion groups of specialist nurses from different organisations engaged in developing new policy and guidance. French (2005) found in discussion of the clinical context of care, that the physical environment in which care is provided, the political and social organisation of the care environment and wider factors such as the economic context of care influenced the nurse’s choice of actions. These choices were selected and interpreted from the same evidence or research appraised use but varied by location of care. Understandably, different contexts and influences on practice leads to differences in priorities and resources required for different nursing settings. As such, there is a need for individual patient groups and practice settings to be understood to influence research use in a positive manner.

3.2.8.1 **Context of the ‘Nurse’**

A key element in any contextual analysis in nursing it what is meant by the term ‘nurse’? Minimal research was found relating specifically to registered mental health nurses in relation to DSD or delirium in general; this is in direct contrast to studies citing ‘nurse’ participants in medical settings within the UK- assuming registered (adult field) nurse participants; for example studies carried out in coronary care units or surgical wards. In addition, there appeared an absence of detailed discussion of care context, leaving the registration of nurse un-specified. Alzayyat (2014), and more recently, The Department of Health (2017) noted that mental health nursing research in general lags behind that produced in other registrant specialities, thus potentially leaving discreet areas of practice unexplored, and forcing RNMHs to base practice on research which may not align to their principles of care and environments.

Aligning with the predominance of generic ‘nurse’ literature or specifically adult/general acute care focus, the literature searches noted only two studies specifically undertaken with mental health registered nurses and the barriers preventing research or evidence base application in practice. Interestingly these were contextually varied with one sub speciality of forensic mental health care (Carrion, Woods and Norman, 2004) and one broad based study of Irish psychiatric nurses (Yadav and Fealy, 2011). Yadav *et al*., (2012) surveyed sources of knowledge used, barriers to finding and reviewing evidence, barriers to practice being changed and facilitative factors for evidence based practice. Regarding changing practice based on evidence, the study found resources and a lack authority respectively as the top two barriers. This shows a congruence with studies not specific to mental health. In addition, facilitators of change based on evidence were found to be practice development coordinators and a supportive multi-disciplinary care team. These findings further strengthen the argument that the context and supportive colleagues are both key factors in what guides or influences care. However, some underpinning attitudinal considerations are highlighted by Carrion *et al*., (2004) pertaining specifically to mental health nurses. Carrion *et al*., (2004) aimed to address the gap in knowledge for RNMHs specifically relating to research utilisation using the Barriers scale discussed previously in Chapter three, Section 3.2.4 (Funk *et al*., 1991). Eighty-eight responses to a questionnaire identified some overlapping themes with generalised nursing research (time, authority, cooperation from managers) but, interestingly, there was a clear articulation from the RNMHs regarding minimal trust in, or uptake of research that they perceived not to be generalisable or transferable to their specific clinical context (i.e. research undertaken in medical settings or outside the forensic speciality); 66.7% on the nurses felt that the available research was not generalisable to their place of work. Whilst specifically noting the beliefs of forensic mental health nurses, this is an important factor to consider in the wider mental health nursing field; although the research identifies multiple issues common across adult and mental health fields, for the RNMHs to be willing to consider clinical guidance or research for practice application, it needs to be contextually specific not only to their field of nursing, but also the clinical context in which the practice is situated. The lack of research being generated from the mental health field leaves a dearth of literature that RNMHs may find useful or deem suitable to base their practice upon. Considering this, in the context of understanding research and clinical guidance (in the form of documents, tools or protocols) is often difficult to develop and then embed in clinical practice, the question is raised: what do RMHNs base their practice upon or what influences their care decisions regarding DSD?

3.3 **Chapter Summary**

The key themes and concepts drawn from the literature have been presented in Figure 7 page 40. The review of the literature shows that DSD has been a growing concept in research for over two decades, with advancements in knowledge and recommendations, but lacking in clinical guidance, tools or research findings which can be readily accessed and translated to practice by nursing staff (Fick and Mion 2008). In addition, there appears to be little focus, supporting guidance or indeed research regarding the specifics of the mental health care setting, and mental health nurses in terms of DSD care. Whilst policy, guidance and research exist for the conditions as separate entities, the combination of the conditions, and the mental health nurse context is not visible.

Research and guidelines should support practice; outputs of the research must be tangible, usable, profession appropriate products. Information from research needs careful consideration, appraisal, and synthesis to influence and transition to practice. Its context and application are individual and population specific.

There is a wealth of research that details the importance of contextual understanding as a priority for research application, and in relation to delirium (note not specifically DSD), there is a clear stipulation from the London Dementia Strategic Clinical Leadership Group (2015) that policy or guidance for practice must be context specific. To produce this, there needs to be a careful exploration of the contextually specific nursing experience, knowledge, needs and influences relating to DSD. As such, this study aims to go part way to fulfilling this by illuminating and exploring the RNMH experience regarding DSD specifically.

Of the DSD literature reviewed, and in keeping with the dominance of several key authors, the majority originated from the United States of America. This identifies a gap in UK research and variance specifically in the use of ‘nursing’ or ‘nurse’ terminology: as discussed in Chapter one, UK nurses undergo education specific to fields of nursing such as ‘adult’ to become a registered adult nurse (RNA) or ‘mental health’ to become a registered mental health nurse (RNMH) for example. Variance in registration and practice requirements exist which may be different to other countries training and registration profiles. This opens up questions of transferability as with literature clearly articulating that DSD care should be conducted by staff with the ability to focus on fluctuation in mental state presentation, it is unknown if UK specialist RNMHs have increased skills, report better experiences or have more understanding than those noted in the literature due to their training and clinical contexts. There is a clear need to understand the UK RNMH experience of DSD.

The literature review was an ongoing process, refined and revisited throughout the duration of the study and thesis development. The initial literature review was broad based in order to fully explore all available literature pertaining to the foundations of the study, including both the nurse care construct, and patient presentation/disease state in practice. With the study’s purpose requiring an exploration of influences on their experience of providing care to people with DSD, the literature review process was divided into two searches: one focussing on literature pertaining to DSD as a clinical condition, available guidance and nursing care of DSD, and a second search reviewing factors impacting on nurses' use of a broad base of guidance in practice. Through the process of refinement and review, common themes and important areas of consideration were illuminated and considered through an activity theory lens. These topics were used to build a new conceptual activity system graphic (Figure 7, Page 40). To maintain a contemporary focus, new literature was added and appraised, to inform and support interpretation and analysis throughout the research phases towards study completion.

The literature review highlighted that DSD is a complex and confusing condition for not only the RNMH and nursing staff, but the person experiencing it, family members and indeed clinical experts. This recognition of the underpinning uncertainty regarding care and impact on clinical outcome for the patient is coupled with an awareness that multiple factors impact on nurses; not only in their desire or ability to locate and use guidance in practice, but also the complex context in which they work. These discussion points offer an overview of components in the nursing AT system that warrant further exploration to understand the nursing experience and what shapes their care in practice. Significant here, is the unique place in practice and literature in which the RNMH and DSD experience sit. The literature review has also demonstrated a lack of RNMH or DSD literature in both primary empirical literature, and opinion or theory from which the RNMHS may draw firm conclusions. This is noted to be of specific importance for RNMHs disregarding or being cautious of literature that is not deemed contextually and professionally relevant to them. The current study starts to fill the gap pertaining to both RNMH literature and DSD care in 24-hour specialist dementia care settings. Leading from this literature review, a latent objective was identified. This new objective was linked to the aim to produce a new questionnaire that could support data collection, but also be further used in other clinical settings and subsequent investigations to provide a ‘state of play’ view of the thoughts and actions of those specifically providing DSD care whilst paying reference to their clinical context.

4. Methodology

Chapter three identified key findings from the available literature which informed the development of a conceptual framework on which the study is based. It identified an important gap in which this study sits, evidenced by the lack of literature pertaining to UK RNMHs, and the discreet experience of these nurses providing care for people with DSD.

This Chapter explores the selected methodology for the study and identifies my own pragmatic position in relation to ontology and epistemology. This position is linked to the selection of a mixed methods approach; partnered with activity theory, and in line with the aims and objectives of the study. The related choice of an exploratory sequential design is justified and followed by an overview of the ethical considerations and participants.

4.1 The Research Approach

On completion of the literature review it became apparent that the constructs influencing the RNMH experience may be complex and poorly understood. Choosing an appropriate methodology that could fully explore the experience and thus meet the aims of the study was paramount. The literature review demonstrated that there was a need to primarily explore the RNMHs experience with them, but also illuminate clearly what influences this experience and the tensions present. As demonstrated by the evolving AT framework, dynamic tensions exist between components of influence which mediate action, and as such, the RNMHs experience in other components. The approach selected needed to identify not only what the experience was, but how the tensions and elements of the experience impacted upon each other. To meet these aims a pragmatic mixed methods approach was adopted.

To recap, the aims of the study were to:

1. Illuminate the experiences, views, and perceptions of RNMHs caring for people with DSD within the 24-hour healthcare setting
2. Identify and describe the experience in terms of influencing and impacting factors within the workplace
3. Generate new understanding pertaining to the RNMHs care provision for DSD and explore how this could be used to support the unique care context in terms of understanding influencing factors impacting on care.

Traditional approaches to exploratory research were considered at an early stage. Qualitatively, ethnography would have served to illuminate cultural factors influencing the RNMHS through observation, interaction and discussion. Whilst inviting, this study did not seek to map the RNMH practice against a set of standards or rules for practice, and was interested in their opinions and experience, not necessarily the actual actions at this time. This study aimed to explore their experiences as they understood them. As such, I considered they needed to tell me their experiences, rather than have them observed at this early stage. In addition, consideration of the time required to build an effective trusting relationship with participants needed for an ethnographical study, and the wider impacts of my presence in the work environment as a clinician, colleague and employee limited this approach. I had to balance my own knowledge and influence as an RNA practitioner and researcher, and review how this may impact on an ethnographical study.

Narrative inquiry is growing in nursing research and was considered as a potential research approach. Again, qualitative in nature, narrative inquiry would have allowed the RNMHs to discuss their experiences by telling their story. Through multiple meetings, meaning could be ascribed to these experiences. But as with ethnography, I was concerned about the closeness of relationship needed to facilitate this approach, and that it only viewed the experience from a qualitative perspective.

4.1.1 **Recognition of a Pragmatic World View**

Research paradigms are viewed in terms of ontological judgements (what constitutes the nature of a reality), epistemological beliefs (how the truth of a subject can be discovered), the axiological stance of the research (the role of values) and consideration of what methods should be employed (Open University, 2008). Guba (1990) and Cresswell (1998) outline how paradigms guide research inquiry through these assumptions. Historically, paradigms have lent themselves to either side of a perceived research dichotomy, sometimes forced, between positivist and constructivist methodologies. Positivism and post positivism seeks value neutrality and control; whilst this has historically dominated research there has been a significant movement towards constructivism, and an onus placed upon societal and cultural influences (Teddlie and Tashakkori, 2003). Spanning the two polarities of opinion and methodology is pragmatism.

Originating in America with the works of Pierce, James, Mead and Dewey (Cherryholmes, 1992; Maxcy, 2003), pragmatism sits in opposition to realism in that it makes no claims of knowledge exposing an underlying reality. Pragmatism dismisses arguments founded in realism centring on the mind as the basis for knowledge and, in turn, argues against the rationalist stance that to gain reliable knowledge an abstract rationality must be present (Cornish and Gillespie, 2009). As such, pragmatism offers researchers an alternative paradigm: embracing the notion of there being single and multiple realities and aims to explore these through empirical inquiry (Creswell and Plano Clark, 2007), and that the context of research includes social, political and historical components (Creswell and Creswell, 2018). These fundamental assumptions are in keeping with the central tenets of activity theory, and drive researchers to focus on actions, situations and consequences. As such, pragmatic research is focussed on what works, applications and solutions (Patton, 2002).

The ‘postmodern condition of plurality of knowledge’ as discussed by Lyotard (1984) and Creswell and Plano Clark (2007) sits in acceptance of competing forms of knowledge (Cornish and Gillespie 2009), and this stance lends itself to the field of social science research which seeks to better understand the complexity of behaviour and experience (Morse, 2003). A key notion in Dewey’s pragmatism is that of fallibilism; accepting that any knowledge, accepted or proposed is not static (Maxcy, 2003; Field, ND). Dewey argues, in opposition to alternative worldviews, all knowledge could be mistaken, and no assurances of absolute certainty are possible (more the fallibility of knowledge does not serve to discredit, but instead raises an awareness that ‘truth’ is bound to the reality in which it stems). As such (in Dewey’s opinion) we should suspend the quest for certainty and the traditional manner of viewing the worlds as objects; instead the world should be known through context and language (Rorty, 1991). Rorty (1991) explores this, noting that research and researchers rearticulate, through their work, what is believed and known. Central to this is an awareness of the researcher’s knowledge of what is already known, and his or her interpretations of this influencing knowledge.

Moving away from another duality in perceptions, pragmatism recognises inter-subjectivity in opposition to the notions of objectivity or subjectivity, embracing a level of researcher understanding of participants and the research audience. These key tenets resonated with the purpose of the study and the dynamic nature of interactions and influences on experience. In addition, having already a prior knowledge of the context to be explored, all be it from a different field of nursing, the inter-subjectivity of pragmatism and interpretations of knowledge achieved a fit with my own (at this time) unknown personal world view.

The way researchers understand, and articulate paradigms perpetuate variance in meaning and cause confusion. Reaching past the stance of paradigms encapsulate a researcher's beliefs regarding their knowledge creation (Morgan, 2007), there is now an argument that paradigms should be less rigid, allowing for fluidity (Freshwater and Cahill, 2013). This notion has started debate around the helpfulness of paradigms (Biesta, 2010).

The traditional hierarchy of evidence supporting meta-analysis of relevant randomised control trials or systematic review as *level one* evidence whilst placing qualitative research at levels *five to seven* (Melnyk and Fineout-Overholt, 2011) perpetuates a dissonance in value placed on different types of data drawn from different methods. It is the variation of methods appropriate to the research question asked, that hold value when exploring the studies aims.

Despite the initial 'paradigm wars', in which paradigmatic 'purists' (Onwuegbuzie and Leech, 2005) argued epistemological and ontological difference in assumptions (Bryman, 1984; Tashakkori and Teddlie, 1998), which perpetuated a belief of incompatibility of methods, pragmatism supports the use of quantitative and qualitative methods through robust and considered integration (Creswell, 1995). Drawing on the statement that 'epistemological purity doesn't get research done' (Miles and Huberman 1984, p21), and valuing no one method as superior to another (Baert, 2004), pragmatism asks the fundamental question: *what fits?* thus forcing a return and focus on the research question, (Fendt, Kaminska-Labbé and Sachs, 2008) and selecting appropriate methods to answer these questions (Feilzer 2010).

Through exploration of the question, reasoning behind the importance of the study and debates regarding the nature of ontological and epistemological stances, an appropriate and fitting methodology for this study evolved. Rejecting the separation of traditional paradigms, I found, in accordance with a pragmatic stance, that this research question could not be fully addressed by 'epistemological purity' (Tashakkori and Teddlie 1998). This supported and clarified my own position as a pragmatic researcher. Holding central the question to be answered, and the goal to robustly answer the research question using appropriate methods, pragmatism offered a freedom to the research (Feilzer 2010). I had a number of considerations and challenges as this feeling was a "sense" of what I believed to be the best manner in which to expose and explore a care construct that was absent in scholarly and practice discourse. My own stance and opinions were based in an RNA context and, potentially, not in congruence with the RNMH. I considered what the RNMHS preference for sharing information was, and what bias I might place on their discussions and information because of my own personal and professional perspectives.

In light of these considerations, it was important to retain a focus on accepting new, evolving and different knowledge from the RNMHs, and supported a mixed methods approach. This allowed the study to draw upon the positives of both traditional research paradigms, strengthening and exploring the experience in different ways, whilst being able to minimise and check for risks of researcher bias throughout the study. The selection of the specific mixed methods design (as discussed below) also allowed for data to be collected in a number of different ways, facilitating and supporting participant preference in the manner in which they chose to share their experiences, whilst facilitating wider data capture.

4.1.2 **Mixed Methods**

A mixed methods approach was selected to offer the study ‘completeness’ in which data are combined to offer a more comprehensive account than that possible if only qualitative or quantitative methods were employed. Consideration was given to the historical and broad discussions of what mixed methods entails, and the variance of its representation in the literature. Brannen (2005) defined mixed methods as the use of more than one research method. This, according to Brannen (2005) can be a combination of both qualitative and quantitative methods in one study, but also using more than one different qualitative or quantitative method. More recently, Creswell and Plano-Clarke (2007) and Teddlie and Tashakkori (2009) redefined the term mixed methods to clarify that there is a requirement for both qualitative and quantitative data collection methods to be used in one study. Teddlie and Tashakkori (2009) aimed to stop the ongoing confusion around the term and composite elements, stating that studies which involve multiple methods from one field (qualitative or quantitative) should be termed multi-methods. In accordance with this, a mixed methods approach is used when the aim is to obtain and analyse both quantitative and qualitative data; linking or mixing the two strands of investigation with purpose and rigour. This offers strength to inferences made and a greater sense of completeness and understanding (Morse, 2003; Tashakkori and Teddlie, 2003). In addition, the mixing of methods serves to counteract any limitations that could be found in multimethod or single focus studies (qualitative or quantitative research in application) (Creswell *et al.*, 2003), thus making the research more than the sum of its composite parts in isolation (Tashakkori and Teddlie, 2009). Mixing of data may offer enhancement and embellishment over what can be obtained in a single methods study (Ritchie and Ormston, 2014) with qualitative data giving depth, and quantitative data allowing for breadth (Mason, 2006).

Terrell (2012) offered a simple justification and explanation for using mixed methods, discussing that quantitative data answers question of 'if' and qualitative answers questions of 'why'. This is in keeping with the assertion that mixed methods allows research questions to be answered that could not have been answered fully by a singular methodological focus (Tashakkori and Teddlie, 2003). These considerations offered the study increased credibility as employing both qualitative and quantitative methods enhances the integrity of the findings, offsets potential weaknesses of singular methods, and utilises the strengths of both. These key justifications are articulated in Bryman's reasoning typology for mixed methods (Bryman, 2006). This typology allows for a comprehensive and consistent understanding of why a mixed methods approach was chosen. In this study, the justification was for increased utility of research findings; producing a comprehensive account of the experience and its influencing or impacting factors whilst minimising the potential for both researcher bias in the qualitative enquiry, and measurement bias in the quantitative phase. Considerations of bias and its minimisation in both phases of the study are discussed in Chapter 5 section 1 in relation to qualitative researcher bias, and Chapter 5 section 2 in terms of quantitative bias through content validity scoring and statistical analysis. The resulting findings could subsequently be represented within an activity theory frame.

Whilst inviting, considerable challenges are associated with mixed methods research. Moving away from the traditional separate fields of qualitative and quantitative data being collected and analysed in isolation, mixed methods research requires considerable time, knowledge, and skill to effectively implement a mixed methods study. Moving against the traditional paradigmatic separation, the mixed methods research must ensure integration of data strands is robust and clear; demonstrating how data can be compatible, complementary and integral to the study (Tariq and Woodman, 2013). Whilst challenging, the benefits of mixed methods research in this discreet area of practice outweighed any critiques, and provided a way in which the weaknesses of each traditional paradigm could be counteracted by the strengths of the other in order to present an in depth exploration of the RNMHs experience. The AT lens supported a clear audit trail through the study, retaining focus on key elements of the experience and documenting the evolution of the experience generation from the literature, through both phases of enquiry into the final presentation in Figure 39, Page 252.

The literature had highlighted a dearth of knowledge pertaining specifically to the RNMH in the UK, therefore it was decided that a qualitative phase should be the starting point of this research. This qualitative phase facilitated the development of a deeper understanding through the exploration of experiences from which subsequent phases of research supported a broader analysis. To obtain details of experiences required careful exploration alongside the ability of the research findings to illuminate a new conceptualisation of the RNMH experience. This was achieved by including both qualitative and quantitative data strands (Creswell and Plano-Clarke 2011).

Considering the above discussion, focus is returned to the justification of mixed methods provided by Tashakkori and Teddlie's (2009) guiding assumptions for mixed methods research which resonated with this study:

- Qualitative and quantitative methods are not dichotomous, but sit on a continuum of approaches
- The research question is the driving force of a study
- Data collection and data analysis methods should be distinguished from the design and that all forms of data collected can be formatted and analysed using qualitative or quantitative methods
- Integration of the methods of data collection and analysis does not hold a fixed position.

4.1.3 **Rigour in Mixed Methods Research**

Rigour in research is the accountability taken by the researcher for the quality of data collection, analysis and inferences drawn (Onwuebuzie and Teddlie, 2003). There should be sufficient documentation and appraisal of facets of study to demonstrate its legitimacy and leave an audit trail for the reader to base their judgements on (Onwuebuzie and Leech, 2007). Rigour in qualitative or quantitative studies in isolation is often well presented; the same level of methodological rigour is needed for mixed methods studies. Often in mixed methods research, rigour is not well attended to; with studies failing to report on the processes undertaken in sufficient depth (Brown *et al.*, 2015). Whilst complex, attention should be paid to both strands of investigation as well as the integration of data (Onwuebuzie and Johnson, 2006; Tashakkori and Teddlie, 2008; O'Cathain, 2010; Younas, Rasheed and Zeb, 2020).

Qualitatively, rigour is concerned with the credibility, dependability, and confirmability, whilst quantitative rigour seeks to address considerations of validity, reliability, and generalisation. Whilst these have been traditionally seen in separation, rigour of mixed methods research draws these together to demonstrate robust integration and supports inferences which could not be possible in isolation. To support clarity and best practice in relation to reporting of rigour in mixed methods research, O'Cathain, Murphy and Nicholl (2008) devised the Good Reporting of Mixed Methods Studies (GRAMM) framework. This attends to quality domains that should be clearly presented to demonstrate rigour. These include justifications for using mixed methods, the design or type of design, individual components of each data strand (including data collection and analysis methods), where and how data was integrated, strengths and limitations of methods used, and insights drawn from mixing data.

Table 3, page 83 presents a summary of key elements of this study in relation to rigour and their location in the thesis. This offers a visualisation of the location of discussions that support rigour throughout the study; and a clear audit trail for the reader

Table 3 Rigour: Location of Discussions.

GRAMM Domain	**Explanation/Elements to Support Rigour**	**Chapter**	**Figure/Table**
Justification for mixed methods	Minimal data held about the RNMH and DSD nursing experiences: Qualitative study will illuminate core themes, giving depth to the discussion. Quantitative study will support further description and wider explorations.	4: Methodology 4.1 Recognition of a Pragmatic World View 4.1.2 Mixed Methods	
Design type	Exploratory Sequential Design	4.1.4 Exploratory Sequential Design	Figure 8
Components of each strand	**<u>Qualitative</u>** Truth and validity Interview process Data management Data analysis **<u>Quantitative</u>** Validity Content validity	5.1 Phase One: Qualitative Data Collection and Analysis 5.1.1 Semi Structured Interviews 5.1.2 Data management 5.1.3 Data Analysis: Framework 5.2.4 Calculating Validity 5.2.4.2 Inter Rater Agreement: Clarity 5.2.4.3 Inter Rater Agreement: Relevance	Figures 16,20,21,22 Table 8 Figure 28 Table 9
Data Integration: where and how	Initial integration post qualitative data analysis to inform quantitative phase	4.1.5 Consideration of Designing and Developing the Questionnaire 5.1.4 Questionnaire Development. 5.3 Integration of Data Sets	Figures 10,11

	Quantitative results are integrated with the Qualitative findings to provide an in depth integrated account	7 Quantitative Results and Integrated Findings	
Strengths and limitations	Of methods chosen Of study	4.1.2 Mixed Methods 5.1.1 Semi Structured Interviews 5.2.1 Survey Research and Questionnaire Approaches 9.1 Limitations	
Insights from mixing data	Integrated findings of the study are presented in an Activity Theory Frame to allow themes, concepts and tensions to be explored	7.2 Qualitative Results and Integrated Findings 8 Discussion and Conclusion	Figure 39

Table 3 adapted from the GRAMM principles put forward by O'Cathain, Murphy and Nicholl (2008)

4.1.4 **Exploratory Sequential Design**

With the selection of mixed methods justified, consideration was then given to how the study would be structured. One critique of mixed methods research is that it can be seen to isolate the methods used and leave them juxtaposed. This perpetuates the polarisation of perspectives (Feilzer 2010) and leaves the dichotomy prevailing in research findings (Bryman, 2007). A design was required that would facilitate explicit integration of both data strands to demonstrate the completeness of the study as one collective whole.

The study had already commenced with a qualitative appraisal of the literature, highlighting that there was a lack of understanding of the RNMHs experiences in relation to DSD care. What was illustrated in the literature had formed the first evolving representation of potential influences on the RNMHs experience (Figure 7 page 40). As such a qualitative approach was required to commence the exploration of experience in relation specifically to RNMHs.

Mixed methods design classifications include sequential, parallel, conversion, multilevel and full integration models (Hall, 2020). These are defined by the number of strands or processes in the research, the process of implementation and the point at which integration between qualitative and quantitative data occurs (Teddlie and Tashakkori, 2006). Briefly, parallel designs undertake both qualitative and quantitative data collection at the same time following predetermined structures, and are often independent of each other. Considering the sparse contextually relevant literature pertaining to the RNMH experience I considered this approach inappropriate since there was no body of knowledge to specifically guide or influence an existing knowledge of the experience.

Conversion designs take one strand of data (qualitative or quantitative) and transform it into the other before analysing as a complete data set. This could have been employed by quantifying interview data into themes and applying numerical coding, however the rich qualitative narrative of experience may be lost, and the accounts minimised.

Multilevel designs utilise qualitative and quantitative designs at varying ‘levels’ of data collection (for example qualitative at an individual and cohort level and quantitative at school level), whereas full integration methods utilise parallel designs but mix qualitative and quantitative data interactively throughout, affecting the developments of the other. Finally, sequential designs occur chronologically, with one component (qualitative or quantitative) being influenced and based on the preceding components findings.

Matching the design to the research aims (Creswell and Plano-Clarke 2011), an exploratory sequential design was identified as achieving the best fit. According to Stebbins (2001), exploratory research aims to achieve a level of familiarity with the research subject. This might be through limited exploration in which systematic searching is employed to identify something particular, or a broad approach in which relatively unknown areas, or theory, with little knowledge pertaining to it is investigated. The value here is seen in what might be discovered (Stebbins 2001). This resonated with use of the literature review to inform an initial activity system; and the recognition that there was a minimal amount of information pertaining to both the condition of DSD and the context of mental health nursing in the UK. A primary exploration was required to help illuminate experiences, with a secondary phase refined and built specifically for the context and care constructs exposed. These elements could then be situated in an activity system to represent the experience in terms of influences and impacting factors.

Noted to have an onus on decision-making, long in duration and achieving findings through a cumulative process, the demands of undertaking exploratory research was considered. Whilst labour intensive and time consuming, an exploratory design achieved a fit with the research aims maintaining a pragmatic focus and a level of flexibility (Van Maanen, Manning and Miller, 2001). The second phase of data collection would take place following initial data analysis, refinement, and reconceptualistion of experiences. This would ensure that the data was contextually driven, enhance the overall findings and offer a richer account.

Within an exploratory sequential design, the sequencing of qualitative and quantitative strands may depend on the status ascribed to each separate element (Ritchie and Ormston, 2014), echoing the pragmatic stance that the design or structure of the research is chosen to best answer the questions asked. Either quantitative or qualitative data can be dominant or assigned equal priority (Creswell *et al.*, 2003; Terrell, 2012). As discussed previously, the study had commenced with an initial literature review, and considering the paucity of RNMH specific literature, I felt it essential to have a qualitative understanding of the nurses' experiences, thoughts and feelings in their own words, using their terminology. This would then allow a robust and refined second quantitative phase in which the themes/ideas or subjects discovered in the first phase could be explored in a more overarching manner.

Figure 8, page 88 represents the most linear iteration of exploratory sequential designs. Whilst the qualitative and quantitative phases are undertaken separately it is paramount that the final inferences or interpretation of data is undertaken drawing upon both data sets (Teddlie and Tashakkori, 2009). Integration of data is seen to occur at two points; first when the qualitative data is utilised to build and inform the quantitative phase, and second in the integration and interpretation of both data strands to comprehensively represent the totality of what has been learnt.

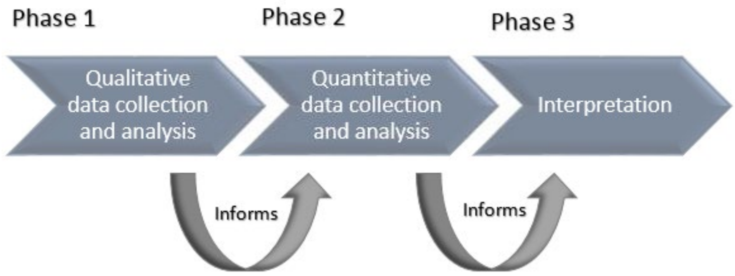

Figure 8 The Exploratory Sequential Process

Adapted from Creswell and Plano-Clarke (2011)

The methods used are detailed in Chapter five, but are discussed briefly here to give an overview of the study in terms of design and sequencing.

The study manifested in three phases which are represented in Figure 9 (page 89). A qualitative phase (1), a quantitative phase (2a and 2b) and a final phase (3) in which interpretations of phase 1 and 2 data were synthesised. Phase 1 indicated the start of active data collection and was conducted using semi-structured interviews. Phase 2a commenced when all interviews had been completed, transcribed, and analysed. Phase 2a consisted of developing a new questionnaire based on the data from phase 1 and its subsequent expert review by subject specialists. This represented the first integration of data. As discussed in Chapter three, this was required due to the lack of contextually specific literature on which to base a questionnaire, and also to minimise any researcher bias I may hold not being an RNMH.

Phase 2b included distribution of the questionnaire to the wider RNMH target population. Phase 3 concluded the study with an integration of data from both phase 1 and 2.

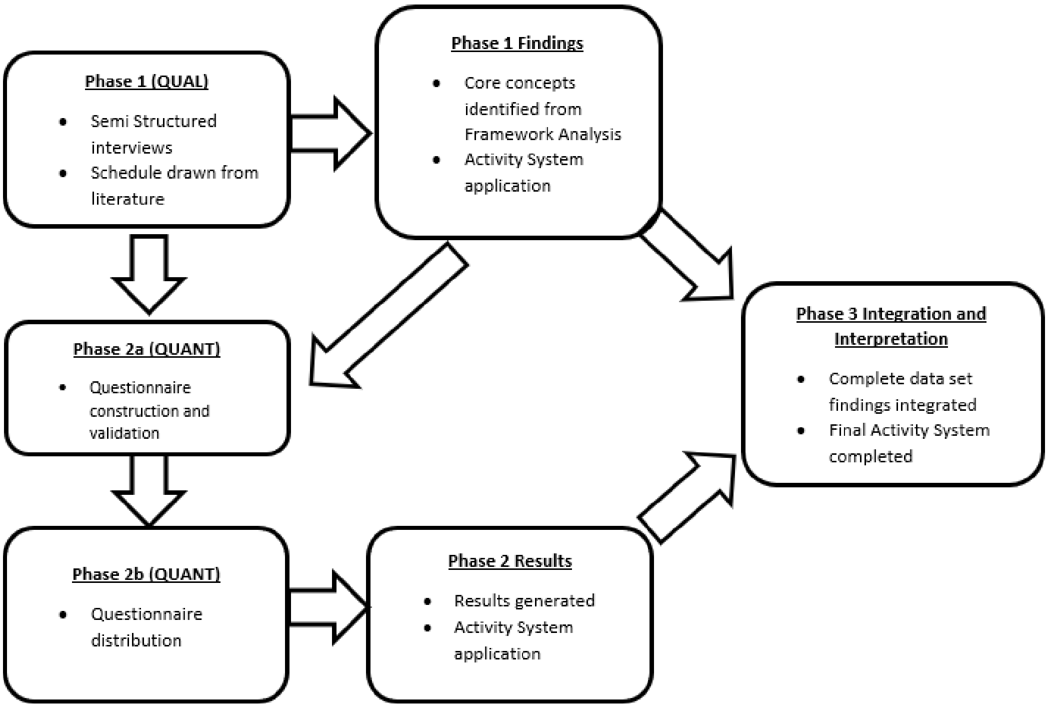

Figure 9 Study Design

4.1.5 **Consideration of Designing and Developing the Questionnaire**

Self-administered questionnaires are not uncommon in healthcare research and medical education; however, the process of development varies in both quality and rigour. The variance in standards of questionnaire production leads to inconsistencies and issues with quality assurance and subsequently, may impact on any conclusions drawn or the use of inappropriate instruments (Boynton and Greenhalgh, 2004; Artino *et al.*, 2014). Collins (2003) discusses a historic drive to standardise the format of questionnaires and instruments in their operation and format. This preoccupation with achieving standard format assumes that everyone will read, process and understand the question in the same way. It is paramount that there is an understanding of how the target respondents understand any questionnaires; it cannot be assumed that questions asked in a 'standard' format are understood as the researcher intended. Coupled with this, in opposition to other forms of quantitative data collection processed (Randomised Control Trial etc.), there are no commonly known, stringent reporting criteria for questionnaires. Considering this, they must be robustly designed with the utmost consideration (Boynton and Greenhalgh, 2004).

Whilst a swathe of authors and texts offer guidance regarding the individual steps that should be undertaken to produce a reliable and valid questionnaire. For example Rattray and Jones (2007) discuss elements of questionnaire development, and Presser *et al.* (2004) advises on the evaluation of survey questions. Much of the supporting literature however focuses on surveys or questionnaires that test hypothesis or psychometric testing from an experimental approach. These focus on specific subsections of the survey design process (such as phraseology or scale development) rather than the complete process required for the first iteration of a survey or questionnaire. For this study, it was important that the questionnaire was designed to remain exploratory, testing a preconceived hypothesis or an experimental approach was not fitting here due to the relatively unknown context of the participants. Therefore, the seven-step guide by Artino *et al.,* (2014) offered the depth and clarity required to ensure that a robust approach was undertaken to questionnaire construction, and aligned with the exploratory sequential nature of this study as a whole rather than a discreet occurrence. In addition, this process enables researchers to validate the questionnaire without a need for psychometric testing of questions in large samples. This was important for this study as it was envisaged that due to the nature of both the RNMH registration requirement, and the discreet practice environment, sampling could be potentially challenging. The approach to questionnaire development undertaken is presented in Figure 10.

Figure 10 Process of Questionnaire Formation

Adapted from Artino *et al.* (2014)

By undertaking the seven steps noted above, Artino *et al.,* (2014) suggest that the resulting questionnaire would hold a have higher chances of gaining quality data due to its cohesive and systematic development. Artino *et al.,* (2014) hold central that questionnaires should ensure all respondents interpret the questions in the same way, respond with accuracy and be willing to respond. The process of questionnaire development is shown in Figure 11 page 93 including the individual steps undertaken and their associated actions and outputs.

Phases one to three were undertaken in this study through the literature review and qualitative investigation, whilst phases four to seven were the quantitative second phase. On completion of the questionnaire and in keeping with the exploratory sequential nature of this mixed methods study, both data sets were integrated, and interpretations were drawn from the entirety of data collected. This is presented in Chapter seven.

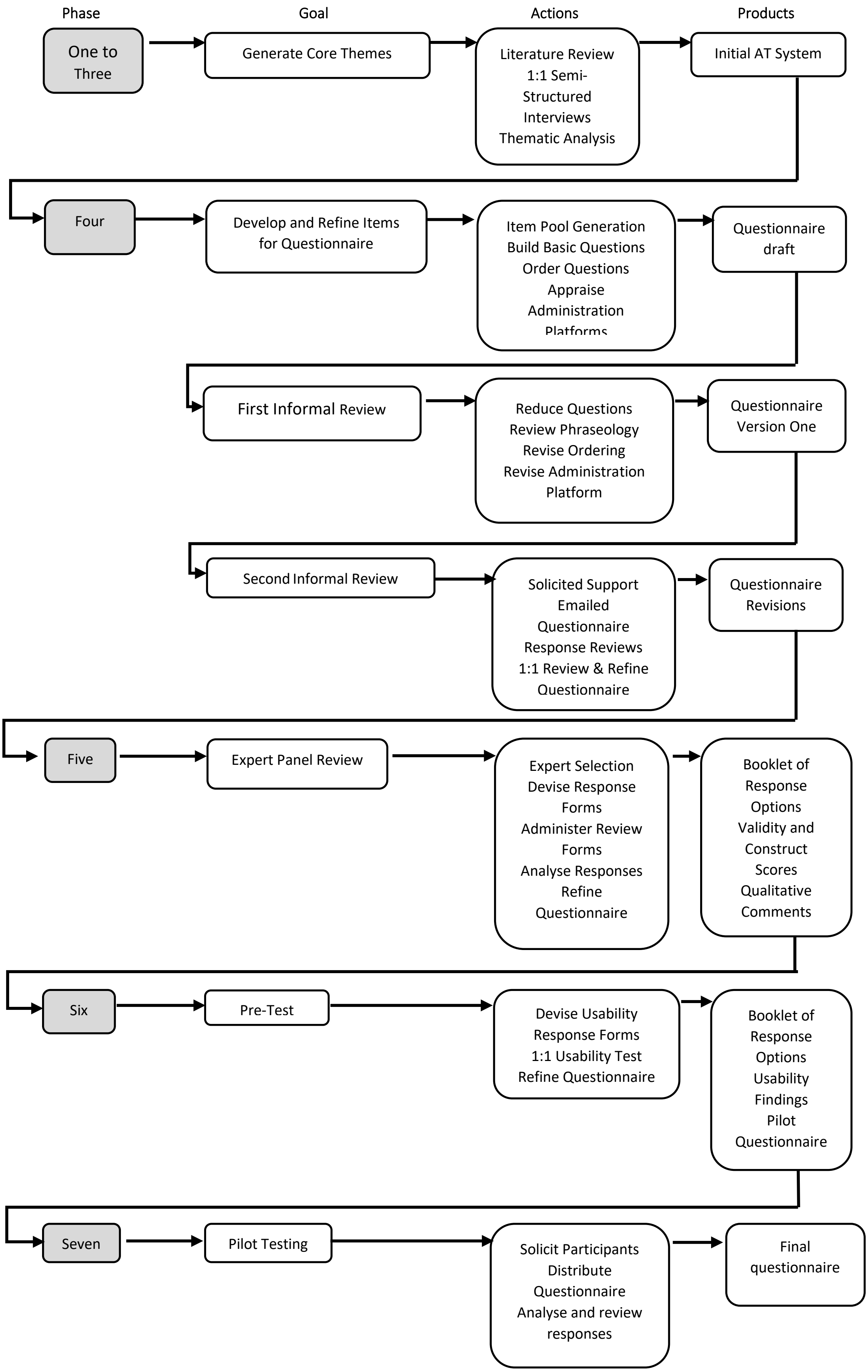

Figure 11 Questionnaire Development Process

4.2 Ethics and Sampling Considerations

There is a consensus that any research study needs to be worthwhile and not ask any unreasonable requests of participants. Universal principles of informed consent, voluntary participation, absence of coercion and the maintenance of confidentiality and anonymity (where appropriate) must be upheld (Webster, Lewis and Brown, 2014).

This study was granted initial ethical approval by the University Ethics committee: study code DHCPryor091015/181115 (Appendix two). Following discussions with the initial research sites research and development team (RDT) it was agreed that the study did not require IRAS approvals due to there being no patient or carer participation. The RDT granted approval: RES-16-012 (Appendix three) and provided access to the communal environments in which participants could be interviewed. Further ethical approvals were sought and granted by the University, private care providers and Health Education England in line with a wider participation base including Health Education England approval for recruitment to phase two at a National Conference, and individual company approvals for care home settings. This is discussed further in this chapter, page 108.

4.2.1 Ensuring Research is Beneficial

For research to be ethical it must be justifiable. This justification can be found in a gap in literature pertaining to a specific subject (Moule, Aveyard and Goodman, 2017). As demonstrated by the literature review, there was a dearth of literature pertaining to DSD in general and, more specifically, the experiences of the RNMHs. This research served to start to fill this gap in knowledge, and may offer a positive contribution to our critical awareness of the nursing experience; illuminating and supporting better understanding of the unique experiences of

RNHMHs and the complexity of the systems in which they deliver care for people with DSD.

4.2.2 **Consent**

The principle of informed consent is central to all research considerations and is a core element of the Declaration of Helsinki, offering ethical principles which must be abided by (World Medical Association, 2018), and is central to my practice as a nurse, and in keeping with my professional code of conduct.

Any potential participants required sufficient information about the study to be provided to them in a manner that they could access, and be afforded time to review this information and ask questions prior to making any decision about participation. This process needed to be voluntary, free from coercion and have a level of confidentiality and anonymity as appropriate (Webster, Lewis and Brown, 2014). All potential participants were sent the approved invitation and information sheets at set times throughout the study. The invitation email to managers, and consent forms are presented in Appendices four and five.

Questionnaires were designed with appropriate information at the fore of the questionnaire format with clear consent and confidentiality statements included as an integral part of the document. Additionally, care home managers received additional information consent forms regarding their home's inclusion in the study in recognition of the multiple private care providers and their individual policies and procedures relating to research participation. All care homes provided signed managerial consent prior to any questionnaire distribution.

4.2.3 **Voluntary Participation**

Important to the ethics of this study is the consideration of my role and potential impact on the study. I commenced the study as a staff member within the initial host Trust for phases 1 and 2, a student of the University, and now a novice researcher. This afforded me to initially seek approval as an internal employee. However, I was acutely aware of the potential impact of my role on the study. Initially, a member of staff, colleague, and peer I needed to ensure I was mindful of any perceived power imbalances or pressure to participate. I left the organisation to take an academic post at the university whilst still in the planning phases of the study, and prior to any active data collection. Careful discussions with the RDT were held with open and clear communication to ensure that the study could still progress and meet all required approvals needed for an external researcher. Timings of research activity and documentation changes were resubmitted to both the University and Trust for reapprove alongside updated study documentation, supplying the proposed study sites with my new details.

Special consideration was given to the principles of consent and assurances of a non-coercive recruitment. I was cautious to ensure that the voluntary nature of the research was stressed. At research meetings, whilst I was still a member of the organisation, I highlighted my University student status, in line with the proposal. At all meetings after leaving the Trust I ensured that I displayed prominently my University identification card and ensured I was identified as working for the University.

Trust is central to the researcher/participant relationship in improving the quality of data through open discussion there needs to be an acute awareness of the difference between building a research rapport with participants whilst not implying friendship (Duncombe and Jessop, 2003). Whilst Duncombe and Jessop (2003) recognise that power imbalances do exist, there is an articulation that these cannot be undone, and as such should not be ignored. However, to address some of the potential perceived power imbalance, the researcher must ensure that the friendly rapport is not misconstrued as, or inappropriately moves towards friendship. In light of my aforementioned professional relationship with the Trust, I was mindful to ensure that I was perceived as a researcher, and not a friend or colleague. I was, however, aware that this might have influenced the level and depth of discussion within the interview phase (Bryman, 2016). To try and mitigate this when potentially interviewing people I had held a professional friendly rapport with previously, I maintained professional communication throughout the recruitment and interview cycle. Correspondence was formal and any discussions leading to non-research based topics were minimised throughout the process. I found this challenging given my previous employment, and the understanding that nursing is built on interconnected relationships. However, I believe I achieved a professional separation from the participants whilst maintaining a friendly warm approach. Within the interviews, any indication of prior knowledge or my working role was explicitly clarified to ensure assumptions of my knowledge base were not made and that I had a full external understanding of the participant’s meaning rather than assuming.

This can be seen in one early interview where a participant was discussing ‘formulations’ and the work that these entail. I was keenly aware that the term had been used several times and that whilst I believed I knew what this meant it had not been explicitly explored. I asked the participant to clarify this which may have seemed strange to them; however, my professional research role meant that I needed to be clear in my understanding of their meanings and discussions, and not base the interview on a perceived shared understanding and colleagues chatting.

4.2.4 **Confidentiality and Anonymity**

The right to confidentiality and anonymity is central to all research. The process for confidentiality maintenance and the articulation of circumstances when this would need to be breached was made explicit in the study information prior to the consent processes and interview commencement. Working with professionally registered and accountable practitioners, the maintenance of the Nursing and Midwifery Council (2015) Code of Conduct was paramount regarding patient safety and raising concerns regarding unsafe practice.

During the interview process, safeguarding of participants and their information was achieved using a unique identifier code applied to all recordings and transcripts. The UI code allowed for anonymization of text but also to ensure the process of withdrawal of data could be completed quickly and with ease if any participant used their right to withdraw interview information from the study. The questionnaires were designed to be anonymous and the nature of the questions did not lend themselves to a disclosure type completion. Formatting of questions is discussed further in Chapter five.

4.2.5 **Ethical Debate Specific to Questionnaire Distribution**

A consideration of the study was the two-phased approach used in exploratory sequential research and allowing appropriate ethical principles to be matched to the data collection phases. Whilst phase one (interviews) was relatively straightforward, recent changes to general data protection regulations (GDPR) prompted careful consideration of the second phase of the study. Following several discussions with the initial organisation RDT, University faculty ethics leads and supervisory team, it was decided that the ward managers would act as access control regarding distribution of the electronic questionnaire. Consent was given verbally by all ward managers to facilitate this and additional discussions updating them on the nature of the research were held. A standardised introductory email was sent after verbal discussion to confirm the process of distribution and offer an additional chance for them to ask any further questions. Following this, an email template was sent to the managers for distribution amongst their staff members via email. This included the URL for the questionnaire platform. By facilitating distribution in this manner, the issue of personal details being sent outside the organisation was mitigated.

For the national conference paper copies of the questionnaire were distributed alongside the public access URL as part of a presentation and conference pack. Care homes received paper copies. This diverse strategy is discussed further in Chapter 5.

4.3 **Sample and Recruitment**

The selection and use of an appropriate sampling strategy allows the researcher to gather the required information from participants who meet specific criteria (Moule, Aveyard and Goodman, 2017). Several different strategies could have been employed for the study, including convenience, snowball, quota or purposive, and all hold specific strengths or weaknesses, however a purposive strategy was decided upon. Purposive sampling is, as the name implies, on purpose. Participants were selected in line with required features and experiences (Mason, 2002; Patton, 2002; Ritchie *et al.*, 2014). The aim here was to obtain a sample of participants who were able to provide information about their experiences of DSD as the phenomena for investigation. In this instance, the sample targeted were RNMH who had experience in caring for people with DSD in 24-hour care settings, employed. Since the study was concerned with RNMHs, those without professional nursing registrations (NHS pay bands 2-4) were not recruited. Whilst there is a significant amount of information and value in the work of other bands and roles within the clinical team (i.e. nursing and healthcare assistants employed at NHS bands 2-4 or equivalent), it was important to focus on the professional group and roles associated with RNMH registration as a professionally accountable, registered workforce. This was specifically justified as the focus of the study in keeping with the UK nurse registration premise and the complexity noted by the literature review regarding broad inclusion of 'nurse' participants in a range of registered and non-registered roles.

The names and titles given to different bands and roles within health care is at present complex. Whilst some protected titles are in place, there may be variance in role and designation. Figure 12 represents the most common generic roles, titles and responsibilities found at each level and the required participant bandings. Band 5 remains the entry point for qualified, professionally registered nurses within the UK to date.

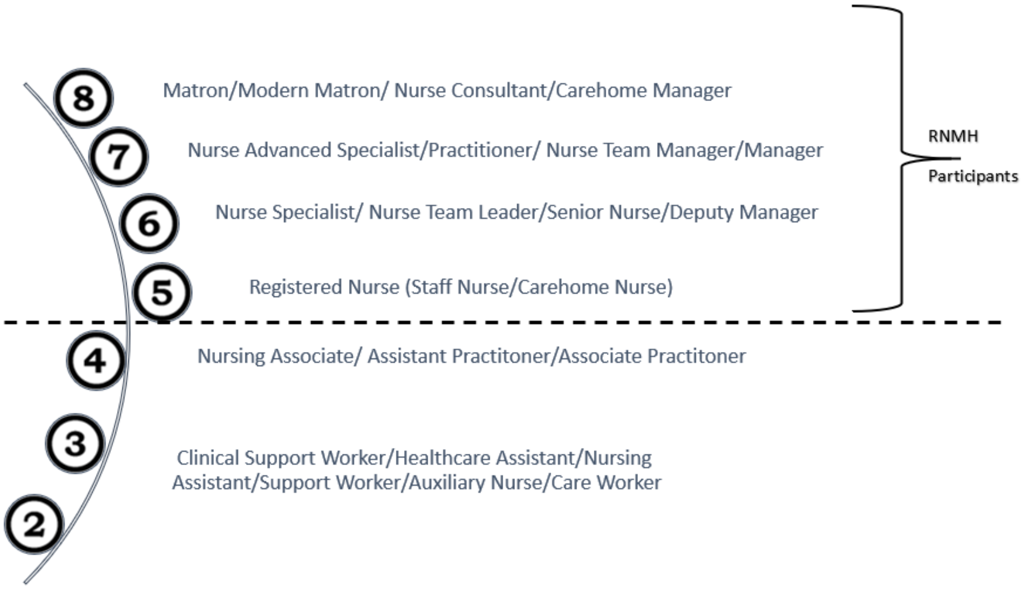

Figure 12 Nurse Role Titles and Banding

4.3.1 **Interview Sample and Recruitment**

The initial sample of RNMH for interview was drawn from the original host organisation (NHS Foundation Trust). Foundation Trust status is awarded to Trusts that can demonstrate a Care Quality Commission appraisal of *Good* or *Outstanding*, have worked with the NHS Trust Development Authority, demonstrate being well led, delivering services of high quality and sustainability whilst having robust and effective governance policies in place alongside being legally constituted (Monitor, 2015). Approved Foundation Trusts are afforded decision making powers independently from central government for their local community, whilst retaining the principles of NHS care provision.

The specific Trust was selected partly due to my original status as a staff member undertaking the research ‘in house’ but, more importantly, as it had chosen to develop and maintain a specialist directorate dedicated to Older People, including those with mental health needs originating from organic processes and, specifically, dementia. The Trust service encompassed the total geographical region and three hospital sites. Clinical areas that did not provide 24-hour organic assessment were not included as the sample needed to be refined to dementia specialities, and the Trust provided care for all those requiring dementia care and assessment within the Older People’s services on a needs-based approach (rather than age). As such, adult acute ward nurses would have little or no contact with DSD and would not fulfil the purposive sample criteria. In line with this, and the evidence from the literature review, a number of dual provision wards were considered in the local acute care Trusts; however, the inclusion of these could potentially detract from the specifics of the RNMH experience specifically in mental health 24-hour organic assessment settings. Therefore, no acute care Trust settings were included in the sampling strategy since they did not employ numbers of RNMHs and predominantly would be focussed on more medicalised aspects of care (as evidenced in the literature review). Their inclusion might have compromised the nature of the study and led to what is known in activity theory as *enlightenment errors.* These occur when data derived from discreet, local small systems are inappropriately applied to varying contexts (Peim, 2009).

The final area for interview sampling was identified as inpatient wards specialising in care of people with dementia or organic mental health care needs. This provision covered three acute organic admission wards (one mixed sex, one male and one female ward), one mixed sex specialist ongoing organic assessment ward, and one dual acute and ongoing assessment mixed sex ward (Table 4 page 105). Participants were identified as registered mental health nurses, working in the above organic assessment units in the older persons nursing directorate as they were more likely to have experience of caring for people who had DSD due to their work setting. After discussion with the Trust RDT, permission was granted to send individual letters to all RNMHs introducing the study through an invitation and information pack. Staff details including name, location and band were provided by the administration teams and packs were distributed via internal mail[9].

As discussed previously, during this initial recruitment phase, my employment changed from being a Trust employee to external employment. After seeking both University and Trust RDT consideration, I obtained an external researcher passport and was re-granted access to the study population. A secondary information pack was sent to the potential participants with the new details of my

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[9] At this time, I was employed by the Trust and had approval for the study as a student and employee

employment and contact details. This was, however, sent via the ward managers since I was no longer able to access individual staff details.

With the cooperation of the management team, I discussed the research at formal directorate meetings and visited all the target wards holding both formal and informal meetings with staff to discuss the research study and answer any additional questions. Interested parties were identified through either emailing me an expression of interest or by giving me their preferred email details so I could arrange an interview.

The size of sample was considered in keeping with the qualitative grounding of this phase of the study. As the aim of qualitative inquiry is to gain depth of understanding from small samples are commonplace (Creswell and Plano Clark, 2011). The size of sample is dependent on what is being researched, with narrative enquiry having as little as one participant, and grounded theory, up to thirty (Creswell, 2007). This fluidity of sample size is noted by Baker and Edwards (2014), who sought the opinion of experts in the qualitative research field. When faced with giving a comprehensive answer to the question of how many participants are required in qualitative research, they concluded *It Depends.* More recently Bagnasco *et al*., (2014 e6) argued that in relation to sampling, ‘size’ did not mean ‘significance’. Creswell (1998) however, offers guidance that, in general, qualitative research usually has a sample size of between five and twenty-five participants.

Due to the intensive demands on myself as the researcher and the sole resource for conducting, transcribing and analysing, it was in keeping with the qualitative premise that no estimates or pre-requisites of sample size were made.

Traditionally ‘saturation’ of data has been used to guide sampling size and as a regulatory idea within qualitative research (Bagnasco, Ghirotto and Sasso, 2014; Saunders *et al.*, 2018); however, this is problematic in respect of when data saturation can truly be claimed. A pragmatic stance was taken regarding when to stop active sampling and recruitment. Thus, using an underpinning theory of diminishing return in relation to volunteers to undertake interviews, sampling was discontinued when: each potential participant in the target area had received an initial letter, ward managers had been invited to participate in discussions about the study, managers had received two follow up emails with further information for dissemination to potential participants, and one location based visit had been conducted for participants to ask any questions about the study. At this stage, further recruitment activities could have been considered inappropriate as several opportunities to be involved has been presented in a range of forms, specifically designed to cover all potential participants (including day/nightshift staff).

The total population from which the sample could be drawn was 52 RNMHs. Overall interview sample size was seven (n=7), consisting of 2 male and 5 Female participants: one band 6, and 6 band 5 nurses. The settings that the participants represented covered acute inpatient assessment units and longer term assessment wards. This provision also spanned single sex, and mixed sex provision of care environment (Tables 4 and 5, page 105). No senior managers expressed an interest in participation despite being in favour of the research being conducted in their clinical areas. This could limit the discussion of experience in relation to managerial and organisational components; however, as the study sought to explore the experiences of those providing care for people with DSD rather than organising the day to day coordination of care activities, this sample ensured that the experiences, discussions and complexity was grounded in, and guided by those who provide daily care.

Consideration was also given to the number of interviews; a sample size of seven was in keeping with Creswell (1998); Creswell and Plano Clark (2011); Baker and Rosalind (2012); Bagnasco, Ghirotto and Sasso (2014), with the specific purpose of the sample being to derive thoughts, feelings and opinions around topics drawn from the literature review, that would inform a second phase of research: the questionnaire, and an overall integration of data in opposition to forming the full study. In this light a slightly lower than desired number was acceptable. The qualitative phase was not a discreet, separate study, but part of the mixed methods continuum. It sought to refine, and further themes found in the literature as a first phase of the overall research; thus the literature was an integral part of this early qualitative exploration. These themes were to be subsequently used to structure in the second phase and ground the research findings inferred from both phases of the study.

Table 4 Phase One Locations by Type and Provision

	Acute Assessment Ward	**Ongoing Assessment Ward**	**Acute and Ongoing Assessment Ward**
Male	1	-	-
Female	1	-	-
Mixed	1	1	1

Table 5 Phase One Participants by Gender and Band

	Band 5	**Band 6**
Female	4	1
Male	2	0

4.3.2 **Questionnaire Sample**

A second sample was derived following the formulation of the questionnaire. This was undertaken to disseminate the questionnaire across a wider population of RNMHs working in 24-hour dementia care settings, and as such were likely to have experience of DSD. This included the Trust, care homes for older people with dementia and participants working in other NHS Trusts and dementia care services. Pragmatically, this wider sample was captured at a local delirium conference (see below for more detail), and also through direct communication with dementia care homes in the region.

4.3.2.1 **Pilot Sample and Expansion to Care Homes**

Prior to wider distribution, the questionnaire was subject to a pilot test (discussed in detail in Chapter five). Pilot testing is a process by which questions are presented as envisaged for the completed questionnaire in a penultimate draft (Burns *et al.*, 2008). This was of utmost importance as no interviewer would be present during questionnaire completion to clarify any points (Bryman, 2016). As an extension to usability testing, (discussed in Chapter five), all questions were tested in a pilot to ensure that they work not only on an individual level, but also that the questionnaire operated as a complete entity. This helped to ensure it functioned as intended (Gehlbach and Brinkworth, 2011; Bryman, 2016).

Sample choice for pilot testing is of debate; Bowden *et al.* (2002) and Gehlbach and Brinkworth (2011) suggest that the sample for pilot testing selected should be comparable, or closely represent the target population of interest, with Bryman (2016) furthering this, by arguing that the sample should not be drawn from the intended target population to preserve the population sampling frame and representivity. However, Artino *et al.* (2014) suggest that the sample can be members of the target population. In keeping with the phase one sampling strategy, purposive sampling was again employed within the original Trust and, subsequently, at a local conference. Within the Trust, the questionnaire URL link was sent to the ward managers for distribution with additional information about the study to ensure transparency of process (see Appendix four). This was followed up with further email contact at timed intervals. No face-to-face contact was made via ward visits at this stage as I wanted to minimise any feelings of coercion and pressure due to my previous role within the Trust.

The online portal was made available for a clearly stated time frame. On expiration of this time frame, despite regular contact and updates the numbers of online respondents were low (n=8). Whilst the total population of the target group in Trust was comparatively small (N=52 at the time). This supported the expansion of the questionnaire pilot distribution to a local conference. This provided a sample on which to review the functionality of the questionnaire prior to wider distribution (questionnaire development and review is discussed in Chapter five).

I had been invited to present the first emerging qualitative findings of the study at a local conference on delirium in March 2019 (Pryor 2019). This was discussed with the University Ethics board and Health Education England. Permissions were granted for me to present the first emerging finding of the qualitative phase as an introduction to the study and an invitation to complete the questionnaire. In keeping with the exploratory sequential design, at this stage, the literature review and qualitative data had been analysed and from this, the questionnaire developed. The presentation was seen as a supportive way to orientate potential participants to the study, show how their voice and experience was desired and needed, but also to give them scope to exert their opinions, and raise any further key areas or considerations (through questionnaire completion). This allowed for dissemination of the new conceptual framework of the RNMH experiential influencing factors (in an activity system format) but also to widen knowledge and engage potential participants in meaningful responsive discussion.

The presentation slides (Appendix six) which built on a previous academic poster presentation of emerging qualitative findings: RCN 2018 International Research Conference (Pryor, 2018) (Appendix seven) were approved alongside the formatting of a paper copy of the questionnaire (Appendix eight). The URL and QR code for the questionnaire was also included in the presentation and in the conference pack to support completion in a manner chosen by the participants.

A total of 21 returned questionnaires (n=21) were collected across the initial Trust based online process (n=8), paper conference packs (n=12) and online completions post conference (n=1). On screening of the returns, 6 were excluded due to inclusion criteria not being met (adult nurse respondents (n=3) and those with non ward based roles, including liaison services, commissioners and unspecified visiting roles in mental health services (n=3). These were identified in free text responses as well as the standard registration questions. In total, 15 returns were deemed appropriate for analysis (n=15)

Following analysis of the data collected reviewing both the online and paper-based versions of the questionnaire, no issues with its operation and completion were noted. Chapter 5, page 182 details the questionnaire analysis process.

Widening the pool of participants at this point was undertaken to include the full remit of 24-hour specialised dementia care settings. Small phrasing changes were completed within the questionnaire to more accurately represent the care home setting and their operational structures (role titles, organisational names etc). Twenty-seven care homes were identified in the geographical region as specialising in dementia care (N=27): ten care home managers did not respond to initial contacts to discuss the research, n=6 identified that they did not have RNMHs working for them, n=1 did initially employ an RNMH, but they left during the questionnaire timeframe.

Ten care homes (n=10) made up the final care home group in the study. In keeping with discussions with the home managers, paper versions of the questionnaires were distributed, and hand collected. This supported recruitment since it gave me the opportunity to answer any questions from the staff or managers and gave a “face” to the research.

The total number of RNMHs in the ten homes was 30 (N=30). Twelve questionnaires were returned from the care homes (n=12) with two (n=2) being excluded as identified RNA completion rather than RNMHs.

4.3.2.2 **Final Sample**

This phased sampling strategy gave space for any refinements to be made (although none were required other than in keeping with local terminology (e.g. location descriptors ward/care home). The total data set for analysis included the total data set in keeping with Artino *et al.* (2014) as no structural or operational changes were made, and no return to sampling populations had been conducted. As such, data was gained which gave a complete picture of the area under investigation and range of nursing profiles within these settings. The total questionnaire sample was n=25 (Table 6, page 110). It is important here to reiterate that this questionnaire formed one component of an exploratory sequential approach, and as such served to further inform and refine the activity system tensions exposed in the preceding phases of the study (borne from the literature review initially, and refined through semi-structured interviews). Generalisation of established constructs or hypothesis testing were not the foci of this part of the study. As such, the purposive sample aimed to include a maximum variation of eligible participants not determined by statistical modelling.

Table 6 Total Questionnaire Sample

Setting	**Total (n)**
Trust	8
Conference	7
Care home	10
Total	25

4.4 **Chapter Summary**

This chapter has presented both the study’s underpinning paradigm and methodological considerations, followed by a discussion of the ethical considerations, processes undertaken and sampling strategy. Grounded in the desire to explore the RNMHs unique and relatively unknown care context in relation to DSD, pragmatism achieved a fit with the aims of the study. Making no claims regarding the underlying reality of the world and knowledge, pragmatism embraces and recognises that both single and multiple realities exist. This duality complements the study and activity theory regarding contextual nature of the research. Moving past the paradigm wars, pragmatism has rejected the notion of epistemological and ontological incompatibility of positivist and post positivist enquiry, embracing the use of multiple methods of enquiry. Matching this inclusive principle, the study design was that of exploratory sequential mixed methods. A qualitative phase started to build an awareness of the nursing experience and context through literature review and semi-structured interviews. Following the qualitative analysis, a subsequent quantitative phase refined and furthered this exploration. This served to add breadth and depth to the research’s integrated findings. This approach is particularly useful in areas of research where little pre-existing data is present. The sampling strategy has been presented, highlighting challenges of recruitment and processes undertaken to mitigate these. The final, total study sample has been articulated following discussions of the discreet phases of sampling.

Chapter five presents the data collection and analysis methods undertaken in their sequential position in the study. This chapter commences with the qualitative interview process, followed by questionnaire development and refinement, culminating in the final integrative process from which the study’s findings are borne

5. Methods and Analysis

Chapter four offered a detailed account of the studies underpinning paradigm, the consideration of this, and its influence on the study design, ethics and sampling strategy. This chapter presents the data collection and analysis methods used and their key considerations. To reiterate, the purpose of this mixed methods study was to explore the experiences of RNMH in 24-hour care settings who provided care for people with DSD.

As a sequential mixed methods study, this chapter commences with a discussion of the qualitative methods of data collection and analysis, before a discussion of the quantitative methods used to develop the questionnaire based on the qualitative findings. The questionnaire review process is detailed prior to the quantitative analysis methods being discussed. The qualitative findings are presented in Chapter six, in keeping with their emerging AT positions, followed by the quantitative results and integration in Chapter seven to form an integrated AT system.

5.1 Phase One: Qualitative Data Collection and Analysis.

As discussed in Chapter four, seven semi-structured interviews were undertaken with RNMHs over a course of three months between December 2016 and January 2017. Framework analysis was used to thematically analyse the interview data prior to the findings consideration in the activity system. The process will be detailed here, exploring the stages of familiarisation with the data, generation of a thematic framework, indexing and sorting, review of data extracts, summarising and display of data, and finally abstraction and interpretation. The final interpretations of the data are then presented in an activity system in Figure

23, page 143.

Qualitative research aims to consider the experiences of participants within a social setting (Creswell and Creswell, 2018). Data was collected in the participants' own professional setting following careful consideration of the most suitable methods for collecting their data. Interviewing is a useful and popular form of data collection and is the most predominant data collection method for qualitative research. This is due to its flexibility and ability to allow participants to discuss topics that they feel are relevant to the overall interview intention (Bryman, 2016). Considering the study design, with qualitative data informing a predominantly quantitative questionnaire development, interviews were seen as the natural fit for the initial phase of inquiry as they provide an opportunity for researchers to gather information of personal experiences, thoughts, opinion and attitude with flexibility (Moule, Aveyard and Goodman, 2017).

Potentially, combined interviews and observations could have been undertaken at this stage, to review and explore if the themes and opinions discussed were matched in practice and interactions in the care settings; however, this was not undertaken as the driving aim of this research was to illuminate and explore the RNMH experience, rather than explore and evaluate perceptions of experience linked to actions. This study, as a first exploration of the experience was concerned with achieving an initial overview of experiences and tensions in an activity system; this information was required first, prior to any future research to match perceptions, actions and impacts in a practical manner. Thus, the selection of qualitative interviews offered a means of securing context specific, authentic accounts of participants' feelings, views and reports of actions.

The concepts of ‘truth’ and ‘validity’ were considered in keeping with this phase’s qualitative foundations. Here, the concept of ‘truth’ is not bound in factual, certain findings, but instead considered if the descriptions gleaned from information gathered are truthful, or faithful to the participant themselves. Gathering data from interviews relies on participant memories, formed experiences and a willingness to share that information in some manner, and to what level. Memory is shaped by time and cultural components, and as such is not a direct replication of an event or experience, but an approximation (Randall and Phoenix, 2008). Drawing from this, validity of interviews then is not bound to a static truth to be exposed, but more that the information gleaned relates to the subject under exploration and holds descriptive validity, (Maxwell, 2002) rather than attempting to match data given in interview to actual occurrences. This phase of the study aimed to explore and further illuminate the participants’ thoughts, experiences, and considerations as they perceive them, not test their attainment of perceptions in practice.

Considering this, the careful selection of type of interview, alongside how the data was to be handled was paramount. For qualitative research, interviews are considered a conversation between the researcher and participant, where the interviewer asks well-thought-out, purposeful questions to obtain specific information (Polit and Beck, 2014); in this case, their experiences of DSD care provision and what influences them. Telephone interviews were considered as they are often perceived as less intruding, and support cost reductions in regard to environment and travel (Bryman, 2016; Moule, Aveyard and Goodman, 2017): however, the remote nature of the interviewer and interviewee means that the ability to see body language and facial expressions is lost. Removing the opportunity to see such nuanced non-verbal communication could lead to missed opportunities to develop an area of questioning further (Yeo *et al.*, 2014). Not being able to read the participants' body language may have impacted on the manner in which questions were posed, how I used supportive, and encouraging phrases to prompt further explorations of topics. From the participant view, not being able to see an open, engaged and relaxed posture from myself may have hindered the interview rapport, their comfort levels to discuss potentially difficult areas of experience and be certain that their information was engaging and being listened to fully and afforded value.

An alternative form of data collection considered was focus groups. Whilst focus groups may minimise time allocations and are relatively easier to organise than individual interviews, they are predominantly used to confirm or explore group insights and components already drawn from other methods of data collection whereas interviews would allow for in depth analysis of information on an individual case by case basis and holds a higher potential for pertinent insights to be drawn. With the dearth of information available from RNMH and the 24-hour care context specifically, the study needed to be able to collect in depth, and insightful data to inform the second phase. In addition, whilst focus groups would allow participants to be able to see myself as the facilitator and read my body language, the personal connection and impact of competing voices may lead to loss of depth of discussion and variations of experience minimised for a dominant theme. Careful attention would have been need to how to manage dominant personalities, confrontation, simultaneous dialogue and issues with recording group discussions either using audio devises or in note forms (Finch, Lewis and Turley, 2014).

Understanding the clinical contexts of the participants I wanted to access, and the importance of gleaning information from a new area of practice, one-to-one semi-structured interviews were chosen as the method of qualitative data collection. This decision was based upon the ability to keep both structure and flexibility in interviewing using an interview schedule. Being interactive in nature, would allow me to gain a depth of discussion reaching below surface issues and open the possibility of generating new thoughts and ideas in the participant through reflection and contemplation which could be gauged through watching the demeanour of the participant (Yeo *et al.*, 2014).

Wanting to use a responsive style of interview, a preparatory list of question prompts was derived from the literature review activity system. Kvale and Brinkmann (2009) highlight that interview questions have two key features:

1. A thematic component that centres on the *what* of the interview
2. A dynamic component that focuses on the issues regarding *how*

These key features were considered when devising the interview schedule and covered topics such as examples of care provision specific to a patient, their self-perceived knowledge base of DSD, guidance that they can access in practice, factors that help or hinder practice or use of guidance, their assertions of care priorities for DSD, areas that they would like to change, and what could support this or hinder that change and any needs they perceive in their area. These topics were intentionally broad as the RNMHs experience had not been articulated in the literature, as such the questions needed to allow the participants to guide the direction of the interview towards what was important to them and their experiences.

The questions formed a prompt sheet (Appendix nine) to facilitate discussion and interrogation of the research questions, but flexible and allowing for individuality of response and direction. This format allowed for both consistency in interview broad discussions, but also for flexibility for each participant to give detail where they felt appropriate. I was aware that there might be instances when the interviewee was ‘knowing’ but found themselves unable to articulate their knowledge or indeed unwilling (Alvesson, 2011). The prompt sheet was fluid enough that if this arose in the interview, I would be able to reframe the questions in a more accessible manner or ask alternative questions to ensure the interview flowed and maintained the interviewee’s confidence in their ability to participate. It was also considered a useful tool for myself as the interviewer to act as an aide memoire (Marshall and Rossman, 2011). This was important, as having a very relaxed and responsive interview style, I still wanted to be assured that all key topics had been covered.

Follow-up questions were used to explore and expand on the initial responses offered. This was used to elaborate, add clarity or understand processes in practice. Follow up questions were also employed to test themes that were emerging and ensure understanding. Probing questions were used to keep the flow of the interview maintained. For example, when participant 0101 struggled to talk about her experience of providing care for someone with DSD, at an appropriate time I asked ‘*How did that feel as a mental health nurse? How did you feel when you were thinking about what maybe you needed to do?’.* These probes sought elaboration on key areas, and were used to steer the direction of the interview towards the questions asked and to confirm or clarify elements (Rubin and Rubin, 2012).

I was conscious that whilst the questions and prompts were drawn from the literature, that my employment and experiences in practice could be influencing my underpinning considerations and influence my language choice, perceptions and reflect my a priori knowledge of DSD from an RNA stance, rather than that of the RNMHs. To help address this, the interview schedule was reviewed, discussed, and revised in partnership with a supervisor and with the emerging themes from the literature review. Leading questions and phrases were amended and the schedule was refined, agreed and formatted prior to the commencement of interviews (Rubin and Rubin, 2012).

My role as the interviewer was to facilitate information sharing, but not to influence the discussion with my own thoughts and opinions. Again, there was a concern for the relationship of interviewer and interviewee in line with my previous employment in the clinical area. The standardised interviewer role is often seen as removed with a distance from the participants to achieve a neutral stance. This has been criticised though as Yeo *et al*., (2014) identify this as purveying a power imbalance in which the interviewer is perceived as dominant. It was important that I was aware of my own position and behaviour in the interview setting and remained open, flexible and non-dominating. Kvale (1996) provides support of my role as interviewer; recognising the value that could be afforded by my a priori knowledge (albeit from a different registration context), discussing that the interviewer can be seen as an instrument of research themselves, in that they hold knowledge of the subject being investigated and may possess a high level of communication skills. I had to some extent a shared understanding of the patient presentations, terminology, and organisational constructs in a broad sense. In support of this, (as an individual known on some level to the participants), Clark (2006) argues that an interviewer’s knowledge of, and rapport with interviewees is invaluable in qualitative research. That said, due to the nature of the interview topic being from an RNMHs perspective, and not my own as an RNA, it was of paramount importance that trust, and transparency within the interview process was maintained. This was to allow the voices of the RNMH to be heard, and not that of a combined RNA and RNMH stance.

It was essential that I maintained a level of reflexivity throughout the interview process; identifying my own assumptions and beliefs whilst being cognisant of how this might impact on the interview information (Corbin and Strauss, 2015).

There needed to be some mechanism for checking and clarifying my understanding of the information given in the interviews and the meaning ascribed to it. Throughout the interviews I was cognisant of any terminology or colloquial phrases used by the participants and asked (even if I felt I knew what it represented or understood their meanings) to explicitly discuss this for me. At key points, I summarised my thoughts and information gleaned from their discussions using phrases such as ‘what I hear you are saying is…’, ‘you have mentioned ……, what is that?’, ‘can I check I’ve got this right…’. This allowed me to check with the participants that I was understanding their information and supported rigour within the study process.

In addition, post interview member checking processes were considered initially in the form of interview transcriptions and evolving themes found on analysis being returned to participants for comments (Cohen and Crabtree, 2006); I decided against this, however, due to the fluid nature of contexts and knowledge. It was feasible that through participating in the interview, the nursing staff, with a professional accountability to maintain their clinical knowledge base, might have sought to update their knowledge post interview. On reviewing the transcripts they could have changed their minds or acquired new knowledge which could have confused the initial interview data (Morse, 1994). Returning to the pragmatic underpinning of the research and recognising the fallibility of knowledge, the assumption made by member checking as having a fixed truth or static knowledge did not achieve a fit with the research proposal (Angen, 2000). Nevertheless, with the need to ensure clarity and accuracy of findings, a more responsive approach was employed; questions were asked in the interview to allow for assurances of my understanding, clarification of meanings and summarising key points. This was undertaken throughout (as discussed above), at natural intervals as the need arose to allow for participants to correct my understanding, afford consideration, and secure surety in both our understanding of what had been said, and how it had been received and understood.

5.1.1 **Semi-Structured Interviews**

Prior to interview commencement, it was paramount that thorough preparations had been undertaken (King and Horrocks, 2010). One key consideration was that of how data would be recorded. Interviews are not always audio recorded, but recording would allow for verbatim transcriptions and inclusion of participant quotes to show clarity of conceptualisation and thematic development alongside maintaining descriptive validity and ensuring rigour (Maxwell, 2002; Moule, Aveyard and Goodman, 2017). This also minimised the risk of data being forgotten or overlooked if collected via notes, thus enhancing rigour further in the findings (Moule, Aveyard and Goodman, 2017). The decision to audio record interviews meant considered thought pertaining to preparation of the technology, my confidence to use the recorder correctly, power supply maintenance and the time and location of interviews to allow for a clear and non-compromised recording. Prior to commencing the interviews, I allowed time to familiarise myself with the recording device and rehearsed the list of interview questions.

To help structure the interview process, Yeo *et al.*, (2014) present a six staged approach for interaction with the research participant. Commencing at arrival and introduction, then progressing through identification of topic, beginning the interview, during interview, ending the interview and after interview, Yeo *et al.* (2014) offer considerations and key points to help achieve a focused flow through the interview process construction and execution (Figure 13).

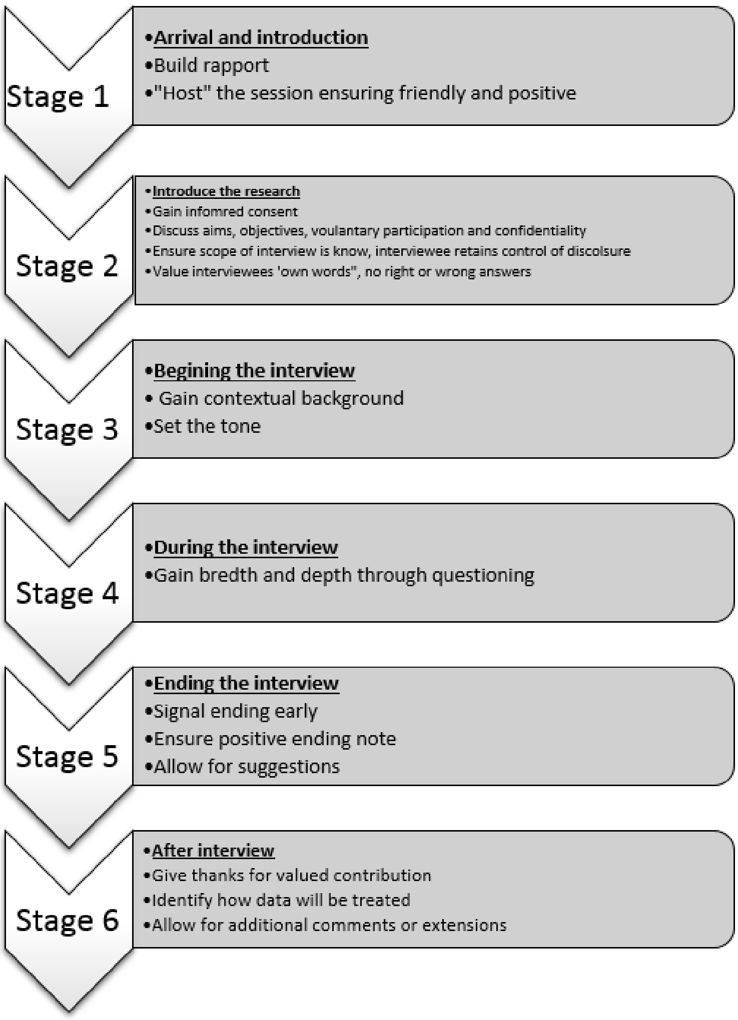


Figure 13 The Six Stages of Interviews

The interviews were undertaken in line with this process.

At the outset of the interviews, the research topic and aim was reintroduced and I ensured that the participant had received a paper copy of the study information sheet prior to the interview and felt they had sufficient time to read and consider it and still wanted to proceed. At this stage, consent was formally taken in written form and recorded using approved interview consent forms (Appendix five).

In total, seven interviews were conducted over a three-month period. For accuracy assurance, all interviews were transcribed with their associated participant code. The transcriptions were completed by myself and subjected to three separate formal reviews in which I listened and re-read the transcripts simultaneously to assure their clarity and accuracy.

As the sole researcher, I was able to immerse myself in the data throughout the process. This was organic in nature as I undertook all processes involved in the research. As discussed later in the data management and analysis process (Chapter five, page 126), two transcripts were selected for review and coding by members of the supervision team to offer assurances of accuracy and trustworthiness through peer checking of coding.

5.1.2 **Qualitative Data Management**

A data management programme (NVivo™) was used as a repository for the data files, transcriptions and as a data management platform. This supported visualisation of the framework analysis process detailed below, and did not extend to software generated coding or analysis. The use of NVivo™ also supported robust and secure custody of data. Password protected files were saved to the U drive including audio files and transcripts. Any paper notes were stored in a locked cupboard in a locked office with only the allocated unique identifier (UI) code as identification. The UI was applied to the audio files on uploading from the digital recording device and used as the file and participant identifier. Once saved securely on the NVivo™ platform and in a separate U drive file the original recording was deleted form the device. Once transcription was complete the participants were sent an individualised email containing their UI to ensure they could recall their data at any time if they wished (shown in Appendix ten).

5.1.3 **Data Analysis: Framework**

Wanting to view the participants' world through their data, a substantive analysis strategy was employed, using recordings and interpretation of meanings to ask questions of the data (Spencer *et al.*, 2014a). It was recognised that answers to these questions may have stemmed from the emerging concepts embedded in the data, but also from my a priori knowledge based in experience and literature (Gibbs, 2007). With this a priori knowledge, and limiting the crossover of my own RNA experience being a central consideration throughout the research, framework analysis was selected as an appropriate data analysis method, helping to show clearly the origins and development of concepts adding to the transparency of the research.

Key to the decision to use framework analysis, was the absence of an affiliation with a specific research approach; be it epistemological, theoretical or philosophical. Framework analysis is flexible in nature, adaptive and suited to qualitative methods in general where a generation of themes is required (Gale *et al.*, 2013). The framework could evolve from the interview themes, alongside the considerations and interconnections highlighted in activity theory, grounded in the data and not preconceived assumptions or epistemological stances.

Achieving a comprehensive fit with the research, framework analysis is concerned with the uncovering, interpretation and robust documentation of trends, patterns, interpretations and consideration of meanings drawn from data (Spencer *et al.*, 2014b). Allowing for a thorough and comprehensive investigation of data whilst producing a clear audit trial, framework analysis increases credibility of any conclusions drawn or findings and enhances rigour (Ritchie and Lewis, 2003) by providing a robust and systematic approach to data management and categorisation (Gale at al., 2013). This is demonstrated through the visual production of initial thematic matrices and frameworks which are refined throughout analysis. This supported the refinement of data into its naturally evolving themes, continual integration of emerging themes (Braun and Clarke, 2006; Joffe, 2012) and application into an activity system. This process also supported tracking their evolution from first iteration in interview and combined presentation in their themes. This provides a clear audit trail throughout the analysis process.

Framework analysis briefly encompasses five key stages: familiarisation, thematic framework generation, indexing and sorting, review of data extracts, and finally data summary and display leading to abstraction and interpretations. This is depicted in Figure 14 and is discussed further throughout Chapter 5.

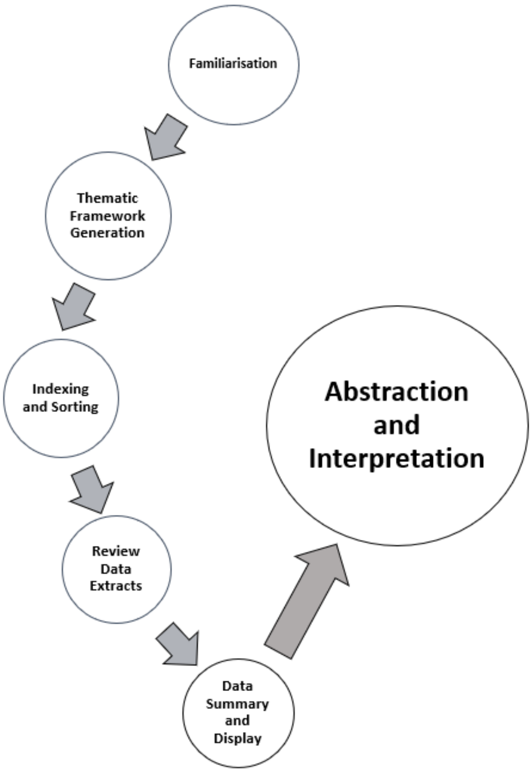


Figure 14 Framework Analysis Process

Whilst outlined in a linear manner, the process of framework analysis is one of constant interplay between all stages involved (Gale *et al*., 2013), but transparency between findings and original interview material is maintained by the data analysis processes involved (Pope, Ziebland and Mays, 2000; Ritchie and Lewis, 2003; Braun and Clarke, 2006). This more fluid process is represented in Figure 15.

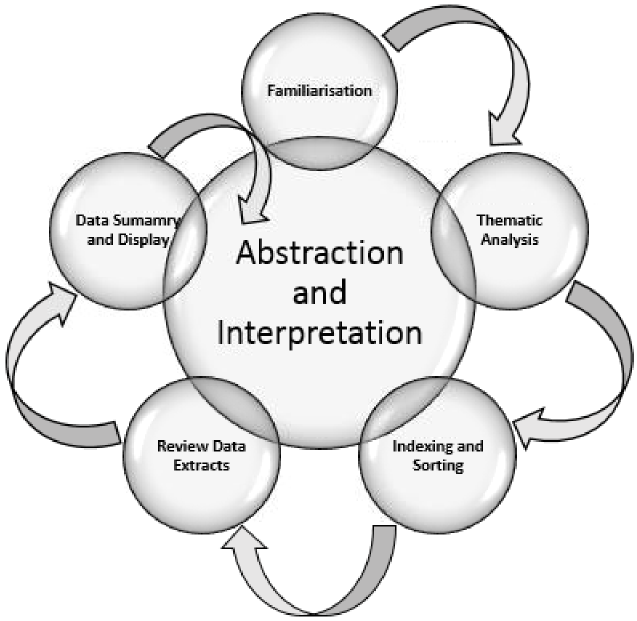


Figure 15 Fluidity in Framework Analysis

5.1.3.1 **Familiarisation**

Familiarisation involved immersion in key data as an active process: engaging with the data to search for potential meaning or patterns (Braun and Clarke 2006). Early familiarisation commenced during the interview and transcription process (Riessman, 1993), to allow for the generation of a framework which could be applied to, and in tandem with subsequent data collection. Whilst it could be argued that familiarisation should occur once all data collected and a sample derived from all data available, the founding principles of pragmatism discuss that there is an abductive connection between data and theory and a movement back and forth (Morgan, 2007). This is reiterated by Spencer *et al.*, (2014a) who discuss that the process of data analysis has no fixed starting point, it can occur at any stage and continues throughout the research process.

Familiarisation, in this study, commenced informally before the formal familiarisation processes began; through my role as interviewer, and by undertaking my own transcriptions. Connected to the data from the start, I rapidly became fully immersed in considerations of what I was hearing. Formal familiarisation begun with the first two interviews and their transcription. This choice was based on a rationale of time of interview (within a day of each other), their variation in location (different base sites and including one acute assessment mixed sex ward and one dual acute and ongoing assessment, mixed sex ward), and participant characteristics (one participant at band five with less than two years registration, and one band six nurse with over ten years' experience). This represented a breadth to the interview characteristics (Ritchie and Spencer, 2002). It was also convenient, due to them being the first set completed. This was beneficial as it meant initial familiarisation would include potential data drawn from different perspectives relating to responsibilities. Whilst it is possible to include an entire data set in familiarisation, due to the total number of interviews conducted, a set of two was deemed appropriate in proportion to the overall data sample size (Spencer *et al.*, 2014b).

The two interviews were listened to repeatedly and read alongside their transcription. An initial list of common themes, topics, phrases and ideas was drawn up whilst reading and listening to the interviews. Initial groups were formed in which certain aspects of data could be identified or labelled. Prior reading, the literature review findings, and a contextual awareness of practice were important here, but with the gap in research and evidence specifically relating the RNMH and DSD in the UK context established, further exploration of the literature was placed on hold to allow for generation of themes from the data as closely as possible at this stage.

From the two interviews selected for familiarisation, ten key areas appeared to emerge. These were given descriptive names. As the interviews progressed, subsections were added to the frame, including relevant information or comments that seemed to build, be a component of or add to the overall theme. Multiple subsections were required for some key themes to allow manageable sections of related text to be brought together. Using the NVivo™ software, diagrams of the initial topics generated were devised to show associations and relationships. These were denoted as T followed by a numerical system for overall theme and component sub theme elements. The initial T considerations are described briefly below to highlight the thought processing throughout familiarisation and initial thematic generation. Figure 16 page 128 shows the full thematic familiarisation process.

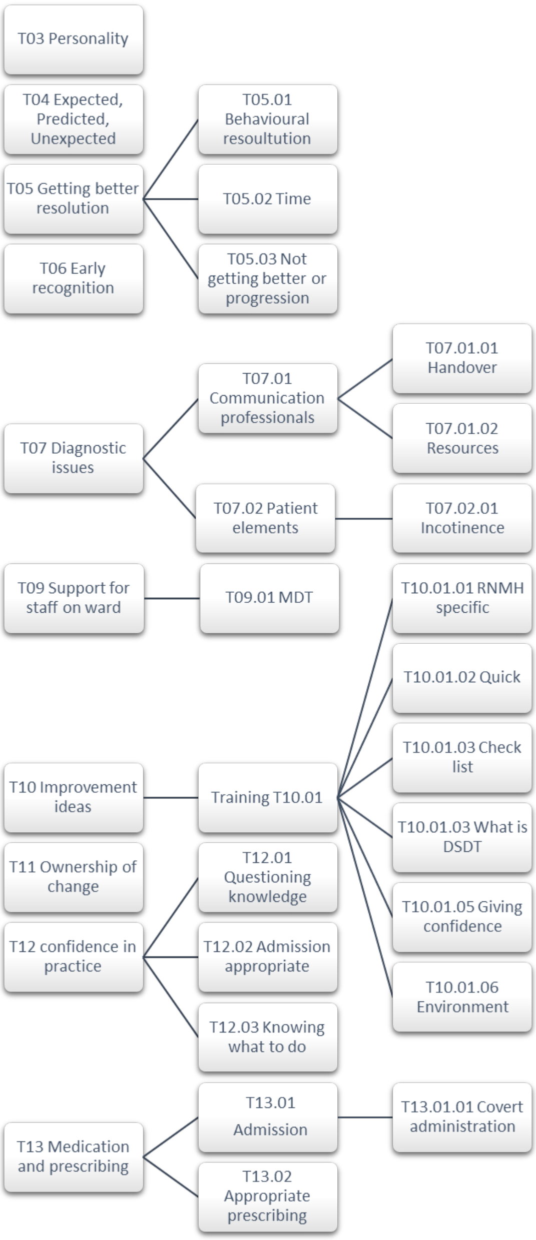


Figure 16 Familiarisation Matrix

Two examples of the initial familiarisation, identification and thematic building process is discussed below in relation to initial theme generation.

T10.01 training (Subsection of T10 improvement ideas) formed a substantial part of both interviewees' latter discussions. Regarding what was needed or what would help them, the importance of education and having a knowledge base was apparent. The participants discussed a lack of resources in terms of professional information provision and requested more training throughout. That said, there appeared to be a notion of being content with current practice, but also an inability to change practice as they lacked the knowledge of how to do things differently, and if anything should be done differently. A formal style of education also appeared favoured with seminars or lectures being noted as beneficial. The gap between university education, learning in practice and the need to continue independent learning was raised, highlighting variance between evidence and practice. Interesting here was the request for training to be *simplified* for mental health nurses. This discussion, whilst brief, appeared to hold significant contextual and cultural information. The request for more '*basic'* education for RNMH raised questions of why it was felt it needed to be simplified, and from what original form? This was matched with discussions of large scale/session education not necessarily being needed, but a very practical outlook with requests for checklist style information to support decision making. Implementation of learning from university appeared hard to translate to practice, with experiential learning coming with experience.

What seemed key here was the variance in perspective between participants. One appeared to hold knowledge from evidence-based guidance, and of evidence-based guidance available, but articulated the difficulty of implementing this in practice whilst, in contrast, the other participant discussed a lack of formal guidance for clinical practice, but a contentment in delivering a high standard of care. The dichotomy of perspectives and awareness of resources and guidance seemed pertinent. I started to consider the variance in tools and guidance, and the regulations or cultural practices in different settings and how the involvement of different professionals might be influencing or mediating practice.

Questioning knowledge (T12.01) evolved through a sense of the participants not only questioning their own knowledge base as the interviews progressed, but also that of peers, fellow multidisciplinary team members, and also DSD knowledge in the much wider care arena. There was an articulation of the commonality of DSD in the older population, and surprise that it was not higher on the care agenda or better known. The nurses discussed community practitioner's recognition of underpinning causes of delirium. This was in contrast to their own 24-hour/inpatient care setting. Highlighting their thoughts and experience of appropriate places of care for people with DSD; and they questioned whether admissions to hospitals might be avoided if practitioners working within community services had appropriate knowledge about DDS. There was an implicit consideration that if more was known about DSD and screening or assessment took place in the community prior to admission, potential admissions could be avoided, and more rapid and appropriate care provided.

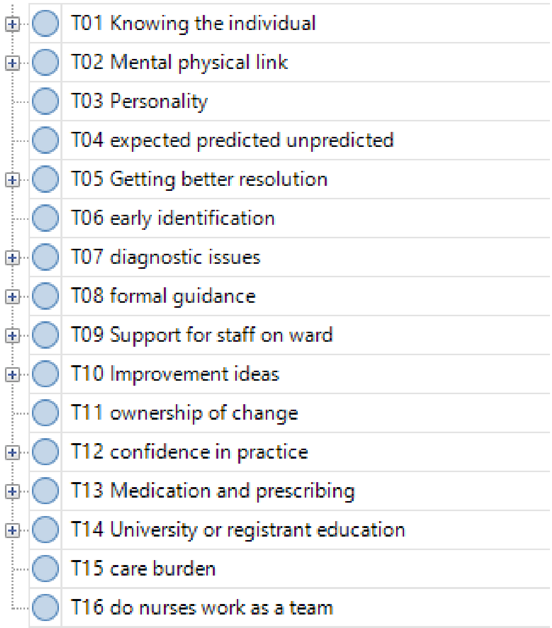
5.1.3.2 Thematic Framework Generation

From the initial familiarisation, tentative themes were identified. Maintaining centrality of the research aims data was revisited and an in-depth process of analysis and formation of key themes undertaken to form a framework to which all subsequent data could be applied (Ritchie and Spencer, 2002). These frameworks are often presented as a hierarchy with subsections in which data can be sorted (Spencer *et al.*, 2014b). Important to note here is the concept of *key* themes within thematic analysis; key themes may not necessarily be founded in frequency of occurrence (which could be both in depth or superficial in nature) but can also be found in the illumination of something important or fundamental to the questions being addressed (Braun and Clarke 2006). Whilst prevalence of discussion points offers an overt indication of the number of participants reporting potential themes, the content, quality and what can be gleaned from the accounts is of paramount importance.

Following initial familiarisation, the interview transcripts were re-read and reviewed alongside the allocation of the familiarisation framework. Emerging key themes were identified and annotated with excerpts or references from the interview transcriptions from which a catalogue of topics was formed with their associated text. Remaining grounded in the data and maintaining a descriptive labelling system (Spencer *et al.*, 2014b) associations and underlying themes linking elements of the transcripts were considered. Central to framework analysis is the notion that it is non-linear (as discussed previously). The process of abstraction and conceptualisation had already begun in familiarisation and continued to progress as the thematic framework was generated, this continued in a cyclic manner through all stages of the analysis process (Ritchie and Spencer, 2002; Gale *et al.*, 2013). Building the thematic framework into which all interviews would be applied led to several inclusions and ongoing refinements. This refinement is recognised as being influenced by the transcripts and audio recordings, the interview process and issues or experiences highlighted by the participants (Ritchie and Spencer, 2002). Additional themes emerged from subsequent interviews and were added to the matrix. Whilst increasing the emerging thematic frame initially, it was paramount that the complexity of the subject was not underrepresented and protected from the risk of misrepresenting data or leaving pertinent issues without a suitable section to be grouped in. As such the matrix, grew, flexed and subsequently refined itself throughout the process.

5.1.3.3 **Initial Themes**

A selection of initial themes generated are represented by Figure 17. T01,02 and 08 are offered below as examples.



T01 Knowing the individual
T02 Mental physical link
T03 Personality
T04 expected predicted unpredicted
T05 Getting better resolution
T06 early identification
T07 diagnostic issues
T08 formal guidance
T09 Support for staff on ward
T10 Improvement ideas
T11 ownership of change
T12 confidence in practice
T13 Medication and prescribing
T14 University or registrant education
T15 care burden
T16 do nurses work as a team

Figure 17 Evolving Thematic Framework

T01 Knowing the Individual/Person.

The participants showed a collective appreciation for seeing the person with DSD as an individual. Knowing their personality, social history and preferences appeared to drive care and treatment decisions. Behaviours and diagnostic subtype of dementia were considered, alongside the fragility or underlying damage caused to the brain by dementia. This supported a link to the *object* domain of activity theory. With the purpose of the RNMHs being to provide care.

T02 Mental-Physical Link

Discussions of causes and treatment of DSD revolved around physical causes and treatment. Interestingly, when reviewing the transcripts, DSD was not mentioned often. A preference for splitting or seeing delirium as an isolated factor was clear, alongside a clear discussion of infection being a prominent issue in DSD practice. There appeared to be a strong focus on treating physical illness but psychological interventions for DSD did not feature overtly in discussion. This was an interesting observation which prompted a specific line of thought regarding role and care premise as it could be expected that (as an RNMH) psychological care would be more commonly discussed in this clinical setting. This supported a link to the *rules* of an activity system: what it is that an RNMH does or what their intention is.

T08 Formal Guidance

Considerable variance was found across the interviews in the discussion of formal guidance or tools in use. Some participants were very clear in their discussions of the use and requirement by the Trust to use formal standardised tools or guides for delirium assessment or identification. However, in a total contrast there were also articulations of no such tools or guides used or available in practice for use. The variation continued further in the discussions showing presence of tools or guides relating to what they were, how they were administered and whose role it was to administer them. This clearly linked to mediating artifacts or *tools* in activity theory.

As with the familiarisation framework each section of the thematic frame had one or more subsections in which data could be allocated depending on its meaning or purpose within the interview. These remained broad and open to refinement throughout the process. Indexing and sorting continued the thematic framework process by making often large and difficult to handle data more manageable.

5.1.3.4 **Indexing and Sorting**

Each key theme had the potential to become an index[10] on which other data could be applied and referenced (Spencer *et al.*, 2014b). These indices, in the initial phases of analysis are often descriptive in nature (Spencer *et al*., 2014a) as each individual interview transcript is applied to the thematic framework.

Each interview was read in turn with emerging issues being questioned regarding their meaning or any associated components (Spencer *et al.*, 2014a). Application of these sections to the thematic frame created an index listing system in which data extracts could be placed. There was no quota on how many indices could be applied to each section of data with several appearing in multiple index locations. This helped to highlight the natural overlap and tension between themes and subthemes present in the data set. These interconnected thoughts or situations were noted for review as they represented an overarching issue requiring further exploration.

Grouping data and drawing understanding from sections of interview data is inherently subjective, relying on the researcher conducting the index process (Ritchie and Spencer, 2002): however the use of indices in framework analysis opens up the process of categorisation ensuring transparency and rigour due to the overt nature of data presentation and analysis process presented (Pope, Ziebland and Mays, 2000; Gale *et al.*, 2013). The process was reviewed continually whist listening to and considering the interviews. I aimed to remove my preconceived notions of the experience as much as possible and continually questioned if the links between the participants voice, transcript excerpts and

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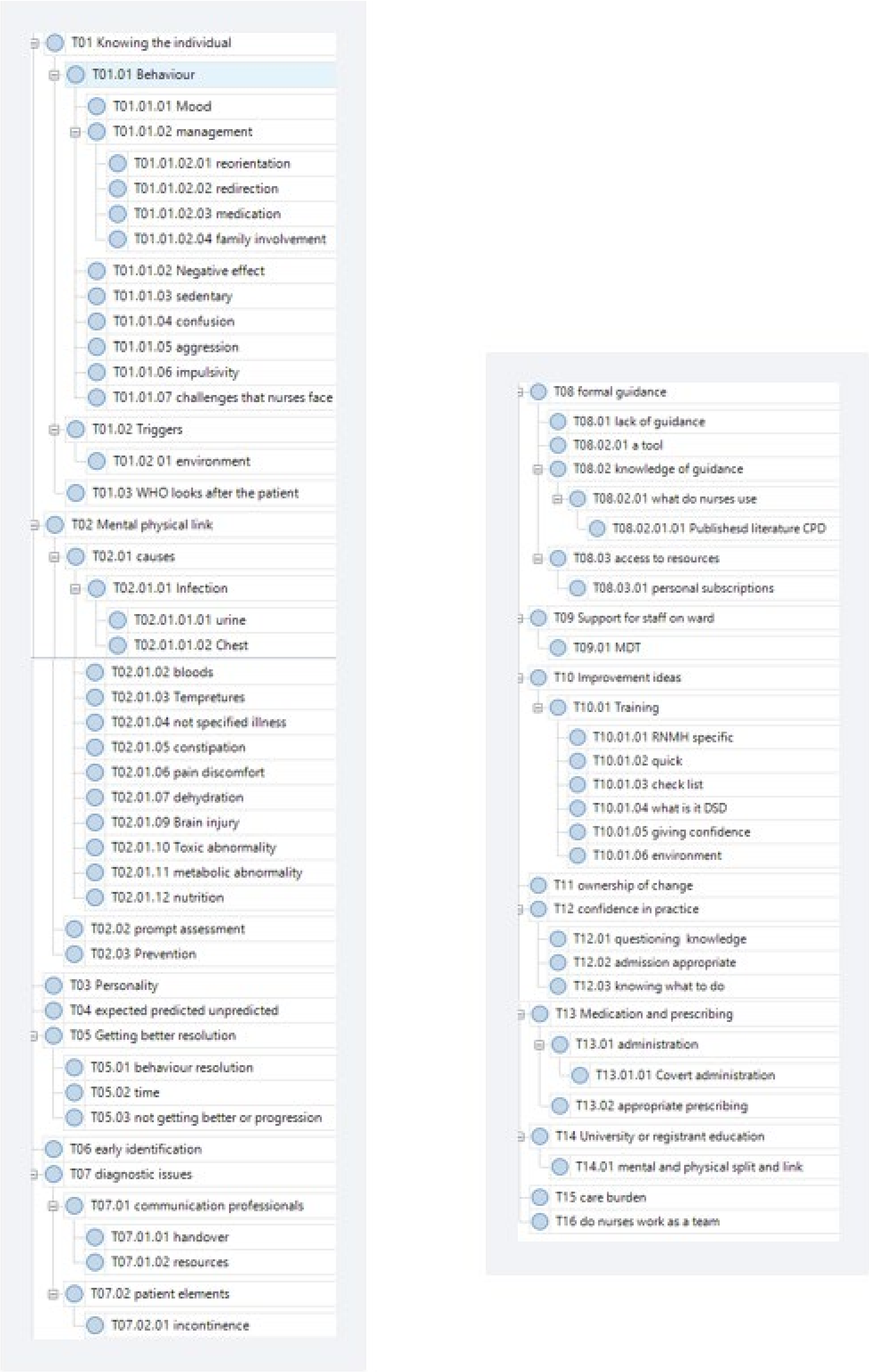
[10] Indexing: Methodological terminology changes have been advised from the previous use of 'coding' for this stage due to multiple interpretations, meanings and lack of consensus in the literature (Spencer *et al.*, 2014a)

aligned index were clear.

Indexing initially was expansive with the thematic frame growing substantially to ensure that points that appeared pertinent or repetitive throughout were accounted for. Whilst unwieldy, it offered certainty that no data would be missed or unrepresented. This is seen in Figure 18 page 136.

Following the generation of an index encompassing all the interviews, the material was sorted to allow for similar elements of discussion points to be grouped together. This allowed for the nuanced elements of a construct to be seen in a collective. It was hoped that by indexing the finer points of the data first and then regrouping that overarching and complete themes could be illuminated. This served to reduce the indices substantially without losing any core elements growing from the data. Themes or topics were found to be discussed at varying times or in relation to different interview probes. By sorting the indexed data, a more cohesive account was drawn together. This allowed for sections of data holding multiple concepts or relationships to be indexed without having to select between locations (Spencer *et al*., 2014b).



- T01 Knowing the individual
  - T01.01 Behaviour
    - T01.01.01 Mood
    - T01.01.02 management
      - T01.01.02.01 reorientation
      - T01.01.02.02 redirection
      - T01.01.02.03 medication
      - T01.01.02.04 family involvement
    - T01.01.02 Negative effect
    - T01.01.03 sedentary
    - T01.01.04 confusion
    - T01.01.05 aggression
    - T01.01.06 impulsivity
    - T01.01.07 challenges that nurses face
  - T01.02 Triggers
    - T01.02 01 environment
  - T01.03 WHO looks after the patient
- T02 Mental physical link
  - T02.01 causes
    - T02.01.01 Infection
      - T02.01.01.01 urine
      - T02.01.01.02 Chest
    - T02.01.02 bloods
    - T02.01.03 Tempretures
    - T02.01.04 not specified illness
    - T02.01.05 constipation
    - T02.01.06 pain discomfort
    - T02.01.07 dehydration
    - T02.01.09 Brain injury
    - T02.01.10 Toxic abnormality
    - T02.01.11 metabolic abnormality
    - T02.01.12 nutrition
  - T02.02 prompt assessment
  - T02.03 Prevention
- T03 Personality
- T04 expected predicted unpredicted
- T05 Getting better resolution
  - T05.01 behaviour resolution
  - T05.02 time
  - T05.03 not getting better or progression
- T06 early identification
- T07 diagnostic issues
  - T07.01 communication professionals
    - T07.01.01 handover
    - T07.01.02 resources
  - T07.02 patient elements
    - T07.02.01 incontinence

- T08 formal guidance
  - T08.01 lack of guidance
  - T08.02.01 a tool
  - T08.02 knowledge of guidance
    - T08.02.01 what do nurses use
      - T08.02.01.01 Publishesd literature CPD
  - T08.03 access to resources
    - T08.03.01 personal subscriptions
- T09 Support for staff on ward
  - T09.01 MDT
- T10 Improvement ideas
  - T10.01 Training
    - T10.01.01 RNMH specific
    - T10.01.02 quick
    - T10.01.03 check list
    - T10.01.04 what is it DSD
    - T10.01.05 giving confidence
    - T10.01.06 environment
- T11 ownership of change
- T12 confidence in practice
  - T12.01 questioning knowledge
  - T12.02 admission appropriate
  - T12.03 knowing what to do
- T13 Medication and prescribing
  - T13.01 administration
    - T13.01.01 Covert administration
  - T13.02 appropriate prescribing
- T14 University or registrant education
  - T14.01 mental and physical split and link
- T15 care burden
- T16 do nurses work as a team

Figure 18 Thematic Framework

5.1.3.5 **Review of Data Extracts**

The indexed and sorted data was reviewed as individual themes using core headings. This process helped ensure cohesive grouping of related topics but also served to show any potentiality linked data that could have been missed

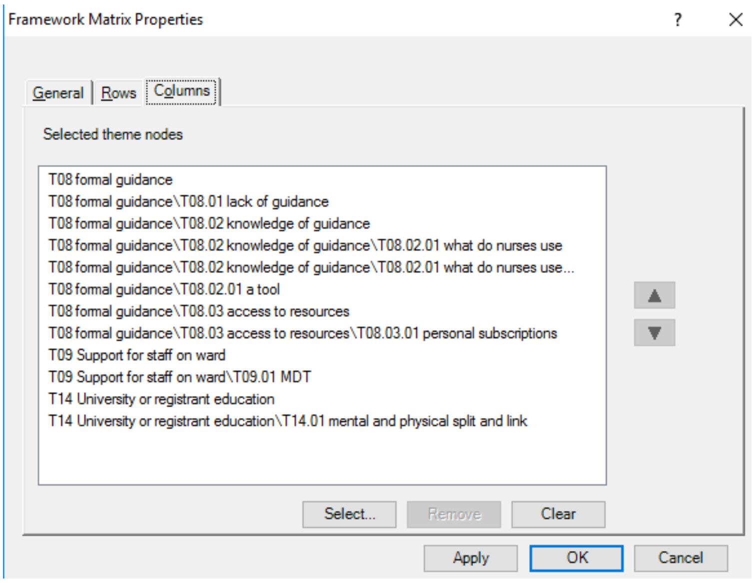
(Spencer *et al.*, 2014b). As the index and sorting proceeded natural core themes started to emerge. These core theses were used to refine and reduce the extensive index into six key themes (C's) which were applied to the activity system.

5.1.3.6 **Data Summary and Display**

In order to support transparent and visual analysis of the total data sets forming the six key themes, a process of summarising and displaying data using NVivo™ was undertaken. Large sections of text from multiple locations within the interviews were indexed, sorted and reapplied to a refined thematic frame, it was important to be able to see cohesively all the data included; the original indexing and sorting had started in close proximity of the data (using verbatim transcripts) and expanded outwards, generating themes and associations. A series of matrices for each theme showing the individual participant's comments and transcripts was produced. These also included summaries developed for each participants' discourse in relation to the theme.

This supported the next phases of abstraction and interpretation by ensuring visibility, usability and clarity (Spencer *et al.*, 2014b). A matrix spreadsheet was generated for each individual theme. Using NVivo™, each sub theme was searched for relating information and drawn together using the software. It is important to reiterate here that the locations and assignment of interview data to codes was completed by myself. Whilst NVivo™ can undertake automated, technology generated coding and data display (using search terms and key words) this was not undertaken.

Figure 19, page 138 shows the NVivo™ generation map for C1 *Awareness of education or guidance*.



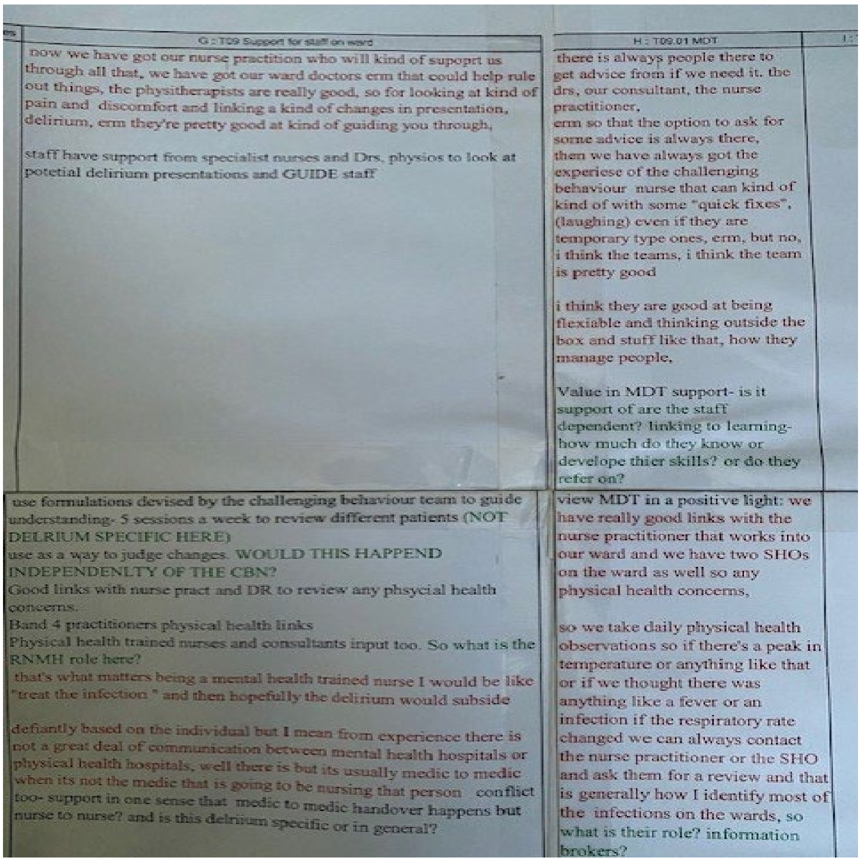
Selected theme nodes

T08 formal guidance
T08 formal guidance\T08.01 lack of guidance
T08 formal guidance\T08.02 knowledge of guidance
T08 formal guidance\T08.02 knowledge of guidance\T08.02.01 what do nurses use
T08 formal guidance\T08.02 knowledge of guidance\T08.02.01 what do nurses use...
T08 formal guidance\T08.02.01 a tool
T08 formal guidance\T08.03 access to resources
T08 formal guidance\T08.03 access to resources\T08.03.01 personal subscriptions
T09 Support for staff on ward
T09 Support for staff on ward\T09.01 MDT
T14 University or registrant education
T14 University or registrant education\T14.01 mental and physical split and link

Figure 19 Generation Map C1

On each of the thematic sheets, each participant was assigned a unique column. This allowed their accounts to be linked visually and directly to them. Encompassed subthemes (as the original location indices) were presented along the top of the matrix. All text associated with the identified theme was displayed in a chart formation. This allowed for a clear visual representation of all contributing sections of data from each participant to be visualised as a collective. At this stage, I moved away from the computer-based process and NVivo™ and printed large scale paper versions of the matrices. By doing this, I was able to move more fluidly between the data sets and found a more responsive way in which I could analyse the data; I felt hindered by the computer-based format and size of matrices presented on screen.

A collective of six thematic matrices was generated. Each theme was reviewed individually to ensure that focus was maintained on that core theme prior to moving on to the next. Within the individual matrices, each participant's data was read and reread. Working with data from one participant at a time and maintaining the single theme focus, questions were asked regarding the essence of the discussion; what was the underlying premise or associated elements? Direct quotes of material or key phrases were left in situ, alongside summaries to amalgamate, annotate or draw together key topics of further questions that were becoming exposed (Figure 20). The summaries produced were differentiated from the participant transcripts to allow for the participant’s voice to remain unchanged. Alternative fonts, handwritten notes and colours were used to highlight participant text and interpretive summaries, or questions posed.



G : T09 Support for staff on ward	H : T09.01 MDT
now we have got our nurse practition who will kind of supoprt us through all that, we have got our ward doctors erm that could help rule out things, the physitherapists are really good, so for looking at kind of pain and discomfort and linking a kind of changes in presentation, delirium, erm they're pretty good at kind of guiding you through, staff have support from specialist nurses and Drs, physios to look at potetial delirium presentations and GUIDE staff	there is always people there to get advice from if we need it. the drs, our consultant, the nurse practitioner, erm so that the option to ask for some advice is always there, then we have always got the experiese of the challenging behaviour nurse that can kind of kind of with some "quick fixes", (laughing) even if they are temporary type ones, erm, but no, i think the teams, i think the team is pretty good i think they are good at being flexiable and thinking outside the box and stuff like that, how they manage people, Value in MDT support- is it support of are the staff dependent? linking to learning- how much do they know or develope thier skills? or do they refer on?
use formulations devised by the challenging behaviour team to guide understanding- 5 sessions a week to review different patients (NOT DELRIUM SPECIFIC HERE) use as a way to judge changes. WOULD THIS HAPPEND INDEPENDENLTY OF THE CBN? Good links with nurse pract and DR to review any phsycial health concerns. Band 4 practitioners physical health links Physical health trained nurses and consultants input too. So what is the RNMH role here? that's what matters being a mental health trained nurse I would be like "treat the infection " and then hopefully the delirium would subside defiantly based on the individual but I mean from experience there is not a great deal of communication between mental health hospitals or physical health hospitals, well there is but its usually medic to medic when its not the medic that is going to be nursing that person conflict too- support in one sense that medic to medic handover happens but nurse to nurse? and is this delriium specific or in general?	view MDT in a positive light: we have really good links with the nurse practitioner that works into our ward and we have two SHOs on the ward as well so any physical health concerns, so we take daily physical health observations so if there's a peak in temperature or anything like that or if we thought there was anything like a fever or an infection if the respiratory rate changed we can always contact the nurse practitioner or the SHO and ask them for a review and that is generally how I identify most of the infections on the wards, so what is their role? information brokers?

Figure 20 Summary Production

Sufficient detail was given in the summaries generated to explore meanings or raise questions but not so much that the data became irrelevant to the original participant text. With the verbatim passages remaining in situ, I was able to start, and remain at close proximity to the original raw data and allow for concepts and summary to merge, drawing upon previous thoughts or ideas, but maintaining a clear link to the participants’ voices (Spencer *et al.*, 2014b). During this process, the importance of being able to return to the original location of text using NVivo™ proved vital as the data excerpts were fragmented in the matrices. NVivo™ allowed for swift return to the original transcription to check for any associated or wider contextual issues in the preceding or following areas of discussion.

In recognition of my own potential influence on analysis, an interview transcript alongside my list of thematic codes was sent to two research supervisors for independent analysis and coding. This was to ensure that I had not missed any key elements of discourse, but also to check that my assigned themes did represent the interview material free from my a priori knowledge. Confirmation of coding was agreed, alongside the themes generated, and no alterations or additional codes were recommended.

5.1.3.7 **Abstraction and Interpretation**

Annotated indexed themes and sub themes can be regrouped with verbatim transcripts in light of core concepts in the form of higher order abstractions and interpretations (Spencer *et al.*, 2014a). These serve to produce core themes within the data. Figure 21 page 142 shows the process of familiarisation: the expansive index evolved from, and then applied to the total data set. The six refined themes are presented in the final column representing the overall themes prominent in the interviews.

As the review of data progressed it could be seen that there was a substantial difference in the level of awareness and use of clinical guidance and formal educational opportunities in practice. Several elements of alternative indexes pertained to this notion of variance in knowledge. Grouping these sections of information together helped build a rounded view of the experiences present across the RNMH interviews. Another key consideration was the impact that DSD care had in practice. Listening to the interviews and reading the transcripts, there appeared to be multiple avenues in which the participants were exploring and unpicking a burden of care. Concern for self, team and patients became apparent and required close exploration. The process of sorting and drawing together key notions and areas for exploration in the data continued until six core themes were generated as a refined thematic frame.

As more data was applied to the framework, a refinement was undertaken as emergent themes and relationships became evident. Conceptualisation of themes occurred to encompass elements that interplay and influence each other to refine themes to central notions. Latent themes emerged, primarily identified from semantic categorisation, but then used to explore and examine the underlying premise and refined through conceptualisations, interpretations and assumptions made of the data (Braun and Clarke, 2006; Spencer *et al.*, 2014b).

Spencer *et al*., (2014a: b) note, as with Morgan (2007), that data management and analysis is not a clearly defined or demarcated process; rather it is one that happens at differing stages and continuously. This was noted in the process as I found myself conceptualising, refining, reviewing, summarising and returning to the verbatim data in an almost cyclic and undulating manner. The stages of qualitative thematic generation and their position in the subsequent activity system are represented in Figures 21 and 22 (page 142), and Figure 23 (page 143) with the subject of the activity system being the RNMH and the influences of the system on their experience.

Figure 21 Key Theme Generation

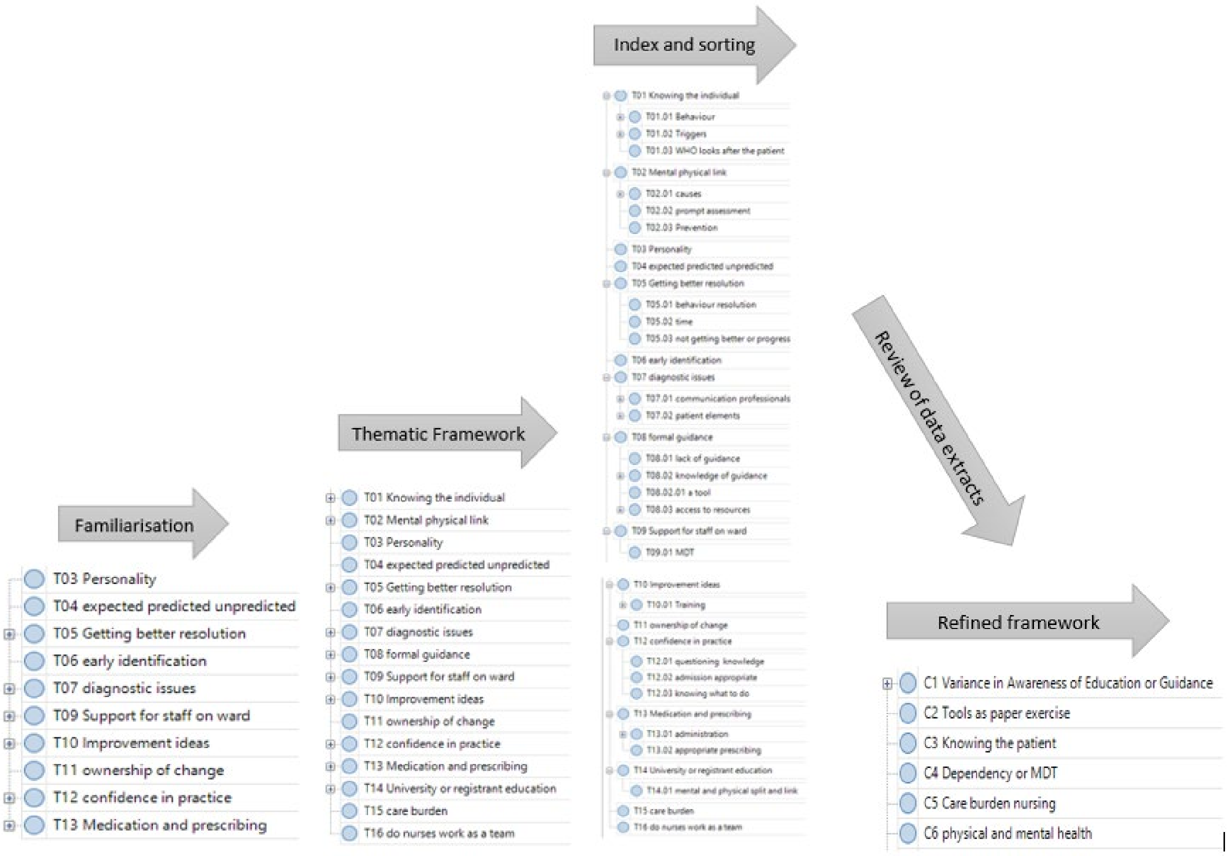


Figure 22 Full Thematic Generation Process

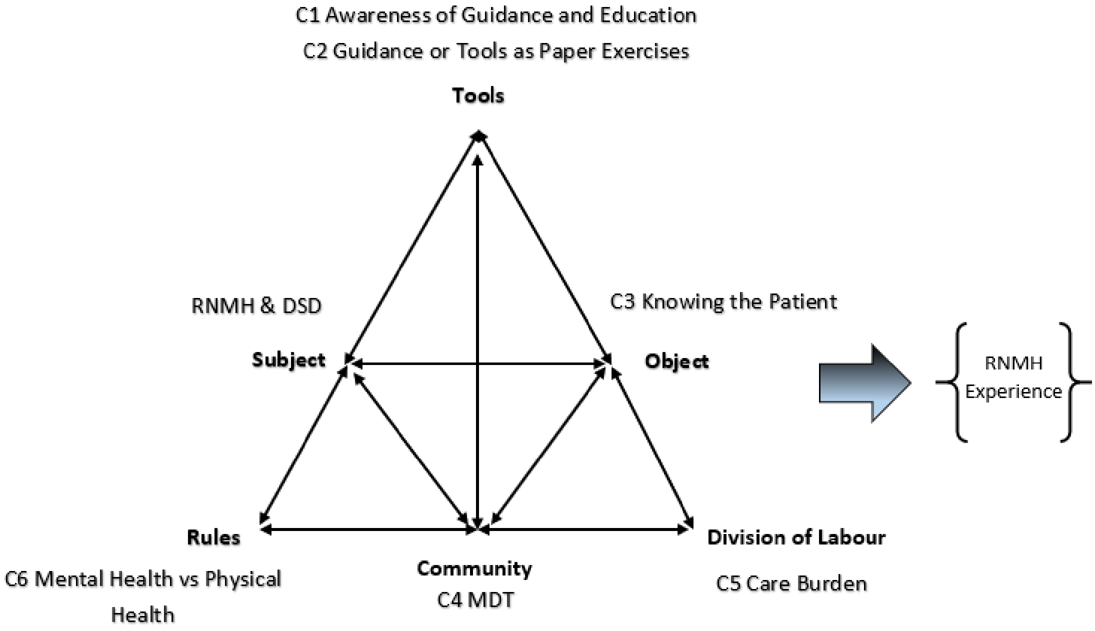


Figure 23 Qualitative Themes Applied to Activity System

5.1.4 Questionnaire Development: Steps One to Three

The research process described thus far achieves a complete fit with steps one to three of Artino *et al*,'s (2014) questionnaire development as discussed in Chapter four page 91. The literature review, qualitative findings and themes were used to frame questionnaire development and define influential components of the RNMHs activity system using the six core themes identified. Whilst the data derived at this stage, was potentially not a complete account of the RNMH experience, this was in keeping with the mixed methods approach to the study, and the pragmatic premise of exploring the constructs through further quantitative processes. The data formed a working articulation of pertinent areas for further exploration and consideration.

5.1.5 Qualitative Data Collection and Analysis Conclusion

A purposive sampling strategy allowed the specific experiences of RNMH to come to the fore. Ensuring that those with key knowledge and experience of DSD could articulate their personal experience, thoughts, feeling and opinions. This was integral to illuminating key factors about the experience. Whilst the interview sample was numerically small (n=7) when compared to quantitative research or even qualitative research without an additional quantitative enquiry, the nature of this phase of the study did not require (or in keeping with the principles of qualitative enquiry) a set quota of participants; emphasis was placed on quality of information, depth of enquiry and in-depth analysis.

Facilitating data collection, semi-structured interviews offered a framework for the interview process, coupled with an essential fluidity to allow the participants to express as fully as they desired, their thoughts, feeling, attitudes, actions or opinions.

Supporting analysis of rich data gleaned from the interviews, framework analysis was selected as an analytical strategy. Whilst theoretically linear in presentation, framework analysis is practically applied in a cyclic and undulating manner as themes are identified, refined, and processed into conceptualisations of the wider situation being explored. The qualitative findings of this study are presented in Chapter six before integration with the quantitative data in Chapter seven.

5.2 Phase Two: Quantitative Data Collection Methods and Analysis.

This section discusses the choice to devise a new questionnaire, built around the emerging the AT frame, and the questionnaire development methods undertaken. In keeping with the exploratory sequential design of the study, the use of a self-report questionnaire is justified through its ability to describe the reality of participants’ experiences, and further explore the themes previously identified (in the first part of this chapter) through quantitative investigation in preparation for final integration of the data sets. This integration was undertaken to produce a complete account of the RNMHs experiences of providing care for people with DSD in an activity system graphic. The quantitative results are presented in Chapter seven alongside their integration with the qualitative findings.

Attention is paid to the need for, and development of a new questionnaire using the framework suggested by Artino *et al.* (2014) (Figure 11, Chapter four, page 93) to support the processes. During the literature review it became evident that the RNMHs experience was missing from the wider discourse. Whilst qualitative interviews gleaned valuable insightful data regarding the experience, this study sought to further explore and refine this understanding across a wider sample. Phases four to seven of Artino *et al,*’s (2014) process are discussed below as the quantitative component of this mixed methods study. This includes the development of items, review of the initial questionnaire, expert validation, and pretesting.

5.2.1 **Survey Research and Questionnaire Selection**

The quantitative phase manifested as an observational (sometime known as descriptive) investigation (in opposition to an experimental or quasi-experimental approach) with the aim to describe a population (the RNMH engaged in DSD care) using a non-random sample (Bors, 2018). This was undertaken to further illuminate the influencing factors underpinning the RNMH experience of DSD care within their activity system.

Several different strategies were available for gathering quantitative data; however, whilst the research aimed to explore the nursing experience, it did not seek to employ an experimental design. This data supported the study's aims to describe the experience in relation to influencing and impacting factors whilst generating new understanding of the RNMHs care premise of DSD. In this area of investigation, understanding and illumination of a construct and context was needed, not testing established knowledge or practice. For this purpose, a questionnaire designed to further understanding of the qualitatively exposed themes achieved the most appropriate fit as it could assist in further describing the reality of the respondents (Mathers, Fox and Hunn, 2007; Bowling, 2009). Rea and Parker (2014) specify that survey research is justified when generalisation is desired, when there is inadequate secondary data to analyse, an accessible population is present, and a personal, self-reporting nature is required in the data. These key tenets of survey research resonated with this research studies aims; however, this study did not seek to confirm or generalise findings, rather add depth and continue the exploration of the RNMH experience. Of importance in this study was the paucity of literature pertaining to the UK specific RNMH experience, and the clinical context of DSD care provision. In light of this, a key understanding of this study and the questionnaire discussed was not to facilitate testing or matching of experiences to desired actions or outcomes. Central to this is study is the recognition that the experiences and actions they needed to be clearly identified, understood, and described first.

Consideration was given to using or adapting existing questionnaires to explore the nursing experience. Using pre-existing, validated questionnaires serves to reduce time and resource demands in research, plus offers comparable data to review findings against (Boynton and Greenhalgh, 2004). However, the context in which they have been validated and applied must be considered. Questionnaires developed in different setting or countries could be used (Boynton and Greenhalgh, 2004), but may not hold equivocal validity and reliability specifically to the discreet and unique context of the RNMH experience and DSD. By example, Funk *et al.* (1991) provides an established questionnaire for assessing perceived barriers and facilitators to nurses using research in practice. This was considered for use in this study; however, the literature review indicates research as one small facet of the experience, and other useful artefacts for the RNMHs (such as clinical guidance, peer discussion etc) are not included. This limits the breadth of the experiential facets that this study sought to explore. In addition, this questionnaire is generic to ‘nurses’ and may diminish the unique context of the RNMHs. Other questionnaires (for example the Nurses Knowledge of Delirium by Hare *et al.* (2008) could measure knowledge base associated with delirium in isolation, but not explore the experience and, in addition, did not hold the contextual relevance needed since nursing registration was not equivocal to the UK RNMH context (being validated in Australia). Therefore, to maintain the central focus on exploring the unknown experience of the UK RNMHs specifically in terms of DSD, a new questionnaire tool was justified and required. It was feasible that with the absence of validated tools specifically for RNMHs and, DSD in particular, (as opposed to generic ‘nursing’ or other workforce tools, and DSD in opposition to delirium as a singular entity), using established questionnaire tools could miss or misidentify facets of the potentially unique experience of the RNMHs in favour of a more general, or contextually inappropriate discussion of experience of DSD care provision. This study aimed to provide a unique insight into the RNMHs experience, revolving specifically around DSD. For this purpose, it was felt inappropriate to use established tools. Both the unique nursing registration and care context needed to be the central concern rather than come second to the ease of information collection that could be achieved by using established questionnaires.

5.2.2 **Questionnaire Approaches**

A key distinction between the terms ‘survey’ and ‘questionnaire’ is apparent. Often inappropriately used interchangeably, a survey is the research process or design undertaken to collect and analyse data (Figure 24), with questionnaire being a method of data collection within a design. One enduring definition of survey is presented in the seminal work of Presser as:

> *‘…any data collection operation that gathers information from human respondents by means of a standardized questionnaire in which the interest is in aggregates rather than particular individuals…’*
>
> (Presser, 1984 p 95)

Noting the terms *Data collection operation* attributed to survey, Presser specifies the exact mode of data collection as questionnaire: it is now recognised that the survey process may include questionnaires, observations or measures and their associated quantitative data analysis processes.

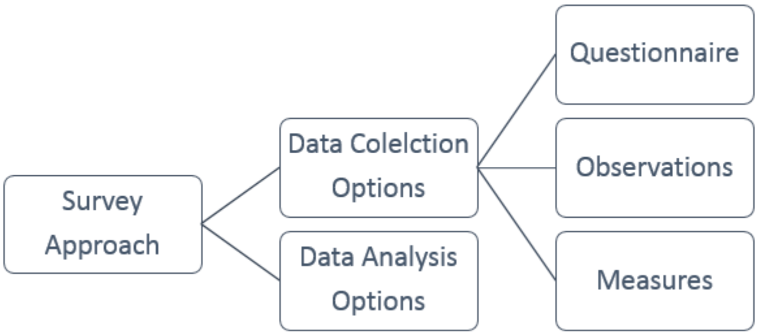


Figure 24 Survey and Questionnaire Relationship

In relation to this study’s aims, observation could be intrusive to both the participant and the wider healthcare context, and as the aim was to explore the experience, by viewing or observing the behaviour or actions of the nurses, the data produced would be inclusive of my own interpretation of the experience, and whilst these could be matched or applied to the participant’s expressed experiences in the interview data, at this stage I considered if this would achieve a fit with the research aims. This study was centred around exposing, illuminating, and exploring the RNMHs self-reported experiences of DSD care. At this time, and with the limited body of knowledge pertaining the RNMH experience and DSD it was not appropriate to try and map or measure their actions against their reported experience, or actions against reported knowledge base or competence (for example) as the information required to complete this (competence indicators or knowledge base values) is not known. As such, the questionnaire was selected as the survey instrument used in obtaining quantitative data for this study.

Whilst the use of a questionnaire achieved a cohesive fit with the research aims, consideration was paid to the critique of questionnaires. One pitfall found here and not in direct observation or measures, is the self-reported nature of information obtained. The questionnaire can only claim to gather data that is reported via it. This information is valid in terms of what is given but, in practice, the respondent could choose to omit, modify or alter responses as they see fit (Boynton and Greenhalgh, 2004). Whist a complexity of questionnaires, self-reporting bias is found in many data collection methods. Additional observations undertaken could add clarity to the experience, matching the RNMHs reports of practice with actions, however as discussed previously, this study was not undertaken to map experiences against criteria for practice or representations of experience in practice. The study aimed to find out what the nurses reported their experience to be. Subsequent studies could explore this further, however a first understanding of the self-reported experience was needed prior to any further investigation. This phase held central the need to apply and explore further the themes generated in the qualitative interviews to a broader population to understand the influencing elements better, and enhance understanding of the RNMHs experience.

Questionnaires differ from qualitative questioning methods in both structure and principles of data analysis. They are stringently systematic and replicable with the same questions being asked of the participants in the same manner. This leads to comparable data upon which statistical analysis can be applied (De Vaus, 2014, Rea and Parker, 2014, Moule *et al*., 2017). Important to the questionnaire method of data collection is its formalised questions and structure; specifically designed to collect information on attitudes, values and behaviours (Bowling, 2009, Rea and Parker, 2014, Moule *et al*., 2017), Rea and Parker (2014) assert that data collected is descriptive in nature, concerned with facts (i.e., demographics or other descriptions of the participant), behavioural information (i.e. what is done) and attitudinal findings (i.e. feelings or thoughts). They suggest that to understand complexity within a population, an investigation needs to consider all types of information. This achieved a fit, and resonated, with the underlying activity system lens of the research regarding complexity of interaction, experiences, and context.

5.2.3 **Questionnaire Development: Step Four, Developing the Items**

Step four of the process detailed by Artino *et al.,* (2014) has two composite elements. One to generate items that could become questions, and a subsequent element of developing these items into well-formed and unbiased questions that can reliably capture the required information. The questionnaire was derived from the qualitative findings presented in Chapter six page 186, and the thematic analysis of both this data and the literature review within an activity system construct. As such it represents a continuum of the complete study rather than a discreet or nested component in isolation.

5.2.3.1 Generating an Item pool

Ensuring a robust design and practical application that was functional was paramount to not only the reliability and validity of the questionnaire, but also the usability and accessibility for the study population. A focus was placed on the second aim of the study, predominantly to gather information that would allow a further exploration and description of influencing and impacting factors. Returning to the qualitative themes, each thematic summary was reviewed to ensure cohesion with the narrative of the interview, the theme and language used by the participants. A list of questions was compiled which explored potential underpinning information required to describe the experience. The rough questions were mapped to separate pages of paper to allow a series of questions to be built for each theme. Individual quotes or annotations were marked next to the questions to highlight their origin or process of formation. Creswell and Plano Clark (2011) support this method in their argument that decisions need to be taken regarding what components of qualitative data are included or inform the quantitative components of an exploratory sequential study. This also demonstrates the first integration of the qualitative data at this early stage in the study in keeping with the study design presented in Chapter four, Figure 8, page 88. The process resulted in an unwieldy set of unrefined questions, derived to ‘bottom out’ what could be underlying influences. A booklet of question topics or points was formed.

5.2.3.2 **Exploring the Item Pool**

Whilst the development of clear and unbiased questions and the selection of response options are inherently bound together in reality as one process, it is important to discuss the theoretical underpinnings and deliberations separately. This serves to give clarity to the process; however, it remains true that in reality these events occur simultaneously.

With an extensive pool of unrefined items which could form a questionnaire, attention now turned to refining these items into a question format that would explore the experiences of the RNMH in a comprehensive and orderly manner. Whilst this questionnaire did not serve to measure a care construct in terms of scale formulation or experimental design, the principles of question formulation needed to be suitably robust. The questions were refined by identifying two important elements: concepts by intuition, and concepts by postulation. The participants' concepts by intuition; being those immediately perceived by the senses without deductive reasoning were reviewed. Whilst seemingly simplistic in nature, these relate to judgement, feelings and are immediately obvious to the individual. For the RNMHs this could represent their clinical decision-making process or nursing intuition. These were grouped and synthesised to form elements for the questionnaire here linked to their feelings and attitudes; did they feel supported, what was their opinion or confidence levels in care, and elements of the experience that manifest as 'gut feelings'.

Concepts by postulation on the other hand have meaning derived from deductions based in others already understood concepts by intuition. They are often less obvious and need clear definitions and may include attitudes (Saris and Gallhofer, 2007). As such, combination of several concepts by intuition build to form a concept by postulation (Figure 25, page 153)

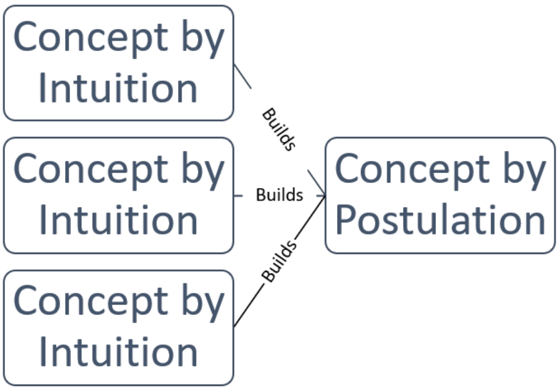


Figure 25 Building Concepts by Postulation

Concepts by intuition can easily by operationalised (or turned into questions) to ask about feelings, actions taken or thoughts. These can be coupled with questions formatted as measures or assertions. Figure 26 depicts how concepts by intuition, postulation, attitudes and action tendencies and are embedded in question building. This supported asking questions that would attend to what the RNMHs thought (postulation and attitudes), and what they did (intuition and actions).

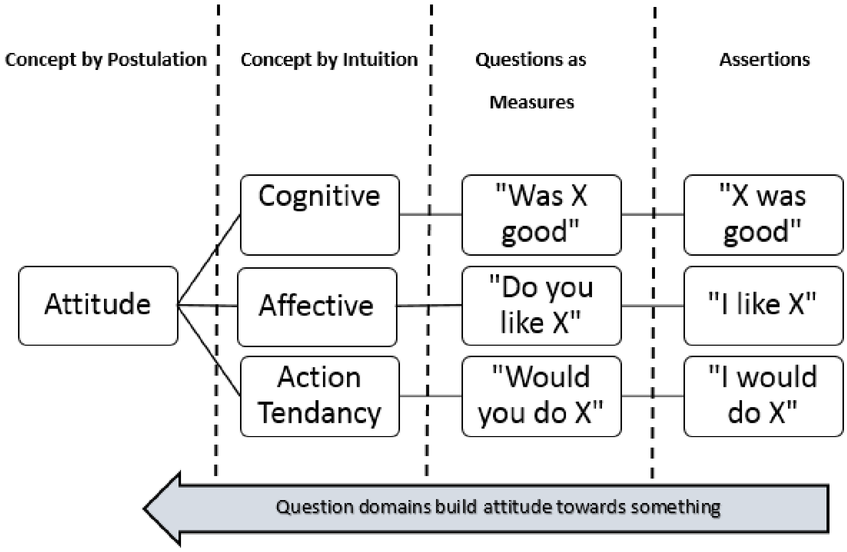


Figure 26 Concepts by Postulation

Adapted from Saris and Gallhofer (2007)

5.2.3.3 **Question Formation**

The meaning of the word ‘question’ in questionnaires requires clarification. Social research literature favours not the term ‘question’ but discusses ‘requests for answers’ as mentioned previously. Saris and Gallhofer (2007) offer clarity to the discourse stipulating that the term *request for answer* is used as interrogative, imperative and declarative statements are found in questionnaires. Such statements may not have a clear request (or provide a clear question) but it is implied in their formatting that there is a request for a response. Conversely, striving to illuminate and explore the RNMHs experience may be perceived as qualitative in nature, focused on the thoughts, feelings, perceptions, and attitudes of the RNMHs directly linked to DSD care. A challenge lies in mixed methods studies such as this as to how language is used to represent a qualitative experience in a manner that is approachable for participants but can be analysed in a quantitative form. The study did not aim to split analysis into two defined and independent analysis, rather gather information that could be combined and integrated as a totality. As such, whilst analysed quantitatively in the main, sufficient open-ended response options where embedded throughout the questionnaire to allow for elaboration, context and commentary. This binds the questionnaire into the mixed methods approach. In addition, some “questions” or requests for answers where presented in absence of an actual question i.e. through statements to which respondents ascribed value or a weighting. For example, when presented with the statement *I feel confident in my knowledge of DSD care.* This was not formatted as a traditional question*, Do you feel confident in your knowledge of DSD care,* however it requests an answer from the participants in their assignment of a weighted answer (strongly disagree, disagree, etc).

This distinction noted, the term *question* will continue to be used in this thesis to represent the formatting within the questionnaire which is underpinned by a request for a response.

The starting point for any question development is a keen focus on what the question is intended to achieve. Brace (2008) suggest that this has two core components: gathering information that facilitates the research plan and data that is collected accurately. As such, the design of the questions is a critical process, time consuming requiring exacting attention to detail.

The formation of the question must be logical and lead the respondent through the process with clarity, allowing for the required data to be collected. Andrews (1984) noted three sections to developing question items:

1. An introduction
2. One or more questions
3. An appropriate response scale

Simplistic in nature, Saris and Gallhofer (2007) expand on this to form a selection list of question components from which the questionnaire developer may select appropriate sections to form an item. This includes, an introduction, a motivation, information on content, a definition or additional information, an instruction for the respondent, and instruction for the interviewer, a request for an answer (question) and response category. Figure 27 (page 156) depicts this development.

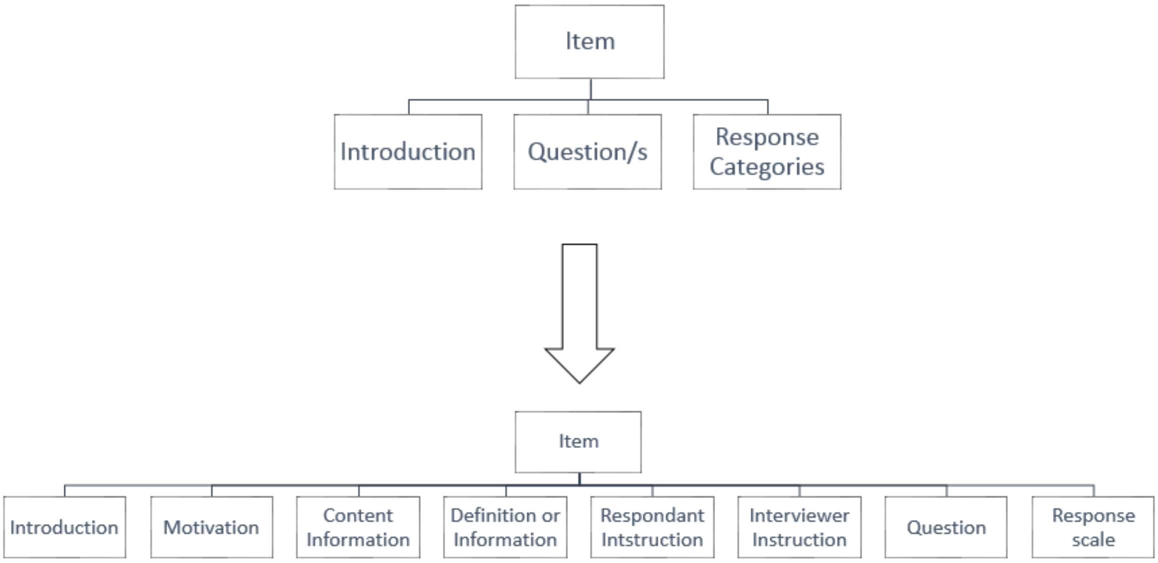


Figure 27 Composition of Questionnaire Items

Adapted from Andrews (1984) and Saris and Gallhofer (2007)

Phrasing and terminology familiar to the population targeted was incorporated, and caution applied to not use jargon that may cause confusion, or emotive phrasing. However, part of the review process prior to distribution of the questionnaire was to ensure that my initial perceptions of shared language and appropriate terms were indeed appropriate for the target participants.

5.2.3.4 **Likert Scales, Likert Items and Likert-Type-Items**

One of the most familiar scales for responses in questionnaires is the Likert scale. The most obvious feature of this scale remains the denominators from which the respondent is asked to choose between: *Strongly Approve, Approve, Undecided, Disapprove and Strongly Disapproved*. Historically based around a neutral middle position, with familiar components, confusion is often found in descriptions of surveys and questionnaires detailing their collection methods to include Likert scales, when only one question, or isolated questions are presented. The key to the Likert scale, is the use of multiple questions presented in this format, and analysed not individually, but as once complete score.

To be termed a Likert Scale, there needs to be four core components:

1. Presence of multiple items
2. Presented as a level horizontal layout
3. Response anchors as consecutive integers
4. Response anchors are verbal labels that suggest an evenly spaced gradient

Additional components may be selected including

5. Bivariant labels which are symmetrical with a neutral middle
6. Labelling signifies attitude of agreement

1-4 must be present to accurately determine a scale a Likert scale, whilst the presence of 2,3,4 & 5 indicate a Likert Item, and 2, 3 and 4 would indicate a Likert-type-item (Ubersax, 2006). For this study, the decision was taken to produce Likert items rather than Likert scales, this was to allow for a differentiated level of agreement with statements but without combining these to form a measure or diagnostic psychometric scale or rating. This was in keeping with the exploratory nature of the study, and not confirmatory.

Variation in number of response categories is also common, with response anchors of five, seven and even nine present in research alongside the removal of a neutral middle point (Clason and Dormondy, 1994). The presence of a neutral middle allows for indecision or indication that no opinion is held. When removed, the presentation forces a decision. Whilst this might be perceived as valuable for analysis and reduces indecision, it may be counterproductive: increasing non-response bias and frustration in respondents who may feel that are not being allowed to express their thoughts, feelings or choices honestly (Burns and Grove, 1997). I wanted to ensure the respondents were presented with items that were familiar to them (as in the nature of the Likert scale/Items etc, that were consistent throughout the questionnaire (i.e. not moving from 5 response options to 7 or nine as this may cause confusion in the weighting their self-reported agreement/disagreement, but also I felt the neutral middle position should be maintained in this questionnaire as it was important to see not only responses that provoked an positive or negative association, but also those questions which provoked a neutral stance. This could give insightful information about the experience of the nurses, if a neutral stance were held the question would be posed as to why. This I believed to be just as important to the understanding of the experience in a totality and could further highlight significant impactful or influential factors, but also those that may not be, which would represent a finding in its own right.

5.2.3.5 **Open Questions in Quantitative Data Collection**

There is debate regarding the use of open questions in quantitative research methods; however, this study was governed by a mixed methods approach, and qualitative explorations of quantitatively indicated information added to the context or level of insight available. Closed questions, as found in the above Likert type response categories, offer the participant limited options for response elaboration or if there are additional considerations. This may cause frustration if the response they wish to give is missing, or if they feel there is more explanation required for their answer (Houtkoop-Steenstra, 2000). One strategy that is often employed to minimise this is that of free text boxes for additional information gathering and can also indicate a shift in perceived power from the researcher dictating responses to the respondent in their decision to complete open ended elements of the questionnaire or not.

Closed questions represent the researcher’s agenda, even if drawn from (as in exploratory research) the participants’ own experiences and thoughts. Open questions or free text boxes on questionnaires may allow the respondent to respond as they choose, using their terminology. I valued this since it gave the respondents space to detail pertinent issues or considerations that could have been missed and also provided additional quotes or material to enhance the written report or findings of the questionnaire (O'Cathain and Thomas, 2004). Whist a seemingly inclusive option, careful consideration was given to open ended response option data use and analysis (Boynton and Greenhalgh, 2004). To use the gathered data effectively, I employed alternative data analysis strategies to draw upon free text and applied this to quantitative research methods. Whilst the data presented in open ended response options is free flowing, it is not considered true qualitative data as it cannot be fully explored in terms of true context, rich descriptions and concept exploration (Boynton and Greenhalgh, 2004; O'Cathain and Thomas, 2004; Parahoo, 2014) however, qualitative analysis principles may be drawn upon to identify themes and then convert these themes into numerical data for statistical analysis. Miles and Huberman (1984); Teddlie and Tashakkori (2003) identify this process as ‘quantitizing’ the data and sits well within mixed methods studies. This quantitizing of data in this study was undertaken by reviewing the free text, consideration of meaning in and exploring themes or key words. This produced a series of thematic codes for each open question to which others were applied or added to. As with the interview data, a process of peer checking was undertaken by a nurse researcher. The open responses were reviewed alongside my thematic coding. This ensured the confirmed coding frame was reliable and remained grounded in the participant’s responses (Fink and Kosecoff, 1996; O'Cathain and Thomas, 2004). Quantification of the qualitative data and thorough coding of the open-ended questions is shown in Appendix 11.

5.2.3.6 **First Draft Questionnaire Formation**

Using the item pool generated and undertaking some refinement to transform the rough initial questions to more workable formats, a draft questionnaire was devised. The six core themes were maintained throughout, with the questionnaire commencing with simple demographic details. Attitudinal and behavioural questions were asked in the main body of the questionnaire, with the articulation of formal education and training undertaken closing the questionnaire. This was to allow mapping of perceptions or opinions against formal or informal delivery of information in a variety of settings if the data indicated this was significant.

At this stage, the questions were predominantly nominal and ordinal in data categorisation, and several Likert Items. Questions were formatted to include an introduction, question/questions and response criteria in keeping with Andrews (1984).

5.2.3.7 **Informal Internal Review**

An informal internal review amongst peers was conducted to clarify the processing of the questionnaire. An initial paper copy was printed and subject to review by my principal supervisor and refinements to content, phrasing of questions and response anchors, and repetition of questions were made.

Sub sectioning and titles were identified in keeping with the questions, and themes derived from the qualitative data and literature, but also being mindful of the evolving activity system frame. Initial section titles were identified as; *what shapes your care, knowledge base, practice experience, evidence base, people as individuals, the multidisciplinary team, and environment*.

After consideration of the available questionnaire platforms the Joint Information Systems Committee (JISC) online survey software was selected over more commercial products due to its assurances of security of data (GDPR compliant) and appropriate access controls regarding anonymization, production of PDF copy, and potential for online distribution of the questionnaire. In addition, JISC facilitated a universal resource locator (URL) link to the questionnaire including '.ac.uk' which offered additional reassurance to the level of integrity and professionalism involved as it signifies an academic institution.

An initial information page titled 'about this survey' was added and held a definition of delirium superimposed on dementia, information about the study and the key aim to explore the RNMHs experience helped orientate participants to the study. The questionnaire was then sub divided to six sections; *About you*, *Your Daily Work, The Multi-Disciplinary Team (MDT) and Clinical Environment, What Informs Your Practice,* and *Your Formal Education.*

Remaining at an informal level, the survey was distributed to a small group of peers (7) for comments. This group was selected for their variety of knowledge pertaining to the study subject and methodology. Specifically, the group consisted of RNMH lecturers from a variety of backgrounds including those with a specialist interest in dementia and delirium, RNMH lecturers with no specialist interest in dementia or delirium, an RNA lecturer with survey construction expertise, and another senior researcher whose specialist interest included ageing.

From the returned responses, a process of refinement and reordering was undertaken to support clarity and flow throughout the questionnaire. Repetitive questions were omitted, and elements combined into groupings for presentation.

5.2.3.8 Expert Validation and Feedback: Phase Five

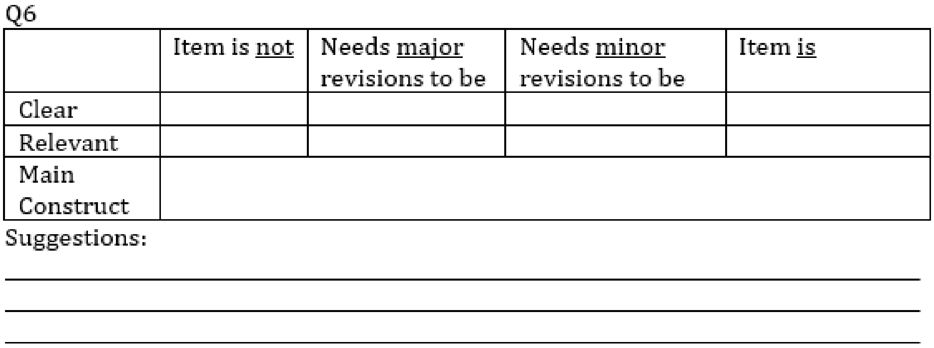
Following the informal review, it was paramount that formal review and validation was undertaken. Whilst Rubio *et al.,* (2003) notes that there is a wealth of measures available to researchers with validated psychometric properties, this was not the case in this area of research. As a new questionnaire, it was essential that it was subjected to stringent development processes including content validity appraisal to ensure the questionnaire was both valid and reliable (Rubio *et al.*, 2003). Whilst this is noted to be an essential stage of questionnaire development, it is often the case that the reporting of content validity testing is minimal when developing new measures (Beck, 1999; Polit and Beck, 2006).

5.2.3.9 Constructing an Evaluation Form

A content validation form was devised to capture information on factors affecting the questionnaire validity. To ensure the form was sufficient in depth and appropriately formal an expert review from template by Gehlbach and Brinkworth (2011) was used. The review form commenced with a welcoming introduction and thanks for participation in the validation process. The working title of the questionnaire offered, a brief overview of the form and the process to be undertaken was documented, followed by an introduction to the study's aims and objective. This would help to ground the experts in the specific purpose of the study, and context in which the questionnaire would be applied. The mixed methods nature of the study was articulated, and the question generation founded on semi-structured interviews was noted. A request was made for the experts to consider each question in terms of clarity and relevance. The construct definition was broken down into the identified themes from the qualitative phase.

Starting at question 5 (as 1-4 were demographical items regarding the respondent's registration, gender, role title and geographical location of practice), each question was presented with an associated grid in which the expert could indicate their perception of clarity and relevance, assign thematic alignment and free text suggestions. Table 7 offers an example of this.

Table 7 Expert Validation Grid



Q6

	Item is not	Needs major revisions to be	Needs minor revisions to be	Item is
Clear				
Relevant				
Main Construct				

Suggestions:

Deviating from the template suggested by Gehlbach and Brinkworth (2011), the phrasing of Grant and Davis (1997) was included to descriptors (*Item is not.., Needs Major revisions to be, Needs minor revisions to be…*) as these offered clarity and direction for recommendations and the perceptions of the experts regarding the item and its inclusion in the survey. This contrasted with indicators found in Gehlback and Brinkworth (2011) who use descriptors such as *slightly,* or *somewhat* (by example) in terms of clarity. I felt these phrases too vague in operational terms and would leave scope for interpretation.

Considerate of the experts' time investment and the potential for this to become a monotonous process, the above grid (Table 7) was devised as an amalgamation of all three elements (relevance, clarity and theme) together. This supported quicker completion and maintained focus on one question at a time. Packs were made up including the instruction and response form, a paper copy of the questionnaire, a self-addressed envelope with stamp and a single tea bag, sachet of coffee and a small chocolate. This was important as I felt it would show my appreciation for the time and investment that the experts were giving to the study but small enough in monetary value not to pose any influence over responses.

5.2.3.10 **Identifying Experts**

Focus was turned to who were considered experts in the field. The selection of experts is paramount as a keen understanding of the context under investigation is required, and an ability to give constructive feedback (Rubio *et al.*, 2003). McKenzie *et al.,* (1999) suggests this needs careful exploration, in terms of identifying individuals with the appropriate knowledge base, expertise and also a willingness to participate. Rubio *et al.,* (2003) clarifies the criteria a little further adding that the experts would usually be perceived as content experts (or those engrained in the context), and professionals who had published papers pertaining to the context. As such, careful attention was paid to who could be considered an expert in the field as the dearth of literature pertaining both RNMHs and DSD was limiting in relation to both the clinical concept, but also the pool of experts to draw upon.

When reviewing potential experts to contact, the proposition that group inclusion would be based upon those with expertise specifically in DSD, and with published research became problematic. With such little literature pertaining to delirium and the mental health setting (in opposition to general or acute care settings) the earlier statements by the Department of Health (2017) and Alzayyat (2014) that mental health registered nursing research lagging behind that produced in other registrant specialities, became ever more apparent. Given the minimal published literature pertaining to DSD and RNMH specifically the pool of experts was chosen for their significant expertise in DSD and its associated care provision.

This selection included medical consultants, psychiatrists, consultant nurses, senior nurses working with DSD and mental health, and also prominent academic staff with research and/or clinical expertise in dementia, delirium and nursing care.

Rubio *et al.,* (2003) suggest that the panel should consist of a minimum of 6 experts, and up to a maximum of 10, whereas Zamanzadeh *et al.,* (2015) suggest five or more. This demonstrates inconsistency in the literature supporting a consistent number of experts required. However, a minimum of three is suggested by Lynn (1986), and Lynn (1986); Rubio *et al.,* (2003); Zamanzadeh *et al.,* (2015). This variation echoes the debate around how many participants are required for a qualitative study (discussed in Chapter four). As such, a target of between three and ten experts was considered feasible in keeping with the literature.

Experts were identified through review of published literature and prominence in locality-based dementia service provision. Potential reviewers were contacted informally to discuss the study and ascertain if they would consider completing a review. This was undertaken face-to-face, via email and telephone. Once an initial expression of interest and willingness was received, the validation pack was sent to them.

In total nine experts initially agreed to support the review. Of the nine packs sent, six were returned. One of these was a blank copy of the questionnaire with no validation form or notes, and one had comments and questions but no indication of validation form completion. Four completed packs were returned.

It is important to note here that whilst the form with comments could not be included in the processing of content validity scores, the qualitative suggestions were valuable and were reviewed initially for any actions to take as I did not want the information, effort and time of the respondent to be lost. However, full inclusion in the formal validation process could not be maintained. As such the expert validation process was undertaken with four result sets.

5.2.4 **Calculating Validity**

A series of validity scores were generated from the expert's responses. These included scores of clarity and relevance for both items and the complete scale. Allocations of construct (themes) were reviewed alongside free text comments for each item and finally the free text associated with completeness of the questionnaire.

5.2.4.1 **Relevance or Representation: Defining Content Validity Indictors**

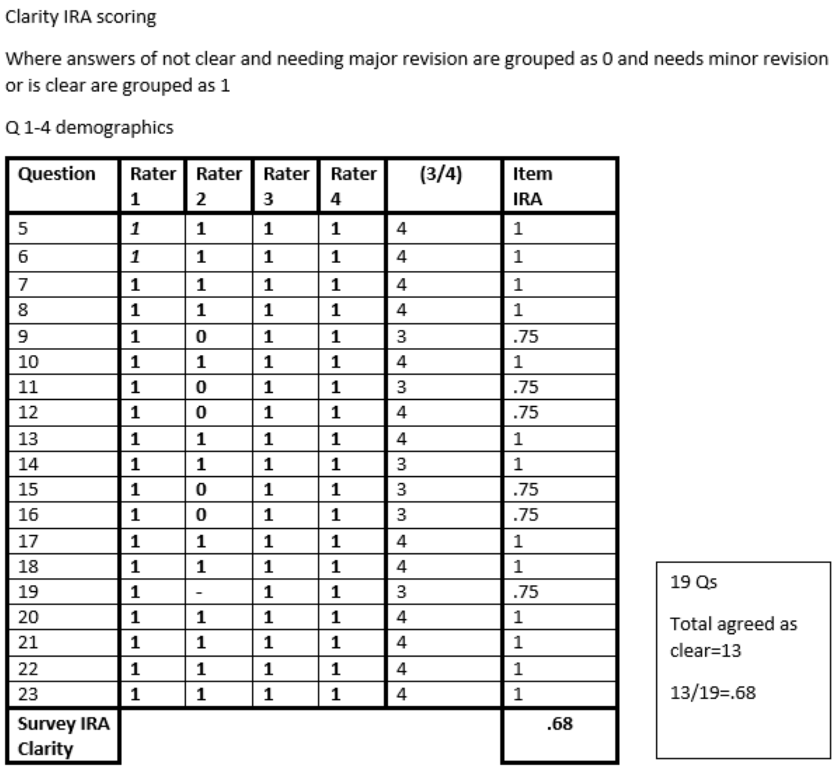
Content validity (CV) testing was undertaken using data returned from the experts to ascertain if the content presented in the questionnaire was indeed valid in relation to the specific context of DSD, and that no important items or indicators had been omitted (Polit and Beck, 2004; Gehlbach and Brinkworth, 2011). CV testing is most frequently done through a process of expert review of two elements. Rubio *et al.,* (2003) suggest these should be clarity and representivity (i.e. how clear the wording is and to what extent the items represent the care construct), whereas Zamanzadeh *et al.,* (2015) suggest the two items should include clarity, but relevance is assessed instead of representivity (where the items are scored regarding their relevance concerning the construct). As this questionnaire was designed to investigate a new construct, with limited literature to support the specific construct understanding, focus was placed on ascertaining if the questions posed appeared relevant to the construct in the expert's eyes. This was important as representivity could not be claimed or considered until a full understanding of what factors effected the construct was developed (as it was aimed this study would provide at completion). Representivity was not seen as a viable option at this stage.

5.2.4.2 Inter-Rater-Agreement of Item Clarity

In order to assess clarity of the items proposed for the questionnaire a process of assessing inter-rater agreement (IRA) was selected. It was essential to know to what extent all reviewers agreed (or not) that the items were clear in intention and phrasing, but also that the experts as raters were reliable in their ratings. It was envisaged that all raters would provide information that highlighted a consensus, any lack of clarity in the item formation, but also to assure that consistency across raters could be assumed for the subsequent ratings of relevance.

A grid was formed with each individual question numbers and a rater box. Ratings of a question being not clear or requiring major revision were allocated a score of zero, those requiring minor alteration to be clear or identified as being clear were identified a score of one: thus, dichotomising the scale. For each item, the IRA for clarity was calculated by adding the sum of the scores and dividing by the total number of raters. This method for calculation is advocated by Rubio *et al.,* (2003) and demonstrates to what extend the experts agree on an item's clarity (in this presentation). It also, in this format, gives an indication of potential revisions required, and to what extent these revisions impact on clarity (by indicating minor revision, or stating it is clear. Table 8, page 168 shows the full IRA for clarity breakdown.

Table 8 IRA for Clarity



Clarity IRA scoring

Where answers of not clear and needing major revision are grouped as 0 and needs minor revision or is clear are grouped as 1

Q 1-4 demographics

Question	Rater 1	Rater 2	Rater 3	Rater 4	(3/4)	Item IRA
5	*1*	1	1	1	4	1
6	*1*	1	1	1	4	1
7	1	1	1	1	4	1
8	1	1	1	1	4	1
9	1	0	1	1	3	.75
10	1	1	1	1	4	1
11	1	0	1	1	3	.75
12	1	0	1	1	4	.75
13	1	1	1	1	4	1
14	1	1	1	1	3	1
15	1	0	1	1	3	.75
16	1	0	1	1	3	.75
17	1	1	1	1	4	1
18	1	1	1	1	4	1
19	1	-	1	1	3	.75
20	1	1	1	1	4	1
21	1	1	1	1	4	1
22	1	1	1	1	4	1
23	1	1	1	1	4	1
Survey IRA Clarity						**.68**

19 Qs

Total agreed as clear=13

13/19=.68

Table 8 clearly depicts that the majority of items were rated as clear, however, six only achieved IRA of .75. One of these was subject to missing score data (Q 19). The survey IRA was completed by adding the total IRA of each item together and dividing by the number or items in total. This gave an IRA of .68. Initially this was disappointing, and uncertainty was felt about the progress of the questionnaire, however on discussion and revision of theory it was noted the IRA of clarity is used as a guide to highlight areas for revision, and is a score of to what extent the experts agree that the items are clear in phrasing and requests, not the relevance of the item itself. The free text boxes provided considerations and comments which pertained to clarity and ordering. Details of the revision process are presented following the discussion of validity calculations.

5.2.4.3 Content Validity as Inter Rater Agreement for Relevance

The most frequent manner of reviewing the relevance of an item to the stipulated construct is via content validity indices (CVI) generation (Polit and Beck, 2006; Zamanzadeh *et al.*, 2015). Content Validity Indices are a form of IRA measure.

CVI is expressed as a proportion of agreement (as is IRA) on a scale of zero to one. Three different calculations can be carried out to test for content validity indices (CVI) as a form of IRA for assessment of relevance of question to constructs: One generates scores for individual items: Item-Content Validity Indexing (I-CVI), and two generate scores for the complete scale: Scale-Content-Validity Index via Universal Agreement (S-CVI/UA) and Scale-Content Validity via averages (S-CVI/Ave). The review of individual I-CVI's was integral to highlight items that were acceptable, require revision, or that need removing from the questionnaire (Beck and Gable, 2001; Polit and Beck, 2006). Figure 28 shows the relationship between CVI tests.

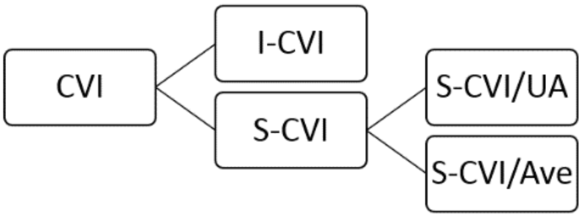


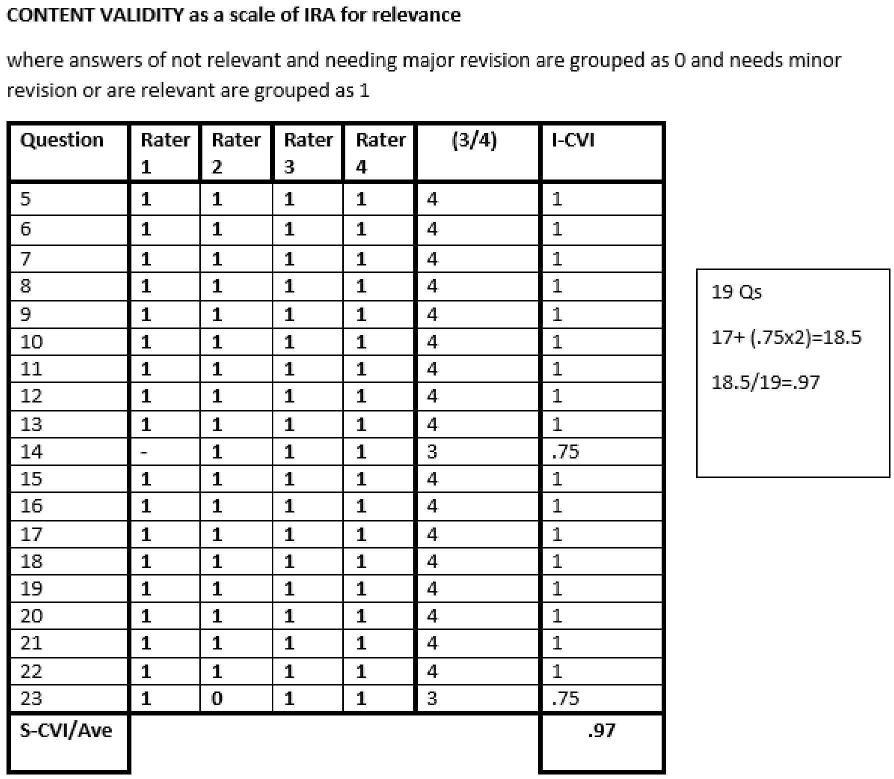
Figure 28 Content Validity Tests

For I-CVI, items were again grouped with items identified as not relevant or needing major revision to be relevant assigned a score of zero, and those requiring minimal revision or identified as relevant were assigned a score of one. The same process of adding the scores assigned to each question by each reviewer and dividing by the total number of reviewers was undertaken to produce the I-CVI. This showed to what extent the experts agreed the question was relevant. Polit and Beck (2006), drawing upon Lynn (1986) suggest that when five or fewer reviewers are involved the I-CVI should be 1, however more recently Abdollahpour *et al.,* (2010) suggest that an item with an I-CVI of .79 (79%) or more is appropriate to use, I-CVI .7 to .79 (70%-79%) required revision, and I-

CVI less than .7 (70%) is not appropriate to use. Fortunately, all items scored .75 or above. This was reassuring regarding the IRA values, as the questions were deemed relevant to the construct.

Lynn (1986) conceptualised CVI scoring as two processes, that of I-CVI and scale CVI (S-CVI), the S-CVI was applied to the complete set of questions to see if they were relevant in keeping with the lack of literature or scale previously designed for the context and constructs. This can be undertaken as an average (S-CVI/Ave) by which the sum of all I-CVIs is divided by the number of questions (Polit, Beck and Owen, 2007; Gehlbach and Brinkworth, 2011). This would give the questionnaire an S-CVI/Ave of .97. As the S-CVI/Ave is a measure of congruency, Waltz, Strickland and Lenz (2005) suggest that the acceptance level should be increased to .9, in opposition to the standard acceptance level of .8 as suggested by Davis (1992). Table 9, page 171 demonstrates the I-CVI and S-CVI/Ave calculated for the questionnaire. Importantly for the study, the S-CVI/Ave was found to be .97 showing a high level of agreement of relevance for all items and the overall questionnaire.

Table 9 CVI Scores



CONTENT VALIDITY as a scale of IRA for relevance

where answers of not relevant and needing major revision are grouped as 0 and needs minor revision or are relevant are grouped as 1

Question	Rater 1	Rater 2	Rater 3	Rater 4	(3/4)	I-CVI
5	1	1	1	1	4	1
6	1	1	1	1	4	1
7	1	1	1	1	4	1
8	1	1	1	1	4	1
9	1	1	1	1	4	1
10	1	1	1	1	4	1
11	1	1	1	1	4	1
12	1	1	1	1	4	1
13	1	1	1	1	4	1
14	-	1	1	1	3	.75
15	1	1	1	1	4	1
16	1	1	1	1	4	1
17	1	1	1	1	4	1
18	1	1	1	1	4	1
19	1	1	1	1	4	1
20	1	1	1	1	4	1
21	1	1	1	1	4	1
22	1	1	1	1	4	1
23	1	0	1	1	3	.75
S-CVI/Ave						**.97**

19 Qs

17+ (.75x2)=18.5

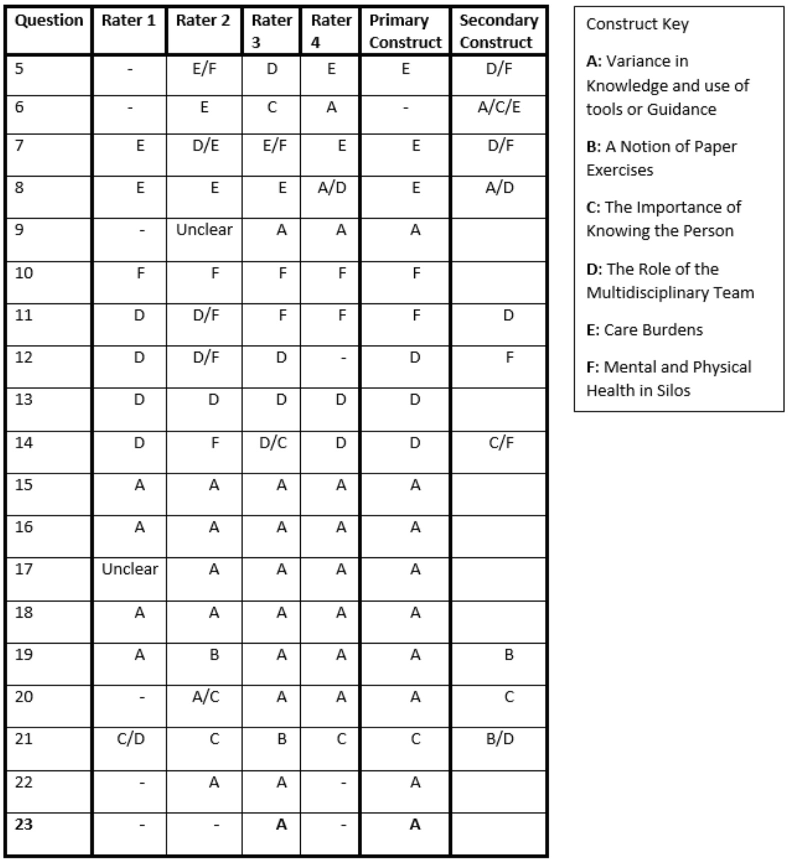
18.5/19=.97

As Table 9 demonstrates, only two items did not achieve a score of 1. Question 14 was recorded as having missing data as the reviewer had scored the item twice, once indicating it as not relevant and also as needing minor revisions to be relevant. As such it was decided to omit its score. Question 23 had free text comments that did not appear to match the actual question; however it had been identified as not relevant so was scored as such. Question 23 could have been ascribed to user error, nevertheless, it was important to review the process of completion to ensure that no obvious flaws were found in the design leading to incorrect association of one question with the response presented. One reason could have been the mode of review being paper based, with the expert needing to review the questionnaire and then compile answers on a separate form. The decision had been taken to not include any requests for name on the returnable validation form to maintain a level of anonymisation for the experts. Some did volunteer to identify their papers by indicating their name in the returns, however this paper did not have a name identified. As no identification data was requested in the first instance, identification and approach of the respondents for more information regarding questions 14 and 23 was not feasible. However keen attention to associated free text comments pertaining to these specific questions was paid to highlight any amendments that might have been required or shed light on the responses. To reiterate, the two items in question scored within the acceptable parameters for use, and as such were not removed from the questionnaire.

5.2.4.3.1 Construct (Theme) Allocation

It was important to identify to what extent the experts noted the six themes throughout the questionnaire, and which they associated each question with. This would give information regarding the balance of the questionnaire, but also the degree to which more subtle and potentially controversial themes were embedded throughout. I was mindful as a person from a professionally registered occupation, that questions pertaining to their knowledge and use of guides or tools might be a sensitive question or cause unease in participants; as they may not want to be seen to be going against, or not using appropriate guidance or support tools. In addition, in light of the very subtle nature of some of the questions a table of allocated primary and secondary constructs was compiled and reviewed for total number or time a construct was identified and in relation to which questions (Table, 9, page 171). This was used to assess the overall balance of constructs perceived by the experts (Table 10, page 173).

Table 10 Construct/Theme Allocation



Question	Rater 1	Rater 2	Rater 3	Rater 4	Primary Construct	Secondary Construct
5	-	E/F	D	E	E	D/F
6	-	E	C	A	-	A/C/E
7	E	D/E	E/F	E	E	D/F
8	E	E	E	A/D	E	A/D
9	-	Unclear	A	A	A	
10	F	F	F	F	F	
11	D	D/F	F	F	F	D
12	D	D/F	D	-	D	F
13	D	D	D	D	D	
14	D	F	D/C	D	D	C/F
15	A	A	A	A	A	
16	A	A	A	A	A	
17	Unclear	A	A	A	A	
18	A	A	A	A	A	
19	A	B	A	A	A	B
20	-	A/C	A	A	A	C
21	C/D	C	B	C	C	B/D
22	-	A	A	-	A	
23	-	-	**A**	-	**A**	

Construct Key

A: Variance in Knowledge and use of tools or Guidance

B: A Notion of Paper Exercises

C: The Importance of Knowing the Person

D: The Role of the Multidisciplinary Team

E: Care Burdens

F: Mental and Physical Health in Silos

The sum of each theme allocated as either a primary or secondary construct was calculated to give an overview of overall presence in the questionnaire (Table 11, page 174). As Table 11 (page 174) shows, themes B and C were not overtly noticed and allocated less frequently by the panel. Whilst it was initially considered as a failing, on reviewing the nature of the themes (B being pertaining to use of tools/guides, and C pertaining to knowing the individual) it was seen that these were potentially sensitive, or challenging areas to explore via numerical data, and in keeping with the mixed methods approach and integration of data, I was reminded that the challenges of these two themes had been articulated in the interviews by participants (for example participant 0501s account discussed further in Chapter six, pages 193 and194).

The formatting and phrasing of the questionnaire was revised to see if they could be drawn more to the fore, but on review, their presence was again noted throughout several question sets, but in a very subtle and nuanced manner. Overt and blunt questioning pertaining to these concepts, attitudes and behaviours may have led to respondent discomfort and poor completion of such direct questions.

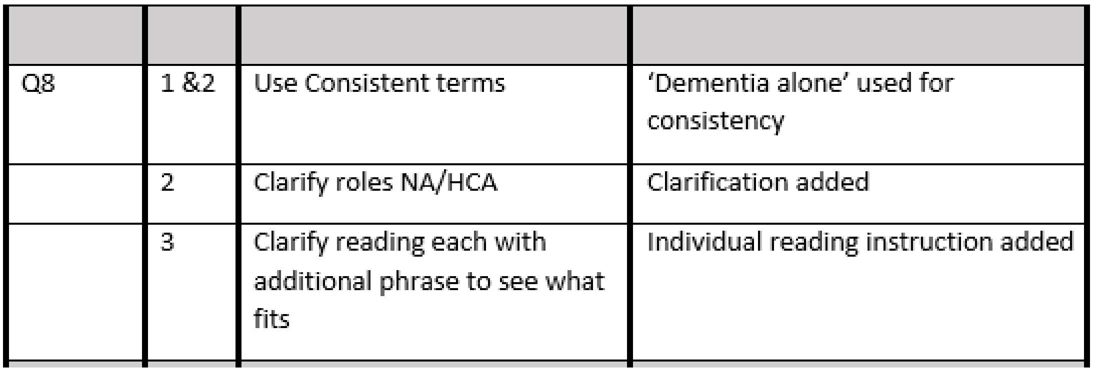
Table 11 Total Allocation by Theme

Theme	Primary Allocation	Secondary Allocation	Total Allocation
A	9	2	11
B	0	2	2
C	1	3	4
D	3	5	8
E	3	1	4
F	2	4	6

5.2.4.3.2 Suggestions/ Free Text Comments

Each question was reviewed in turn and then as part of the questionnaire in relation to the free text suggestions given. This process was undertaken for each expert in isolation and then as a group. Here it was paramount that the focus of the study's context, aims and objectives were kept at the forefront of the review as there was potential for reviewers to have their own specialist interest or ideas which may prove valuable, but sit outside the scope or context of the questionnaire. A table was compiled for ease of use with a summary of points made for each question, by which expert reviewer and actions taken or not (Table 12). Any actions not taken were briefly annotated with a rationale as to why.

Table 12 Questionnaire Suggestions and Comments



Q8	1 &2	Use Consistent terms	'Dementia alone' used for consistency
	2	Clarify roles NA/HCA	Clarification added
	3	Clarify reading each with additional phrase to see what fits	Individual reading instruction added

5.2.4.4 **Instinct and Intuition**

One debate that followed the questionnaire development throughout all stages was that of the appropriate choice of term regarding nursing ‘gut feelings’ and clinical decision making in practice: intuition and instinct. It was important to gain a sense of how the nursing staff perceived their knowledge, experiences and views informed their care decisions. Dictionary definitions report *Instinct* to be ‘an innate, typically fixed pattern of behaviour…’ (Oxford Dictionaries, 2018a) and *Intuition* as ‘the ability to understand something instinctively, without the need for conscious reasoning’ (Oxford Dictionaries, 2018b).

In the initial draft questionnaire sent for internal peer review comments were passed regarding the use of *intuition*. Feedback indicated that the basis of intuition and interplay of guidance did not accurately represent that question posed. There was a sense that intuition was based on, as the dictionary definition indicates, unconscious processes. On review, for the formal panel review, the term was swapped for instinct, however this term was met with similar comments and debate following expert review. Again, the notion of instinct was questioned in relation to the interplay and impact of guidance or tools on instincts. The question posed needed to unpick what the nurses perceived their nursing actions were based upon in line with experience and unconscious nursing skill use. With conflicting discussions pertaining to the terms, additional literature was required to ensure the correct terminology was selected.

A review of the nursing and associated literature revealed that intuition is indeed frequently seen as an unconscious process; defined by Pearson (2013 p 213) as ‘knowing without knowing how’. Hamers, Abu-Saad and Halfens (1994) and

Parahoo (2014) support this notion of unconscious processes being central to intuition. In opposition, instinct is seen as engrained and innate; a natural, born response, however the process is noted, and it appears fixed or static in behaviour.

Benner's Theory of Novice to Expert (Benner, 1984) is seminal in nursing understanding of intuition; however, contemporary critique and alternative theory seeks to unpick intuition, and advance theory towards understanding the multitude of elements that build up to form the concept that we recognise as intuition (Gobet and Chassy, 2008). Melin-Johansson, Palmqvist and Rönnberg (2017) discuss that the composite elements of intuition may include pattern recognition, a gut feeling, common sense, skill to know how, tacit knowledge and rationality which cannot be practically separated (Benner and Tanner, 1987). These may all form a process which is manifested in intuitive behaviour and is fundamentally different to innate instinct driven actions. Intuition and analytical thought processes have been seen as running parallel to make up cognition (Melin-Johansson, Palmqvist and Rönnberg, 2017), however it is established that a person can be capable of both, and that they can be perceived as a continuum or sliding scale (Hammond, 1988; Standing, 2008). Recently, Morewedge and Kahneman (2010) noted that intuition could be the result of the use of rapidly accessed associated memory processes. This gives intuition a dynamic and evolving underpinning, again distinct from an innate instinct driven action or behaviour. Whilst Benner and Tanner (1987) acknowledge that it is impossible to extrapolate or separate gut feelings from external signals or cues received and any associated knowledge, the unconscious premise gives a mystical sense to the term *intuition* which is often found in the literature; an unexplainable phenomenon, when in fact a more practical stance would be to view intuition as rapid pattern recognition. Central here then is the knowledge that underpins the patterns recognised. Gobet and Chassy (2008) break this down further discussing that frequent pattern recognition supports templates from which to act upon, core, or stable information takes time to process; however, with core information, slots are noted into which variables can be positioned and drives rapid use of information. Thus, intuition can be perceived as a mobile concept, evolving, and being shaped as more core information and variables are formed in slots. As such, intuition, whilst it may appear on the outside to be unconscious in nature, is in fact an adaptive and rational process with its core foundations in experience and (in terms of nurses) an accessed evidence base. Gobet and Chassy (2008) suggest in their template theory, that intuition has five key components:

1) A rapid perception of a situation or occurrence that is built from established chunks of information or formed templates.
2) A lack of awareness regarding the cognisant processes occurring due to unconscious long-term memory access. Here only the variable elements are recognised and gives the sense of 'not knowing'.
3) A total or holistic understanding by which templates are formed from smaller chunks of information so a large overview if seen using small pieces of information. This produces rapid and overarching recall and appreciation.
4) The intuitive actions are usually correct. This though is based on an understanding that time, environment, complexity of information to process may influence decisions. So, the action may not be correct: but this does not detract from the use of intuition as it is learned from and forms new memories and templates to access.

5) Emotional interplay occurs when intuition is used. Emotions are linked to memory which serves to drive the intuitive process (Chassy and Gobet, 2005), and as such emotional responses and associations are engrained in intuition and decision making.

These processes can be simplified into an adapted formula of:

Intuition= Knowledge + Experience + Expertise

Adapted from McCutcheon and Pincombe (2001)

This adapted formula shows the synergy and dynamic processes that underpin the use of intuition. Therefore, and alongside the recognition that the seminal nursing literature and theory uses the term intuition, the original term intuition maintained its place in the questionnaire.

5.2.5 **Usability Pre-Testing: Phase Six**

Usability testing was conducted to review the format of delivery. Usability testing subjects the respondents to the questionnaire in a manner as close to the context of administration, and is an acknowledgement that the respondents may process questions in a different manner to the researchers (Rubin, 1994).

Whilst different methods for pretesting a questionnaire and assessing usability are available, general principles appear to run through them all: respondents are asked to answer in some format probes regarding:

1. Repeating questions in their own words
2. Reporting thoughts
3. Being asked follow up probes (Gehlbach and Brinkworth, 2011).

5.2.5.1 **Pre-Testing**

Following the recommendation of Presser *et al.,* (2004) and being mindful of the modes of administration, pre-testing was planned to focus on wording, alternative or missing response items or assumptions made. The questionnaire was reviewed by lay people in keeping with Rubio *et al.,* (2003) assertions that the overall review panel should encompass not only experts (as discussed previously), but also lay people. A variety of viewpoints were required to fully assess how it would be perceived and managed, not only content experts (Rubio *et al.*, 2003), as some of the intended participants may have experience of DSD but to varying levels. Again, with validity confirmed through expert review, the focus here was on usability of questionnaire presentation. A booklet was compiled as a partner to the online questionnaire. Specific focus was placed on the consent information, text size and navigation.

Two research assistants with no links to the study volunteered to review the questionnaire. At a convenient location and time, a one to one meeting was held with each. Each volunteer reviewed the questionnaire, using the navigation, identifying response options, checking the processing and ease of applying their responses throughout. A discussion was facilitated by the partner document to review key aspect of clarity in process of completion instruction clarity, possibility of not being any to respond and why, how answers were formulated, ease of difficulty in answering, question navigation rephrasing and if the question matched my intended question. Comments were noted on the partner document for each volunteer.

The completion process was timed and found to be (including discussion) between ten and fifteen minutes. This did not seem burdensome to the volunteers and it was noted that without discussion the questionnaire completion time would be reduced further. The modified partner document can be found in Appendix 12. A tabular format was used to compile findings and represent each response in line with the probe asked and any actions taken. An example of this can be found in Appendix 13.

5.2.5.2 **Pre-Test Modifications**

The usability pre-test was a positive step towards ensuring a working questionnaire. No issues with use, failure to respond issues, or uncertainty in process were highlighted. The addition of a more in-depth introduction to the study including the articulation of wanting a ‘gut response’ was highlighted as positive alongside the data use information.

5.2.5.3 **Distribution**

There are several well-known and routinely used approaches to distributing and collecting questionnaire data. The most common approaches of mail, telephone and web-based questionnaires were considered alongside the target population and their known characteristics (required by their role and RNMH). All registered nurses must have a level of both written and computer-based literacy. This meant that all forms of questionnaires (paper based/ computer generated, or telephone) could have been undertaken.

As discussed in Chapter four sampling of multiple sources of participants to achieve a data set spanned three different settings: NHS Trust, conference participants and care homes. The method and formatting of the questionnaire was driven contextually throughout this study, revised, and reviewed in keeping with the local information and permissions granted by each setting. As such, a combined approach of web-based, and paper questionnaire design and distribution were undertaken. This supported wider data collection and increased sample size matching the formatting of the questionnaire to the context of participants. Using this strategy, the participant could access the questionnaire at a time or place acceptable to them and increased self-determined privacy levels. For the web-based application, data collection was rapid, with return process or turnaround times, whereas paper-based questionnaires were more labour intensive as they required distribution and collection to the care home sites. This though proved useful as I was able to have ad hoc conversations with the clinical staff if they had any questions, I was visible to them as a person, and felt this helped achieve a connection with a participant group which could support their trust in their data being handled appropriately. Assurances of the data management of paper questionnaire within the care homes were detailed and managed in line with their needs and requirements, allowing them to guide me as to what they felt was required to maintain their anonymity. All paper-based questionnaires were distributed with a sealable blank envelope in which they could put their complete (or not) questionnaire and return any unused questionnaires anonymously.

5.2.6 **Quantitative Data Management**

Data was entered into a self-built data set using IBM SPSS® software V25.

Each response was input by hand into the set to allow for continual review for accuracy. Each participant was given a unique identifier code. The online submissions retained their JISC participant number with an additional code given to those completed after the conference. Paper based submissions were individually coded to indicate this format. In keeping with the anonymous nature of the survey no questions were asked to link individuals to the responses; more that identifiers were given to allow the data sets to remain identifiable as a whole. The SPSS data set was stored on my university password profile and accessed via password protected computer systems.

5.2.7 **Missing values**

Missing values were identified and coded in SPSS® as -99 as this value could not be achieved in the questionnaire response coding context. This allowed for the missing values to be clearly identified and processed when undertaking analysis. Each missing value equated to 4% when calculating percentages. For consistency, the ‘valid percent’ was used for all reporting and discussions (in which the missing data is removed from analysis).

5.2.8 **Data Analysis**

In keeping with the non-experimental, exploratory premise of the questionnaire, non-parametric tests in the form of descriptive statistics were used to analyse the data. The goal was to describe and better understand the nursing experience rather than test relationships or effects. Likert Item scoring for analysis followed standard numerical allocation moving from 0-4. For example, 0= Strongly Disagree, 1=Disagree, 2=Neither Agree nor Disagree, 3=Agree, 4=Strongly Agree. The items and associated numerical value always ran from a negative to positive association. No reversal of questioning had occurred and no standardisation for alternative scale lengths was required. Open response options were coded to themes and quantified as discussed previously. Returning to the framework of core themes, the questionnaire data was analysed in keeping with the research aims and activity theory thematic allocations drawn from the literature and qualitative findings.

5.3 Integration of Data Sets

Integration of the two sets of analysis was undertaken to inform and give greater depth of understanding to the experience, and was applied to the activity system frame. Clearer and more complex insights were found that could not have been seen by using either qualitative or quantitative findings in isolation (Creswell and

Creswell, 2018).

Mixed methods research holds central the robust integration of data in a number of different positions. Returning to the exploratory sequential design, in this study, qualitative data integration (or level of mixing) was already embedded into and throughout the qualitative phase as it was from, and upon this that the questionnaire was built. The findings from the quantitative phase were reviewed in the context of the activity system to explore and expand upon the driving, influencing, and impacting components that build the experience.

Paramount importance was placed on drawing inferences that represented the totality of the experience. Data from both stands were read and reviewed in tandem to allow for inferences to be drawn. On reviewing data sets and drawing inferences in such a way, two potential patterns of data were expected:

1) Convergence of data: in which it tells the same story and adds strength to inferences drawn
2) Complementing data: in which new data is added in addition but is supplementary and in congruence.

A third type outcome, namely divergent data, is proposed by Erzberger and Keele (2003). Whilst divergence could be initially be seen as negative, or signpost towards inappropriate application of methods or initial analysis, for this study its potential added further detail in the exploration of experience and lead to amended and developed accounts. The purpose of the questionnaire was not to explain or test an established theory, and as such any divergence would offer additional insight and understanding of the nurse experience.

From the final integrated analysis, a conceptual framework was built that presents an answer to the research question and purpose (Venkatesh, Brown and Sullivan, 2016). This is presented in Chapter eight, Figure 39, page 252 after the discussion of the study findings and results.

5.4 **Chapter Summary**

Chapter five has detailed the qualitative and quantitative methods for data collection and analysis undertaken following the study's justification as a mixed method, exploratory sequential design, discussed in Chapter four. Semi-structured interviews were undertaken to expand upon and refine the initial activity system drawn from the literature review. The analysis of qualitative data through framework application offers a robust audit trail of thematic development and establishment of key areas for quantitative explorations with a view to further explore and understand the RNMHs experience.

Thematic analysis was undertaken with the interview data, commencing at familiarisation where initial themes and pertinent points were identified from a small selection of interviews. Analysis of subsequent interview data was interpreted and considered against these early themes and a process of building and refining a thematic framework was undertaken. Whilst linear in presentation, a cyclic approach to analysis was undertaken, in which analysis and interpretation occurred fluidly. The framework was expanded and refined in keeping with the interview data and processed using NVivo™ software. This allowed a robust and clear audit trail throughout the analysis process.

An interim process of questionnaire development kept the exploratory, not confirmatory basis of this study central, whist maintaining clarity and relevance to the nurse care construct. Extensive internal and external expert review offered assurances of clarity and relevance and, from this, a questionnaire was formatted for multiple participant settings using both paper-based and web-based applications. This was subjected to a pilot analysis in which operationalisation was confirmed as acceptable prior to full distribution and analysis. Quantitative data was analysed using descriptive statistics, again seeking to explore facets of experience, rather than test or prove predetermined understanding or components.

Chapter six details the qualitative findings before Chapter seven presents the quantitative results and integrates the data sets expanding and exploring their position and facets within an activity system.

Final integration of the data, stemming from the initial literature review activity system, through the qualitative, quantitative and integrated analysis concludes the activity system for the RNMHs, and is presented in Chapter eight in the form of the discussion.

6. Qualitative Findings

This chapter discusses the qualitative findings gleaned through framework analysis of semi-structured interviews. As explored in Chapter four, the semi-structured interview participants' profile included two male and five female RNMHs; one band 6 RNMH and spanned both acute and ongoing organic assessment wards. The key findings are presented in their activity system positioning and core theme code (denoted by C) in Figure 29 page 212 prior to the final stages of framework analysis: abstraction and interpretation. This new iteration of the activity system is developed from the original system born from the literature (Figure 7, page 40), and subsequently revised in keeping with the qualitative findings to produce the final integrated activity system presented in Chapter eight, Figure 39 page 252. Two factors were found in relation to Tools in the activity system and are presented as C1 and C2 for clarity.

It is important to reiterate here that this was a mixed methods study, integrating qualitative and quantitative findings to form a cohesive, final presentation of the RNMH experience presented in chapter seven and discussed in relation to the established literature in Chapter eight. The findings presented here represent a facet of the study, not the totality or end point of analysis. In terms of the studies chronology, these qualitative findings served to illuminate key areas for further exploration through the production of a quantitative questionnaire.

6.1 C1 Awareness of Tools (and/or Guides)

Exposed in the interviews, was a clear difference in each participant's awareness of the tools in their workplace to support DSD care. Tools, as discussed in Chapter three, are mediating artefacts that formally guide care external to other components of the activity system; such as guidelines or scores. This discussion included perceived access to, and application of such tools in their work environments.

When asked questions around what guided their care for someone with DSD, the participants suggested that tools had been used in the past, rather than in current practice:

'…there was a tool where you had to rule out possibilities, of kind of pain related delirium, infections, I can't remember what the thing was now…'

0101

'…there used to be a delirium assessment tool what we kind of trialled here for a while, but we have kind of stopped that now and I don't really know. There probably is, there will be, an assessment thing...'

0202

Both these participants indicated that at one time there was a tool in place, but this was no longer present or used. The inability of both to name the tools used added to the overall feeling of uncertainty, alongside 0202's admission that they did not know why it was discontinued or if there was an alternative in place.

The use of the phrase '*an assessment thing'* for potential tools by 0202 suggested, that for them, the use of such tools was not seen as important or fundamental to their care provision. Organisationally, the historical discussion of tools no longer in use indicated that these had been removed from practice, or not mandated for use, and the inability of the RNMHs to recall why or discuss what was currently in place suggested that they were not seen as a priority or useful.

The lack of awareness demonstrated by 0101 and 0201 was not echoed across the participants. This indicated that there might be individual variance in practice and awareness and therefore the RNMHs experiences:

'…we really only use the delirium rating scale […]

0401

'…so we have got MMSE which, ACE-3 which shows… we leave the doctors to use the ACE-3 most of the time, and we do use MMSE and they show us confusion, orientation and if they can recall...'

0402

The naming of tools here implied that these participants held a level of familiarity with them. The tool named by 0401 (the Delirium Rating Scale or DRS) is specifically a delirium diagnosis and severity scale tool. Its naming suggested that this individual was aware of the association of the tool with delirium. In contrast, whilst 0402 reported a pair of tools (MMSE[11] and ACE-3[12]), neither of these are delirium specific tools. Rather they are cognitive impairment screening tools used predominantly to assess dementia. And although the MMSE can be used repeatedly to observe fluctuations in cognition, there was no discussion of the tool's single or repeated use to gain insight into cognitive fluctuations which could signify DSD. This showed, in 0402, a potential lack of knowledge pertaining to DSD and appropriate selection of clinical tools. In addition, 0402 highlighted that these tools were not all used by RNMHs; with the RNMHs using the MMSE,

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[11] Mini-Mental State Examination (MMSE) is a test of cognitive function often used in dementia assessments

[12] Addenbrooke's Cognitive Examination 3 (ACE 3) was developed as an extension to the MMSE and supports identification of cognitive impairments including dementia

and the doctors use the ACE-3. Here, 0402 indicated that their nursing experience of DSD and tools was bound together with the doctors. And whilst they had an awareness of tools being used in practice, they did not necessarily use them themselves.

The inclusion of other professionals in their accounts provided potential insight into how the RNMHS experienced caring for someone with DSD. Their experiences and reports of their own actions were bound up in those of other professionals working alongside them. In this instance, 0402's experience was synchronous with the doctor, and the care of the person with DSD appeared shared across professions. This is discussed further in the discussion of the multidisciplinary team below.

Adding to the complexity, there was variance across the participants' accounts in relation to accessing learning resources and clinical updates, and who they viewed as responsible for this provision:

'…we have got our dementia guide, how to treat dementia, we've got the delirium guidance but, …I've access to the library, so I've put the password in so I can access Athens …and it's got all the information and we have got support…'

0402

'…I look at, if you look at NICE guidance or Royal College of Nursing stuff, but I tend to use the learning modules on BMJ…I suppose not specifically on dementia to be honest, because I think the learning modules I do are delirium in general, erm, with aspects of dementia and textbooks again that's generalized delirium so no specifically in dementia, actually yea…'

0201

0402 and 0201's responses suggested an individual responsibility for maintaining awareness of key topics, whilst 0402 described how this was facilitated to some extent by the organisation in terms of access to libraries and support. The proactive approach shown by these participants is synonymous with the expectations of their professional code as outlined by the NMC (2018b) in section 22.3 which stipulates that nurses must keep their own knowledge and skills up-to- date. In contrast, 0401, whilst continuing to indicate individual responsibility, demonstrated frustration that this was up to the individual, and appeared discontent with the lack of organisational support in terms of updates or training:

'… if we have an interest or want to know anything that will help, so I think that can be quite frustrating as well that we don't always get updates or any training or things to understand or recognise delirium…'

0401

Analysis of the interviews overall revealed a variance in perception of organisational provision of resources to support care. As shown above, 0402 discussed access to library systems, and whilst 0201 detailed using professional resources and journals, there was a clear articulation that they (0201) believed that there was no access to organisational libraries or wider provision of education.

'…not really, I don't think so, like there's no library or no professional journals, I don't think we do any additional seminars…'

0201

6.1.1 C1 Consideration

Of interest here was the conflicting accounts of both the provision and availability of tools in terms of DSD assessments in practice, and the knowledge of wider support resources perceived as being available to them. No standardised experience, or commonalities in awareness of, or use of tools could be drawn. The uptake of available tools appeared to depend on both the organisational culture of the clinical environment (as in what tools or guides were embedded in practice), but also the individual RNMH, shown in their willingness or personal drive to seek out resources aside from those provided by the organisation. As registrants, nurses have a responsibility to provide care based on contemporary evidence and guidance, and as such a degree of self-directed update is required alongside the organisational responsibility to use, facilitate and make accessible appropriate evidence-based care strategies.

Forming part of the emerging activity system, the RNMH awareness of tools and guides showed an interaction between *Tools* (explored further in C2), *Community* (C4, the community of practice in the multidisciplinary team) and *Division of Labour* (C5, how work is distributed across professions).

6.2 C2 Tools (or Guidance) as Paper Exercises

The purpose of completing tools was explored with participants who reported their use. 0402 appeared to use the tool on a set timed basis:

‘…I would say, I would just class it as part of the monthly tool you know…’

0402

Here, 0402 reported the assessment was completed as part of a monthly exercise and did not indicate that it was linked specifically to the patient’s presentation.

This suggested that the tools available were not used as a responsive part of patient assessment and care provision; and potentially, were not seen as useful in the acute presentation of DSD. This highlighted a potential disconnect between the intended purpose of DSD tools and their application in practice. This disconnect was echoed and elaborated further by 0401 when discussing the use of the delirium rating scale:

'…I think sometimes when we do use it, and that's the only one we tend to use, sometimes nothing's done about it, you get your weight and sometimes it depends upon the person, you don't always go back and say 'that persons scored 14' it's kind of scanned or filed and that's it until its discussed in a meeting and say 'oh yes 'that persons scored 14' or 'they scored 16' or whatever, so sometimes I don't think that's fully utilised…'

0401

This might indicate that the tools had little impact on patient care:

'…and obviously you've got a set of numbers and you tick them, according to what the person is on the rating from 0 to five or whatever, but the front bit that tells you about if a person sort of scores a certain amount has possibly got a delirium, or they don't have a delirium.'

0401

It appeared possible that the RNMHs did not perceive numerical scoring systems as influential on the care decisions and care provision. That is not to say that appropriate care was not being delivered, but that the tools were not conceptualised as supporting nursing care.

As the participants started to unpick their perceptions of the tools, 0401 and 0501 showed an acute concern regarding inappropriately scoring someone and ‘giving them’ delirium or a diagnosis:

‘…and I think also with that tool, sometimes you’re torn between two different levels, you , your person is kind of in-between, so they are not fully advanced with their illness but could fit into both categories, but if you fit them into maybe the number 3 and not a number 2 on the scoring thing, it’s like they come out more poorly, than necessarily having a delirium at the time, but you score them high coz they have got more symptoms that goes into a one but they are more or less likely to fit into the lower number but it doesn’t always …’

0401

‘…But then you quite easily give somebody delirium when they haven’t, not that you know of, but it might be their norm. Or not where they need it, so I say they are valid, the questions are, but it’s your knowledge, you need to expand your knowledge…’

0501

Here, 0501 suggested that it is not only the presence of a tool that is required, but also a fundamental knowledge of the person as an individual. They appeared to indicate that knowing what the patient’s normal presentation *(‘norm’)* is paramount to complete the tools. This is explored further in the discussion of knowing the individual (Chapter 6, page 196).

Collectively, participants suggested a disconnected feeling: the RNMHs did not associate patients’ presentation with a binary number or categorisation derived from a tool. That said, they did recognise the potential limitations of their own knowledge of the person and the impact that this might have on care provision.

This demonstrated a complex tension between the tool’s use, and the RMHNs’ own clinical judgment based on their knowledge of the individual. It appeared that even though their knowledge base might be lacking in a number of areas (knowledge of the person, knowledge of delirium tools, and use of non-delirium tools), they seemed assured in their nursing judgement over the use of the tools.

Interestingly, one participant (0501) appeared to change their opinion of the DRS tool; initially, noting it as flawed and standardised (described negatively as ‘*ticky box’*), they started to consider the reasoning behind clinical scoring and the potential befits of application in practice to patient outcomes. Here, the usefulness of the tool appeared linked to a heightened understanding of the DSD as a care priority:

‘…well, I’ve decided, identify, DRS, I’d say because its flawed, it is, you know, it is. Serves a purpose, but I think it’s become too standard...., ticky box, […] but prior to that I think was just, I think a lot of people went undiagnosed, or with you know, I think now more, you know, they have realised the importance of delirium so it’s, we screen better, but I think, but yer, I think, I’ve won trust for it really…’

0501

This provided a useful insight into the conceptualisation of tools; 0501 highlighted a disconnect from scoring people in a ‘*ticky box’* manner, but on reflection, and potentially in light of a raising of awareness of delirium as a clinical priority, there was a shift in opinion, towards valuing it in practice. The reason for this apparent change in opinion appeared to be linked with an awareness of underdiagnosis and the importance of delirium.

6.2.1 **C2 Consideration**

Tensions were seen between the RNMHs awareness of tools in practice, and its use. Tools were conceptualised and understood to be part of monthly timed processes rather than linked to patient presentation or care planning. There appeared to be a concern that tools might inaccurately score patients as having, or not having delirium. This appeared to stem from the specific registration and education of RNMHs (discussed in Chapter one) being based upon impact of the condition on the person rather than diagnostic labels, but also from a limited awareness of DSD and the intended use of tools to support care decisions.

It is possible that the completion of scores and tools was not valued highly by the RNMHs, and they did not wish to reduce the individual to a number, or place numerical values on the patients and their experiences of DSD. Care for someone with DSD seemed poised as a balance between the RNMHs' awareness of tools (C1) to some extent, their conceptualisation of tools as remote paper exercises (C2) and was mediated and influenced by individual RNMH's understanding of the importance of delirium diagnosis in people with dementia.

Whilst there was a demonstration of tools winning over the RNMHs (as shown by 0501), the overarching suggestion was that tools and guides were completed as a routine procedure, a paper exercise for the organisation (in terms of monthly tools), but not to support the RNMHs' practice.

6.3 **C3 Knowing the Individual**

As indicated in C2, participants appeared concerned not to reduce people with DSD to a number (in terms of generating scores to represent patient presentation). Leading on from, and growing out of C2, it appeared that they were more comfortable discussing patients as people, rather than as numbers or scores; the RNMHs needed to know if the patient's behavioural presentation was changing to inform their care decisions. Inherent to this was a knowledge of the person as an individual.

When asked about a time when they had cared for someone with DSD, 0101 said:

'…erm, a gentleman erm, who had been well known to us, there were changes in his behaviour, he was more confused, he was more aggressive and impulsive, I suppose the triggers, the known triggers to the aggression and other behaviours weren't as easily identifiable, they seem to come out of nowhere, …'

0101

Here, there was a clear sense that the RNMH knew that the patient was behaving differently to their normal presentation, but also that they were aware of the factors which might be causing this change. This was echoed by 0202, who recognised changes from the patient's normal condition:

'…I think if you know the patient as they are, and then they suddenly deteriorated or suddenly became more aggressive, you, I think you initially think, yer they have got an infection…'

0202

Whilst 0202 identified a change in presentation and linked this to delirium (by nature of the question) they did not use the term delirium. Instead, they discussed the change in terms of infection; a known underlying physical precipitative factor for DSD.

0501 also tentatively linked a person's presentation changing to delirium:

'…but with superimposed, I think that's one of the early signs, that when we know it's out of character, […] but the possibilities of delirium you know…'

0501

These similarities in discussion provided a useful insight into the RNMHs' experiences and thoughts regarding presentation of potential DSD. Common across the accounts was *knowing* the patient, recognising changes, (becoming *more* aggressive, *suddenly* deteriorated, *out of character*).

Alongside the firm belief that they held personal knowledge of the patients as individuals, the participants also commented at length on how this knowledge was gathered and formatted. There appeared a central repository of information, a *formulation* which operated as support tool in itself in order to help the RNMHs identify changes in a patient and explore potential reasons for such change:

'…what I think we do rely on is the formulations, knowing the patient, knowing a possible trigger, but yer…'

0101

0102 discussed *formulations* clearly, offering a mental map of the process:

‘…it’s basically an A4 piece of paper that described a person all together, you've got a life story section, […] about the persons history, who their family are, what they did for a living what lead up to admission. You've got a box for behaviours that you may see from the person […], so the next box down is kind of like a flow chart, so the behaviour box flows into what the triggers are for those behaviours, […] so it’s a really in depth analysis of that one person, as person centred as we can be…’

0102

This appeared to give the RNMHs a visual tool for patient assessment and care; one in which the patient could be viewed and considered as an individual rather than reduced to a numerical value. This need for information and the value placed on it, was tangible throughout the interviews. For example, 0501 discussed deriving information and knowledge from the patient's home setting, other wards, family and carers, with an impetus on promptness and meaningfulness in utilising a variety of sources:

‘…We also do that straight away, a proper life story that has some meaning to it, all within 72 hours…’

0501

This supported the building of a qualitative understanding of the person (versus a quantitative score), drawn together into a formulation which could be used by the whole multidisciplinary team. This identification of the person as an individual on paper, helped to guide and articulate the RMHNs’ knowledge of that individual. Participants in the interviews reported that knowledge and understanding of the patient was key to their identification of DSD or a rapid change in the patient’s behavioural presentation. 0401 noted this clearly, recounting:

'…and they can have a period if they do have the delirium where throughout that period they can hallucinate, have more of a cognitive decline, they are more irritable, totally out of character…'

0401

Importantly, by discussing what was out of character, the nurse displayed confidence in knowing what the 'usual' character of that patient was. 0501 reiterated this sentiment, describing knowing what the 'norm' was for patients, and discussed aggression in relation to types of dementia and signs of DSD:

'…*I think that's one of the early signs, that when we know it's out of character, and we get family history and that, and that it's not their norm, that's when more or less decide, well don't decide, but the possibility of delirium you know, it can come on acute…'*

0501

6.3.1 **C3 Consideration**

It was clear that the RNMHs placed keen value on knowing the people that they cared for as individuals, focussing their care on a knowledge of the person and not a diagnosis. This knowledge of the person appeared to form the basis of assessments, not clinical scoring tools or guidelines (such as the DRS discussed in C1). The participants seemed to consider what the person was usually like when 'well' and what happened to provoke a change of presentation, rather than a number found in scoring tools generating action.

6.4 **C4 Multidisciplinary Team**

A key component to the RNMH experience was found in the working partnerships with the multidisciplinary team. These appeared influential and common across the interviews. The nurses predominantly discussed allied health professionals, other specialist nursing teams and medical staff as informative and helpful, guiding and supporting their practice:

'…now we have got our nurse practitioner who will kind of support us through all that, we have got our ward doctors erm that could help rule out things, the physiotherapists are really good, so for looking at kind of pain and discomfort and linking a kind of changes in presentation, delirium, erm they're pretty good at kind of guiding you through…'

0101

Whilst 0101 discussed a range of practitioners being accessible to them and providing support, the level to which they required support was unclear. 0101 suggested that they required guidance relating to DSD care, stating '*they're pretty good at kind of guiding you through*'. This suggested that, rather than leading care, the RNMHs were uncertain about their part in DSD care provision and were unable to proactively participate in care without clear instruction from the multidisciplinary team. This provided additional insight into, and expanded upon C1 and C2 in which the RNMHs demonstrated variable awareness of guidance to support their practice. There appeared to be a lack of responsibility for leading on their own clinical updates, and also a potential aversion to using tools when they were available. It could be concluded that the RNMHs here, were asking to be told what to do; wanting to follow direct instructions, rather than lead on care. What was not clear was if they were content with this; some (as seen later in C5) appeared to want to share what knowledge they had; however, others seemed content to defer to other professionals:

'…so there is always a doctor on or a nurse, * Nurse practitioners named*, *so there is always someone to talk about or bounce ideas off, then there are formal reviews, what is it, I think three times a week now, I think it is, a lot of experienced staff, So I would like to think that if anybody had got delirium it would not go unnoticed…'*

0202

Whilst this appeared to be overtly positive regarding the level of support from the multidisciplinary team, a dependency was also indicated. 0202 seemed uncertain if delirium would be identified without the wider team, hoping that it wouldn't go unnoticed rather than being assured about their own practice. This could suggest that the multidisciplinary team acted as a mechanism for "catching" delirium diagnosis rather than the RNMHs assessing or recognising it with certainty.

0401 discussed the association of DSD care provision with senior medical staff:

'…we have daily reviews. Sometimes, it depends upon, my experience, it depends on the consultant- so sometimes there's some consultants that are willing to listen and say 'oh yes they have got a delirium', and we will investigate. And sometimes they will say 'well I don't think they have got a delirium because they have been in for a number of weeks and nothing's changed and we have tried them with this medication, so it could be this medication'. But when you actually push them to do anything like an investigation or something, and you know they have come out with where the markers show that they possibly have an infection, […] but I think you have got to make the idea his, if it comes from you…'

0401

Here, 0401 indicated that they recognised a change in the patient and considered delirium; however, their practice was bound by navigating the way in which they could persuade the consultant to listen to their concerns. The RNMH seemed to be unable to promote action independently, showing a lack of autonomy even when demonstrating knowledge of potential underpinning causes of delirium.

Traditional tensions found in healthcare hierarchies can be seen here, with the RNMH subordinate to the consultant for care decisions and plans. This is in contrast with the discussion presented by 0202, where there was a positive sense of support provided by the multidisciplinary team. This provided a valuable insight into the RNMH experience, signifying that their care and experience was influenced, not only by their knowledge, but also by the effectiveness of multidisciplinary team working and cohesion of the team.

6.4.1 **C4 Consideration**

The multidisciplinary team appeared to be engrained in the RNMH experience of DSD care. Whilst the RNMHs suggested that they felt supported, the level of support indicated that the multidisciplinary team was a dominant force for DSD care. As individuals, the RNMHs deferred to other professionals to guide and plan care. As such, the effectiveness of DSD care, and the RNMH experience was intrinsically linked to the multidisciplinary team dynamics and, if the RNMHs felt that their views and opinions were listened to.

6.5 **C5 Care Burden**

Care burden emerged as a theme not inherently linked with the patient or patient care directly, but from the associated wider work that the participants associated with DSD. There were two common themes that seemed to influence a perception of care burden: the need to support others' understanding of DSD, and doing other people's work.

6.5.1 **Supporting Others' Understanding.**

There was a sense of responsibility demonstrated by the participants who felt that they had a good enough understanding of delirium in order to take on a supportive role; sharing their knowledge with other nurses, but were uncertain about how their support was received.

Participant 0401 highlighted a lack of understanding of DSD in other nurses. This appeared to increase the burden of care that they felt personally:

'…so that could be a bit frustrated coz you have to educate and teach the person who hasn't got the experience as well, even if you've got a little bit of knowledge in the area as well, so just help to make them understand. Sometimes you think 'am I making much sense, do they understand where I am coming from?…'

0401

0402 reiterated this need to support others and share knowledge, clearly viewing it as a challenge, but one of great importance:

'…coz at this, the big challenge, making people identify, understand that dementia is not always dementia, don't label people with dementia, and delirium can be treated so why with delirium can be treated and can go home […]'

0402

Here, the common area across the accounts appeared to be a requirement to support others; however, the RNMHs saw it as challenging, frustrating and had doubts about their ability and were concerned with the impact of others having a lack of knowledge on themselves, others and patients.

6.5.2 **Doing Other's Work**

Doing what was perceived to be other people's work was highlighted in multiple interviews indicating it was a predominant feature of the RNMH experience. Participants appeared confused, aggrieved, and concerned that patients were being brought to their clinical settings for reasons other than dementia assessment, or with presentations that they perceived could be managed in the community by agencies external to their immediate multidisciplinary team. The distress and impact on the patient of this, alongside the service provision featured heavily:

'…we still get the odd person admitted with an infection, and you do question whether, you know, had they, had their infection been recognised and treated whilst they were in the community, they might not have needed to come into hospital, I mean possibly they would, but you know, I don't know, you'd think that it would be ruled out for everyone coming into hospital…'

0101

0101 recounted an admission which was triggered by the presence of infection. This was important to 0101 since the subsequent care and treatment revolved around a change in oral antibiotics. 0102 echoed this feeling, but noted some associated factors impacting on decision making and the individuality of care needs. The complexity of where best to assess or treat someone with potential DSD appeared a challenge across all settings, including external agencies:

'…I think it would be weighing up what's more distressing for the person, keeping them in the community, where its, but then it's the carers, how much the carers are managing,

or the care homes, coz some care homes, they will see a slight change in behaviours and say we can't manage this…'

0102

'…I can think of a few people that we have nursed who have been what I would say were inappropriate admissions at times, coming in from the community, when they get here we identify delirium once the delirium has gone that person is absolutely fine, so it's just been a really distressing experience for someone to be put on a mental health sections, brought into hospital away from their family because of a delirium and you think well if that could have been treat in the community we could have avoided an admission…'

0102

Collectively, there was feeling of inappropriate admissions, from a patient care and service provision stance. This built on 0101's frustration with the wider service provision for people with dementia and the direct impact that this had on the patient as an individual, alongside the burden of care then placed on the clinical staff subsequently responsible for patient care.

6.5.3 **C5 Consideration**

The burden of care articulated by the RNMHs was not overtly linked to the actual care delivered to the person with DSD, it was found in the wider issues expressed when supporting others by sharing knowledge, and the sense of doing other people's jobs. As such, the division of labour in the activity system is impacted upon by organisational and systems across healthcare providers both internally and externally.

6.6 C6 Mental Versus Physical Health

C6 echoed the literature insomuch as provision of care is reported to be person centred, but the organisational and governing infrastructures are maintained in discreet pockets, providing care based on what is seen to be the predominant need (i.e. mental health or acute hospitals and nursing or specialist dementia care homes with RNA or RNMH provision). The discourse of the RNMHs highlighted three tensions impacting on their experience: how they conceptualised DSD (as cognitive, mental, or physical in origin), organisational constructs and infrastructures, and the underpinning causative agent of DSD.

6.6.1 Conceptualisation of DSD

In terms of the conceptualisation of DSD, the RNMHs attended to the complexity of the condition, illuminating multiple influences impacting on their patient group:

'...Because we are working with the elderly and we are working with people who have a cognitive problem and it's not always mental health problems it's normally their physical health problems…'

0401

Here, 0401 identified that they were aware of three concepts in care: cognitive care, mental health care, and physical care. This was echoed by 0201, showing a level of recognition of the physical underpinnings of DSD:

'…I think with mental health nursing you do some basic physical health care training in your first year and your second year, but I suppose specifically to delirium to understand underlying physical aspect what might be going on would be helpful erm in practice…'

0201

0201 demonstrated a bracketing of care into mental health and physical heath, articulating that understanding the physical elements would *be helpful* (rather than essential or required) for their practice. This added weight to the notion that they might not have seen this as central to their work, and possibly not part of their remit since this appeared to be delegated to the wider multidisciplinary team (as seen in C3 and C4).

The registration specific, and clinical splitting of care provision between mental health and physical health was raised again by 0402 who appeared frustrated and concerned at the lack of understanding of other nurses. 0402 started to explore how each construct (physical or mental health) may not be understood by other registrations of nurses:

'…I, when I was at university I was with nurses from, other nurses and they had no idea about dementia, and I think it is the reverse of the coin in here, cos we are mental health, and seeing from another perspective, not mental health, it's a physical health problem-delirium. Just to make people aware that delirium can be part of the illness, it's not always dementia…'

0402

Whilst in 0402's account, care is again split into silos of mental and physical care, there was a recognition of the interplay between the two; with 0402 noting that delirium can be *part of the illness, it is not always dementia*. This was also demonstrated by 0202's discussion of dementia, plus a causative physical agent impacted on patient presentation:

'…I know a lot of people with dementia have more like fragile brains, so any kind of infection or anything that's mildly wrong with them that normal people would just shrug off and deal with can be very, like exacerbated by the dementia, it can make people

confused. More aggressive, more unwell. It kind of makes a bad situation even worse.

0202

0101 summed up the sentiments well; noting the combined presentation of DSD and how it is linked between mental and physical wellbeing:

'…and I know it's a physical cause that kind of kind of causes it but obviously has a knock-on effect on their mental health…'

0101

6.6.2 Organisational Constructs

Whilst the RNMHs demonstrated an awareness of the mental and physical cohesion of DSD, a combined and equitable focus appeared to pose a challenge for them, extending past the conceptual, into considerations of organisational set up and skills base:

'…it's an old problem, I'm sure you've heard, is the line between mental health and physical health. People get admitted to physical wards with delirium and there's batting from side to side, back and forwards, we get people sent back, and they send, but you know, it delirium, it's a mental health problem we cured that, but its caused by, 99% of the time by physical… And sometimes they tend to have this notion, we come from an NHS ward, and they say 'oh they can go back' but we have limited resources here. So, we can't do IV fluids here, […], all we have is the, we are (inaudible) basic, and people are sent back and they don't get any better […] they end up going back…'

0501

0501's frank account showed the impact of separating physical and mental health; exposing key organisational tensions and technical skill provision from both sides involved. There appeared to be a lack of shared understanding between apparently competing services. This was evident by the detrimental movement of patients between care settings.

0202 adds to this discussion, considering the physical geography of service provision, and how this could be better placed to offer increased support to the RNMHs and ultimately the patients.

*'…It may be better if we were on, not by ourselves, be back at the [*general hospital name*] or [*general hospital name*] or something coz the people here have lots and lots of physical health problems anyway and we are kind of a standalone unit really aren't we, so it may be better to treat their physical and mental health problems with others in a more medical setting where there is more support and treatment is more readily available. Coz people are quite isolated here, and if anybody presents as physically ill, even in a more moderate well people just send them across…'*

0202

0202 demonstrated frustration at not being able to provide the care that was perceived as required for DSD, and the impact this had on patients. It suggested that isolated specialities are seen as a concern, leaving staff unable to fully access the services they feel are required to support their care provision and the wellbeing of the patient. Interestingly, whilst both participants detailed the mental and physical tensions in DSD their accounts indicate that they perceived DSD care to require predominantly a more physical orientation to care (in opposition to mental or cognitive health).

6.6.3 **Underlying Cause of Delirium**

Throughout the interviews, the participants demonstrated confusion in relation to what delirium was; instead, several different physical causes were raised as potential underlying causes (pain, constipation, and medication changes for example). One was repeated across the discussions frequently. The RNMHs appeared to see infection as the ‘go to’ condition to rule out in relation to DSD care:

‘…so that's what it keeps coming back to, not knowing exactly, knowing about delirium but that's, you can so someone's got a delirium, and someone says how do you treat it? That's what matters being a mental health trained nurse I would be like ‘treat the infection and then hopefully the delirium would subside…’

0102

In the presence of delirium, 0102 deferred to an ethos of physical health to such an extent that they are left *hoping* that the delirium subsided with physical health intervention, showing an uncertainty in care, and a clear onus on physical health, leaving the mental health and cognitive health principles of care behind or unarticulated:

‘…That’s what I think, basically, and it’s treatable. I’m not sure, I was never quite sure, I know people get chest infections and urine infections that’s like a delirium…’

0202

And whilst 0402 eluded to there being potentially other underlying causes, only infection was named, showing a clear focus on this:

‘…I think there are a set of tests they get in here, we just talk to the patient and observe

the progress once its identified they have an infection or underlying cause for delirium and things like this, and start to be treated we just start to observe the progress of how it works…'

0402

There was uncertainty regarding the admission processes carried out. This added to the sense that it was not the RNMHs completing these episodes of care. The uncertainty and vague description highlighted, and returned focus to the multidisciplinary team providing care, with 0402 reporting their role as observational. This return to observing behaviour could indicated a strong focus on behavioural presentations and their RNMH education and care philosophies.

6.6.4 **C6 Consideration**

C6 highlights the challenges the RNMHs face when providing care for people with DSD and links this to the premise of nursing registration and the UK, and healthcare organisational structures. Here it could be suggested that the RNMHs are charged with providing person centred care; however, their education, registration and the organisational set ups work against this, forcing care into silos, leaving the RNMHs to navigate the complex physical, cognitive and mental health construct of DSD care.

From the interviews, the causative underlying issue driving the DSD presentation was associated as infection predominantly, but the care of DSD was uncertain past treating infections. Delirium, (and as such DSD) did not seem conceptualised as a condition. Instead of a combined condition requiring both mental health and physical health care, it was divided into the physical elements of care (treating infection etc.) and deferred to the multidisciplinary team. When trying to articulate what DSD is, there was an awareness that it is delirium occurring in the person with dementia, or ‘on top’. They struggled to clearly define delirium in terms of diagnostic criteria: however, their discussion showed a clear awareness of the presentation and underlying pathophysiology of DSD that impacted on the patient, but focused on physical treatment, underexploring in their discussions the cognitive and mental health support they provided.

It appeared that once delirium or the underlying physical health condition was identified, the RNMH care was overtly conceptualised as focused on the physical needs, with the nurses taking an observational role. This could signify that they deferred to the multidisciplinary team or indeed, that they returned to their professional roots of mental health care provision.

6.7 Core Themes in the Activity System

The six core themes were applied to the activity system (Figure 29) and showed the emerging core themes and tensions that existed and impacted upon the RNMHs experience of providing care.

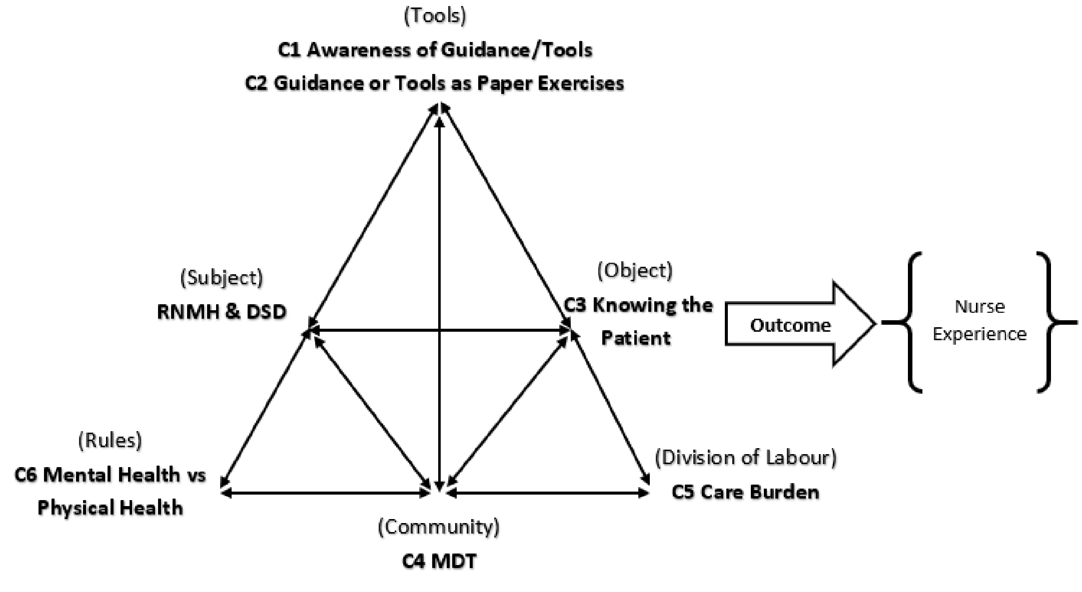


Figure 29 Qualitative Themes in Activity System

6.8 Abstraction and Interpretation: Generation of Superordinate Themes

The final steps in framework analysis are abstraction and interpretation. Returning to the framework process, but being mindful of the constant fluidity in analysis, an analytical strategy of 'stepping back' from the fine detail of the themes was employed. Allowing time to re-process the data, I returned to the matrices of verbatim quotes and summaries. Reviewing each again in turn, I was able to refresh my understanding of the concepts as a whole and see them as individual sections, not fragments of data or individual participants. I once again reminded myself of the key aims of the research:

This study aimed to:

1. Illuminate the experiences, views, and perceptions of RNMHs caring for people with DSD within the 24-hour healthcare setting
2. Identify and describe the experience in terms of influencing and impacting factors within the workplace
3. Generate new understanding pertaining to the RNMHs care provision for DSD and explore how this could be used to support the unique care context in terms of understanding influencing factors impacting on care.

With a renewed focus, I asked questions of each core theme; exploring in the text *what is happening?* Whilst the majority of the analysis had been managed on the NVivo™ software, at this stage, I returned to large paper printouts of the matrix sheets. This allowed me to gain a total view of all the verbatim content alongside the associated summaries and comments I had previously made. By returning to the original data, but now in light of the analytical processes that had occurred following the interviews, I processed the accounts of the participants to re-describe what was happening in the core themes as a collective overview. This process of both broad scale, and fine detail abstraction and interpretation, led to the formation of two superordinate themes that appeared to encapsulate the RNMH experience and underpin their opinions; these were *Role* and *Intuitive Care*. The role of the RNMHs was synonymous with their entity as the subject within the system. And whist intuitive care captured the essence of the object within AT, it was linked to their RNMH status.

6.8.1 Superordinate Theme One: Being an RNMH and their Role

Present in all accounts when seen as a whole, was the level of certainty or indeed uncertainty that the RNMHs displayed in relation to DSD, what tools or guides were available to them and what their role was in DSD care. There was an inconsistency across the sample in relation to their confidence in providing DSD care, their awareness of supporting tools or guides, and access to these. This supported a view that the RNMH did not have a firm foundation of what was expected of them in relation to DSD care, and therefore their role. This may be born out of the complexity of the presentation and condition itself, spanning the mental, cognitive, and physical health requirements in all facets of care.

A key observation here was that the RNMHs discussed predominantly the physical care of DSD, and this sits in direct opposition to what would be assumed to be the main principles of their care provision. This led to questions pertaining to why RNMH, educated and specialised in mental health care more readily verbalised a focus on the physical elements of delirium and not the psychological components? Did they see DSD as a physical or mental health condition in isolation? Or did they not articulate elements of practice that were engrained in their daily care provision? What was apparent, was that the mental healthcare required for DSD care was undisclosed in the majority interviews and as such needed to be further explored.

6.8.2 Superordinate Theme Two: Intuitive Care

Born predominantly from C3, the notion of care based on a nursing intuition featured across all themes. The notion of using tools or scores to influence care was not one that the RNMH participants appeared to proactively engage in. This could stem from their education and registration specifically as RNMHs. Their work is seen in the value of person centred, individual care (as discussed in Chapter one). There appeared to be minimal uptake or assigning of importance to the tools that were discussed. The predominant guiding factor in care appeared to be the nurse’s personal knowledge of the patient. Whilst this was formalised for use within the team (as a formulation), it revolved around an in-depth knowledge of the patient as a person. The subtlety in presentation change was noted and discussed rather than quantified or assigned numerical values for processing. This information was, however, dependent on the actions of others as the RNMH role predominantly appeared as an information collector and distributer. So, whilst indicating that knowledge and care was intuitive, based on knowledge of the patient, this information and intuition was heavily reliant on other multidisciplinary team members, and it was for those members to devise a treatment plan.

6.9 **Chapter Summary**

This chapter presented the initial qualitative findings from the semi-structured interviews. Following thematic analysis using a framework approach, six core themes emerged from the data: awareness of tools or guidance, tools or guidance as paper exercises, knowing the individual, the multidisciplinary team, care burden and mental health versus physical health. These themes were reviewed and applied in the AT system to give a sense of the interplay and influence on the RNMH experience. Further interpretation of the data concluded in the generation of two superordinate themes: Being an RNMH and Intuitive care.

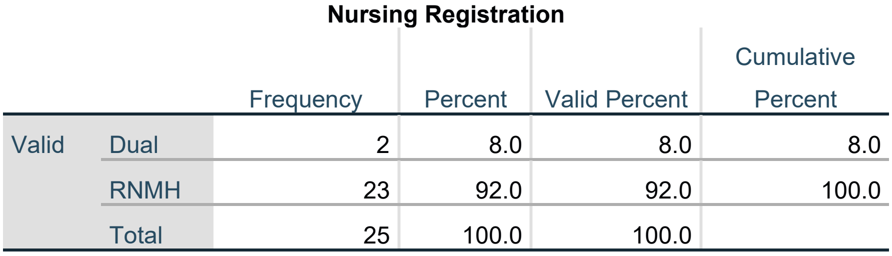
7. Quantitative Results and Integrated Findings

This chapter presents the quantitative results generated from the questionnaire and analysed using nonparametric, descriptive statistics. It is important here to note that the questionnaire did not seek to test a knowledge base or hypothesis; but sought to further explore, develop, and refine understanding of the RNMH experience in preparation for integrated analysis of data sets. The results are again presented in the evolving activity system components demonstrated in Chapter six, figure 29, page 212. The chapter commences with a demographic profile of participants before the quantitative results are presented and integrated with the qualitative findings. This serves to produce a complete picture of the RNMH experience of managing DSD organised in relation to their activity system. Chapter eight presents a discussion of the findings in relation to the wider discourse relating to nursing and DSD experience.

7.1 Participant Profile

Of the distributed questionnaires, 25 were deemed suitable for inclusion based on the inclusion criteria specified previously in Chapter four. Of the respondents, 92% had undertaken initial registration in the UK with 8% undertaking their initial nurse registration in other countries. In addition, 8% of the participants indicated holding dual (RNMH and RNA) registrations, all of whom worked in the care home sector. These participants were both at band 5/staff nurse or equivalent level. One was male and one was female. Table 13, page 218 and Figure 30, page 219 detail the questionnaire participants' demographics. Of the total sample, 48% held band 5/staff nurse posts, 16% band 6/deputy manager/clinical lead roles, 28% band 7/manager posts and 8% band 8 +/matron or senior manager/care home manager. It is important to note here that this study did not aim to look at seniority as factors within the activity system as a first exploration. However, some variation was noted and discussed in its associated activity system section.

Table 13 Nursing Registration



Nursing Registration

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Dual	2	8.0	8.0	8.0
	RNMH	23	92.0	92.0	100.0
	Total	25	100.0	100.0	

The respondents had a wider span of years qualified; with the least number of years registration held reported as 1 year, and the maximum 45 years. Statistical analysis showed the mean to be 17.8 years; however, the mode of 2 indicated a population of more newly qualified nurses completing the questionnaire and echoes the participant profiles from the interview sample.

7.1.1 **Demographics by Role**

For the purpose of this discussion, the numerical banding system will be utilised for ease; however, the equivalent banding and role descriptions were discussed in Chapter four and shown in Figure 12 on page 100. For band 5 or equivalent nurses, the range of years qualified spanned from 1 to 28 years, with a mean 12.75 years. Band 6 nurses held a minimum of two years registration and a maximum of 14 years. The mean length of qualification held for band 6 was 7.75 years. Band 7 nurses held between 12 and 45 years qualification (mean of 28.7 years), and the two band 8 nurses both reported being qualified for 30 years. The length of qualification by band is shown in Figure 30 page 219.

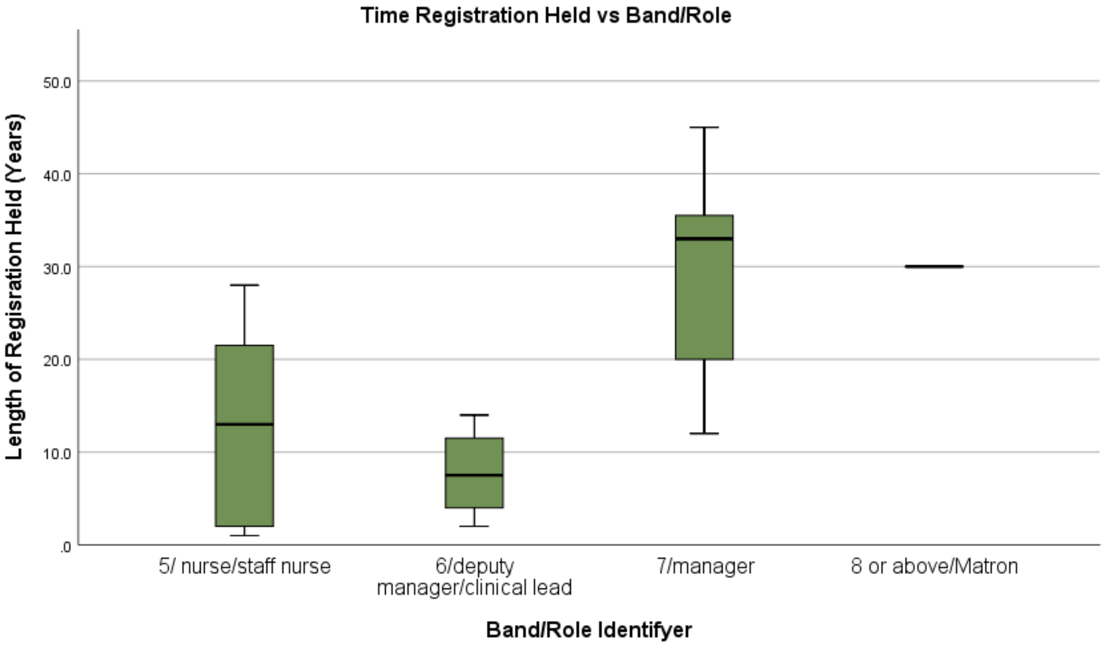


Figure 30 Registration by Years and Role

Based on the above profiles, the decision was taken to facilitate additional coding of the staff profiles into *junior* and *senior* data sets using the NHS banding and associated equivalent role profiles. This was undertaken to facilitate analysis of any factors where role or length of qualification may have an impact. It is important to reiterate that this was not a primary aim of this study (exploring the experience in terms of role profiles for example) but could potentially add supplementary clarity to data. The junior data set indicator was defined as bands 5/6 and equivalent, with the senior data set being defined as bands 7/8 and equivalent role profiles. This resulted in a distribution of 64% of the sample coming from junior questionnaire returns, and 36% from senior responses.

7.2 **Qualitative Results and Integrated Findings**

The quantitative results are presented below, alongside the integration of the qualitative findings and summarised as a complete data set. The positioning of the data is again located in the activity system positions in order to show the systems development as an audit trail throughout the study.

7.2.1 **C1 Guidance and Tools**

Following on from the qualitative data, it was important to further understand to what extent the RNMH population were aware of, used and engaged with both formal guidance (such as written policy or clinical tools) and informal guidance from peers. Question 15 explored awareness of guidance in relation to delirium prevention, diagnosis, and treatment. This question was phrased in relation to delirium guidance (as opposed to DSD) to mirror the availability of specific delirium guidance in practice as there are, to date, no specific DSD guides; instead, DSD appears within these to some extent. Following a request to rate their own awareness of prevention, diagnosis and treatment knowledge, a question was posed pertaining to their confidence in knowledge of DSD care. Table 14 shows awareness of guidance for delirium prevention as an example. This was to support the identification of awareness of available delirium guidelines, but also to expose how or if this translated to DSD confidence.

Table 14 Responses: Awareness of Evidence Based Guidance

Awareness of Evidence Based Guidelines for Delirium Prevention

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	0	0	0	0
	Disagree	3	12.0	12.5	12.5
	Neither Agree nor Disagree	4	16.0	16.7	29.2
	Agree	13	52.0	54.2	83.3
	Strongly Agree	4	16.0	16.7	100.0
	Total	24	96.0	100.0	
Missing	-99	1	4.0		
Total		25	100.0		

Overall, 70.9% agreed or strongly agreed that they were aware of evidence-based guidelines for delirium prevention; however, there was a disparity between junior and senior staff, highlighting that senior had more awareness of evidence-based guidelines than junior staff (Figure 31, page 221).

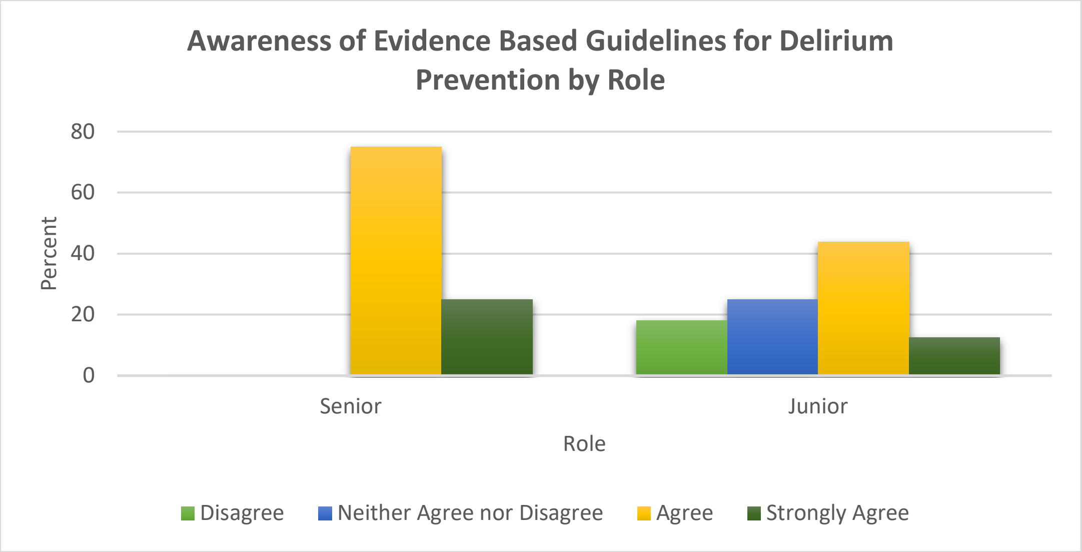


Figure 31 Awareness of Evidence Based Guidelines for Delirium Prevention by Role

In terms of evidence-based guidelines for delirium diagnosis, 76% agreed/strongly agreed aware of evidence-based guidelines; however, junior staff showed increased levels of neutral stances and disagreed to some extent (which senior staff did not). Regarding treatment, overall agreement (Strongly agree/ Agreement) was 72%, with the pattern of increased self-perceived awareness of evidence-based guidelines continuing in senior staff. Whilst senior staff reported increased awareness across the question domains, there is also consideration that as a self-reported assessment, the senior staff may have answered in the positive, believing that there was an expectation placed on them to hold this awareness in line with their senior position, rather than it being an accurate representation of their awareness level.

This was furthered to align awareness with confidence in their own knowledge of DSD care. Interestingly, the confidence reported by participants fell to 60%, despite the increased articulations of awareness of prevention, diagnosis and treatment guidance. It was considered whether this was due to the lack of DSD specific guidance (as indicated in the single condition focus on delirium), but also what needed to be in place to move awareness of guidance into confident practice.

Questions 16 and 16a sought to expand upon the assertions of awareness and confidence; did they utilise the guidance they were aware of to support their care decisions, and what types of guidance were used. 84% of participants reported using guidance to support their DSD care decisions (noted as 100% of the Senior group and 75% of the Junior group).

In terms of the type of guidance used to support DSD care decisions, discussions with other staff members (as informal peer guidance) and clinical guidelines were most used, demonstrated by each being indicated by 72% of respondents. This was followed by tools or score sheets (52%). Professional journals and textbooks did not indicate high levels of use; nursing journals were reported as being used by 32%, other professional journals by 24%, other professional textbooks by 16%, and nursing textbooks being used least, identified by only 12% of respondents.

Question 17 served to contextualise the use of guidance (when used) within a timeframe, helping to illuminate if any professional information used was contemporary to the rapidly evolving field of practice. 16.7% of respondents indicated that they had never read any professional literature on delirium, 33% indicated they had in the last month, with 16.7% in the last week. This was coupled with question 18 which also revealed low levels of scores, or tools being used for DSD assessment. Here, 58.3% of respondents reported that within the last month they had not used any tools or scores for DSD assessment.

For those who did use tools or scores, question 18 provided clarity about the tools: 12 respondents named a total of 10 tools or scores used in practice. The CAM was identified as most prevalent (33.3%), the 4AT and delirium rating scale (DRS) were identified next by 25% each of those who gave additional information. These tools are specific to delirium and represent what is deemed appropriate for delirium assessment in older people and delirium superimposed on dementia.

Several other delirium specific tools (e.g. Delirium Observation Screening Scale *DOSS* and Delirium Early Monitoring System *DEMS*) were identified by individuals, alongside articulations that showed a delirium focus was in practice *Deliriums screening tool* being identified but it was unclear which one this was, and the inclusion of the PINCHES ME (potentially a variation of PINCH ME) mnemonic as a method of exploring underlying causes of delirium rather than identification or assessment of delirium presence specifically. Whilst this could indicate inconsistency of tools used across practice, it was evident that there was an awareness of multiple delirium specific tools and practice across the sample. To note here though is that only one participant working in the care home setting reported the use of a tool or guide in practice: the 4AT.

There were overt articulations from both the interview responses and survey that some clinical areas had no tools or guidance in place, other respondents failed to identify any and, additionally, some reported having used or known about some tools previously, but they were no longer available or used in their area. This suggested a variance in clinical priority or access to support pertaining to DSD in practice, which appeared to manifest in varied levels of awareness and ability to name tools or guides used.

Concerningly though, echoing the interview data, several tools not specifically used for delirium were named here; including the Cornell scale (validated for identification of depression in dementia) and ACE 3 and MACE[13] . This built upon the interview data, indicating that whilst the RNMHs articulated a level of knowledge of awareness of evidence-based guidelines, and did to some extent use tools to support practice, this knowledge base could in fact be incomplete, flawed, or based on misunderstanding around the appropriate use and purpose of the tools they used in practice. Whilst the RNMHs self-reported a high level of awareness, they appeared to use as a collective group both appropriate and potentially inappropriate tools together to form a more general 'cognitive testing' premise of care rather than delirium specific. This could impact on the appropriateness of patient assessment, planning and care delivery. Therefore, the use of tools and knowledge appeared to be varied and misaligned in terms of consistency and appropriate use.

7.2.1.1 **C1 Consideration**

Integration of qualitative and quantitative data showed consistency when reviewing what the RNMHs used in practice to support their DSD care. Echoing the qualitative interviews, there was variation between those who used guidance, and those who did not use guidance to support practice. This inconsistency expanded across settings, most notably with only one care home respondent indicating the use of a tool. The RNMHs articulated a preference for guidance; however, this was equivocal to their use of peers to guide and support their care. Low levels of professional reading were demonstrated, alongside infrequent completion of assessment tools or scores. This was coupled with a range of both delirium appropriate and non-delirium specific cognitive tools being discussed as

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[13] An assumption is made here that the MACE refers to the Mini- Addenbrooke's Cognitive examination rather than the Maltreatment and Abuse Chronology of Exposure scale. However, this is not defined by the respondent past the abbreviation of MACE.

used in practice. As such, the RNMHs experience of guidelines in practice was inconsistent.

7.2.2 **C2 Tools or Guidance as Paper Exercises: Use and Usefulness**

Breaking down what informs or influences their practice; specifically, in relation to tools and guidance, two series of questions were presented to participants to gain insight into their views (Q19 and Q21). These attitudinal questions aimed to show in more depth what elements influenced their opinion of current tools and clinical guidance. 61.9% of respondents found tools easy to understand, with only 4.8% disagreeing (indicating a low perceived complexity of the tools), and 57.1% perceived the tools used as useful in people with dementia (note two participants disagreed: indicating that they were not useful (9.5%). 42.9% indicated that they felt the tools did identify DSD correctly, verses 14.1% who did not perceive they correctly identified DSD. 60% of respondents indicated agreement that the tools provided them with enough information to help plan care, with 15% disagreeing.

Exploring the functionality of the tools, and ease of use further, there was no clear opinion found in relation to perceived time to complete accurately: 30% perceiving they took a long time to accurately complete, versus 25% reporting that they did not feel they took too long (45% indicated a neutral stance). This close perception was echoed when asked if they felt that they often did not have enough information to complete the tools. 28.6% agreed that they did not have enough information, versus 28.6% who disagreed: again, a high neutral stance was taken here by 42.9% of respondents. This increased neutral position was considered and reviewed across the question set and found to be 16-20% per sub question. This could indicate that those omitting to answer (or indeed those selecting a neutral position) held either no strong opinion or were respondents that did not use tools in practice when caring for someone with DSD. As noted previously, only 12 respondents named specific tools in the survey and some participants in both data collection phases clearly indicated not having tools in practice to use. This pattern was reflected in question 18 in which 8 survey participants omitted a response (32% of the sample) when asked if they completed tools with the person being assessed present, versus without them.

Whilst the above indicated to a certain extent that the tools were easy to understand, seen as useful and provided information, when asked if the outcome of tools influenced their care decisions and plans more than their knowledge of the person, 8 respondents held a neutral position (40%) and the proportion of those who indicated agreement or disagreement (to any extent) was identical (30% agree versus 30% disagree). This indicated a central split across respondents in terms of ease of use and usefulness of the tools, coupled with a proportion that chose to take a neutral position.

This lack of apparent influence of tools on care provision could be explained by the interview data in which the use of tools or guidelines was attributed on several occasions not to patient presentation or clinical need, but more as an embedded process within the context of the care. Tools were noted to be part of an audit, monthly or planned process which seemed detached from nursing care driven by patient presentation. The notion of standardised or pre-planned completion of tools was in tandem with an articulation that the final tool score or result did not change or influence the care delivered. As such, the use of, or usefulness of the tools in practice must be questioned in relation to its intended purpose.

Exposing what the RNMHs did find useful in relation to DSD assessment, questions were posed to explore their thoughts around specific components of

DSD assessment. The survey showed a high level of agreement that clinical parameters and person centred information were seen as important to the RNMHs: gathering information from friends and relatives appeared most important, with 95.7% agreeing (4.3% took a neutral position), followed by clinical test results (i.e. blood tests), (91.3% agreed with 8.3% talking a neutral position), with gathering information from scores achieving the lowest level of agreement in terms of its importance when considering DSD at 65.2%, (34.8% taking a neutral position). Specifically, as a direct comparison, 73.9% of respondents agreed that the clinical team's knowledge of the person was more important than a score or written guidance. The responses indicated and reiterated that a collective knowledge base, from the multidisciplinary team, clinical knowledge, and information from family or carers was seen as more important to the RNMHs when considering DSD, than the outcome of tools or scores. This reaffirmed and added strength to the interview data in which the multidisciplinary team was integral to the RNMH experience of DSD, alongside the usefulness and purpose of family and carer information to support the RNMH to know the person as an individual.

Revisiting the questionnaire data, 61.9% of respondents found tools easy to understand, 57.1% perceived the tools used as useful in people with dementia, 42.9% indicated that they felt the tools did identify DSD correctly, and 60% of respondents indicated agreement that the tools provided them with enough information to help plan care. However, the detail of experiences in the interviews shed light on participants' underpinning thought processes in relation to the statistics and link to practice. Fitting people between scores was discussed as being based on not having enough information about what to do in such a situation, and participants reported not being shown how to use the tools or guides (0401). Relating this back to 0501's interview and the discussion of gaining support and trust of the tools; frequency of use and support was required by the RNMHs to help them understand the tools use, see it's intended goals, and increase their motivation to use tools and guides.

0401 discussed the need to use tools regularly, considering when it is seen for the first time, they may not understand why it is being completed and how to do so appropriately. This indicates a level of experiential learning 'on the job' and use or exposure to DSD and tools may increase understanding and action, rather than a clear instruction or explanation being offered by the tools or guides themselves.

Participant 0501 wrestled with the tools, naming a selection of delirium and wider cognitive testing tools: initially calling them '*a mine field*', seen as complex and a '*ticky box'* mandatory process that had to be completed. This indicated a low value initially placed on the tools or scores. As the discussion evolved, 0501 seemed to explore this opinion, and suggested that use and familiarity were important, before concluding that the tool had won their trust. This was linked to the frequency of screening raising awareness of delirium and a willingness to move practice forward. This shed new light on the perceived standardisation of the process, seemly embedding the concept of delirium in their mind as they recounted that the tools they used were to be completed on admission, then at specific timed intervals. This practice focus guiding and impacting on the RNMHs knowledge and use of tools was reflected in the data, showing only 43.5% of respondents indicated having had taught sessions on delirium, decreasing to 30.4% of respondents reporting any form of taught sessions specifically pertaining to DSD. In relation to taught sessions on delirium (not DSD), employer provision was highest, reported by 39.1% of the total sample, with university sessions being noted by 30.4%; this was further split between 17.4% reporting this at pre-registration level, and 13% at post registration. It could be surmised from this close provision, that there was no clear articulation of the university viewing delirium as a topic for more general education, or specialist post registration care.

For DSD, education provision was found to be almost exclusively practice based with 26% of the total population reported having taught DSD sessions provided in practice. DSD sessions were again equal in terms of pre and post registration provision, with 8.7% of the total sample indicating both pre and post registration sessions. This alluded to a conceptualisation of DSD as a practice-based concern, or in the remit of specialised services and potentially not provided for in-University nurse education. Alternatively, it could be that the practice area valued or provided practice-based sessions in preference to attending University. That said, the overall level of any awareness or education sessions pertaining to DSD remained low and indicated that this might not be seen as a priority in practice from an organisational or individual perspective. However, with such little education or support sessions available to the RNMHs, 42.9% of the sample indicated that they felt the tools did identify DSD correctly, suggesting that they felt they had awareness of what DSD is (to articulate that the tools identify DSD correctly, they must perceive that they knew what DSD is); however, by the low uptake of tools, the discussion here is that they gain, and use their intuition and knowledge from other sources (such as the multidisciplinary team) on which these judgements could be based.

Reviewing the manner of the tools used, when those that did use tools reported on their manner of use, 47.1% indicated that they completed them without the person being assessed present, versus 52.9% who reported completed them with the person present (Table 15 page 231). Rationales were provided here as to the main considerations of completion with or without the person being present, revolving around patients being involved in their own care, distress and a lack of capacity. There was a noticeably absent discussion of needing to observe the patient throughout the assessment process, which potentially indicated that the nurses may have judged that they had sufficient knowledge of the patient and their presentation, which precedes their use of tools. Whilst the concern for distress of the patient noted in the open-ended response section was in keeping with Morandi *et al.,* (2015b) who found that patients having recovered from delirium reported fear, anxiety and shame: the RNMH may recognise this potential for distress and feel that it is not appropriate to subject the person to the assessment. Other reported rationales for completing assessments in the absence of the person being assessed highlighted a misunderstanding of the nature of the assessments, i.e. inability to engage may indicate hypoactive delirium, and a lack of capacity does not preclude assessment. Interestingly, one participant indicated that they completed their scores and assessments without the person present giving a reason of a preference for therapeutic activity. This suggested that the RNMH may have prioritised their own preferences for care intervention and opinions of appropriate care; choosing to engage in practice which they felt was beneficial to complete on a face-to-face basis (therapeutic activity). This led to the assumption that they felt they could complete scores and tools based on their knowledge and awareness of the person, rather than with the score and person present at the time of completion. This might be through summarising their experiences of the patient, and reports from other staff, however it must be considered that the participant felt they could choose what elements of care they engaged with. This might or might not have been in line with what the patient's actual needs were, and potentially suggested that they did not see completion of tools as a useful element of care.

Table 15 Rationale for, and Presence of Patient During Tool Completion

Respondent	With the person present	Without the person present			
	Involvement in own care	Inability to engage	Distress	RNMH Preference for therapeutic activity	Lack of Capacity
CP01		1			
CP03			1	1	
CP06	1				
CP07			1		
39619216	1				
39691718					1
40947971					1
CH11	Indicated "with" person present- decision based on lack of capacity, stress, and anxiety				

7.2.2.1 C2 Consideration

Tools and guidance appeared to split the RNMHs opinion around their use and value in clinical practice. Whilst they were seen as being relatively easy to use, they appeared to hold no firm position in the RNMHs' experience of providing care for people with DSD. What the RNMHs did appear to value as important for people with DSD, was gathering information from family, the results of clinical samples and tests (as discussed in C3). The results of scores influenced their care the least, and they felt that the clinical teams' knowledge of a person took precedence over the result of a score. Their learning and experience of DSD stemmed from their personal experiences on the clinical areas, with little formal DSD education or training being provided.

7.2.3 C3 Knowing the Individual

Knowledge of the individual was associated with intuition and its use in practice. The foundation of intuition and its application was explored (Figure 32 page 232), 91.3% of respondents indicated agreement or strong agreement when asked if their intuition was based on their knowledge of the individual. A low neutral stance was taken (8.7%), and no disagreement was seen. This high agreement was echoed across all components, including intuition being based on previous experience (86.9% agreement) and clinical guidance (82.6% agreement). This implied that the respondents' practice was perceived to be evidence-based and, this in turn influenced their decisions; 78.3% agreed or strongly agreed that their intuition influenced their care decisions.

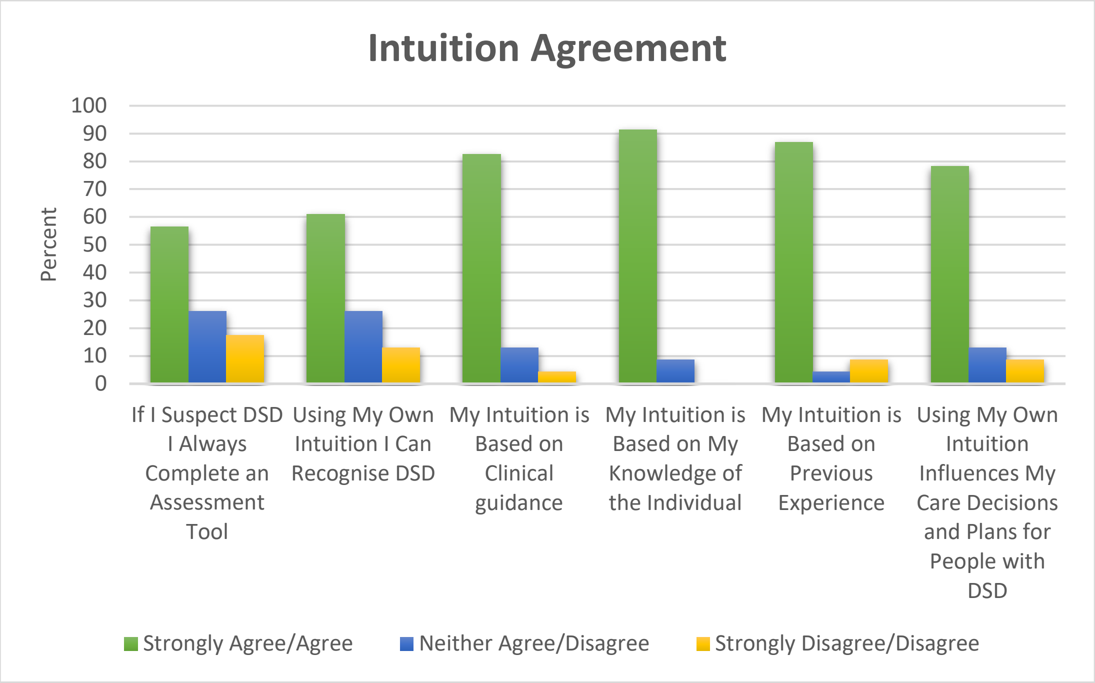

Figure 32 Intuition and Practice Components

In relation to what informed their practice, 95.7% of participants found gathering information from friends and relatives important in DSD care.

Compared to the positive response towards knowing the person, and importance of gathering information about them from friends, family and carers, there was a reduction in the importance of tools/scores informing care (65.2% agreement). Here, the reiteration of knowledge of the person being a driving factor reiterated and strengthened the qualitative data in which participants confidently recounted identifying changes in behaviour and associated these with DSD. Their confidence in care was seen in the interviews by recognising the “usual” presentation of their patients, and how this knowledge was gleaned from discussion with relatives, friends, the multidisciplinary team and used to plan care for the person. Given these high agreement rates could indicate a certainty in practice, only 60.9% indicated a level of agreement that, when using their own intuition, they could recognise DSD, with just 56.5% indicating that they would always complete a score or tool if DSD was suspected. Continuing this, only 28% reported that they felt DSD was identified quickly. Combined, these assertions suggested that the RNMHs, whilst confident to a level, and certain in their DSD practice, may not have seen themselves as responsible for assessing, or making a diagnosis of DSD.

7.2.3.1 **C3 Consideration**

For the RNMHs, the discussion of tools and their use expanded into their knowledge of the individual. The RNMHs suggested that their nursing intuition was based on their knowledge of the person receiving care and their nursing experiences. They also clearly articulated that they perceived this intuition to be also based upon evidence-based guidance. Echoing the use of tools, the RNMHs clearly conveyed that, for people with DSD, their intuition influenced their care decisions more than a score or tool outcome.

7.2.4 **C4 Multidisciplinary Team**

To understand further the RNMH experience with the multidisciplinary team and their position within it relating to DSD care, the respondents were asked to rate who they perceived was *responsible* for guiding DSD care; ranking 1st, 2nd, 3rd from a selection of team members pertinent to the care environment. The question was formatted in rank order to explore not only who were perceived to be responsible, but also to what extent or order was responsibility attributed to these clinicians. This question was repeated with an onus on who *actually* guided their care (again a ranking order). This question response format posed a complexity which was not noted at the pilot phase as some responses from the latter sample reported multiple indications of first, second and third most responsible. As such, data from five respondents was unable to be coded and was omitted from the analysis.

Reviewing the set response options, no clear consensus or majority was seen in who was believed to have overall responsibility for guiding DSD care (Figure 33 page 235). Of the respondents, 45% thought it would be primarily the consultant psychiatrist, but the remainder articulated no clear overall primary responsibility. When reviewed with 1st, 2nd, 3rd responsible combined, there was an 80% recognition that they were responsible for guiding care to some degree, which was only exceeded by their perception of the consultant physiatrist, which exceeded them by 5% (85%).

Here, consideration was given to the variety of work settings encapsulated in the data. Analysis was completed for the total data set (Figure 33, page 235) but also the Trust and conference respondants (Figure 34, page 235), alongside the care home data (Figure 35, page 236). Interestingly, place of work did not change the overall findings; that the consultant psychiatrist and the nurses themselves were responsible for guiding care for people with DSD, with the addition of the general practitioner for the care home respondents as primarily most responsible.

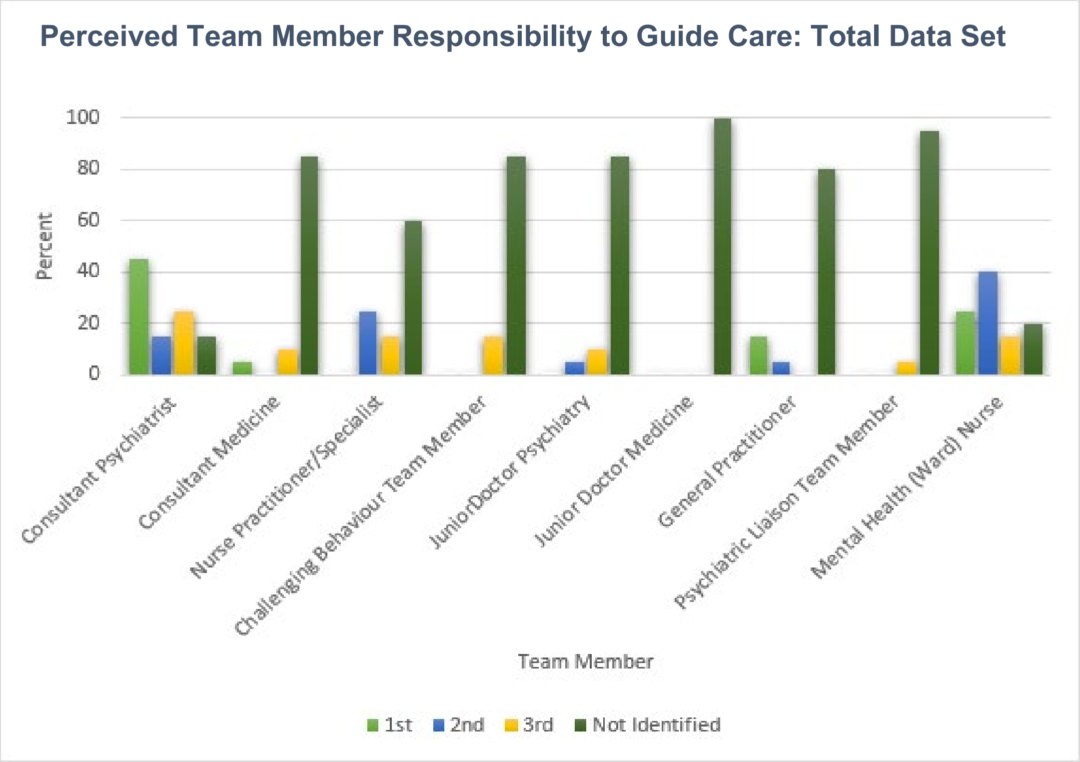

Figure 33 Responsibility: Total Data Set

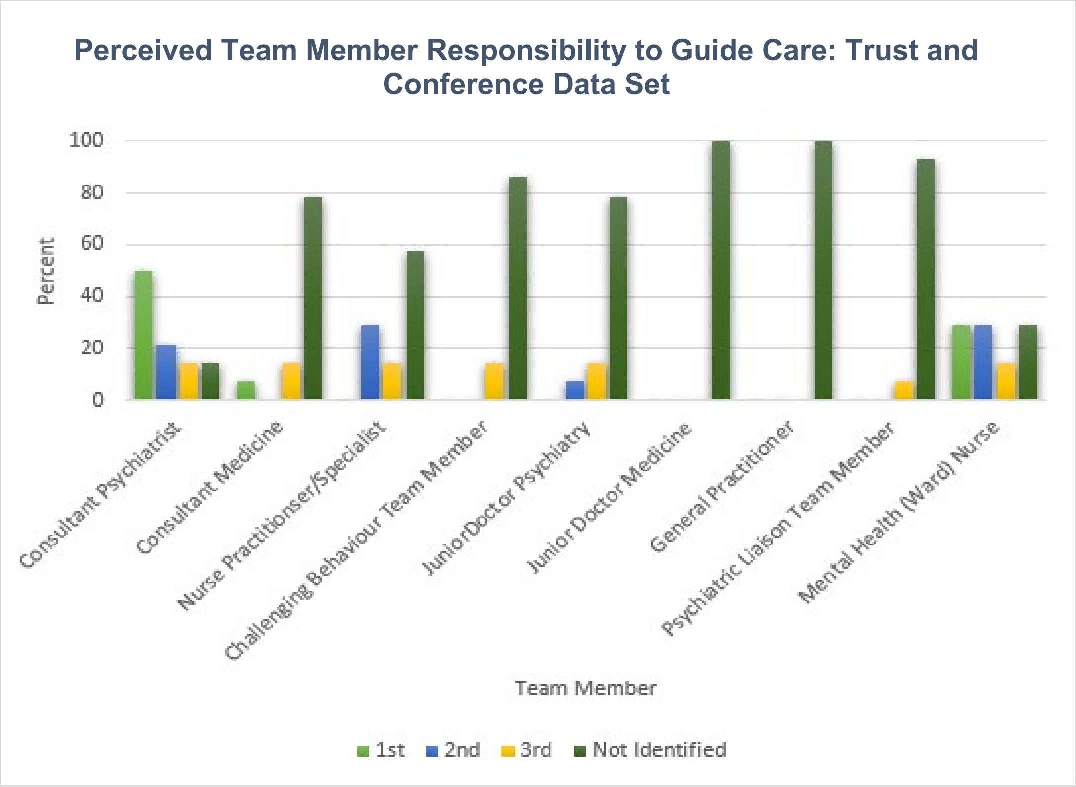

Figure 34 Responsibility: Trust/Conference Data Set

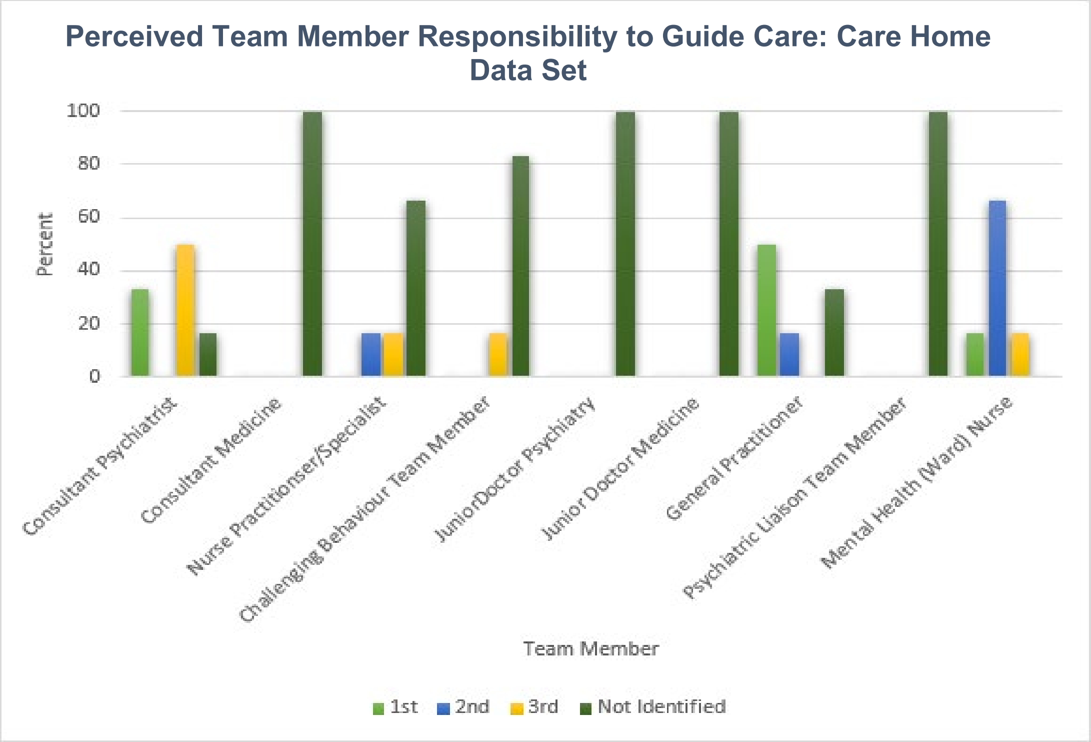

Figure 35 Responsibility: Care Home Data Set

The *actual* support and guidance for DSD care was predominantly shown as stemming from the consultant psychiatrist and, again, the RNMH themselves. This indicated that the RNMHs had a sense of self-responsibility and active role in guiding DSD care; but they viewed themselves as secondary to, and deferred to, the consultant psychiatrist. Overall, the nurses articulated that they felt listened to and attributed themselves second only to the consultant psychiatrists in responsibility for guiding DSD care in their settings. Whilst this could be seen as a strong position, partnering with the doctors, there was evidence of an engrained hierarchy, by which the nurses were under the guidance of the senior medical staff. This was specific to the senior medical staff (consultant psychiatrist and GP) and not aligned to seniority perceptions of more junior medical staff.

Whilst the RNMHs positioned themselves as taking a level of responsibility for, delivering and guiding DSD care, their position within the multidisciplinary team was not clearly defined. Of respondents, 64% agreed or strongly agreed that their opinions were listened to by the multidisciplinary team, with 20% disagreeing to some extent. This was replicated in the level of support shown, with 64% again agreeing to some extent that they felt supported by the multidisciplinary team, and a reduction to 16% reporting a level of disagreement. This indicated a level of perceived support and engagement with the multidisciplinary team expressed by the respondents specifically around DSD care; however, the complexity appeared to stem from what the RNMHs may have perceived as supportive or positive working:

‘… We have a good consultant at the moment who does focus a lot on delirium, and he will work with you sometimes, but I think you have got to make the idea his, if it comes from you, and I think some consultants are like that, some are welcome to your opinions but some of them are kind of ‘no I don't think so’ but they maybe a week of something along the line they will agree that you were right in the first place …’

0401

Whilst the view of one respondent, here there was a clear dichotomy between the initial articulation of a “good” consultant who was delirium focussed, but then appeared to work with the RNMHs only “sometimes” and the sense that the RNMHs were subject to dismissive interactions. Whilst there was a tension underlying the multidisciplinary team interactions, this did not seem overtly known to the RNMHs themselves, and their feeling was one of support from and towards their multidisciplinary team members. This was represented by 64% of the RNMHs articulating that they felt supported by the multidisciplinary team. 0202 and 0101 discussed collaborative working, bouncing ideas off team members, alongside having regular formal meetings where there was an appreciation for the collective knowledge of the group. However, this appeared in relation to the immediate, internal multidisciplinary team.

The respondents showed a concerning perception of the wider multidisciplinary team's actions in relation to supporting people with DSD to remain in their own home environments (called the community for the purposes of the questionnaire). There was no clear articulation of perceptions of individual multidisciplinary team member support level for people with DSD to remaining in their own home, with a high proportion opting to take a neutral position (Figure 36). Overall, community psychiatrists (48%), community mental health nurses (44%) and social care agencies (44%) were perceived to support people most in relation to remaining in the community setting (indicated by agree or strong agreement); however, the overall level of positive agreement was low throughout, indicating a potential low level of perceived support for people with DSD to remain in their home environments, or a lack of awareness of the external multidisciplinary team's input and role.

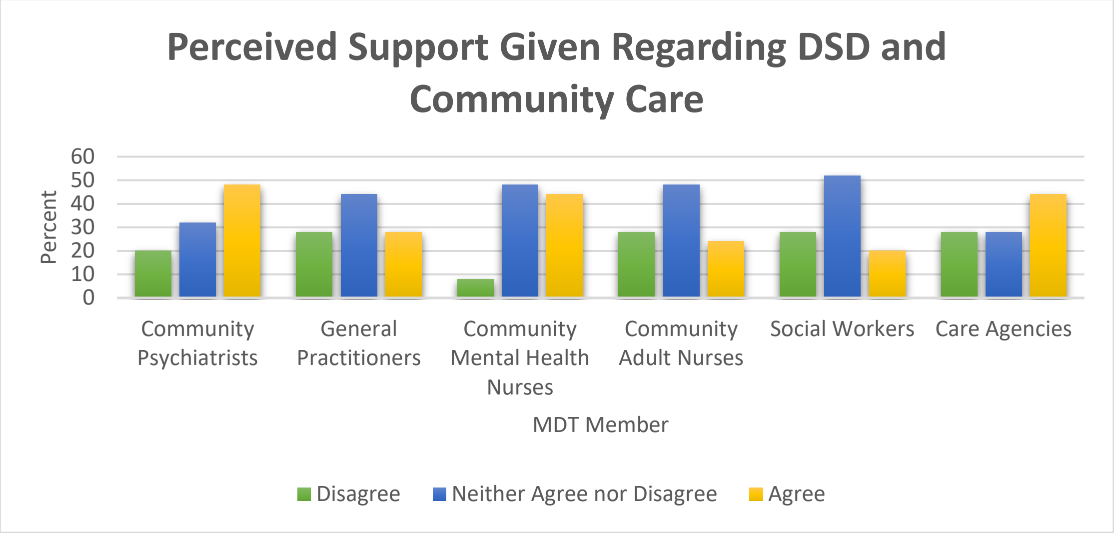

Figure 36 Multidisciplinary Team Community Support

7.2.4.1 **C4 Consideration**

The RNMHs saw themselves as responsible for guiding DSD care in practice, secondary only to senior medical team members (Consultant Psychiatrist and General Practitioner, specifically). More junior medical team members and acute medical consultants did not feature in their responses. Whilst the RNMHs overtly reported feeling supported and listened to, there appeared a traditional hierarchy permeating the experience; one in which they deferred to and came secondary to the doctors.

Their experience and awareness of the multidisciplinary team as a helpful entity seemed bound to their immediate practice environment. Whilst they held no overt negative perceptions toward the wider multidisciplinary team, they did not appear to articulate an opinion clearly. This indicated they may not have had knowledge of the team external to their areas to draw upon.

7.2.5 **C5 Care Burden**

Leading from theme four and the complexity seen in both feeling supported and listened to, but coupled with an increased neutral perception of the wider multidisciplinary team supporting people with DSD to remain in the community, it was pertinent to analyse what level of care burden was present in the RNMH experience (Figure 37, page 240).

The components of care were derived from the literature, interviews and my own experiential knowledge of the nursing process; but, in recognition of the diverse nature of care settings and provision, an additional free text box was supplied for the participants to name other care elements they engaged with and add any other facets of daily work not included. Response rates indicated that more than 79% of the RNMHS actually engaged in each care domain listed. This spanned care that could be seen as universal to all areas (medication administration, documentation of care given), but also domains seen as traditionally sitting within mental or physical care (obtaining clinical samples, direct mental health care and support).

There appeared consistency in what the nurses were actually engaged in relation to components of their daily work. When asked what they engaged in, and if they felt they should or should not undertake this work, no strong opinions regarding this were found.

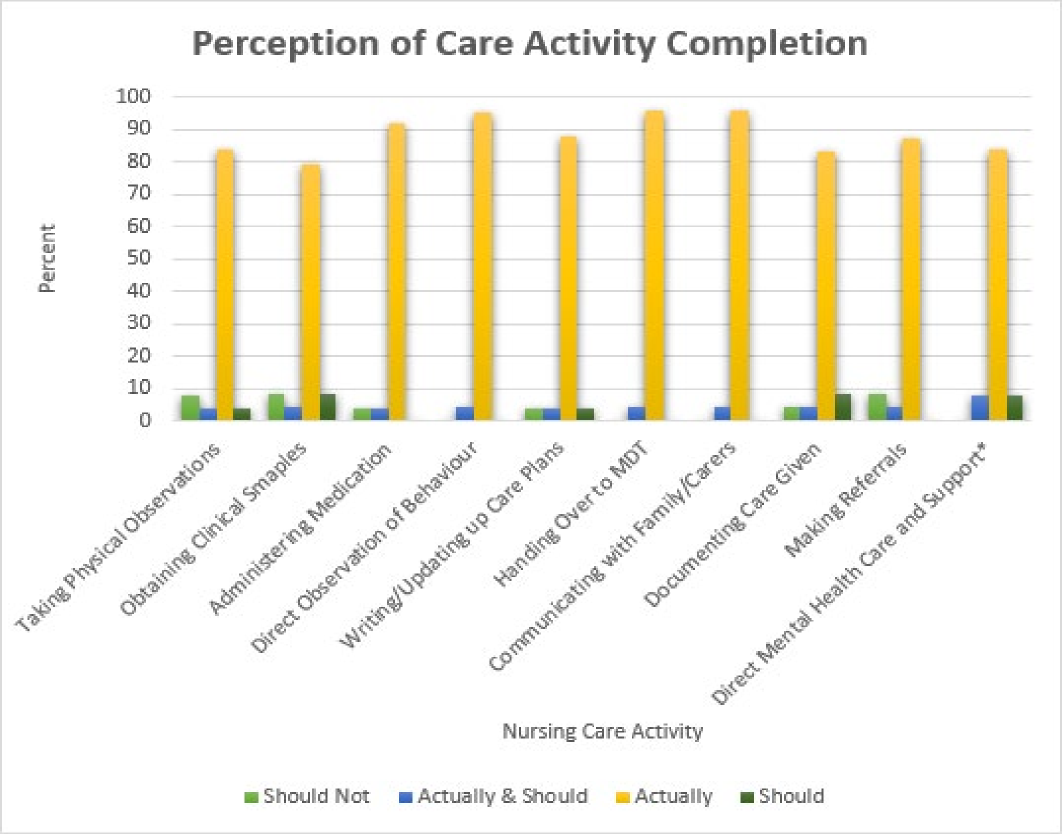

Figure 37 Care Activity Perceptions[14]

None of the domains prompted a clear stance regarding their opinion of whether these should or should not be undertaken by themselves. This strengthened the finding in Chapter 6 that the RNMHs found their daily work appropriate at a

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[14] In the questionnaire, taking physical observations was noted to include examples of temperature, blood pressure, pulse, oxygen saturation level and respiratory rate, and direct mental health care and support was expanded to suggest examples of therapeutic engagement, meeting psychological or emotional needs.

fundamental level (in relation to the provision of care) but there appeared to be a tension regarding the organisational and service level complexities that may result in the movement of people into their care which they perceived to be inappropriate admissions, (as seen previously in 0102's discussion) and spans the themes of C4 Multidisciplinary Team, and C6 Mental health versus Physical Health:

'…I can think of a few people that we have nursed who have been what I would say were inappropriate admissions at times, coming in from the community, when they get here we identify delirium once the delirium has gone that person is absolutely fine…'

0102

From the open response sections in question five, participants offered additional indications of what work they were engaged with on a daily basis, outside of the options presented. These responses indicated an active engagement in non-clinical roles, with an onus placed on managerial or support work such as audit or advocacy/support groups. This showed a strong link to the encompassing person-centred philosophy of the RNMHs' education and care provision including the families, carers and wider facets of care provision, as discussed in Chapter one.

Moving on from what the RMHNs actually undertook and their perceptions of this care's appropriateness, the questionnaire helped explore to what extent the care was perceived as challenging to them. Orientation and parenteral hydration provision were least indicated as regularly challenging in DSD (36%), with providing therapeutic environments, meaningful activity, and supporting behaviours that challenge as most indicated as regularly challenging (68%). This was interesting as this could be seen as a traditional part of the mental health nursing care role and questions if it is the required care itself, or presentation of the patient with DSD that determines this as particularly problematic. Alternatively, this could indicate the core focus of the RNMH linked to their understanding of what patients with DSD require and their mental health principles of care. These areas also showed an alignment with therapeutic interventions recommended for people who have delirium or DSD. This potentially suggested that whilst the nurses did not overtly articulate their care activities, they were nevertheless there, and visible in their actions and were aligned with contemporary delirium and DSD care recommendations:

'…I think, behavioural management is always a difficult one coz sometimes I think it's probably a period when they are going to be confused and it's just a matter of reorientation, redirection, continuing with that really, and just trying not to use any medication for behavioural problems, but sometimes that can make the delirium worse…'

0201

'…to be honest when they have got delirium, we just identify the cause or identify if its a proper, so the Doctors, do the blood pressure, we do all the observations that need to be done and to identify a if its, feel delirium or dementia we just assess the cognition and things like this, we use the tools…'

0402

Interesting, in the two quotes presented, was the sense that what they were undertaking, for them, was not overly taxing, albeit highlighted the most in the questionnaire. This indicated DSD as at the forefront of their minds. Their discussion alluded to a feeling of being conformable with the care that was required and the use of 'just' could indicate it was common, standard practice for them that did not seem to cause concern. Alternatively, it could signal that this was the only part of care (identification of cause and observations) they were involved in, leaving the remaining decision making and provision to other clinicians as discussed by their involvement with the multidisciplinary team. Whichever part they played, their contribution to DSD care did not seem to concern them or appear unmanageable.

Consideration was given to the diversity of settings in the group and subset analysis was performed to identify any specific practice environment issues (Figure 38, page 244). The care home subset indicted administering oral medication in 90% of respondents, clearly showing this as a challenge for their care environment. In addition, oral hydration and nutrition was indicated as a challenge by 70%. Whilst representing the unique practice areas, there was no statistical significance found between groups (p=0.05) across all tasks apart from administering medication (determined using Mann-Whitney U, p=0.016). Whilst not showing statistical significance, providing oral hydration and nutrition appeared more challenging to the care home RNMHs

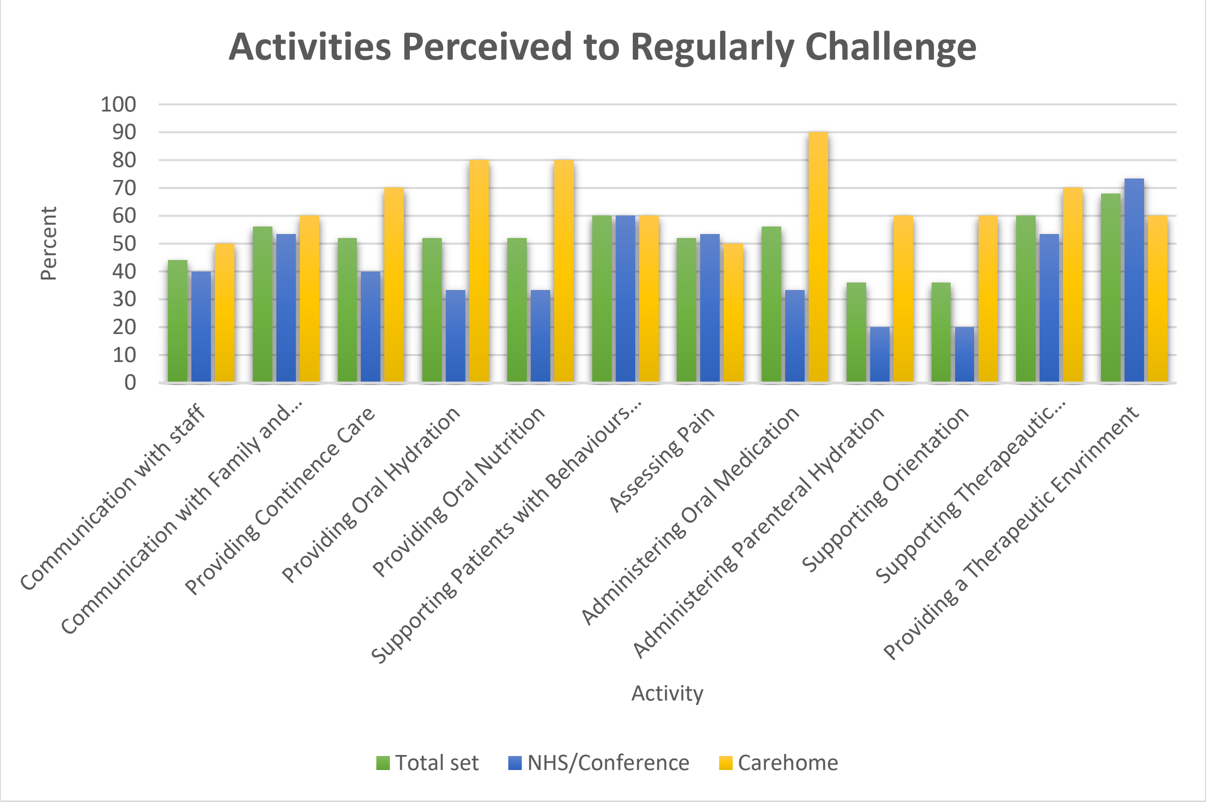


Figure 38 Activities That Regularly Challenge RNMH

The impact of caring for someone with DSD was assessed in terms of the individual, ward setting and team. A total of 64% of respondents found an increased or greatly increased demand on their daily workload when caring for someone with DSD. This increase in workload demand was echoed in 62.5% of respondents reporting increased or greatly increased ward/care home stress level; however, individually, only 40% of the RNMHs reported their own stress levels increasing, with the remaining 60% expressing a neutral stance. In addition, 60% took a neutral stance in relation to the care of DSD increasing or decreasing the clinical team working closely together (4% reported a decrease, and 36% an increase). So, whilst the RNMHs articulated that daily demand of work was increased, and that ward/care home stress levels to some extent increased, they themselves did not feel increased stress, and continued to feel the multidisciplinary team worked in partnership; though not at an increased level.

Question eight explored this further, asking specifically about care for people with DSD rather than dementia alone. 72% reported that caring for someone with DSD was more challenging or a lot more challenging than for someone with dementia alone. Splitting the perceived care required between RNMH and nursing assistants (bands 2/3/4) indicated an opinion that people with DSD (rather than dementia in isolation), required comparable increases in care provision from the RNMHs and nursing assistants; 52% of respondents indicated that more care was required by RNMHs and 56% indicated more care was needed by nursing assistants. This may suggest why the ward stress level and care was seen to increase, but not to great effect in the actual individual RNMHs' stress levels, as the activity increase was seen as equitable. Adding to this, and exploring the notion of care burden past staff and into patient impact, the first section of Question 9 (originally situated in C1) was reviewed. This question asked for an articulation of perceived impact on care provision for other patients. Here, there was an indication that the respondents considered DSD to impact on other patients' care provision; 52% agreed to some extent, 36% neutral, 12% disagreed to an extent.

7.2.5.1 **C5 Consideration**

For the RNMHs, burden of care appeared to stem from their discussion of the multidisciplinary care team in some respect, with admissions on occasion being seen as inappropriate for their service. Considering this, the care itself was not overtly presented as burdensome, and the RNMHs maintained a strong focus on their role of an RNMH. They identified challenges with care provision which were in keeping with the RNMH mainstay of providing therapeutic environments.

The RNMHs did not feel an overt burden of care when someone had DSD, and the care required increased equally across the RNMH and nursing assistant provision. In addition, they did not appear to see the care of DSD impacting on other patients. From this, it appeared burden of care was not linked to the care required of them specifically, but more the conceptualisation of what care should look like or focus upon. Once significant variation was seen between the data sets, with care homes finding medication administration particularly challenging. This was coupled with hydration and nutrition and indicated that different care contexts find different components of care more challenging than others. These elements of care, and the contexts in which they present as challenging are explored further in Chapter 8.

7.2.6 **C6 Mental Health Versus Physical Health**

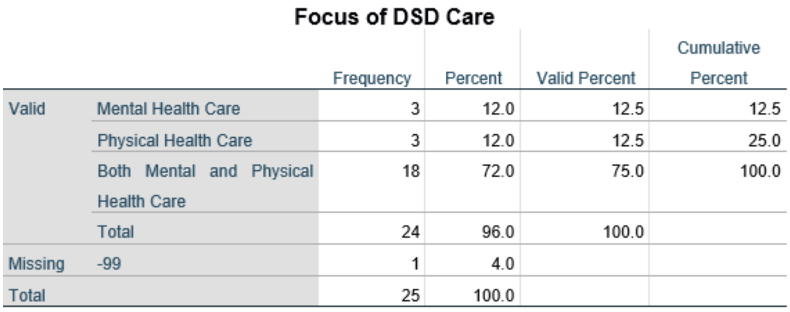
The overarching conceptual premise of care, and where that care was best delivered was complex and relied on a system of labelling the type of care required in terms of organisation and staff provision. Such labels determined not only the location of care, but also the underpinning philosophy of care and professional ownership of the person with DSD. Briefly returning to the qualitative data, the RNMHs appeared to perceive DSD predominantly as physical in nature, and caused tension within the mental health setting and care provision. This tension was present not only when patients were moved between care settings, but in the rationale for admission to hospital and the suitability and processes involved (as seen in *Care Burden*). 0101 and 0102 discussed patients being admitted with infections, and questioned if DSD had been recognised and treated in the community, would the patient have needed an admission to the mental health ward? The discussions focussed on 'infection', and whilst acknowledging that there was a reason for admission, there was a sense that this was inappropriate. The consideration of ruling out or commencing treatment for illnesses such as infection earlier shows the RNMHs thought steps were missed by others, and the RNMHs noted the complexity of balancing patient distress, care provision and willingness of other care providers to continue to care for someone if their behaviours changed (0102). This, in their eyes led to the potential for inappropriate admissions to mental health settings at the expense of, and causing distress, to both the patient and their family. This demonstrated a link between their of knowledge of the person, care burdens, and silos of care perpetuating distress in their patients:

'…it's an old problem, I'm sure you've heard, is the line between mental health and physical health. People get admitted to physical wards with delirium and there's batting from side to side, back and forwards, we get people sent back, and they send, but you know, it delirium, it's a mental health problem we cured that, but its caused by, 99% of the time by physical…'

0501

To explore this further, two key questions were asked to illuminate the perceptions of the RNMH regarding of the underpinning concept of DSD care and how it related to care environments. Of the respondents, 75% felt that DSD care was mostly focussed both on physical and mental health equally; with an even split between the remaining responses between physical or mental health care dominance (12.5% each) (Table 16).

Table 16 Focus of DSD Care: Mental Health Vs Physical Health



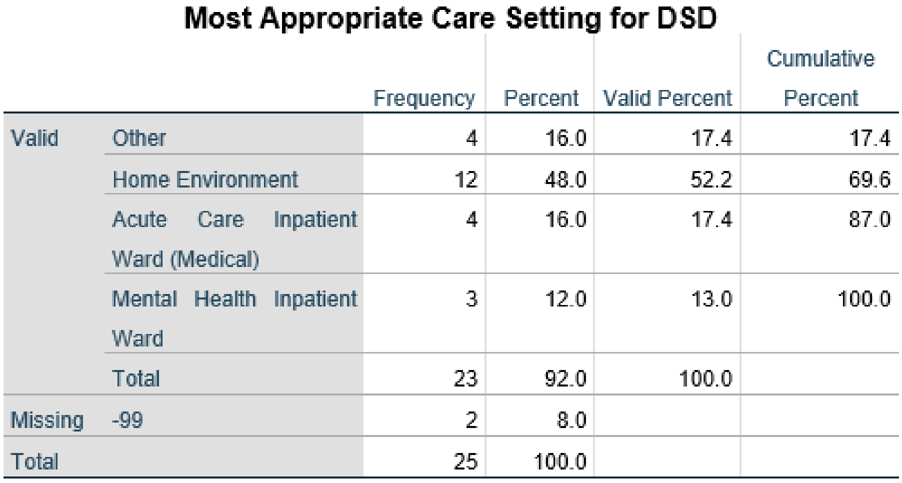
Focus of DSD Care

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mental Health Care	3	12.0	12.5	12.5
	Physical Health Care	3	12.0	12.5	25.0
	Both Mental and Physical Health Care	18	72.0	75.0	100.0
	Total	24	96.0	100.0	
Missing	-99	1	4.0		
Total		25	100.0		

The minimal response level associated with predominantly mental health care was matched when asked where they thought the most appropriate place of care was for someone with DSD (Table 17 page 249). A majority indicated the home setting (52.2%) with the acute medical inpatient setting and ‘other’ tied second (17.4%), leaving the mental health in-patient setting last (13%). It should be noted here that one respondent indicated two preferences (home and acute environments); therefore, analysis was undertaken twice. This secondary analysis showed no change in overall preference, with the home environment remaining dominant at an increased percentage of 56.5%, ‘other’ second at 17.4% and acute care and mental health inpatient settings tied third at 13% each. No participants indicated intermediate care (noted as short-term rehabilitation settings) as appropriate.

Further information was found through quantification of free text responses in relation to ‘other’ settings they may think were appropriate. From those that offered supplementary information, there was a notion that the best place of care was determined by an assessment of the individual’s needs (67%), a consideration of risk and safety (33.3%), and sat alongside a concern for the distress a change of environment may cause (22.2%). This returned focus to the RNMH’s need to know the patient as an individual as seen in the discussions in Chapter six, and this chapter relating to C3 in the *Object* element of the activity system (Chapter six, page 196, Chapter seven, page 231). Combined, this showed a strong consideration of the patient as an individual driving the RMHNs’ perceptions of appropriate care provision and settings.

Table 17 Appropriate Place of Care DSD



Most Appropriate Care Setting for DSD

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Other	4	16.0	17.4	17.4
	Home Environment	12	48.0	52.2	69.6
	Acute Care Inpatient Ward (Medical)	4	16.0	17.4	87.0
	Mental Health Inpatient Ward	3	12.0	13.0	100.0
	Total	23	92.0	100.0	
Missing	-99	2	8.0		
Total		25	100.0		

7.2.6.1 **C6 Consideration**

Whilst the qualitative data suggested through the nurses’ use of language that they saw DSD as predominantly associated with physical health care (in terms of *infection for example*), the quantitative data strengthened the overall discussion; highlighting that the RNMHS saw DSD as needing an equal focus. This illuminated the complexity in practice, and ways in which RNMHs articulate their knowledge of DSD. Whilst delirium was categorised (via its inclusion in the DSM V (American Psychiatric Association, 2013), and the subject of this study was RNMHs experiences, the RNMHs did not associate DSD as a predominantly mental health focussed condition or care concept. They valued the equal provision of both. In addition, they clearly demonstrated that they did not perceive a mental health in patient setting to be the most appropriate place of care. Indeed, they situated these care locations as last, showing a strong opinion that people with DSD should be cared for in their own home settings (including care homes if already a resident).

7.3 Chapter Summary

This chapter has detailed the results of the descriptive statistical analysis applied to the quantitative data gleaned from the second phase of data collection in this mixed methods study. Here, the core themes in the activity system were further questioned and additional information and insight into the RNMH gained, adding to the understanding of their experience gained through the literature review and qualitative findings. The integrated findings form an overall view of the RNMH experience when providing care for someone with DSD within their activity system.

8. Discussion and Conclusion

By using activity theory as a lens to guide investigation, this study has gained a new insight into the RNMH experiences when caring for someone with DSD. These experiences were influenced and mediated by the organisations and environments in which the RNMHs provided care.

This study contributes a unique and new perspective on RNMHs' experiences of caring for people with DSD. To date, this appears to be the first study focussing on specifically the RNMH experience of DSD within 24-hour care settings rather than delirium in general, and acute medical or surgical contexts. The manner in which the discussion is presented is purposefully tentative; as a first exploration of the RNMH experience of DSD, caution needs to be applied to making grandiose or sweeping statements. Little context and professionally equivalent study has been undertaken previously looking at both the RNMH and DSD. The below discussion situates this experience in an activity theory system, but also highlights commonalities of the RNMH experience in the context of other healthcare or nursing studies in this area. As such, this study fulfils its central aim to illuminate the RNMHs' experience of providing care for DSD.

Predominantly the discourse in the published literature, and subsequent knowledge base has focussed on RNA, RGN/RN (country specific) and has been dominated by the acute healthcare system. As discussed in Chapter one the RNMHs' premise of care is guided by concepts such as Caring *with the person*, not *for them* and this appears to influence their experience greatly.

Following integration of the data sets, and in light of the available literature, the activity system impacting on the RNMHs' experience of providing care for someone with DSD is presented below in Figure 39. This helps to expose the tensions, influences and impactful components that build the RNMH experience, but also to highlight their interplay. Each component is discussed in turn.

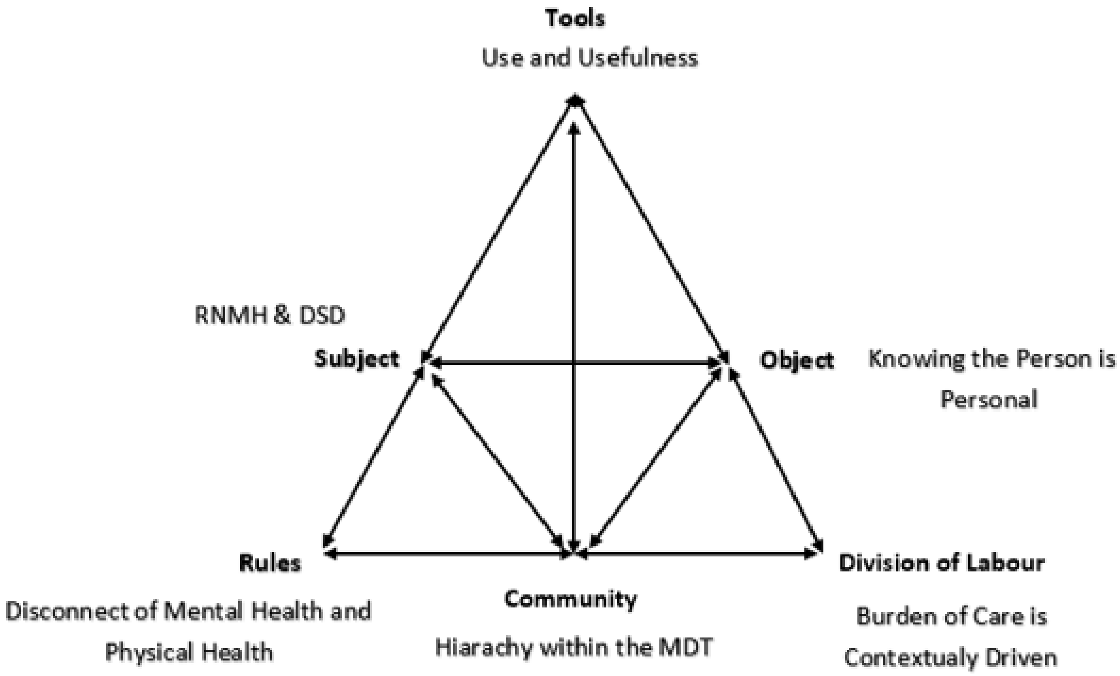


Figure 39 The RNMH Experience of DSD Care Provision: Influences in an Activity System

8.1 Tools: Use and Usefulness

In activity theory, a "tool" is a mediating artefact, something which is used or facilitative of action. Such tools can be liberating, or restrictive (Wilson, 2008). Here, tools in the activity system relate directly to guidelines, scores and clinical tools for DSD assessment and care. Conceptually, Barker (2004) discusses that any assessment is undertaken with future action in mind, so the RNMHs' assessment activity or use of DSD tools, should facilitate an intended future action.

Healthcare has seen a rapid increase in protocol and policy driven practice. This has resulted in a proliferation of guidelines and clinical tools championed and advocated for implementation, which place an onus on evidence-based practice (Roycroft-Malone, Morelle and Bick, 2004). Such protocols and guidelines are reported to streamline and improve practice, whilst reducing any variation (Roycroft-Malone, Morelle and Bick, 2004; Abrahamson, Fox and Doebbeling, 2012; Veeramah, 2016). This, however, only works if such protocols and guidelines are used, and used appropriately. Both internal and external factors influence update and use of guidelines, including those intrinsic to the individual (knowledge of the guideline, their attitudes and motivation) and external to the individual (patient factors, environment, organisation, and the guideline itself) (Abrahamson, Fox and Doebbeling, 2012). These factors can be seen in the specific domains of the activity system impacting upon the RNMHs in this study.

In contemporary practice, there is movement away from the traditions of physical health assessment focusing on formal methods of investigation, and mental health using informal methods. Advocated now is choice of assessment determined by both patient and situational factors (Barker, 2004). Traditionally, RNMHs use two types of assessment: the interview, and observation (Barker, 2004). This seemingly qualitative assessment profile does not negate or render the use of quantitative information valueless; indeed, the combination of clinical judgement, inclusion of patient values, and actuarial measures can be beneficial (Hamilton, 2001). Empirical, or actuarial decisions form the mainstay of tools and scores, transforming patient data into numbers which takes the user on a path of outcomes and actions (Hamilton, 2001).

There is an ever-growing plethora of delirium assessment tools available in wider practice; however, each has its individual strengths and target populations, purpose (screening, diagnostic, severity assessment or case finding for example), and intended use for people with DSD. Recent reviews have indicated over 20 delirium assessment tools validated for practice (De and Wand, 2015; Network for Investigation of Delirium: Unifying Scientists (NIDUS), 2018) and these predominantly assign a numerical value to a person's presentation.

Specifically, for DSD, Morandi *et al.,* (2012) found only six tools with sufficient high-quality methodologies and data reporting to be included in their systematic review. Indicating that guides or tools with a robust and well explored use in DSD is not equal to their use in delirium alone, and even more so, such tools are predominantly validated in acute or general medical or surgical areas. Thus, leaving the mental health or psychogeriatric settings under assessed in terms of the tools use and applicability here. Compounding this, the ongoing literature searches undertaken throughout the current study, indicate that to date, there are no UK based studies of DSD tools specifically undertaken by RNMHs within older people's organic mental health services. Therefore, whilst not solely the aim of this study, the inclusion of tools use in the activity theory here represents a first exploration of the RNMHs' experience of using tools in DSD care.

8.1.1 **Use**

The wide availability of tools (most commonly in relation to delirium alone) was seen throughout the study, with multiple tools named and discussed. Whilst this suggests that the RNMHs were aware of tools, use of these tools echoes the literature in terms of being unrefined to the clinical context of DSD. Quantitatively, the CAM, 4AT and DRS were identified most, and are DSD appropriate and validated, showing to some extent, a level of awareness of tools that are appropriate for use in DSD care.

Some participants, predominantly those working in care homes, but also some NHS settings, stated that no tools were used in practice and, only 56.5 % of the sample reported that they always completed a tool if DSD was suspected. As such, the experience of the RNMHs appeared to be inconsistent. In both their qualitative comments and quantitative answers, participants noted using general cognitive assessment tools (MMSE, MACE, ACE 111) in place of a delirium or indeed DSD specific tool, and one participant highlighted using the Cornell scale for depression.

In terms of suitability, there is some discussion in the literature around the use of the MMSE: the MMSE has been found to be the most widely-used cognitive assessment test (Mitchell *et al.*, 2014) and, in some studies was found to be used to identify delirium when serial scores were taken since it is responsive to short-term changes in cognition (O'Keeffe *et al.*, 2005). It could be a helpful test to distinguish between delirium and dementia; however, its single use does not differentiate between delirium or dementia (and as such DSD) since it offers only an objective measure of cognition at the time it is undertaken (O'Keeffe *et al.*, 2005). With regards to serial scoring, the current study does not suggest that this is commonplace, with tools being discussed as part of monthly audits and a relatively low update or use in practice.

A meta-analysis by Mitchell et al., (2014) concluded that the MMSE should not be used as a case finding confirmatory test of delirium, but could be useful as part of a wider cognitive assessment strategy reviewing fluctuations in cognition. They caution against MMSE being used to replace a full delirium specific assessment. Sampaio and Sequeira’s (2015) investigation into nurses’ knowledge and practice in terms of acute and chronic confusion (noted to be delirium and dementia) also recognised the MMSE as the most commonly used tool by their participants (53%). This study included a range of professions, with 27.7% of the sample having a psychiatric or mental health nursing degree and 23.4% working in a mental health setting. Sampaio and Sequeira (2015) found that the nurses specialising in mental health/psychiatry had an increased median awareness/naming of tools (M 2.12), in contrast to non-specialist nurses who reported M 0.81. However, the reporting of non-delirium specific tools as discussed previously, may indicate a superficial knowledge of both tools available, and delirium as a distinct cognitive issue. Thus, whilst nurses may self-report high levels of awareness regarding delirium specific guidance and name many tools, there is a risk that some are unaware of the intended or appropriate use of clinical tools in practice. This may manifest (as seen in the current study) in more specific tools being passed over for non-delirium orientated cognitive screening.

In keeping with Sampaio and Sequeira (2015) the current study also suggests that there is minimal consistency in practice in terms of tools identified, indicating that the wider organisational goals of reducing variation in practice is not being achieved in terms of DSD assessments. The RNMHs' experience of tools was one of inconsistency and non-standardised practice both internally to, and externally to organisations. This suggests that there is a disconnect between the self-reported awareness of guidance, knowledge of tools and their intended purpose, and application in practice.

8.1.2 **Usefulness**

For tools to be used they need to be perceived as useful; RNMHs need to be motivated to use them. The goal of the tool or guidance needs to hold meaning for the RNMH and have clarity of purpose (Bryce, Flemming and Reeve, 2018). Poorly visible outcomes or lack of collective value placed on the tools or guides can undermine this sense of usefulness (Emme, 2020). It was clear from the qualitative data in the current study that the tools in practice were not overtly valued by the RNMHs in terms of influencing their care delivery. Completion of tools for audit or routine planned monthly processes led the RNMHs not to see them as influential in terms of their care provision, but more as an organisational requirement. In this study, the DSD tools appeared detached from patient care.

This study suggested that nurses used judgement about when to use tools in practice, but that this judgement was influenced by the RNMHs' perception of the tools' usefulness and appeared individual to them as practitioners, not the patient. The participants were split between those who thought the outcome of tools influenced their care decisions more than their knowledge of the person and those who did not. In addition, there was variation in the participants' views of the meaningfulness of the tools in practice. This variation extended to echo the variation in awareness of tools discussed previously. Only 56.5% of the participants indicating that they would always use a tool if DSD was suspected, and a lower perception that tools identified DSD correctly (42.9%). 60.9% of the participants felt that they could use their intuition to identify DSD correctly. This suggested that for RNMHs, the lack of perceived accuracy of tools could be impacting on their uptake and use.

The current study draws some parallels with the findings of Emme (2020) in which Danish hospital nurses' experience of delirium guidelines were investigated. Whilst the nurses in this study were Danish and from non-mental health settings, they were purposively selected for their experience with frail, older people at risk of delirium. Emme exposed of a lack of meaningfulness attributed to delirium tools use and usefulness when caring for someone with delirium. These participants held a negative attitude to tools; expressing frustration with the requirement to screen all patients for the sake of completing screening. They saw tool completing as a paper to 'make some marks' on because they had to, rather than because it was useful. Coupled with this, there was a sense that the guidelines devalued the nurses' professional judgement and professionalism (Emme 2020, 1a RN & 2c RN). This was also articulated by Van De Steeg *et al*., (2014) who found that delirium screening was not seen as an essential element of care for older people; the nurses here felt that the screening tools limited their autonomy in practice.

The tension between guidelines and clinical judgement is well recognised: often policy makers and managers view clinicians as slow to take-up policy, with clinicians upset by the perceived devaluing of their judgement, autonomy and professional identity (Gabbay and Le May, 2016). In the current study, the RNMHs appeared to perceive that the tools and guidelines both devalued their professional judgement, but also depersonalised the care provided to patients. They seemed anxious about assigning an incorrect number to the patient's presentation and the subsequent consequence of this. This barrier to using empirical data in mental health care was recognised by Hamilton (2001) who questioned if practitioners who rely on numerical values to devise care could be construed as detached from their patient, and be perceived as uncaring. This could represent a continuation of the emotional, and relational premise of the RNMHs' care provision transcending through their practice yet again.

Gabbay and Le May (2016) proposed that clinical mind lines exist in practice, with clinicians holding guidelines in their heads. These guidelines are blended with knowledge of the care context, their own experience and flex these to the individual situation. Bryce, Flemming and Reeve (2018) expand upon this, finding in their study about frailty, that participants felt tools both over and under diagnosed patients, and as such, reverted to using their clinical judgement to make decisions. Some participants shortened the tools, whereas some stopped using them completely. This was also evident in the RNMHs' practice in the current study.

Whilst Gabbay and Le May (2016)'s argument regarding clinical mind lines mapping and moulding to the patient is persuasive, in relation the RNMHs in this study, it appears flawed to some extent as it is based on an assumption that the underpinning knowledge and guidelines used are indeed fit for the intended purpose. As seen previously, the RNMHs' perceived awareness of DSD tools and guidelines might have appeared high but, in reality, there was variation regarding both what, and how DSD tools were applied. This was further highlighted by the use of potentially inappropriate tools in practice.

Exploring what makes tools or guides useful, this study indicated that there was limited priority placed on the tools' use (and as such their usefulness); indicated by the lack of formal training or education on DSD. The nurses in this study had relatively low levels of university based education pertaining to DSD at both pre and post registration level (17.4%) and, whilst predominantly it was the employer who provided much of the education that the participants had completed (26.4%), this was still to a minority, with 69.6% reporting no education on DSD. The lack of training or education suggested that the employing organisation did not see this as a priority, and as such neither did the nurses potentially. This was reflective of Godfrey *et al's* (2013) study who also found that no training was provided to the study participants (including nursing and therapy staff) when developing an integrated delirium prevention system. The lack of training suggested a lower level of organisational priority ascribed to delirium and DSD in comparison with other care considerations: for Godfrey *et al.,* (2013) this was reflected by falls training being part of a mandatory process. Whilst Godfrey *et al*.'s study was situated in acute care, the lack of organisational priority and low levels of training resonated across the care settings. Godfrey *et al.,* (2013) also found that where there was delirium knowledge, it did not promote action, beliefs, or practice. This mirrors the current study, in which scores were completed (generating knowledge of delirium presence or absence) but did not influence care: the scores were filed and awaited meetings to discuss them. This was clearly articulated by 0402 who recounted that scores did not change care; indicating that the purpose of assessing to drive future action was lacking in the RNMHs. This study goes further than previous research in the area, and strengthens the concept of disconnection from tool and actions; adding to the knowledge base in-so-much that the tools themselves are seen as easy to understand, useable, and useful to some extent in identifying DSD. The nurses felt they could physically complete the scores; however, they did not appear to value them as a collective group. There was an equal split seen in those who thought scores influenced their care more than their knowledge of the patient and those who did not. Here, the conceptualisation of the tools as being useful for them in practice appears to be the crux of their decision making in relation to its use; and not a concern relating to their ability to actually use the tools in place.

Van De Steeg *et al.,* (2014) added to the recognition of nurses choosing not to complete scores and tools, finding in their study of barriers to delirium guideline adherence, that where guidelines were in place, nurses did not follow them. They proposed that motivation and goals, knowledge and skills, professional role and identity, and context and resources were all factors in guideline adherence. These four themes were reflected in the RNMHs' perception of use and usefulness discussed in the current study. They did not appear motivated to use the tools: apparently driven by unclear goals (to file them) and benefit (as they felt that if they could identify DSD using their own intuition, why complete a tool?). The tools, appeared to be completed (when completed), not for patient need or the nurses' need for extra information, but because they were required to do so: as an audit; or, as 0501 put it …*it's become too standard.., ticky box…*

The use and usefulness of tools appeared lost to the RMHNs; instead, replaced by paper exercises that did not serve to influence their care.

This study found that in DSD care, tools need to be useful to be used. The goal and intention of the tools was not driving care decisions, and this notion of usefulness was not present in the RNMH experience. Whilst not an explicit aim of this study, the inclusion of tools use in the activity theory here, represents a first exploration of the RNMH's experience of using tools in DSD care.

8.2 **Object: Knowing the Person**

The meaning of 'object' in activity theory has been debated and contested, primarily due to translation issues from the Russian interpretation of the word holding multiple meanings (Yamagata-Lynch, 2010) such as goals, motivating factors, and acquisition of material products from the activity system. There is agreement though that the object pertains to the reason for undertaking the activity, or the space in which the problem sits (Kaptelinin, 2005). What became clear from the literature review, and interviews, was that for the RNMHs, the goal or motivation encompassing their DSD care experience was the person or people being cared for, and the intention to provide care; to *know the person.*

The concept of 'knowing' patients as individuals, is the foundation of person-centred care. Based on fundamental principles that patients should be valued as people, their personhood maintained and respected irrespective of condition (or in this study, cognitive impairments), person centred care is necessary for care of the older person and improving both quality of life and quality of care for those with dementia (Kitwood, 1997; Dewing, 2004; Skaalvik, Normann and Henriksen, 2010; Clissette *et al.*, 2013). This has seen it embedded throughout UK nurses' professional codes of conduct and required skills for practice (Nursing and Midwifery Council, 2015; 2018b) irrespective of field registration.

Central to person-centred care is *Knowing the person*. This *knowing* may take different forms. Carper (1978) provided a fundamental theory to help expose how, or patterns of knowing in nursing. This seminal work discussed four ways of knowing: aesthetic knowing in which the art of noticing is displayed, moral or ethical in which the nurse practices with an ethical discipline, empirical knowing, employing the science of nursing and utilising quantitative and objective knowledge, and personal knowing, in which value of *being with* another person and having a sense of self in relation to others is seen. The current study found that RNMHs were involved predominantly in aesthetic and personal ways of knowing and saw this as paramount to their care provision.

8.2.1.1 **Knowing the Person is Personal**

Prior to devising the Tidal model of care which underpins contemporary mental health nursing practice (as discussed in Chapter one), Barker, Jackson and Stevenson (1999) explored the professional status of mental health nurses. They found that their practice was founded on their unique relationship with the person and embodied the nurse-patient relationship advocated by Peplau (1952) encompassing the nurse, person receiving care, and the person's family. Barker, Jackson and Stevenson (1999) concluded that the RNMH was engaged in the constant activity of getting to know the person, and their evolving needs. The Tidal model of care championed in mental health services suggests that recovery from illness requires nurses to use sympathy (as an awareness of others suffering) supporting their needs and focussing on their wellbeing whilst attempting to alleviate distress (Barker and Buchanan-Barker, 2004). To do this, the RNMHs need an empathy and awareness of the person’s experiences, ‘knowing’ what it is to be the person and talking the time and effort to reach out to them (Barker and Buchanan-Barker, 2004). Whilst not specifically aligned to mental health nursing explicitly, relationship based care as advocated by Nolan *et al.*, (2004) through the SENSES framework (discussed in Chapter one), demonstrated these relationships and their importance not only for the person who required care, but also for those who are charged with providing it. This foundation of being with the person, knowing them as individuals and how their biography reflects the principles and values discussed by (Peplau, 1952; Barker, Jackson and Stevenson, 1999).

The participants in the current study clearly discussed how they knew the person, and how this knowledge formed the foundation of their care. For the RNMHs knowing the person with delirium improves care, and not knowing them is challenging for both themselves and for the patients. Teodorczuk *et al.,* (2015) supports this; discussing a false economy is perpetuated in relation to time if medical tasks are prioritised over understanding the individual in the longer term in relation to delirium.

Central to this discussion was the manner in which nurses considered *knowing the person*. In this study, the nurses saw this as integral, informative and central to their role. They valued the importance of gathering personal information and exploring the person’s attitudes, values and behaviours with family and carers. However, the RNMHs focus on understanding the person, displayed in the current study, does not appear to be universal across nursing fields. The findings of Dahlke and Phinney (2008) highlighted this difference in terms of acute “physical” care settings, even when the patient group remained older people at risk of delirium. Comprising of medical and surgical nurses, Dahlke and Phinney (2008) found that the nursing experience and care comprised three main components: *taking a quick look, keeping an eye on them, and controlling the situation*. The nurses’, recognition of delirium was based on disruptive behaviours (such as removing gowns or disrupting intravenous therapy tubing) and, whilst they spoke to the patients’ families about usual patient presentation, this was reported as only occurring once the nurses had deemed the patient's cognitive status to be ‘off’. This demonstrated that using family or carer input to build up their knowledge of the patient was a post thought, reactionary to an incident. This was in direct contract to the RNMHs in the current study who saw gathering contemporary information about a person as an important and informative part of care for someone with DSD; with 91.3% of participants indicating that their nursing intuition was based on knowledge of the individual. Here, in tandem with the work of Dahlke and Phinney (2008) there appears contrast between the RNMHs’ experience of DSD in their focus on deep understanding of the person, thus reducing potential for a malignant social psychology in their working culture, in contrast to the participants in Dahlke and Phinney (2008) who appear to typify this negative practice.

One participant in the study by Dahlke and Phinney (2008) summed up their colleagues’ thoughts regarding delirium; noting that delirium was seen as more of a facet of personality rather than a signal of acute illness. Dahlke and Phinney

(2008), reviewed in line with this study, exposed an important irony at play here: that medical/surgical nurses (or those working in acute settings) may conceptualise delirium as a facet of the person themselves (part of their personality); or, as previously discussed, attribute it to dementia, failing to recognise the acute medical emergency that it is signalling (Wick and Zanni, 2010; Steis and Fick, 2012). In direct contrast, RNMHs (as seen in the current study) do not attribute it to the person as part of a normal behaviour or facet of their personality; more so that changes to the *known* person prompt considerations of deteriorating physical wellbeing or the presence of a new illness. Thus delirium, and as such DSD are conceptualised by nurses in line with the potentially opposite field of nursing to which they are trained.

8.2.2 **Empirical Knowing**

Empirical knowledge is a fundamental part of Carper's theory of knowing (Carper 1978), and potentially impacts across the RNMH experience.

The current study suggested that for RNMHs, *empirical knowing* or using actuarial judgement, was not held in such esteem as *aesthetic* or *personal knowing*; and this may impact upon care to some extent. Bonis (2009) reported that knowing in nursing is unique in that it requires objective knowledge to be blended with subjective perspectives, reflection and experience. The participants in the current study appeared to focus more on the subjective, reflective, and experiential components of knowledge. This was seen in 91.3% agreeing that their intuition was based on knowledge of the individual, 82.6% agreeing that their intuition was based on guidance and only 56.3% reporting that they always completed a tool if DSD was suspected. This indicated that the nurses used their clinical intuition and knowledge of the person in DSD care more than tools; reiterated by 73.9% of participants agreeing that the clinical teams' knowledge of a person was more important that a tool or score.

Interestingly, this study suggested that, whilst not holding empirical knowledge in the form of tools in high regard, the RNMHs did have knowledge of a wide range of delirium and DSD assessment tools. This echoed Sampaio and Sequeira’s (2015) study of nursing knowledge and practice in relation to acute and chronic confusion. Sampaio and Sequeira (2015) selected a sample which included a range of different nursing specialities and locations of work. They found that whilst the mental health nurses had a greater awareness of, or reporting of named tools, they felt they had less need to use them regularly in comparison with nurses on medical, surgical, or emergency settings. This highlighted a tension between awareness of and use of tools and knowledge. These tensions can be seen in the dynamic interplay between tools and the object of *knowing the person* in activity theory, but also feedthrough to nursing intuition and the specific notion of being an RNMH.

An influential factor here is discussed by Crowe (2006) in terms of psychiatric diagnosis and mental health nursing. Crow discusses that psychiatric diagnosis is at risk of being seen not to recognise the patient experience of mental distress, and more as a categorisation activity. Crow advocated the focus should be on the patient experience, rather than diagnosis. Expanding on this, and moving the debate forward, Macneil *et al.,* (2012), whilst recognising diagnosis is a process of categorisation from which treatments can be selected, argued that there needs to be collaboration and partnership between the person and clinician to identify appropriate interventions based on the individual and reaching a shared understanding of them as a person, and their challenges.

In this study, the RNMHs appeared to favour informal information and assessments; infrequently using tools in DSD care, and as such not achieving cohesion between assessment and appropriate care options. This could suggest that the RNMHs wished to see the person rather than a number; but, whilst they did not frequently use tools as formal empirical assessments, they did undertake regular informal assessments of their patients which could be considered as contributing to their aesthetic knowing of the person. This preference for informal knowledge and assessment is in keeping with Fourie *et al.,* (2005); Mackay, Patterson and Cassells (2005); Delaney (2006) and (MacNeela, 2010) who also found that mental health nurses favoured informal information versus formal information (such as checklists, case notes and other empirical sources of information). This drive away from actuarial judgement is well known in mental health care; there remains a strong focus on the person as an individual and not a number; however, this does not take into consideration that actuarial measures in mental health have been found to be equal or superior to clinical judgement (Hamilton, 2001).

In mental health care provision, assessment is seen as an estimation of a person's character, what they are and what they may become in opposition to the medicalised concept of assessment and diagnosis which focusses on identification of pathology and asks questions about *what is wrong* with the person (Barker, 2004). As such, the mental health nurse's premise of *being with*, and *caring with* the person, may move them away from quantitative, empirical ways of knowing them at the expense of accurate diagnosis and subsequent appropriate care planning.

Returning to Carper (1978), the current study suggested that RNMHs displayed and valued aesthetic, personal ways of knowing over empirical knowing. For the

RNMHs, knowing the person was personal; they were engaged with *being with the person* in order to deliver care and appeared to value this nursing activity over scores or tools.

8.3 Community: Hierarchy within the Multidisciplinary Team

'Community' in activity theory is the social group with which the participant identifies with or is situated when undertaking the activity (Yamagata-Lynch, 2010). In the current study, the community was the care environment and its associated multidisciplinary team.

The healthcare multidisciplinary team is founded on the premise that it facilitates a clinical environment in which different professions are allowed to utilise their skills, beliefs, values and abilities (within their scope of practice) (Orovwuje, 2008). They are seen as part of a whole systems approach which improves quality of care, facilitates complex decision making and navigation of multiple treatment options for the patient (Cook *et al.*, 2016), working to support sharing of knowledge, and hold an egalitarian foundation with good patient outcomes being the core focus (Orovwuje, 2008). To do this, Stuhlinger, Schmutz and Gudela (2019) suggested that having a shared language supports collaboration and is mediated by relational coordination and psychological safety. The current study suggested that relational coordination was an influencing factor for the RNMH experience, and one which remained underpinned by traditional medically dominated hierarchies.

8.3.1 RNMHs' Position in the DSD Multidisciplinary Team: Relational Coordination

As discussed by Orovwuje (2008) multidisciplinary teams should be egalitarian, and value each profession's contribution equally. Teodorczuk et al., (2015) explored sociocultural barriers in ward settings and their impact on delirium and dementia care. Relational coordination within multidisciplinary teams advocated mutual respect, and shared knowledge and goals (Stuhlinger, Schmutz and Gudela, 2019). The hierarchy of the organisation was found to be an important influence and noted that staff with critical knowledge may not feel empowered or confident to share this knowledge. Overtly, the RNMHs in the current study reported feeling listened to, valued and supported within the multidisciplinary team; however, this was mediated by them positioning themselves in a secondary role, deferring to the senior medical staff (consultant psychiatrists) when asked who guided DSD care in their areas. This indicated a level of engrained hierarchy permeating their experience; one in which medical seniority was dominant over other professions. This is reflective of Emme (2020) who linked the nursing premise of care to more non-pharmacological care, with the nurses feeling a sense of responsibility to the patients. This may be ascribed to the aesthetic and personal stance the RNMHs appeared to be motivated towards. The divide is perpetuated by nurses believing that doctors are the diagnosticians, with their role being to observe and document observations (to support diagnosis by the doctors) (Coyle, Burns and Traynor, 2017).

This suggested a potential tension between medical and nursing care priorities: whilst collaborative care can be achieved, nurses may find that the medical staff focus on pharmacological treatments for delirium and lack an overall view of the patient's condition (Emme, 2020). Whilst it has been shown that the RNMHs valued aesthetic and personal knowledge over empirical knowledge, the poor uptake or use of tools could have placed them in a position where there was an

absence of shared language within the multidisciplinary team. One in which DSD can be discussed using the same terms, values and goals.
The value of shared language is well reported (Leonard, Graham and Bonacum, 2004; Rabol and Ostergaard, 2011; Stuhlinger, Schmutz and Gudela, 2019) and, within multidisciplinary teams, there is an awareness that all members may have been educated to communicate in different ways. However, overcoming this challenge and creating a shared language increases collaboration, effectivity, relationships and care (Stuhlinger, Schmutz and Gudela, 2019).

For the RNMHs in this study, their lower use of tools, and the preference for aesthetic knowledge may have left the depth of information they hold unrecognised if it was presented in an anecdotal, non-clinical or informal manner (Van De Steeg *et al.*, 2014; Coyle, Burns and Traynor, 2017; Emme, 2020). Whilst this study suggested the RNMHs did not value empirical data highly (in terms of scores and tools completion) Van De Steeg *et al,.* (2014) found that utilising the Delirium Observation Screening Scale (DOSS) had a positive impact on the nursing position within the multidisciplinary team, strengthening it, and helping them clearly articulate the risks and symptoms they were observing.

Whilst achieving congruence in terminology and language, this drive for nurses to adapt their communication style, again implies that the RNMHs needed to change (not the other disciplines). Rather than supporting equality placed on their role in the multidisciplinary team, this could reiterate their perception as being inferior to doctors. Indeed, asking nurses to change their language to accommodate doctors could be potentially hazardous for patients, when the role of the RNMH and their training and education revolves around the experience of the patient and not empirical, value judgements. The content and quality of their knowledge could be lost if it were to be a repackaged in medicalised terms that are not part of their professional ethos.

As such, there is an argument that the multidisciplinary team needs to value and listen to the aesthetic and personal anecdotal accounts of the RNMHs and take action upon this information rather than request it to be repackaged into their language (Leonard, Graham and Bonacum, 2004).

From both the qualitative and quantitative findings, the RNMHs' experience was positive, having several members of the multidisciplinary team to call upon to guide their care; however they felt that they needed guidance (for DSD specifically) rather than guiding DSD care. Whilst the DSD multidisciplinary team appeared not to be egalitarian, this study suggested that the RNMHs were positive about their position within it. They showed contentment in their position, felt supported, and as such displayed psychological safety. Referring to achieving relationship centred care, these articulations of support and being part of a team indicates congruence with Nolan *et al.,* (2004) assertion that staff should have a sense of security and belonging in practice. However, for the RNMHs this security does not come from their own knowledge, but that of those around them.

8.4 **Division of Labour: 'Burden of Care' is Contextually Driven**

"Division of labour" in activity theory refers to tasks and how they are distributed within the community. Whilst community in this study relates to the multidisciplinary team and would be a persuasive area to explore divisions of labour, this study aimed to explore the RNMHs' experience. With the multidisciplinary team discussed in community sections of the activity system and throughout, divisions of labour here are seen not only across settings, but importantly, in the division of labour between work the RNMHs undertake. This study exposes the emphasis placed on different facets of the RNMHs’ practice and finds that the division of labour is not necessarily physical (i.e., who does what), but relates more to the level of challenge that these facets of care present when caring for someone with DSD.

Chapters six and seven identified that the RNMHs felt a sense of doing other people’s work. They related this to perceived inappropriate admissions, stemming from their belief that the most appropriate place of care for someone with DSD was predominantly in their home setting. This, though, was met with a caveat and contextualised by individual patient needs and the risks presented. The RNMHs clearly did not perceive the mental health setting to be the most appropriate place of care. Unique to this study was the scope of older people’s dementia care settings it encompassed; including inpatient assessments, inpatient longer-term assessment and care home environments. The division of labour, and burden that the RNMHs experienced was shown in this study to be contextually driven, with RNMHs from different settings experiencing different care burdens.

8.4.1 **Burden of Care in Relation to Nurses**

This study found that for the RNMHs, burden of care was distributed across care assistants and themselves in an equal manner, but they recognised that when someone had DSD, the overall stress level of the environment increased. Whilst it could be assumed that this would impact on other patients, the RNMHs did not indicate this as a collective (52% agreed to some extent that DSD impacted on other patients, 36% neutral, 12% disagreed to an extent).

The response of the RNMHs to care burden type appeared unique to this study and, in opposition to findings from studies where no mental health nurses were identified as participants such as Dahlke and Phinney (2008); Agar *et al.*, (2011) and Morandi *et al.,* (2015a). Here, burdens of care were associated with the patient, skill mix, ability to deliver quality care, time pressures, and organisational constraints. Such burdens can be surmised as ethical and moral distress in which the needs of the patient with delirium are balanced against the needs of others. In Emme's study (2010), there was a notion that the focus and burden of care was not necessarily solely driven by the patient's need, but rather that the staff thought that the burden lay with them:

'…but it is also in the best interest of the staff that patients aren't too delirium, because it takes up a lot of energy and is time consuming'

(Emme (2020) participant 7, SNN)

In Emme's (2020) study, for healthcare professionals working in non-mental health settings, symptom management and emotional burden was situational and stemmed from a perceived or actual lack of support and control. This presented with a sense of feeling underprepared, lacking competence and anxiety (Coyle, Burns and Traynor, 2017; Mossello *et al.*, 2020). The management strategy discussed by Dahlke and Phinney (2008) of 'keeping an eye on them', in which the nurses felt a demand on their time going to and from delirium patients in need, could be an attempt by the medical and surgical nurse participants to regain perceived control over their working situations. Alongside this, Coyle, Burns and Traynor (2017) found that the RNs felt sadness when caring for someone with delirium, and this emotion impacted on the wider staff group and their workloads.

The literature cited above, and the studies included in the state-of-the-art review by Mossello *et al.*, (2020) failed to address or acknowledge the experience of mental health nurses. There is a plethora of literature and research pertaining to general medical settings and *registered nurses.* The current study suggested that delirium, and specifically DSD was not conceptualised in the same way in relation to burden as non RNMHs and those working in acute care setting. In the current study, the RNMH's work was grounded in their desire to build therapeutic relationships, providing therapeutic environments, and *know* their patient. This relational work was not seen to be burdensome as a concept itself, but fundamental; sitting in opposition to the premise of "*taking a quick look, keeping an eye on them, and controlling the situation"* discussed by Emme (2020).

8.4.2 **Burden of Care Across Mental Health Settings**

This study also concluded that burden of care (when it was felt) was not universal across locations of mental health care provision. In addition, different facets of patient care appeared more difficult in different clinical areas.

As a collective, the RNMHs associated challenges in practice with maintaining therapeutic environments and supporting behaviours that challenge, which paid reference to their core foundation of mental health care provision. The main stay of the RNMH role is one of therapeutic engagement and relationships, and returns to the seminal work of Peplau (1952) who advocated that the therapeutic relationship was the foundation of nursing care. This was reiterated more recently by McAllister *et al.*, (2019) who state that to fulfil the need to build therapeutic relationships, therapeutic environments must be maintained (McAllister and McCrae, 2017); however, what is meant by therapeutic relationships and what this entails is not clearly defined and is often an ad-hoc process (Browne, Cashin and Graham, 2012; McAllister and McCrae, 2017).

Whilst for all settings, there was a sense of challenge collectively felt regarding providing therapeutic environments, the perception of burden was conceptualised by what the nurses viewed their core focus of work to be. This alludes to why there is variance between fields of nursing, and nurses in different settings within the same field. Here, burden can be seen as linked to the perception of what care should be like from a philosophical stance, but also the organisational priorities decreed.

In this study, the care home nurses perceived more challenge associated with medication, nutrition and hydration, in contrast to the NHS/conference participants who articulated that providing a therapeutic environment was more challenging.

Recent policy has focused specifically on improving medication administration and hydration provision in care homes (National Institute for Health and Care Excellence, 2014a; Care Quality Commission, 2019; NHS England, 2020a; b), and raised the awareness of good practice and decision making relating to medicines management. This included the roles of nurses in care homes, and delegation responsibilities regarding medications administration by support staff (e.g. nursing assistants) (National Institute for Health and Care Excellence, 2014a; Department of Health, 2016b). Considering this, organisational and setting wide priorities may influence the manner in which care home RNMHs conceptualise medication administration and hydration aspects of care to be more burdensome; as this is where their focus lies in a wider sense.

Whilst this study found that different settings represented different contextual burdens to the RNMHs, it was not intended to suggest that the other areas neglected these elements of care, but might have found them easier to support; so less challenging or burdensome. In addition, care homes are viewed as the person's home, not a temporary place of treatment. This different purpose influences their environmental structure, organisation, physical layout, and potentially affords the RNMHs working in them more time to establish relationships. This contrasts with the hospital setting with a ‘ward’ lay out, infrastructure and relatively shorter duration of admission.

With a dearth of research into the RNMHs’ DSD care premise, this study set a precedent, having explored potential burdens of care from the RNMHs’ stance. Burdens of care were seen to be different to the RN literature and delirium in isolation. The RNMH experience of burden was driven by the work and conceptual priorities of the RNMH role.

8.5 Rules: Disconnect of Mental Health and Physical health

“Rules” in activity theory refer to both formal and informal rules or regulations. These regulations determine what procedures or interactions are appropriate for the participants to undertake (Yamagata-Lynch, 2010). For the RNMHs, rules of categorisation of healthcare, and professional nurse registration displayed themselves in their language and conceptualisation of DSD care. From the quantitative data analysis, the RNMHs in this study showed an equal focus on the mental health and physical health of the person with DSD; however their qualitative discussion appeared to place focus on the physical precipitating elements of delirium, and their identity of being *mental health* nurses in mental health services. This indicated that management of DSD was in flux between perpetuated silos of care for the RNMH.

8.5.1 Contextual and Organisational Rule

This study suggested that for RNMHs, the persistent categorisation of care into mental health and physical health continued to impact on their experiences. This, despite significant steps towards integrated care. RNMHs work in complex health and social care systems which were organised and governed by the person's diagnosis, type of care required, resources for care activity and skills needed to provide care. This may be required to ensure that the right care is delivered by the right people at the right time; however, this could perpetuate isolated and segregated ways of thinking about care.

Integrated care pathways for mental health and dementia span statutory, voluntary and private provision and therefore should encompass the services needed by someone with dementia; with care being coordinated and tailored to the individual (National Collaboration for Integrated Care and Support, 2013). This has obvious implications for those delivering and organising care services; however, the NHS Five Year Forward View (NHS England, 2014) determined that integration would take a triple approach, spanning primary and specialist care, physical and mental health care, and health and social care. With the complexity of delirium superimposed on dementia, and dementia care in a broader sense, this integration is paramount to be able to provide appropriate services to these individuals.

In the current study, it appeared that silos, and splitting up of care provision and conceptualisation remain active in the RNMH experience. The RNMHs in this study suggested that wider social and private services may (in their opinion) not adequately support people to remain in their own homes/community; discussing more could and should be done to prevent admissions, or maintain the home care environment. That said, they accepted that the best place of care for someone with DSD was based on patient specific factors.

Whilst the Department of Health's (2016a) Dementia Challenge Implementation Plan advocates training for all people working with people with dementia to provide care in the most appropriate setting for those with complex needs and multiple conditions, this is situated in relation to physical health detailed as long-term conditions, and mental health in terms of depression and SMIs. The plan offers no discussion of the cognitive health of the individual. In addition, and importantly, the hospital care discussed focusses exclusively on acute services with no note of mental health hospital provision of care. This is coupled with the specific Five Year Forward View for Mental Health (Mental Health Taskforce, 2016) focussing on SMIs.

The RNMH mental health care provision and RNMHs in care homes appear absent from consideration. As such, the RNMHs in this study found themselves in a system which, despite the integration drive, perpetuated silos of care between their services and that of acute general hospitals. These silos impact on professional ownership of patients.

Often in acute services, people with delirium are not perceived as ‘belonging’ to the medical speciality doctor or the clinical area in which they are admitted (Teodorczuk *et al.,* 2013). In acute areas, standardised pathways of care can result in a lack of flexibility in accommodating the needs of the person with delirium (such as additional staff resources), with mental health professionals reporting to medical colleagues shifting, the perceived burden of the older person with delirium to a mental health or psychiatry focussed clinician prior to undertaking assessments to understand or expose the precipitating factor (Teodorczuk *et al.*, 2013). Thus, acute settings may seek to remove that person and return the area to its usual running (Teodorczuk *et al.*, 2015). Conversely, in mental health settings, the increased need for physical care may initiate a request for, or actually transfer the person with DSD to acute services. In the current study, this was demonstrated by participants noting patients being moved back and forth, between mental health and acute general medical services. Whilst this could be purported to be for the patient's wellbeing, transfers of care are an established cause of increased confusion, a risk factor for delirium and distress for people with dementia, and should be minimised (McCusker *et al*., 2001; Davis, Searle and Tsui, 2019). This highlights the disadvantageous isolation of services, skills and fragmentation of care, despite an integrated care agenda.

There is a key need to support staff in taking ownership of the person with DSD in both acute and mental health settings in opposition to passing over patients to others if they are perceived as difficult to manage, or outside of their usual remit of care (Richardson, Fisher and Teodorczuk, 2016). This, however, needs to be tempered with an understating of appropriate skill and knowledge base for the RMHN to provide safe and effective care. Whilst steps have been taken towards integrated care by upskilling professional workforces and a change in nursing education, the nature of DSD remains a challenge which does not sit well in healthcare silos and spans all areas which may provide care for people with dementia.

8.5.2 **A Healthful Perspective**

Despite tensions and silos in organisational structure and professional boundaries, there was a link established in this study to the overall philosophy of the RNMH and their clinical reasoning which draws parallels with McCarthy (2003)'s identification of three philosophical perspectives of ageing held by RNs in an American acute care hospital. The ability of the RNs (in McCarthy's study) to distinguish acute confusion (delirium) from chronic confusion (dementia) was bound to their characterisation of ageing. McCarthy (2003) identified three perspectives:

1. A decline perspective, where nurses viewed health as being restricted over time, decremental, with inevitable cognitive decline- as confusion was stereotyped as a part of older age. Confusion was seen here as a work-related stress issue, not a patient issue, and no distinction between chronic or acute confusion as cognitive processes was drawn.
2. A perspective of vulnerability: this was noted to coincide with ambivalent reasoning, in which ageing presents challenges and the older population is at risk of ill health with frequent cognitive and physical decline. The vulnerable perspective philosophy in nursing did note the reversibility and treatment of acute confusion, however if there was an absence of strong cognitive baseline information to signify an acute change in cognition, there was a shift to a default position dementia being the underlying cause.

The RNMHs appeared to demonstrate the third philosophical stance:

3. A healthful perspective. This is noted to be a sophisticated ideology by McCarthy (2003) in which there is an appreciation of normal ageing and the older person being inherently ‘well’. Here any change in cognition is seen as a marker of an underpinning issue which should be explored, identified and treated. These changes are seen to have pathophysiological causes and action is taken to find them.

This healthful perspective was demonstrated in this study by the value placed by RMHNs on knowing the individual as a person, their ability to map behaviours and their articulation of DSD. In the current study, the RNMHs described DSD in relation to infection, pain and predominantly physical illness. This selection of discussion topic as physical, rather than cognitive or mental health focussed, led to an understanding: they recognised DSD by the patient’s changing presentation of self, and by a change in cognition; but this change was an external sign of underlying physical health needs (or pathophysiological processes) which required attention. By doing this, the RNMHs showed that their care of DSD is not necessarily linked to a mental health context, but is grounded in their understanding of cognition, engagement with patients as people, and the importance of physical health as a totality. They moulded their language to the context that their patient needs presented in.

8.6 **Chapter Summary**

The RNMHs valued people inherently, including the person being cared for, themselves as professionals, and those with whom they worked. This value was seen in the prioritisation of people and the knowledge and experience of all involved. The RNMHs discussed DSD care in terms of medical diagnosis underpinning the person’s presentation (such as infection or pain), but this was in relation to the impact of DSD on the person as a being. This appeared bound to the RMHNs’ education and philosophy of care. Tools (such as guides and scoring sheets) were seen as useful; however, the RNMHs were conflicted in their use, taking account of the emotions of the person being assessed, coupled with a perception of the tools as organisational systems rather than facilitating care decisions. They did not appear to feel they were necessary in their practice to identify DSD and, whilst they did report their positive influence on decisions for people with DSD, tools in practice were used very infrequently.

The RNMHs in this study placed great value on the multidisciplinary team support structures and reported feeling listened to and supported in their daily work. Overtly, this appeared balanced and beneficial: acting alongside the consultant psychiatrists to whom they ascribed overall responsibility to guide care; however, there was a subtle undercurrent of the RNMHs deferring to others for guidance and plans, rather than they themselves leading care.

The work of caring for people with DSD was seen to be contextually driven, with burdens of care being expressed in line with different care settings and the associated premise of care and organisational priorities. The RMHNs did not see the person with DSD as burdensome, nor the care relating to their emotional wellbeing or supporting their behaviours. The philosophies of person-centred, and relationship centred care were seen throughout, driving the RNMHs in their premise of caring for patients as individuals through their knowledge of them.

The RNMHs discussed DSD in terms of physical illness, and the associated mental health or wellbeing care did not appear to present a problem to them. Whilst there was overt recognition that they were intertwined and impactful (not only on the mental and physical, but also cognitive health of the individual), their discussions focussed on the physical care for people with DSD.

What was clear was the RMHNs' concern that the person with DSD was cared for in the most appropriate place for them as individuals, taking into account individual needs, risks and distress: the majority of the RNMHs considered this to be the home environment.

8.6.1 **Strengths and Limitations of the Study**

This study has some limitations that should be considered. The methodological approach and methods suggested have been discussed in Chapters four and five, hence the limitations presented here focus on other limitations.

Commencing with the qualitative data collection, the themes identified here were gleaned from a small sample of RNMHs working in one organisation and not the entirety of the clinical team caring for people with DSD. This could call into question the transferability of the themes to a wider population; however, this sample was one discreet element of an overarching sampling strategy and required refinement to the core focus of the RNMH experience.

The themes here were derived from an initial integration of the literature and qualitative accounts to refine an emerging activity system. Subsequent further refinement was undertaken with the quantitative data and a return to the literature, bringing the study full circle. This was a particular strength of the study methodology and supported early contextualisation to the RNMHs from the outset as the lack of RNMH input was profound in wider studies. In addition, this sample did align with the sampling recommendations in the wider literature for qualitative investigation (Creswell, 1998; Creswell and Plano Clark, 2011; Bagnasco, Ghirotto and Sasso, 2014).

In relation to the quantitative sample, the total number of returned surveys included could be considered small in comparison with single methods studies. However this study did not seek to prove an experimental hypothesis or generalise the findings to the totality of RNMHs. Here, the quantitative data builds upon, explores further and expands the exploratory understanding of the RNMH's experience in relation to DSD as part of the overall research process.

Considering the transferability of findings, the nature of the RNMHs' professional role, education and philosophy of care was presented in sufficient detail to clearly illuminate the contextual and related detail. This affords the reader enough information to make informed decisions about its applicability to wider settings. The transferability of this study's findings to an international audience must be judged. A particular strength of this study is the clear and consistent focus placed on the UK field registration of RNMHs. There is no ambiguity in this study context or sampling. All participants were Nursing and Midwifery Council registered mental health nurses working in the UK health and social care system. Whilst this may be unique to the UK, it clearly defines who the participants in the study were. This contrasts with the majority of the UK and international literature that cite participants as nurses or registered nurses without further explanation. This supports transparency and considerations of applicability of findings to other settings. However, this is a first tentative exploration with many facets, circumstances and considerations potentially remaining to be investigate further.

8.7 **Conclusion**

This study has met its aims to:

1. Illuminate the experiences, views, and perceptions of RNMHs caring for people with DSD within the 24-hour healthcare setting
2. Identify and describe the experience in terms of influencing and impacting factors within the workplace
3. Generate new understanding pertaining to the RNMHs care provision for DSD and explore how this could be used to support the unique care context in terms of understanding influencing factors impacting on care.

This study was unique in both its exploration of the RNMHs' experience of DSD in relation to both the nursing field and locations of care. Using an exploratory sequential mixed methods design, and the novel application of an activity system lens, this study has illuminated the experiences, views, and perceptions of the RNMHs caring for people with DSD in 24-hour care settings. It has identified and described these experiences in terms of influencing and impacting factors which can be used to support local and wider understanding of the RNMH care provision. The development and validation of a new questionnaire formed an integral part of the study as no such questionnaire was present in the contemporary literature.

From this study, and throughout as a continuum, key themes have been conceptualised, built, and refined using activity theory as a sensitising lens to explore influences and impacts on the RNMH experience. These refinements have been made through careful exploration and integration of both qualitative and quantitative data which offers insights that would have been unknown using single methods of enquiry. The use of activity theory as a sensitising lens offered a robust structure in which to investigate and explore the component parts which influence the RNMHs experience. This structure helped maintain a focus throughout the totality of the study and supported an evolution of the experience from the commencement of investigation through literature review and, subsequently, through both phases of data collection and analysis.

The methodological approach employed was integral to the development of new understanding, exposing, exploring, and enhancing data from the first qualitative explorations, devising a new survey instrument and subsequent quantitative data collection. The value of this approach is seen in the new insight and depth of understanding that is achieved through integration of the data, each analysis process expanding upon the previous before integrating to further to allow for new cohesive understanding of the experience. Conclusions and insights have been shown that were not possible through qualitative or quantitative methods alone.

These activity theory centred themes and their tensions are presented throughout Chapters three, six, seven and eight to show their foundations and evolution. The final activity system of the RNMH experience of caring for someone with DSD is presented in Chapter eight, Figure 39 page 252 and offers new insight into and understanding of the RNMH experience.

The study is clearly a first exploration of the RNMH experience, and analysis of data as a cohesive whole. This studies contribution to existing knowledge and original insights can be seen in Table 18 page 288. This study also serves to move theory in this field of practice forward both in relation to practice and methodology of study. The unique and novel application of activity theory here helped open up, explore and refine the exploration in relation to the RNMHs systems and organisations in which their work is situated.

Importantly, this study did not aim to address the RNMH knowledge base and knowledge gaps through any form of measurement or alignment to policy or standards. It strove instead to explore their experiences and influences on those experiences using an activity system.

Occurring simultaneously to the study, there has been a critical shift in awareness of delirium in clinical practice. National guidance has been reviewed in light of the changes in practice and priority ascribed to delirium, and specifically DSD. Momentum is growing in this field of practice, and there is increased recognition that delirium represents ‘acute brain failure’. Whilst this is a helpful description linguistically as it places emphasis on the organ involved and its outcome, this may support acute and medicalised professions to understand that confusion is a harbinger of ill-health, and also serves to place priority on it as is seen in acute renal failure, acute liver failure etc. Whilst it is a positive step forward that acute trusts and localities are becoming more critically aware of DSD, the focus in policy and practice initiatives remains on acute inpatient care or general nursing premise.

To the knowledge of the author, this study remains the first specific exploration of DSD from a RMHN's stance, the first study to explore the experiences of these nurses in their unique contexts of 24-hour care provision, and the first novel use of activity theory in these specific fields of practice.

Table 18 Original Contribution to Knowledge

Theme	Existing knowledge	Findings of this study	Original contribution to knowledge
Tools	Multiple delirium specific tools exist for screening and diagnosis (Morandi *et al.*, 2012; De and Wand, 2015; Network for Investigation of Delirium: Unifying Scientists (NIDUS), 2018; Shenkin *et al.*, 2019)	RNMHs report having a high awareness of delirium tools, but do not use them frequently. Of those who do use tools there is not consistency in tools chosen	Suggests a disconnect between self-reported awareness, knowledge of tools intended purpose, and application in practice
	Nurses[15] may use cognitive assessment tools to support delirium recognition which are not suitable for this DSD or delirium (O'Keeffe *et al.*, 2005; Mitchell *et al.*, 2014; Sampaio and Sequeira, 2015)	The RNMHs report using non-delirium specific cognitive assessment tools in practice	Suggests knowledge of cognitive assessment tools is not refined to purpose
	Tools need to be useful to be used or devalue professionalism or autonomy (Godfrey *et al.*, 2013; Van De Steeg *et al.*, 2014; Gabbay and Le May, 2016; Bryce, Flemming and Reeve, 2018; Emme, 2020)	Overall use of tools was low Tools may be seen as part of organisational requirements, not patient care influencers RNMH choose when and who to complete scores on	Suggests that tools are not valued highly by RNMHs in terms of DSD recognition and care provision Tools may devalue professional judgement Suggests tools must be perceived as useful to be used by the RNMHs
Object	Person centred care is fundamental in nursing care (Peplau, 1952; Kitwood, 1997; Skaalvik, Normann and Henriksen, 2010; Clissette *et al.*, 2013; Nursing and Midwifery Council, 2018b) Contemporary RNMH theory advocates caring with the	Gathering a history from friends and family is paramount Care is based on knowing the person, not on diagnosis	Suggests priority is given to individual personal histories and understanding

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[15] As discussed in the literature review and throughout, there is a dearth of RNMH specific literature, and literature pertaining to DSD. As such inferences and conclusions are drawn from a wider range of nursing fields and combine delirium in isolation and DSD in care of the older person.

	person and not just for or about them (Barker and Buchanan-Barker, 2004)		
	In the absence of screening tools, nurses can recognise confusion in older people (Grealish et al., 2019) Mental Health nurses are engaged in a constant process of *knowing* (Barker and Buchanan-Barker, 2004)	Tools are not valid without knowledge of the person Nursing intuition is based on knowledge of the individual	Suggests RNMH's practice aesthetic and personal *knowing* but do not place great emphasis on empirical knowing
	Non-RNMH delirium care may centre on *taking a quick look, keeping an eye on them, and controlling the situation* (Dahlke and Phinney, 2008)	The person is of paramount importance Delirium is not seen as part of personality or normal behaviour	Suggests RNMHs need to 'know' and understand the person to practice effectively
Community	Multidisciplinary teams should value individuals and can improve care quality (Orovwuje, 2008; Teodorczuk *et al.*, 2015; Cook *et al.*, 2016) Members of multidisciplinary teams should have psychological safety and the multidisciplinary team should have strong relational coordination (Stuhlinger, Schmutz and Gudela, 2019)	RNMHs feel listened to and supported by the multidisciplinary team The RNMHs feel supported and listened to. This offers them security in practice	Suggests the RNMHs is content with their position within the hierarchical multidisciplinary team
	Hierarchies of power remains present in care provision with sociocultural barriers impacting on delirium and dementia care (Teodorczuk *et al.*, 2015) Shared language is paramount for successful	RNMH value their role in DSD care but defer to consultants and other members for guidance Collaborative working is valued and well	Suggests RNMHs operate in perpetuated hierarchy within their multidisciplinary teams Suggests multidisciplinary team support is

	multidisciplinary team working (Leonard, Graham and Bonacum, 2004; Rabol and Ostergaard, 2011; Stuhlinger, Schmutz and Gudela, 2019) Tools and their associated language may strengthen nurse position within the multidisciplinary team (Van De Steeg *et al.*, 2014) Changing a nurse’s language is hazardous and value should be given to their information (Leonard, Graham and Bonacum, 2004)	used. RNMHs may not use language that is widely recognised by the multidisciplinary team	valued and needed
Division of Labour	Delirium is distressing for patient, family and those providing care (Agar *et al.*, 2011; Morandi *et al.*, 2015a; Emme, 2020)	RNMH associate burden of care with wider care determinants DSD is not seen to overtly impact on other patients	Care is not overly burdensome to the RNMH.
	For the RNA, the needs of delirious patients are balanced with the needs of other patients causing moral and ethical distress (Dahlke and Phinney, 2008; Agar *et al.*, 2011; Morandi *et al.*, 2015a). Care homes specifically have nationally been guided towards improving medication management and hydration for residents (National Institute for Health and Care Excellence, 2014a; Care Quality Commission, 2019; NHS England, 2020b; a)	Different settings in this study found different care needs challenging Overall stress level of the care environment increases more than individual RNMH stress level	Suggests burden of care if felt differently in different contexts RNMHs experiences of burden are not the same as RNA or RNs working in acute medical or surgical settings
Rules	Professional ‘ownership’ of DSD is complex, and people with delirium often don’t ‘belong’ in the eyes of	RNMH focus on the ‘physical issue’ in DSD care as a signal of unexpected illness	Suggests organisational and professional registrations perpetuate silos of care

	specialists (Teodorczuk *et al.*, 2013) An integrated care focus is championed for coordinated and person centred care (National Collaboration for Integrated Care and Support, 2013; NHS England, 2014) Policy and mental health specific pathways focus on SMI and acute care settings (NHS England, 2014; Mental Health Taskforce, 2016; Mental Health Foundation, 2020)	RNMH identify strongly as ‘mental health’ and recognise delirium ‘physical health’ RNMH articulate the intertwining of care (mental health and physical health)	Suggests that RNMH understand the importance of person-centred care and take a healthful approach to ageing and DSD

8.8 **Implications for Practice**

Findings from this study have highlighted tensions in the activity system in which the RNMHs practised. From these tensions, key understandings of the RNMH experience were drawn. The RMHNs' experience of providing care for people with DSD was mediated by the availability of tools and guidance, their perception and use of these, and how their actions and role were influenced by those around them and organisational priorities.

The RMHNs demonstrated a persistence to keep central their premise of knowing the patients, and the core foundation of being a mental health nurse. Without a focus being placed on the value of this professionally, the RNMHs' experience and practice might be eroded by other professions. Conversely, promoting the RNMHs' knowledge of the person as an essential value will support not only the patient, but also bring recognition to the RMHMs' unique skills and philosophy of care. By recognising their unique professional contribution, the multidisciplinary team structure could be aligned to a more egalitarian premise, and the pervasive hierarchy disrupted.

This study suggests three key considerations:

1) RNMHs need to 'know' a person, and this influences them to 'know how' to care for their patients with DSD as people
2) To support the RNMHs to care for people with DSD, the multidisciplinary team and any tools or guides need to place overt value on the RNMH, and clearly align with the RNMH ethos of care

to be useful

3) Integrated initiatives around DSD care need to be fully collaborative and equal across the multidisciplinary team to forge clear expectations of role and breakdown silos of both profession but also care premise (physical health, mental health, cognitive health).

By better understanding the impacting factors on the RNMHs experience this study has identified where their practice may not be in congruence with the wider literature. This understanding may support local organisations and services to support RNMHs proactively, and the multidisciplinary team surrounding them when providing DSD care. RNMHs occupy a unique position in practice; one in which the aesthetic knowing of a person is central. Whilst this is present in other areas of nursing, RNMHs employ this in a unique way (hence their field registration). Without this knowledge, the DSD care that a person receives may be protocol driven, or overtly aligned to a structural clinical process, but the person with DSD as an individual may be overshadowed. Fitting the RNMHs into strategy and process born from wider research and understanding of RGN, RNA or acute settings may leave the RNMHs at odds with their philosophical, conceptual, and unique field of nursing.

The findings from this study as a whole; including the synthesis of the literature and empirical findings have been used to suggest one recommendation for practice and three recommendations for future research.

8.8.1 Recommendations for Practice: Knowing Each Other to Know the Patient

To navigate the tensions and interplay between influencing factors in the nurse experience, further work needs to be undertaken to foster a cohesive approach to care provision. Whilst the multidisciplinary team in this study is seen as supportive of the RNMHs (demonstrated in Chapters six and seven) there are clear areas in which improvement could be made. Recognising the RNMHs professionally, and highlighting their position as active and key participants within the multidisciplinary team and integral in their care setting is a priority. Whilst this study demonstrates the RNMHs do feel listened to and supported, they place themselves secondary to consultant psychiatrists in terms of guiding practice, however they appear to know their patients intimately. In DSD care, this knowledge of a person is integral and vital to care provision. It is apparent that the value of the RNMHs' knowledge is key to patient care, but work needs to be undertaken to explore this further with the MDT. This study only explored the RNMHs' experience, so findings are gleaned from their perspective. That said, there appears to be scope for focussed work around interprofessional recognition of roles from a professional and team perspective.

Teodorczuk *et al.,* (2015) proposed interprofessional education around delirium, championing all members of the clinical team to be involved; including healthcare assistants and porters. This was recommended by Teodorczuk *et al.,* (2015) to better understand professional roles and knowledge of the patient each may have. This idea should be advanced, though from this study it is proposed that this is not initially undertaken as an educational strategy related to a clinical diagnosis or care provision as such, but in terms of knowledge of each other professionally. Such education or team sessions should explore roles and expectations, tools, and their conceptualisation of DSD as a collective group of practitioners.

8.8.1.1 Address Silo working

It is apparent throughout the study that there is a persistence of silo working spanning not only nursing registration, but also within care environments. Whilst each profession may hold merit in specialist knowledge and treatment available, the tension between ‘siloed’ professional remits and the ‘integrated’ nature of DSD was very apparent. This is clearly demonstrated in the participants’ articulations of what it means to be a mental health nurse. In addition, the separation of mental health services (be it in hospital or care home infrastructure) results in a lack of ownership of patients; as such patients may be at increased risk of being moved around settings to try and find a “fit”. It is recommended that more detailed exploration and understanding of the impact of silo working is undertaken through practice discussion and sharing of experiences, expectations of care, and service provision.

In relation to the next generation of RNMHs, the Future Nurse standards (Nursing and Midwifery Council, 2018a) may be seen as a move towards a more unified nursing profession in relation to core skills, however the registration of nurses in fields (Adult, Mental Health, Children and Learning Disability) still perpetuates the engraining of silos in the nursing psyche even before registration occurs. Whilst general nurse training (RGN) is no longer available in the UK, it can be recommended that there is a call for a specialist field in gerontology nursing. This could support the breaking down of silos of care and enhance positive patient care and experiences.

8.8.1.2 Roles and Expectations

Drawing upon the RNMHs’ need to know the person as an individual to provide care, it is suggested by the current study, that the clinical teams need to know each other as professionals to provide care. Time should be taken to discuss and define a shared language, but also to understand the different types of language used by professions and the value that these differences hold for communicating knowledge.

Understanding and value should be explored and maintained about the different roles and goals of professionals, but specifically for RNMHs, there is a need to clearly open discussion around their aesthetic knowledge of people with DSD and their philosophy of care. Once this is known, it is envisaged that their anecdotal or less medicalised conveyance of patient information may be more readily received by other clinicians, without them necessarily having to change their language to have their work valued. Hearing from the team members about their practice, expectations, influencing factors and scope, any tensions or conflicts can be identified, rationalised and addressed. Thus, knowing each other's roles and principles may foster a more cohesive approach, understanding what is required from and for each other.

8.8.1.3 **Tools**

In addition to the manner in which the clinical team communicates their knowledge and professional requirements for care, the use and usefulness of any tools present in practice should also be clearly discussed. This needs to be in terms of why they are used, how and what these are used for in practice. This is recommended to support the RNMHs to understand the intentions behind the use of tools, be considerate of the appropriate use of tools, and make evidence based judgements about their usefulness in practice.

Collectively, the team may find value in presenting and discussing their use of tools, clinical practice priorities in relation to DSD, and what they expect or wish of each other to support their work. This should not be dominant to any profession, but an understanding of each other's role, requirements and challenges posed without hierarchy. By undertaking a robust and open discussion of care practice and priorities, cohesion and a mutual shared understanding could be formed in which to better provide care for the person with DSD.

8.8.2 Recommendation for Research: Articulating the RNMH Role in DSD Care

This study has highlighted the lack of RNMH specific literature pertaining to their experiences and care provision. Whilst this study commences the exploration, significantly more investigation is needed to further the understanding of the RNMHs in this area of care. The available research focusses on either broad nursing registrations (RGN/RN) and is situated in acute care hospitals, or non-specialist mental health care homes. Whilst some findings from these studies may be transferable, and all of value, there needs to be more clarity around the RNMH care premise of DSD.

Whilst the RNMH experience is articulated through this study, one discussion seems absent, or veiled. The actual daily work of the RNMH in terms of their mental health or cognitive care provision was alluded to in their discussions of other facets of care (e.g. that they identified as physical care) or minimised and moved past without depth of discussion, such as *just a matter of reorientation* etc.

Importantly to reiterate here, is that this study did not seek to map their knowledge or actions against an expected level of care, process, or protocol. This study aimed to explore their experience and describe its influencing and impactful factors as they perceive them. It can be considered that their DSD work could be so embedded in their way of conceptualising care that they are unable to articulate it, or did not feel it needed to be spoken, assuming a collective understanding. However, in the nature of this research, this was not assumed or predefined.

To further the understanding of the RNMHs' experience of DSD, and as such, DSD care provision in mental health settings, it is suggested that further investigation is needed. There is a need to more formally expose and define their work, the roles they undertake, and as a profession, shine light on the complexity of this work.

Further studies should pair qualitative explorations of their DSD work as described by them, with observations of their practice. This may highlight elements of care that are undertaken which might not be immediately visible; or those actions that are so integral to the RNMHs that they are unable to articulate them when discussing their own working practices. This may also highlight key parts of delirium care recommendations that are both actioned or omitted. As such, this exploration could help shape and drive future practice improvements.

8.8.3 **Recommendation for Research: Exploring Similarities and Variance in Practice Between RNMH and RNA Providing DSD Care for People in 24-Hour Care Settings**

A second recommendation for future research is to explore if there is variation between RNMH and RNA knowledge of DSD. Working on the assumption that all fields of nursing hold comparable knowledge and operationalise this knowledge in practice could be flawed. It is paramount that in this rapidly evolving and complex area of practice, there is an understanding of how the different fields of nursing conceptualise and conduct their practice.

For this exploration, a paired study of RNMHs and RNAs working in equivalent acute care settings (i.e., a care of the elderly medical ward and care of the elderly mental health assessment wards) should be undertaken. The aim of this study would be to compare knowledge of DSD across the fields of adult and mental health nursing in acute assessment environments (organic admissions units in mental health settings, and medical admission or medical wards). A partner study is also suggested to look at RNMHs and RNAs working in care home settings. This could utilise the Knowledge of Delirium Questionnaire devised by Hare *et al.,* (2008), but would need initial review and adapted to include the specific premise of DSD.

These studies in tandem would provide both professional nursing field, and contextual understanding of delirium and DSD understanding that the nurses working in these areas hold.

8.8.4 **Recommendation for Research: Widening the Scope of the Initial Exploration.**

As demonstrated in Chapter four, this study was undertaken by participants in one geographical region. It would be useful to replicate this study in different geographical areas to compare findings. This would add to the discussion of the RNMHs' experiences whilst offering additional insight into any differences in the Activity Systems and professionals that are integral to DSD care. This could aid potential transferability, but also expose potentially new influential and impactful facets of the RNMHs experience.

One consideration of this would be to replicate the study in locations which are known for having robust delirium and dementia strategies in place, and also in areas where this may not be a current care priority. This could support a broadening of the initial findings, and again expose any variance in the experience, or confirm core features which are fundamental to the RNMHs practice specifically.

8.9 **Final Considerations of My Own Development.**

During the course of this study, I have often found myself reflecting on my own personal and professional journey. At the outset I was (as outlined in Chapter one) an adult nurse practitioner, who had just taken what felt like a leap of faith to work in a mental health trust. By my own admission, I was a very “adulty” adult nurse, exceptionally process driven, and did not sit comfortably with uncertainty. The transition from being surrounded by other adult nurses and medics, to a field of nursing where the language and priorities were not overtly aligned to my own was profound, and I struggled with what I perceived to be variance in practice. Throughout this study, I have come to realise this was not variance, but just a different way of seeing and hearing a patient’s needs, wishes and expectations. My understanding of the scope and integrity of nursing has broadened greatly throughout this journey. Sufficient to say that I have considered retraining to become a dual registered nurse as the need to see a collective picture of the person being cared for has been profound.

Throughout the study, as my awareness of my own preconceptions of care, and judgements placed on care grew, I found my RNA stance deeply engrained, as such I constantly re-evaluated what I had heard from the nurses in interviews to support analysis free of my own bias. I found I had lacked a knowledge of the RNMH premise of care, and that was particularly challenging and confronting as I had worked alongside them, in a perceived partnership for several years. I had considered myself well integrated into their ways of working.

Undertaking this study has opened my eyes to how nurse education and registration in different fields can engrain deep rooted silos into care structures. It must be considered that this strong sense of my own adult nursing position could have influenced the interviews despite my best efforts. Reflecting now at the end of the study, I can clearly see that I may have perpetuated silos of care in my initial consideration of mental health versus physical health. Conceptually, cognitive health did not feature in my dialogue at the outset. I was concerned with two fields of nursing practice, and had omitted to define the condition as a process that encompassed the whole being.

Whilst the process of interviews and alignment of themes into a validated questionnaire sought to rectify and remove any of my own judgements, I now consider if these silos are so engrained that they are perpetuated subconsciously. The very utterance of a split for physical and mental health now seems perverse in many ways, splitting someone into two un-splitable components. However, these silos still remain to give structure and order to a health system that may not function appropriately without them to some level. The importance of learning about, hearing and sharing professional practice and improvements for care across all composite parts seems even more important.

To return to Beales (2002) *‘delirium is also the disorder that illustrates the folly of those who wish to create clear distinctions between physical and mental disorders: it is clearly both’*

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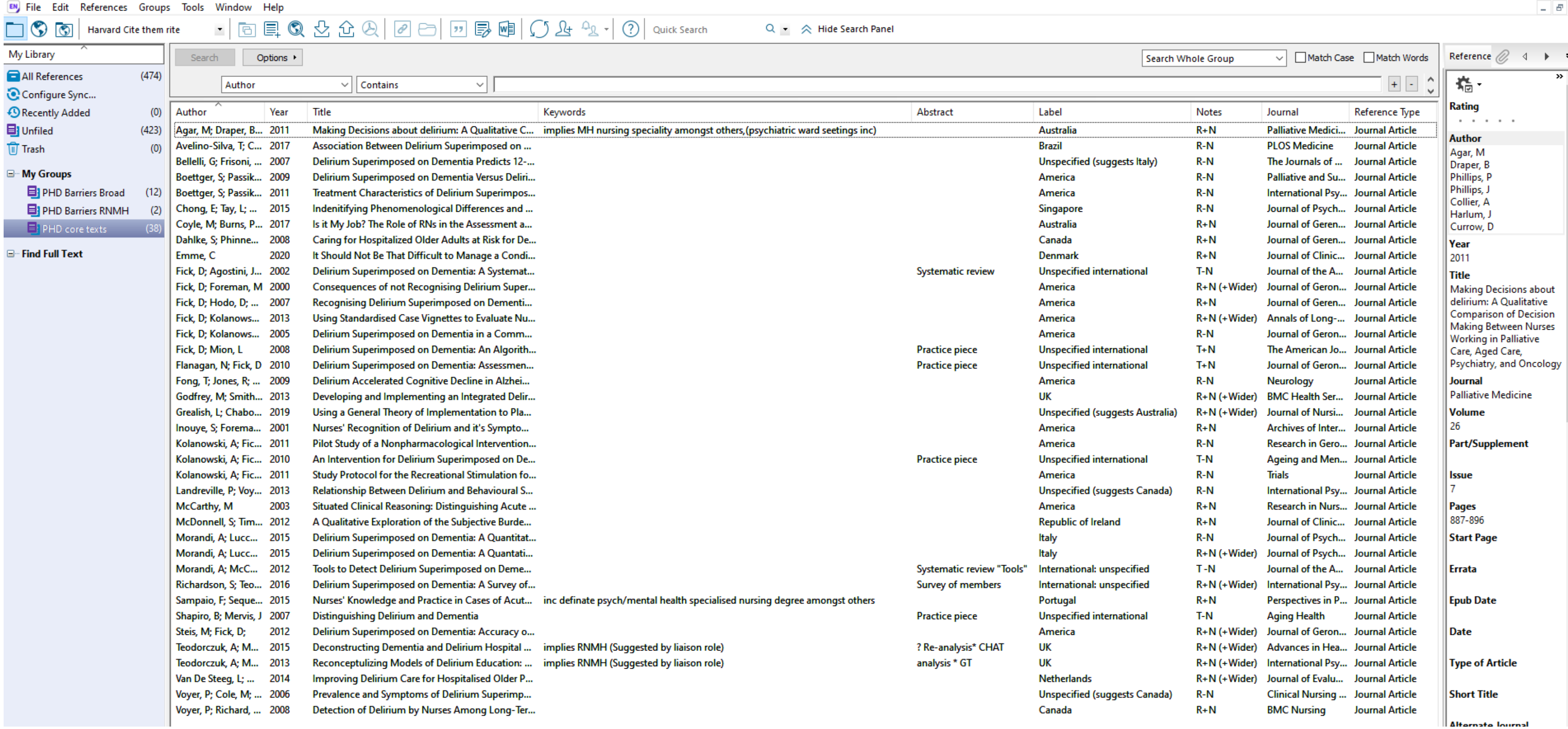
Yeo, A., Legard, R., Keegan, J., Ward, K., McNaughton Nicholls, C. and Lewis, J. (2014) 'In-Depth Interviews', in Ritchie, J., Lewis, J., McNaughton Nicholls, C. and Ormston, R. (eds.) *Qualitative Research Practice: A Guide fo Social Science Students and Researchers.* 5th ed. London: SAGE.

Younas, A., Rasheed, S. and Zeb, H. (2020) 'Using Legitimation Criteria to Establish Rigour in Sequential Mixed -Methods Research', *Nurse Researcher,* 28(3), pp. 44-51.

Zamanzadeh, V., Ghahramanian, A., Rassouli, M., Abbaszadeh, A., Alavi-Majd, H. and Nikanfar, A. (2015) 'Design and Implementation Content Validy Study: Development of an Instrument for Measuring Patient-Centred Communication ', *Journal of Caring Sciences,* 4(2), pp. 165-178.

Appendices

Appendix 1: Example Literature Data Management Sheet



Author	Year	Title	Keywords	Abstract	Label	Notes	Journal	Reference Type
Agar, M; Draper, B...	2011	Making Decisions about delirium: A Qualitative C...	implies MH nursing speciality amongst others,(psychiatric ward seetings inc)		Australia	R+N	Palliative Medici...	Journal Article
Avelino-Silva, T; C...	2017	Association Between Delirium Superimposed on ...			Brazil	R-N	PLOS Medicine	Journal Article
Bellelli, G; Frisoni, ...	2007	Delirium Superimposed on Dementia Predicts 12-...			Unspecified (suggests Italy)	R-N	The Journals of ...	Journal Article
Boettger, S; Passik...	2009	Delirium Superimposed on Dementia Versus Deliri...			America	R-N	Palliative and Su...	Journal Article
Boettger, S; Passik...	2011	Treatment Characteristics of Delirium Superimpos...			America	R-N	International Psy...	Journal Article
Chong, E; Tay, L; ...	2015	Indenitifying Phenomenological Differences and ...			Singapore	R-N	Journal of Psych...	Journal Article
Coyle, M; Burns, P...	2017	Is it My Job? The Role of RNs in the Assessment a...			Australia	R+N	Journal of Geren...	Journal Article
Dahlke, S; Phinne...	2008	Caring for Hospitalized Older Adults at Risk for De...			Canada	R+N	Journal of Geren...	Journal Article
Emme, C	2020	It Should Not Be That Difficult to Manage a Condi...			Denmark	R+N	Journal of Clinic...	Journal Article
Fick, D; Agostini, J...	2002	Delirium Superimposed on Dementia: A Systemat...		Systematic review	Unspecified international	T-N	Journal of the A...	Journal Article
Fick, D; Foreman, M	2000	Consequences of not Recognising Delirium Super...			America	R+N (+Wider)	Journal of Geron...	Journal Article
Fick, D; Hodo, D; ...	2007	Recognising Delirium Superimposed on Dementi...			America	R+N	Journal of Geren...	Journal Article
Fick, D; Kolanows...	2013	Using Standardised Case Vignettes to Evaluate Nu...			America	R+N (+Wider)	Annals of Long-...	Journal Article
Fick, D; Kolanows...	2005	Delirium Superimposed on Dementia in a Comm...			America	R-N	Journal of Geron...	Journal Article
Fick, D; Mion, L	2008	Delirium Superimposed on Dementia: An Algorith...		Practice piece	Unspecified international	T+N	The American Jo...	Journal Article
Flanagan, N; Fick, D	2010	Delirium Superimposed on Dementia: Assessmen...		Practice piece	Unspecified international	T+N	Journal of Geron...	Journal Article
Fong, T; Jones, R; ...	2009	Delirium Accelerated Cognitive Decline in Alzhei...			America	R-N	Neurology	Journal Article
Godfrey, M; Smith...	2013	Developing and Implementing an Integrated Delir...			UK	R+N (+Wider)	BMC Health Ser...	Journal Article
Grealish, L; Chabo...	2019	Using a General Theory of Implementation to Pla...			Unspecified (suggests Australia)	R+N (+Wider)	Journal of Nursi...	Journal Article
Inouye, S; Forema...	2001	Nurses' Recognition of Delirium and it's Sympto...			America	R+N	Archives of Inter...	Journal Article
Kolanowski, A; Fic...	2011	Pilot Study of a Nonpharmacological Intervention...			America	R-N	Research in Gero...	Journal Article
Kolanowski, A; Fic...	2010	An Intervention for Delirium Superimposed on De...		Practice piece	Unspecified international	T-N	Ageing and Men...	Journal Article
Kolanowski, A; Fic...	2011	Study Protocol for the Recreational Stimulation fo...			America	R-N	Trials	Journal Article
Landreville, P; Voy...	2013	Relationship Between Delirium and Behavioural S...			Unspecified (suggests Canada)	R-N	International Psy...	Journal Article
McCarthy, M	2003	Situated Clinical Reasoning: Distinguishing Acute ...			America	R+N	Research in Nurs...	Journal Article
McDonnell, S; Tim...	2012	A Qualitative Exploration of the Subjective Burde...			Republic of Ireland	R+N	Journal of Clinic...	Journal Article
Morandi, A; Lucc...	2015	Delirium Superimposed on Dementia: A Quantitat...			Italy	R-N	Journal of Psych...	Journal Article
Morandi, A; Lucc...	2015	Delirium Superimposed on Dementia: A Quantati...			Italy	R+N (+Wider)	Journal of Psych...	Journal Article
Morandi, A; McC...	2012	Tools to Detect Delirium Superimposed on Deme...		Systematic review "Tools"	International: unspecified	T -N	Journal of the A...	Journal Article
Richardson, S; Teo...	2016	Delirium Superimposed on Dementia: A Survey of...		Survey of members	International: unspecified	R+N (+Wider)	International Psy...	Journal Article
Sampaio, F; Seque...	2015	Nurses' Knowledge and Practice in Cases of Acut...	inc definate psych/mental health specialised nursing degree amongst others		Portugal	R+N	Perspectives in P...	Journal Article
Shapiro, B; Mervis, J	2007	Distinguishing Delirium and Dementia		Practice piece	Unspecified international	T-N	Aging Health	Journal Article
Steis, M; Fick, D;	2012	Delirium Superimposed on Dementia: Accuracy o...			America	R+N (+Wider)	Journal of Geron...	Journal Article
Teodorczuk, A; M...	2015	Deconstructing Dementia and Delirium Hospital ...	implies RNMH (Suggested by liaison role)	? Re-analysis* CHAT	UK	R+N (+Wider)	Advances in Hea...	Journal Article
Teodorczuk, A; M...	2013	Reconceptulizing Models of Delirium Education: ...	implies RNMH (Suggested by liaison role)	analysis * GT	UK	R+N (+Wider)	International Psy...	Journal Article
Van De Steeg, L; ...	2014	Improving Delirium Care for Hospitalised Older P...			Netherlands	R+N (+Wider)	Journal of Evalu...	Journal Article
Voyer, P; Cole, M; ...	2006	Prevalence and Symptoms of Delirium Superimp...			Unspecified (suggests Canada)	R-N	Clinical Nursing ...	Journal Article
Voyer, P; Richard, ...	2008	Detection of Delirium by Nurses Among Long-Ter...			Canada	R+N	BMC Nursing	Journal Article

Rating

Author
Agar, M
Draper, B
Phillips, P
Phillips, J
Collier, A
Harlum, J
Currow, D

Year
2011

Title
Making Decisions about delirium: A Qualitative Comparison of Decision Making Between Nurses Working in Palliative Care, Aged Care, Psychiatry, and Oncology

Journal
Palliative Medicine

Volume
26

Part/Supplement

Issue
7

Pages
887-896

Start Page

Errata

Epub Date

Date

Type of Article

Short Title

Alternate Journal

Appendix 2: University Ethical Approval

Professor Kathleen McCourt CBE FRCN
Executive Dean

This matter is being dealt with by:
Professor Pauline Pearson
Ethics Lead
Department of Healthcare
Faculty of Health and Life Sciences
Coach Lane Campus
Newcastle upon Tyne
NE7 7XA
Tel: 0191 2156472
Email: *pauline.pearson@northumbria.ac.uk*

Claire Pryor
Coach Lane Campus
Newcastle upon Tyne
NE7 7XA

22 March 2016

Dear Claire

Faculty of Health and Life Sciences Research Ethics Review DHCPryor091015/181115
Title: Delirium Superimposed on Dementia: Closing the 'Know-Do' Gap

My apologies for the delay in responding to your revisions. Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent Disclosure & Barring Service (DBS) and occupational health clearance if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available from the following web link:
http://www.northumbria.ac.uk/researchandconsultancy/sa/ethgov/policies/?view=Standard

You may now also proceed with your application (if applicable) to:
- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).

You must not commence your research until you have obtained all necessary external approvals.

All researchers must also notify this office of the following:
1. Commencement of the study;
2. Actual completion date of the study;
3. Any significant changes to the study design;
4. Any incidents which have an adverse effect on participants, researchers or study outcomes;
5. Any suspension or abandonment of the study;
6. All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
7. All publications and/or conference presentations of the findings of the study.

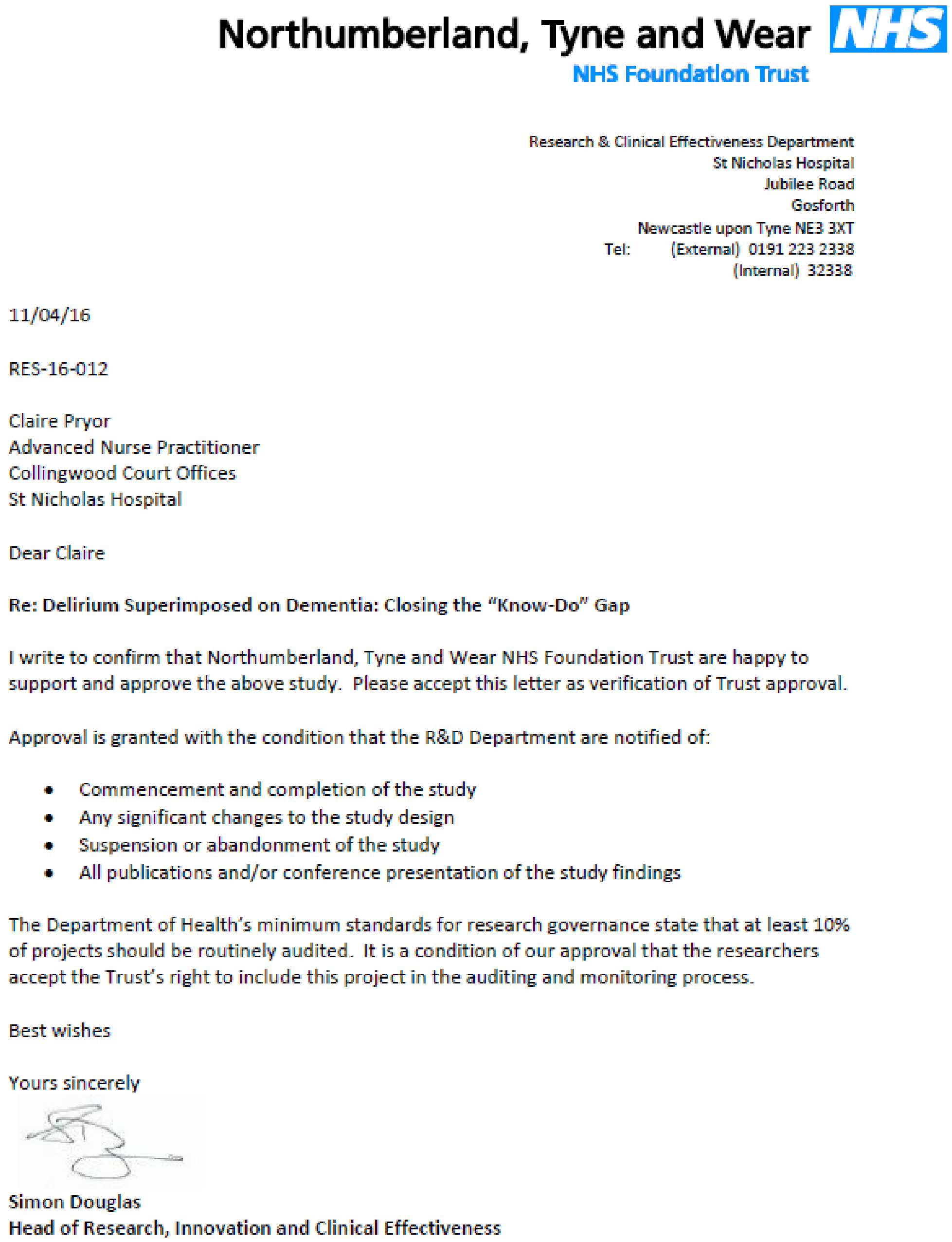
We wish you well in your research endeavours.

Yours sincerely

Pauline Pearson

Professor Pauline Pearson
Ethics Lead for Healthcare, on behalf of the Faculty Research Ethics Review Panel

Appendix 3: Trust Ethical Approval



Northumberland, Tyne and Wear NHS
NHS Foundation Trust

Research & Clinical Effectiveness Department
St Nicholas Hospital
Jubilee Road
Gosforth
Newcastle upon Tyne NE3 3XT
Tel: (External) 0191 223 2338
(Internal) 32338

11/04/16

RES-16-012

Claire Pryor
Advanced Nurse Practitioner
Collingwood Court Offices
St Nicholas Hospital

Dear Claire

Re: Delirium Superimposed on Dementia: Closing the "Know-Do" Gap

I write to confirm that Northumberland, Tyne and Wear NHS Foundation Trust are happy to support and approve the above study. Please accept this letter as verification of Trust approval.

Approval is granted with the condition that the R&D Department are notified of:

- Commencement and completion of the study
- Any significant changes to the study design
- Suspension or abandonment of the study
- All publications and/or conference presentation of the study findings

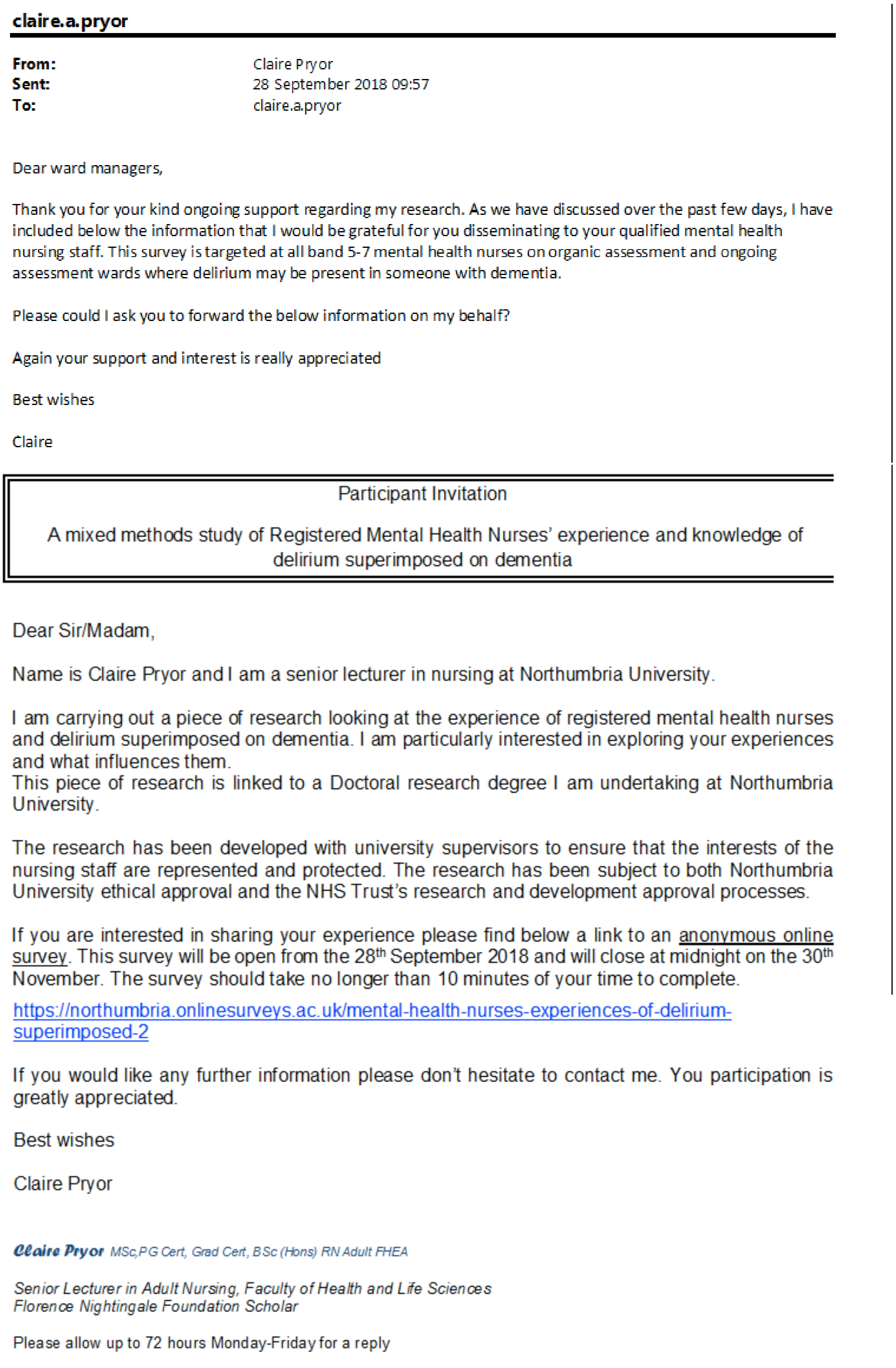
The Department of Health's minimum standards for research governance state that at least 10% of projects should be routinely audited. It is a condition of our approval that the researchers accept the Trust's right to include this project in the auditing and monitoring process.

Best wishes

Yours sincerely

Simon Douglas
Head of Research, Innovation and Clinical Effectiveness

Appendix 4: Email Correspondance Request for Questionnaire Distribution



claire.a.pryor

From: Claire Pryor
Sent: 28 September 2018 09:57
To: claire.a.pryor

Dear ward managers,

Thank you for your kind ongoing support regarding my research. As we have discussed over the past few days, I have included below the information that I would be grateful for you disseminating to your qualified mental health nursing staff. This survey is targeted at all band 5-7 mental health nurses on organic assessment and ongoing assessment wards where delirium may be present in someone with dementia.

Please could I ask you to forward the below information on my behalf?

Again your support and interest is really appreciated

Best wishes

Claire

Participant Invitation

A mixed methods study of Registered Mental Health Nurses' experience and knowledge of delirium superimposed on dementia

Dear Sir/Madam,

Name is Claire Pryor and I am a senior lecturer in nursing at Northumbria University.

I am carrying out a piece of research looking at the experience of registered mental health nurses and delirium superimposed on dementia. I am particularly interested in exploring your experiences and what influences them.
This piece of research is linked to a Doctoral research degree I am undertaking at Northumbria University.

The research has been developed with university supervisors to ensure that the interests of the nursing staff are represented and protected. The research has been subject to both Northumbria University ethical approval and the NHS Trust's research and development approval processes.

If you are interested in sharing your experience please find below a link to an anonymous online survey. This survey will be open from the 28th September 2018 and will close at midnight on the 30th November. The survey should take no longer than 10 minutes of your time to complete.

https://northumbria.onlinesurveys.ac.uk/mental-health-nurses-experiences-of-delirium-superimposed-2

If you would like any further information please don't hesitate to contact me. You participation is greatly appreciated.

Best wishes

Claire Pryor

Claire Pryor *MSc,PG Cert, Grad Cert, BSc (Hons) RN Adult FHEA*

Senior Lecturer in Adult Nursing, Faculty of Health and Life Sciences
Florence Nightingale Foundation Scholar

Please allow up to 72 hours Monday-Friday for a reply

Appendix 5: Consent Form

northumbria
UNIVERSITY NEWCASTLE

Faculty of Health and Life Sciences
CSC0020 Clinical Skills Centre
Coach Lane Campus
Northumbria University
Newcastle upon Tyne
NE7 7XA

Date:

CONSENT FORM:1 **One-to-One Semi Structured Interview**

DELIRIUM SUPERIMOSED ON DEMENTIA: CLOSING THE “KNOW-DO” GAP

RESEARCHER: Claire Pryor

PARTICIPANT: ________________________________

Please read each individual statement and initial the associated box provided if you agree with the statements. If you give full consent, please sign the bottom of the form.

1. I confirm that I have had opportunity to, have read, and understood the participant information sheet provided for the aforementioned study ☐
2. I have been given opportunity to ask questions, consider and receive answers to my satisfaction ☐
3. I am aware that my role as a participant is voluntary and I may cease to participate at any time without having to provide a reason ☐
4. I am aware statements made in interview may be used in publications, reports or presentations anonymously ☐
5. I am aware that data is being digitally recorded and transcripts will be anonymised. Transcripts and recordings will be kept in accordance with Data protection legislation and University guidance ☐
6. I agree and consent to participating in the aforementioned study ☐

Participant Name: ……………………………Signature……………………..Date

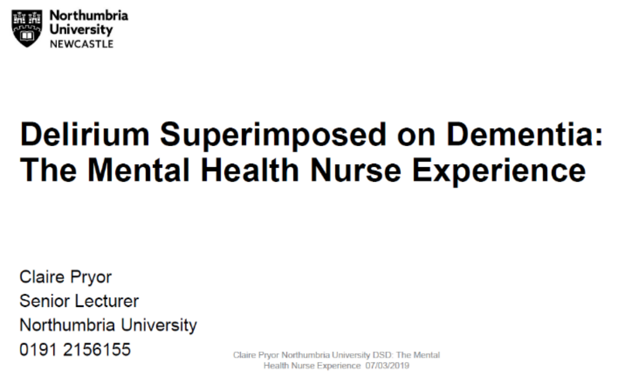
Researcher:……………………………………..

The Florence Nightingale Foundation

Consent form: One-to-One 08/11/2016: Version 6

NHS Professionals

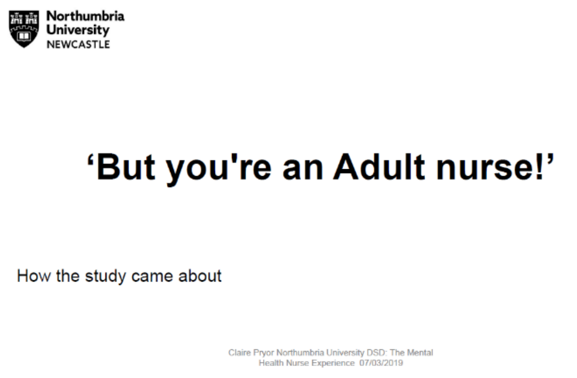
Appendix 6: Conference Presentation



Northumbria
University
NEWCASTLE

Delirium Superimposed on Dementia: The Mental Health Nurse Experience

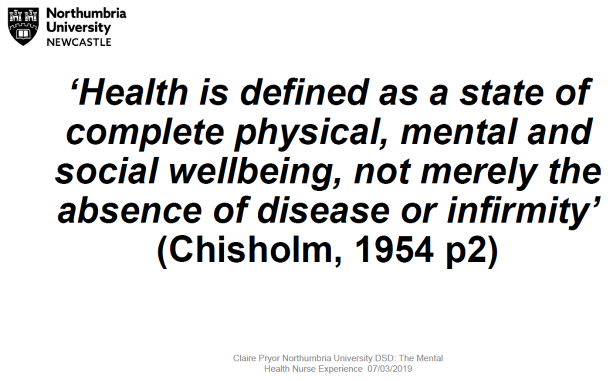
Claire Pryor
Senior Lecturer
Northumbria University
0191 2156155



Northumbria
University
NEWCASTLE

‘But you're an Adult nurse!’

How the study came about



Northumbria
University
NEWCASTLE

‘Health is defined as a state of complete physical, mental and social wellbeing, not merely the absence of disease or infirmity’ **(Chisholm, 1954 p2)**

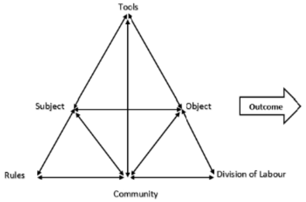
Brain and Body?

A Person

AIMS OF THE STUDY

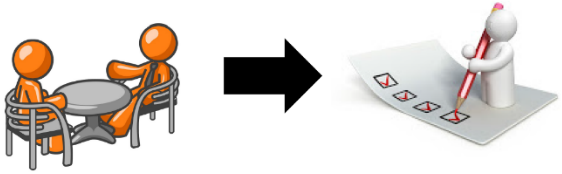
Aims

- Illuminate the experiences of RNMH caring for people with DSD in an inpatient setting
- Identify and describe the experience in terms of influencing and impacting factors within the workplace

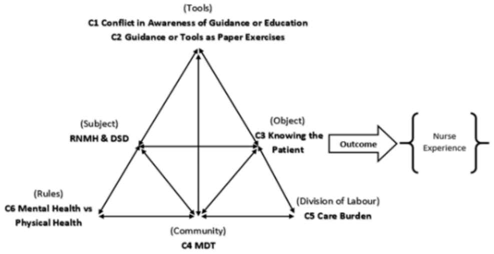


(Engeström, 2001)

PRAGMATIC MIXED METHODS



SIX CORE THEMES (evolving)

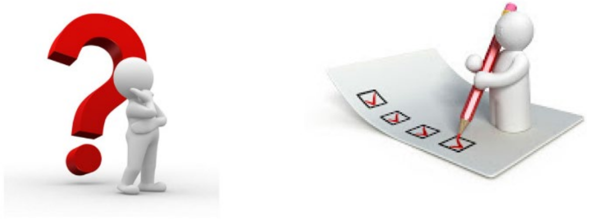


TWO SUPERORDINATE THEMES

- Certainty in Role
- ? What is expected of the RNMH
- Becoming a "physical" nurse

- Intuitive Care
- Knowing the individual is key

So what?



The consent bit……..

- This is part of a PHD study undertaken by Claire Pryor at Northumbria University

- If you have any concerns or questions regarding this survey or the study please contact either Claire Pryor or Andrew Melling (Supervisor)

- claire.pryor@northumbira.ac.uk 0191 2156155
- andrew.melling@northubira.ac.uk 0191 2156727

Voluntary Participation

- Packs on table
- Complete if you wish here
- Drop off box located
- Business card with web link (link open for a month)
- Web link in conference pack

- Data is anonymous

- By completing this survey you are giving your consent to your anonymous data being analysed and used in conjunction with other participants' data.
- Your information is strictly confidential and you will not be identifiable to your organisation unless you share your own responses.
- Your data will remain stored on University “U” drive for a time frame of 5 years post last publication of research findings. Hard copies of consent forms and associated documents will remain in locked storage only accessible to the researcher for a period of 5 years post last publication of research findings. The research study, including this survey has been approved by the University ethics committee

---

Who gets my data?

The study findings may be shared with:

- The research participants
- Northumbria University as a Doctoral thesis
- The Florence Nightingale Foundation
- NHS Professionals
- NHS Trusts
- Wider sharing may take the form of conference presentations, publications or discussions
- The study is part sponsored and funded by NHS Professionals and The Florence Nightingale Foundation

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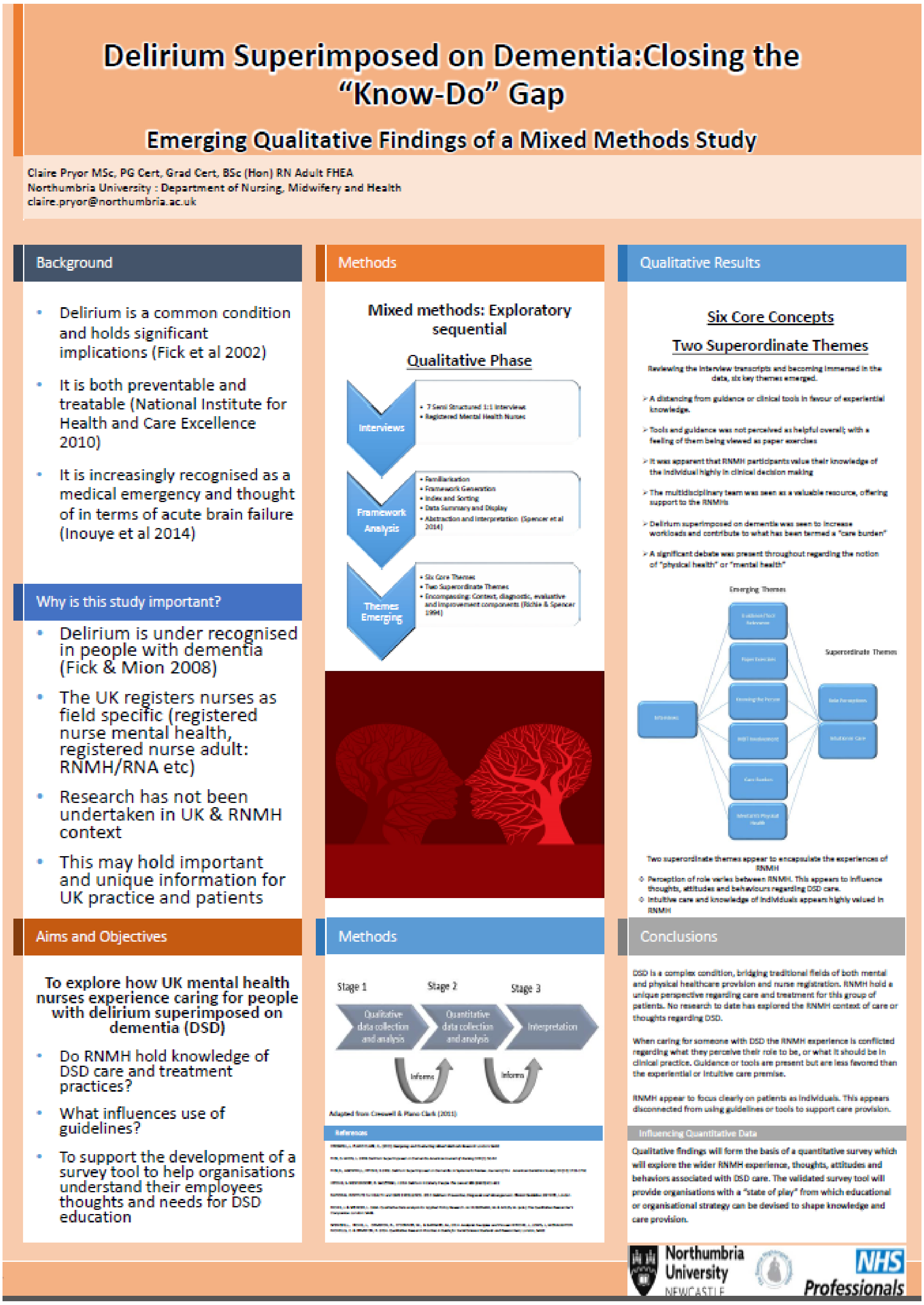
If you wish to complete this in another setting, an online version can be found at

https://northumbria.onlinesurveys.ac.uk/dsd

Appendix 7: Poster Presentation and Abstract



Delirium Superimposed on Dementia:Closing the "Know-Do" Gap

Emerging Qualitative Findings of a Mixed Methods Study

Claire Pryor MSc, PG Cert, Grad Cert, BSc (Hon) RN Adult FHEA
Northumbria University : Department of Nursing, Midwifery and Health
claire.pryor@northumbria.ac.uk

Background

- Delirium is a common condition and holds significant implications (Fick et al 2002)
- It is both preventable and treatable (National Institute for Health and Care Excellence 2010)
- It is increasingly recognised as a medical emergency and thought of in terms of acute brain failure (Inouye et al 2014)

Why is this study important?

- Delirium is under recognised in people with dementia (Fick & Mion 2008)
- The UK registers nurses as field specific (registered nurse mental health, registered nurse adult: RNMH/RNA etc)
- Research has not been undertaken in UK & RNMH context
- This may hold important and unique information for UK practice and patients

Aims and Objectives

To explore how UK mental health nurses experience caring for people with delirium superimposed on dementia (DSD)

- Do RNMH hold knowledge of DSD care and treatment practices?
- What influences use of guidelines?
- To support the development of a survey tool to help organisations understand their employees thoughts and needs for DSD education

Methods

Mixed methods: Exploratory sequential

Qualitative Phase

Interviews
- 7 Semi Structured 1:1 Interviews
- Registered Mental Health Nurses

Framework Analysis
- Familiarisation
- Framework Generation
- Index and Sorting
- Data Summary and Display
- Abstraction and Interpretation (Spencer et al 2014)

Themes Emerging
- Six Core Themes
- Two Superordinate Themes
- Encompassing: Context, diagnostic, evaluative and improvement components (Richie & Spencer 1994)

Methods

Stage 1 | Stage 2 | Stage 3

Qualitative data collection and analysis → Quantitative data collection and analysis → Interpretation

Informs

Informs

Adapted from Creswell & Plano Clark (2011)

References

Qualitative Results

Six Core Concepts

Two Superordinate Themes

Reviewing the interview transcripts and becoming immersed in the data, six key themes emerged.

- A distancing from guidance or clinical tools in favour of experiential knowledge.
- Tools and guidance was not perceived as helpful overall; with a feeling of them being viewed as paper exercises
- It was apparent that RNMH participants value their knowledge of the individual highly in clinical decision making
- The multidisciplinary team was seen as a valuable resource, offering support to the RNMHs
- Delirium superimposed on dementia was seen to increase workloads and contribute to what has been termed a "care burden"
- A significant debate was present throughout regarding the notion of "physical health" or "mental health"

Emerging Themes

Superordinate Themes

Two superordinate themes appear to encapsulate the experiences of RNMH

- Perception of role varies between RNMH. This appears to influence thoughts, attitudes and behaviours regarding DSD care.
- Intuitive care and knowledge of individuals appears highly valued in RNMH

Conclusions

DSD is a complex condition, bridging traditional fields of both mental and physical healthcare provision and nurse registration. RNMH hold a unique perspective regarding care and treatment for this group of patients. No research to date has explored the RNMH context of care or thoughts regarding DSD.

When caring for someone with DSD the RNMH experience is conflicted regarding what they perceive their role to be, or what it should be in clinical practice. Guidance or tools are present but are less favored than the experiential or intuitive care premise.

RNMH appear to focus clearly on patients as individuals. This appears disconnected from using guidelines or tools to support care provision.

Influencing Quantitative Data

Qualitative findings will form the basis of a quantitative survey which will explore the wider RNMH experience, thoughts, attitudes and behaviors associated with DSD care. The validated survey tool will provide organisations with a "state of play" from which educational or organisational strategy can be devised to shape knowledge and care provision.

How do Mental Health Nurses Experience Caring for People with Delirium Superimposed on Dementia: Initial Qualitative Findings from a Mixed Methods Study

Introduction

Delirium superimposed on dementia (DSD) is not uncommon and potentially fatal. Associated with increased length of stay in acute care settings and worsening cognitive and physical function it is paramount that it is recognised early and treated appropriately. International research shows nurse recognition of DSD is poor, and changes in behaviour are often attributed to dementia in isolation. Compounding this is the dearth of research pertaining to the unique position of UK nurses who hold specific fields of registration (e.g. Adult/ Mental health).

Aims The study aimed to explore if mental health nurses had knowledge of DSD care and treatment in practice, and their experiences of caring for people with DSD. The researcher was motivated to understand what impacted on nurses using their knowledge of DSD with a view to produce strategic guidance, education and policy recommendations.

Methods Registered mental health nurses were invited to participate in a mixed methods study. Grounded in pragmatism and following an exploratory sequential design, seven semi structured interviews were conducted between December 2016 and February 2017 in one NHS Foundation Trust specialising in Mental Health. Data was analysed using the principles of framework analysis. This was supported by NVIVO computer software.

Results and discussion Six key themes were found to be pertinent to the mental health nurse experience of caring for someone with DSD; awareness of guidance, tools as a paper exercise, knowing the individual, multi-disciplinary team participation, burden of care and splitting of mental and physical care.

Conclusion Key areas for further quantitative exploration were noted, with pertinent insight into what impacts upon mental health nurses care of people with DSD and their clinical decision

Appendix 8: Questionnaire (Conference & Online)

Northumbria
University
NEWCASTLE

Mental Health Nurses Experiences of DSD

Page 1: Mental Health Nurses Experiences of DSD

As part of a PHD study undertaken by Claire Pryor at Northumbria University

If you have any concerns or questions regarding this survey or the study please contact either Claire Pryor or Andrew Melling (Supervisor)

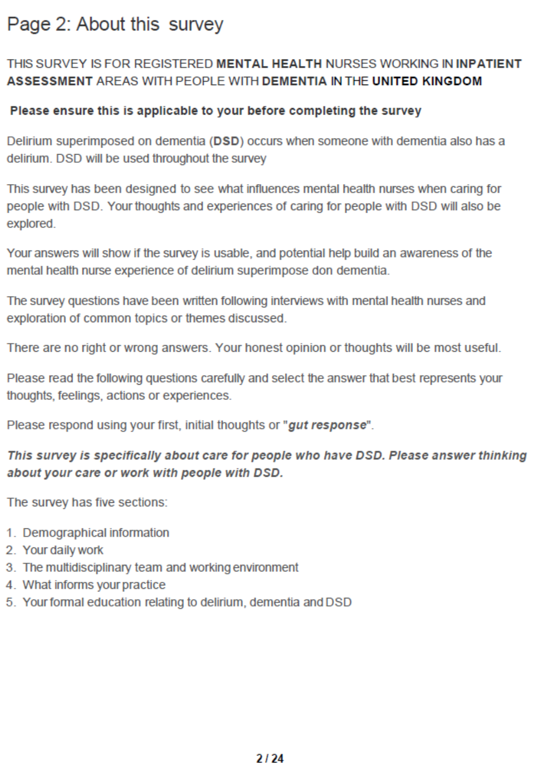
claire.pryor@northumbria.ac.uk

0191 2156155

andrew.melling@northubria.ac.uk

0191 2156727

1 / 24



Page 2: About this survey

THIS SURVEY IS FOR REGISTERED **MENTAL HEALTH** NURSES WORKING IN **INPATIENT ASSESSMENT** AREAS WITH PEOPLE WITH **DEMENTIA** IN THE **UNITED KINGDOM**

Please ensure this is applicable to your before completing the survey

Delirium superimposed on dementia (**DSD**) occurs when someone with dementia also has a delirium. DSD will be used throughout the survey

This survey has been designed to see what influences mental health nurses when caring for people with DSD. Your thoughts and experiences of caring for people with DSD will also be explored.

Your answers will show if the survey is usable, and potential help build an awareness of the mental health nurse experience of delirium superimpose don dementia.

The survey questions have been written following interviews with mental health nurses and exploration of common topics or themes discussed.

There are no right or wrong answers. Your honest opinion or thoughts will be most useful.

Please read the following questions carefully and select the answer that best represents your thoughts, feelings, actions or experiences.

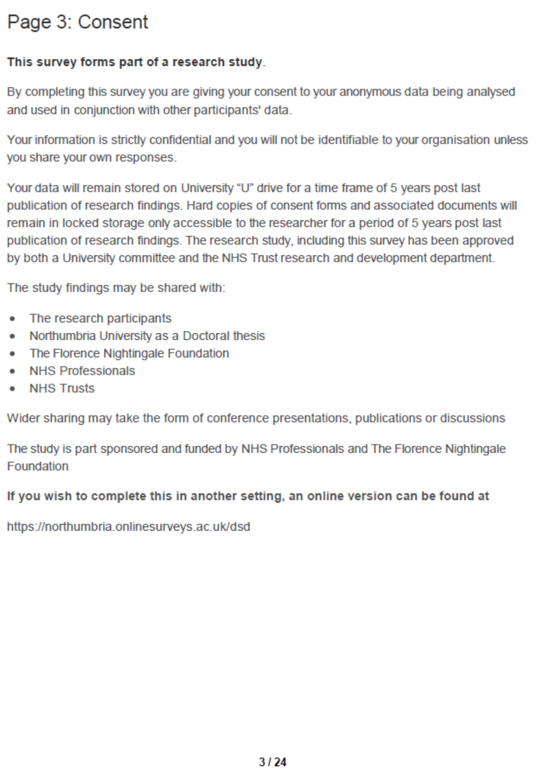
Please respond using your first, initial thoughts or "***gut response***".

This survey is specifically about care for people who have DSD. Please answer thinking about your care or work with people with DSD.

The survey has five sections:

1. Demographical information
2. Your daily work
3. The multidisciplinary team and working environment
4. What informs your practice
5. Your formal education relating to delirium, dementia and DSD

2 / 24



Page 3: Consent

This survey forms part of a research study.

By completing this survey you are giving your consent to your anonymous data being analysed and used in conjunction with other participants' data.

Your information is strictly confidential and you will not be identifiable to your organisation unless you share your own responses.

Your data will remain stored on University “U” drive for a time frame of 5 years post last publication of research findings. Hard copies of consent forms and associated documents will remain in locked storage only accessible to the researcher for a period of 5 years post last publication of research findings. The research study, including this survey has been approved by both a University committee and the NHS Trust research and development department.

The study findings may be shared with:

- The research participants
- Northumbria University as a Doctoral thesis
- The Florence Nightingale Foundation
- NHS Professionals
- NHS Trusts

Wider sharing may take the form of conference presentations, publications or discussions

The study is part sponsored and funded by NHS Professionals and The Florence Nightingale Foundation

If you wish to complete this in another setting, an online version can be found at

https://northumbria.onlinesurveys.ac.uk/dsd

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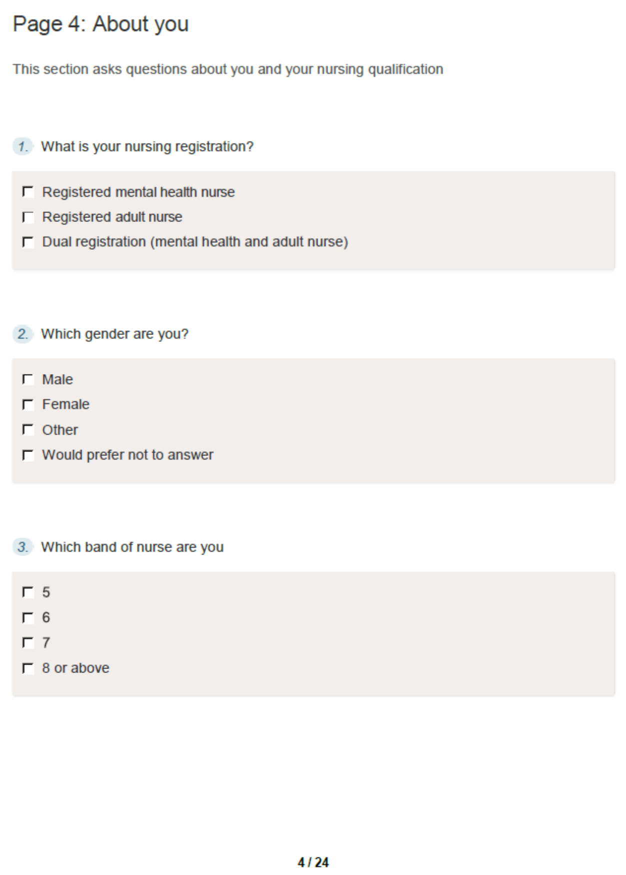


Page 4: About you

This section asks questions about you and your nursing qualification

1. What is your nursing registration?

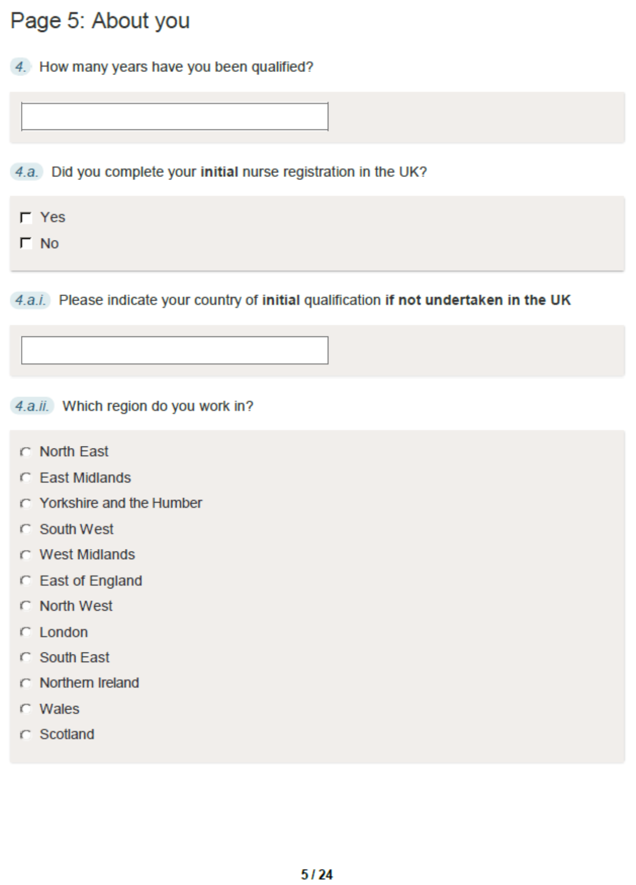
☐ Registered mental health nurse
☐ Registered adult nurse
☐ Dual registration (mental health and adult nurse)

2. Which gender are you?

☐ Male
☐ Female
☐ Other
☐ Would prefer not to answer

3. Which band of nurse are you

☐ 5
☐ 6
☐ 7
☐ 8 or above



Page 5: About you

4. How many years have you been qualified?

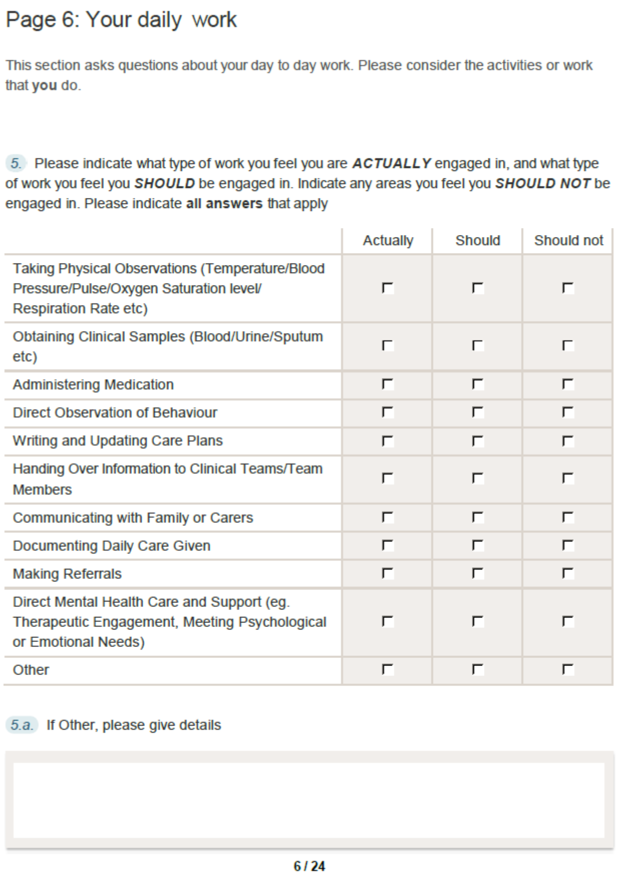
4.a. Did you complete your **initial** nurse registration in the UK?

☐ Yes
☐ No

4.a.i. Please indicate your country of **initial** qualification **if not undertaken in the UK**

4.a.ii. Which region do you work in?

○ North East
○ East Midlands
○ Yorkshire and the Humber
○ South West
○ West Midlands
○ East of England
○ North West
○ London
○ South East
○ Northern Ireland
○ Wales
○ Scotland



Page 6: Your daily work

This section asks questions about your day to day work. Please consider the activities or work that **you** do.

5. Please indicate what type of work you feel you are ***ACTUALLY*** engaged in, and what type of work you feel you ***SHOULD*** be engaged in. Indicate any areas you feel you ***SHOULD NOT*** be engaged in. Please indicate **all answers** that apply

	Actually	Should	Should not
Taking Physical Observations (Temperature/Blood Pressure/Pulse/Oxygen Saturation level/ Respiration Rate etc)	☐	☐	☐
Obtaining Clinical Samples (Blood/Urine/Sputum etc)	☐	☐	☐
Administering Medication	☐	☐	☐
Direct Observation of Behaviour	☐	☐	☐
Writing and Updating Care Plans	☐	☐	☐
Handing Over Information to Clinical Teams/Team Members	☐	☐	☐
Communicating with Family or Carers	☐	☐	☐
Documenting Daily Care Given	☐	☐	☐
Making Referrals	☐	☐	☐
Direct Mental Health Care and Support (eg. Therapeutic Engagement, Meeting Psychological or Emotional Needs)	☐	☐	☐
Other	☐	☐	☐

5.a. If Other, please give details

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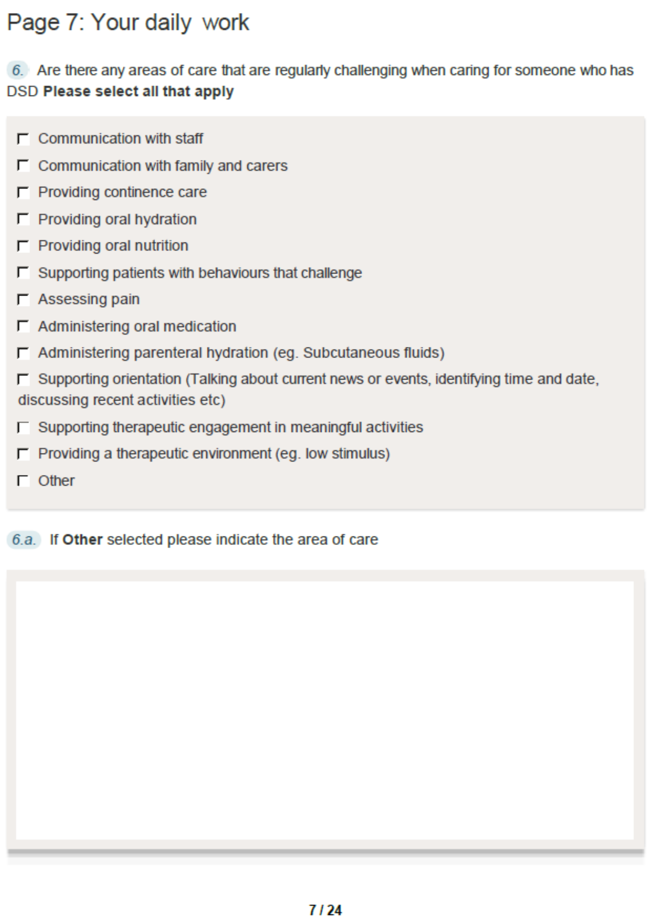

Page 7: Your daily work

6. Are there any areas of care that are regularly challenging when caring for someone who has DSD **Please select all that apply**

- ☐ Communication with staff
- ☐ Communication with family and carers
- ☐ Providing continence care
- ☐ Providing oral hydration
- ☐ Providing oral nutrition
- ☐ Supporting patients with behaviours that challenge
- ☐ Assessing pain
- ☐ Administering oral medication
- ☐ Administering parenteral hydration (eg. Subcutaneous fluids)
- ☐ Supporting orientation (Talking about current news or events, identifying time and date, discussing recent activities etc)
- ☐ Supporting therapeutic engagement in meaningful activities
- ☐ Providing a therapeutic environment (eg. low stimulus)
- ☐ Other

6.a. If **Other** selected please indicate the area of care

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Page 8: Your daily work

7. Please consider the impact that caring for someone with DSD has on you or your team (as opposed to caring for someone without DSD) **Please select the answer that best represents your opinion**

	Decreases Greatly	Decreases	Neither Decreases nor Increases	Increases	Increases Greatly
My stress level	☐	☐	☐	☐	☐
Ward stress level	☐	☐	☐	☐	☐
Demand on daily work load	☐	☐	☐	☐	☐
Uncertainty regarding clinical care	☐	☐	☐	☐	☐
The clinical team working closely together	☐	☐	☐	☐	☐

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Page 9: Your daily work

8. Please consider the statements below individually and select one option which you feel fits the sentence best

	A Lot Less	Less	Neither More or Less	More	A Lot More
Caring for someone with DSD is ------- challenging than caring for someone with dementia alone	☐	☐	☐	☐	☐
People with DSD require -------- care from qualified nurses than those with dementia alone	☐	☐	☐	☐	☐
People with DSD require -------- care from nursing assistants than those with dementia alone. (Or other nursing support staff below band 5 qualification e.g. Health Care Assistants)	☐	☐	☐	☐	☐

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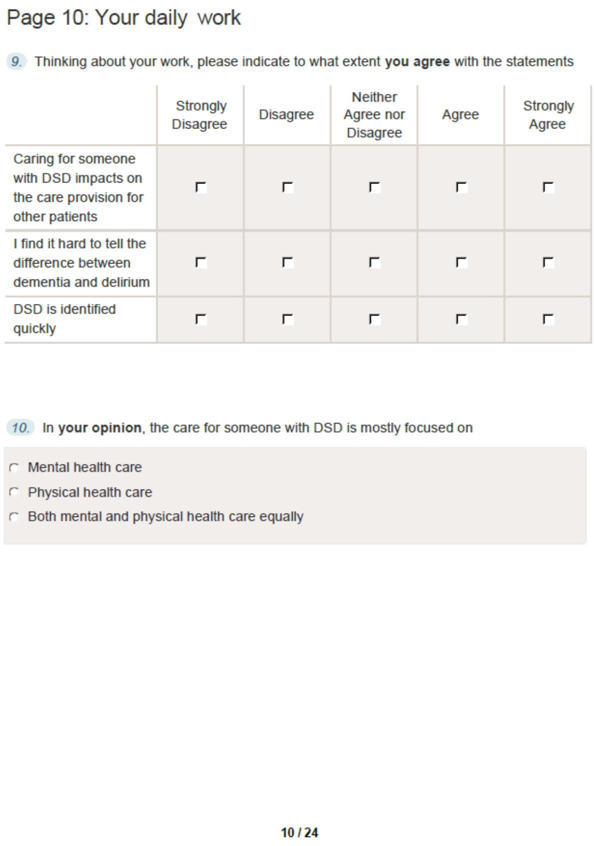

Page 10: Your daily work

9. Thinking about your work, please indicate to what extent **you agree** with the statements

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Caring for someone with DSD impacts on the care provision for other patients	☐	☐	☐	☐	☐
I find it hard to tell the difference between dementia and delirium	☐	☐	☐	☐	☐
DSD is identified quickly	☐	☐	☐	☐	☐

10. In **your opinion**, the care for someone with DSD is mostly focused on

- ○ Mental health care
- ○ Physical health care
- ○ Both mental and physical health care equally

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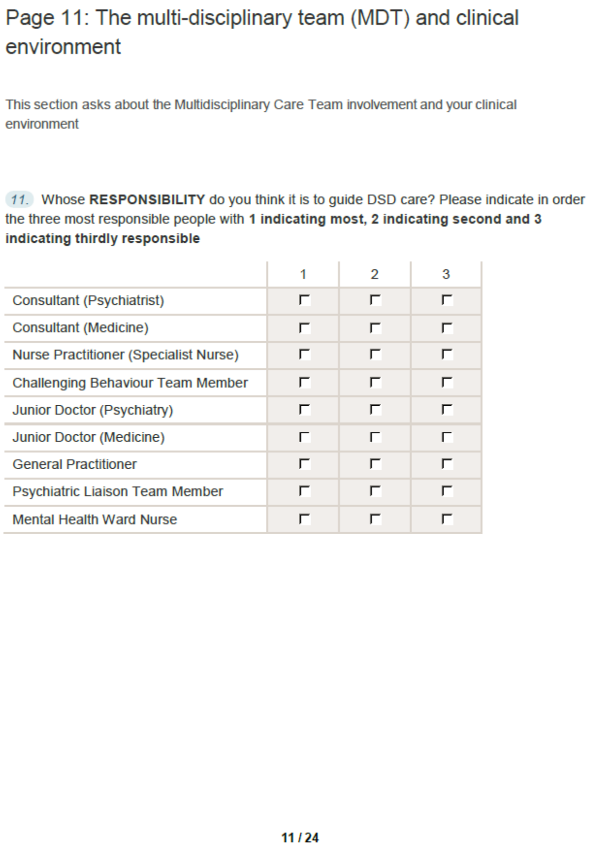

Page 11: The multi-disciplinary team (MDT) and clinical environment

This section asks about the Multidisciplinary Care Team involvement and your clinical environment

11. Whose **RESPONSIBILITY** do you think it is to guide DSD care? Please indicate in order the three most responsible people with **1 indicating most, 2 indicating second and 3 indicating thirdly responsible**

	1	2	3
Consultant (Psychiatrist)	☐	☐	☐
Consultant (Medicine)	☐	☐	☐
Nurse Practitioner (Specialist Nurse)	☐	☐	☐
Challenging Behaviour Team Member	☐	☐	☐
Junior Doctor (Psychiatry)	☐	☐	☐
Junior Doctor (Medicine)	☐	☐	☐
General Practitioner	☐	☐	☐
Psychiatric Liaison Team Member	☐	☐	☐
Mental Health Ward Nurse	☐	☐	☐

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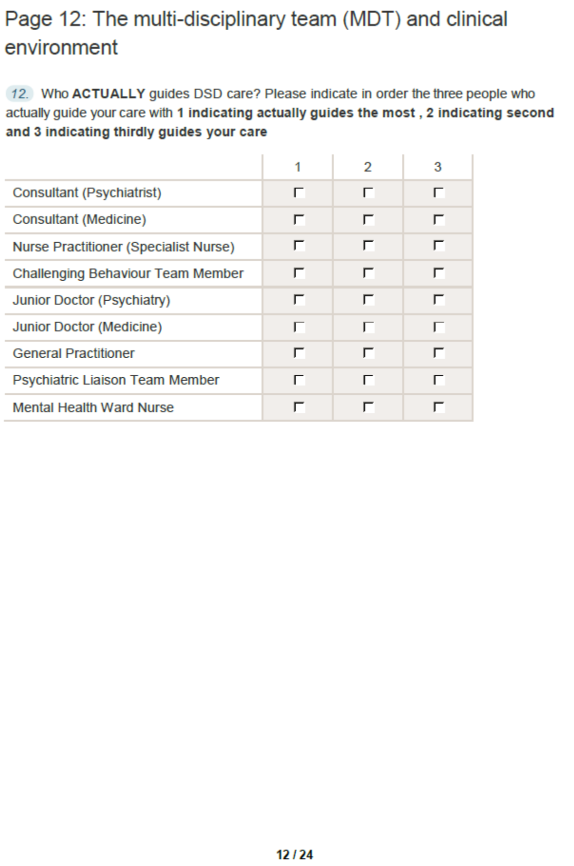

Page 12: The multi-disciplinary team (MDT) and clinical environment

12. Who **ACTUALLY** guides DSD care? Please indicate in order the three people who actually guide your care with **1 indicating actually guides the most , 2 indicating second and 3 indicating thirdly guides your care**

	1	2	3
Consultant (Psychiatrist)	☐	☐	☐
Consultant (Medicine)	☐	☐	☐
Nurse Practitioner (Specialist Nurse)	☐	☐	☐
Challenging Behaviour Team Member	☐	☐	☐
Junior Doctor (Psychiatry)	☐	☐	☐
Junior Doctor (Medicine)	☐	☐	☐
General Practitioner	☐	☐	☐
Psychiatric Liaison Team Member	☐	☐	☐
Mental Health Ward Nurse	☐	☐	☐

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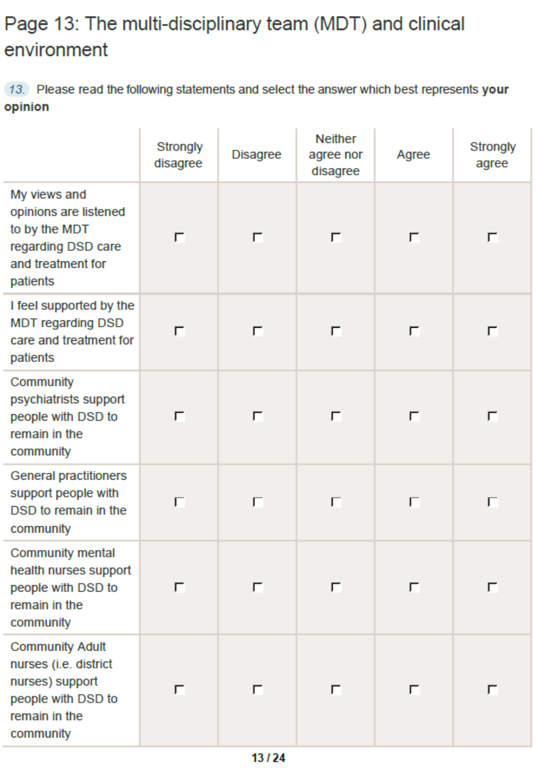
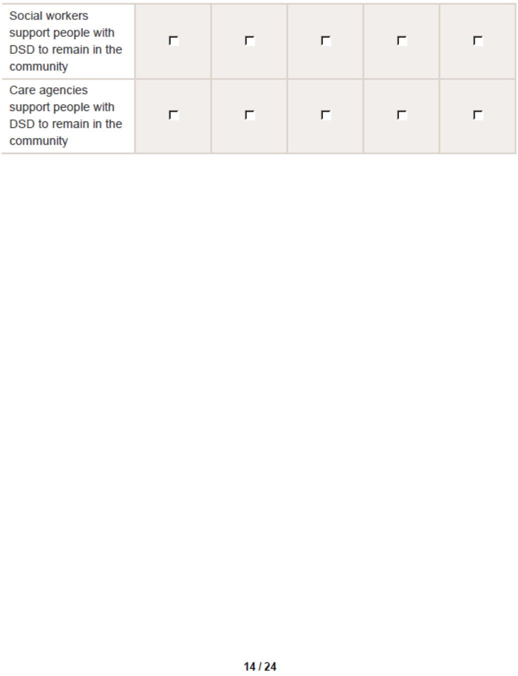


Page 13: The multi-disciplinary team (MDT) and clinical environment

13. Please read the following statements and select the answer which best represents **your opinion**



	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
My views and opinions are listened to by the MDT regarding DSD care and treatment for patients	☐	☐	☐	☐	☐
I feel supported by the MDT regarding DSD care and treatment for patients	☐	☐	☐	☐	☐
Community psychiatrists support people with DSD to remain in the community	☐	☐	☐	☐	☐
General practitioners support people with DSD to remain in the community	☐	☐	☐	☐	☐
Community mental health nurses support people with DSD to remain in the community	☐	☐	☐	☐	☐
Community Adult nurses (i.e. district nurses) support people with DSD to remain in the community	☐	☐	☐	☐	☐
Social workers support people with DSD to remain in the community	☐	☐	☐	☐	☐
Care agencies support people with DSD to remain in the community	☐	☐	☐	☐	☐

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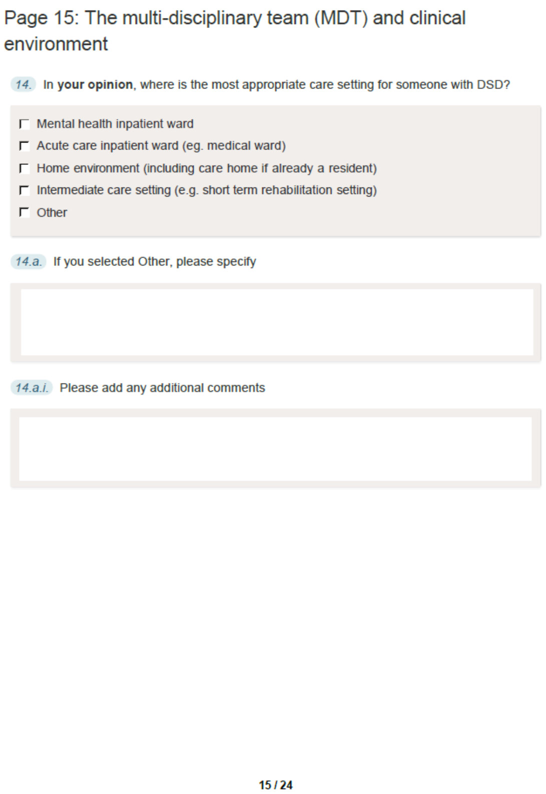

Page 15: The multi-disciplinary team (MDT) and clinical environment

14. In **your opinion**, where is the most appropriate care setting for someone with DSD?

☐ Mental health inpatient ward
☐ Acute care inpatient ward (eg. medical ward)
☐ Home environment (including care home if already a resident)
☐ Intermediate care setting (e.g. short term rehabilitation setting)
☐ Other

14.a. If you selected Other, please specify

14.a.i. Please add any additional comments

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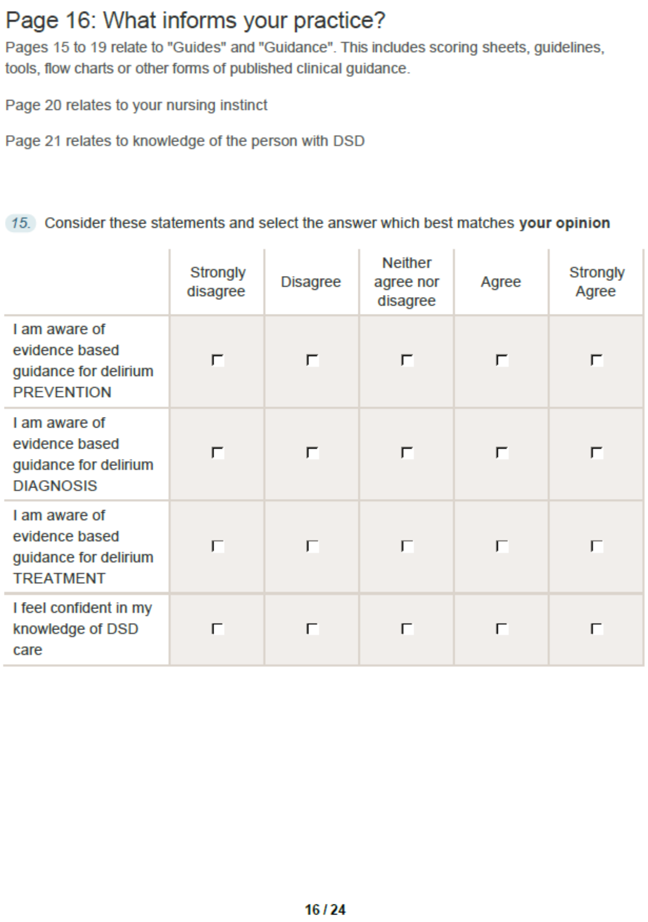

Page 16: What informs your practice?

Pages 15 to 19 relate to "Guides" and "Guidance". This includes scoring sheets, guidelines, tools, flow charts or other forms of published clinical guidance.

Page 20 relates to your nursing instinct

Page 21 relates to knowledge of the person with DSD

15. Consider these statements and select the answer which best matches **your opinion**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
I am aware of evidence based guidance for delirium PREVENTION	☐	☐	☐	☐	☐
I am aware of evidence based guidance for delirium DIAGNOSIS	☐	☐	☐	☐	☐
I am aware of evidence based guidance for delirium TREATMENT	☐	☐	☐	☐	☐
I feel confident in my knowledge of DSD care	☐	☐	☐	☐	☐

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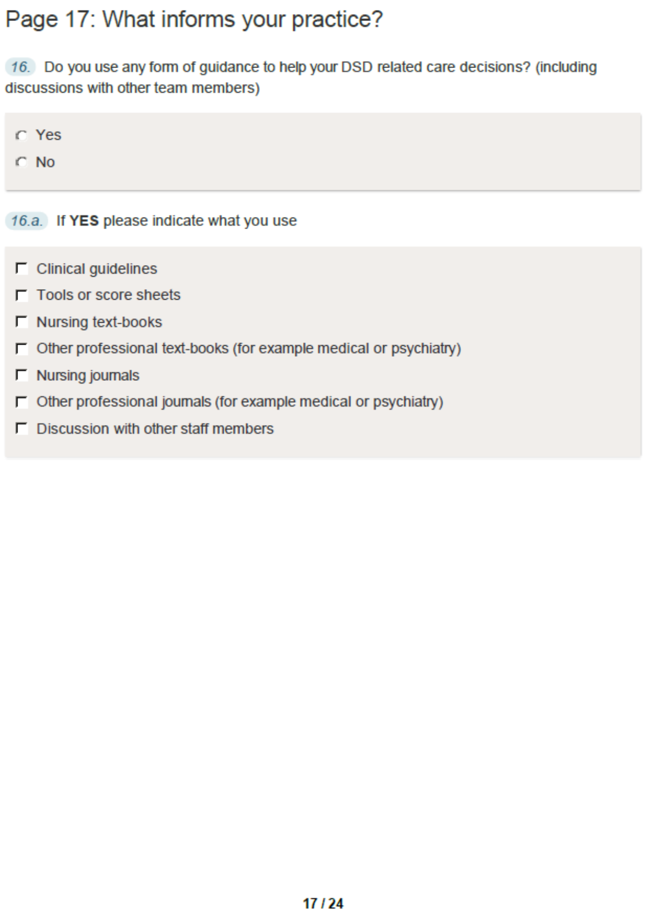

Page 17: What informs your practice?

16. Do you use any form of guidance to help your DSD related care decisions? (including discussions with other team members)

- ○ Yes
- ○ No

16.a. If **YES** please indicate what you use

- ☐ Clinical guidelines
- ☐ Tools or score sheets
- ☐ Nursing text-books
- ☐ Other professional text-books (for example medical or psychiatry)
- ☐ Nursing journals
- ☐ Other professional journals (for example medical or psychiatry)
- ☐ Discussion with other staff members

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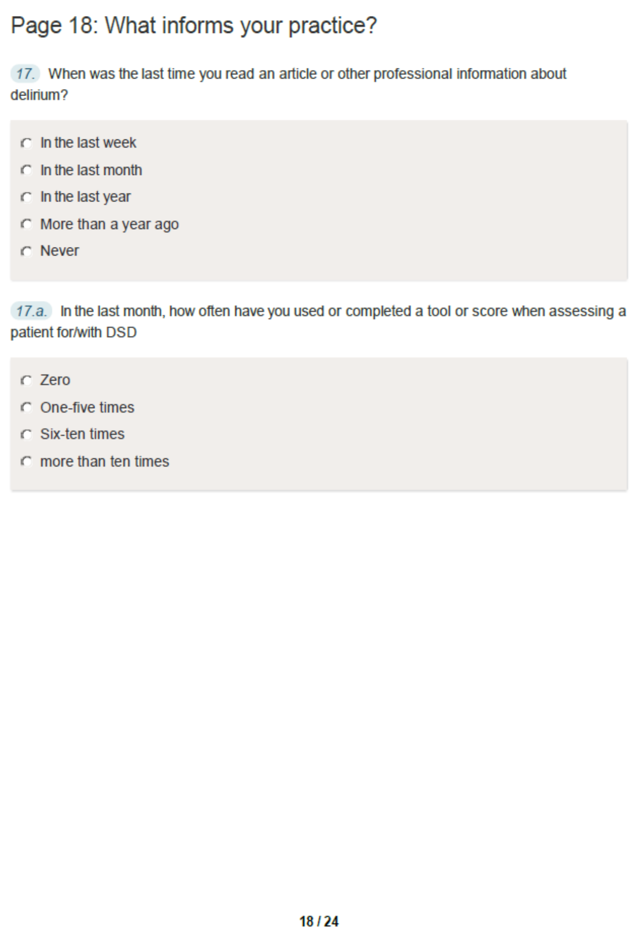

Page 18: What informs your practice?

17. When was the last time you read an article or other professional information about delirium?

- ○ In the last week
- ○ In the last month
- ○ In the last year
- ○ More than a year ago
- ○ Never

17.a. In the last month, how often have you used or completed a tool or score when assessing a patient for/with DSD

- ○ Zero
- ○ One-five times
- ○ Six-ten times
- ○ more than ten times

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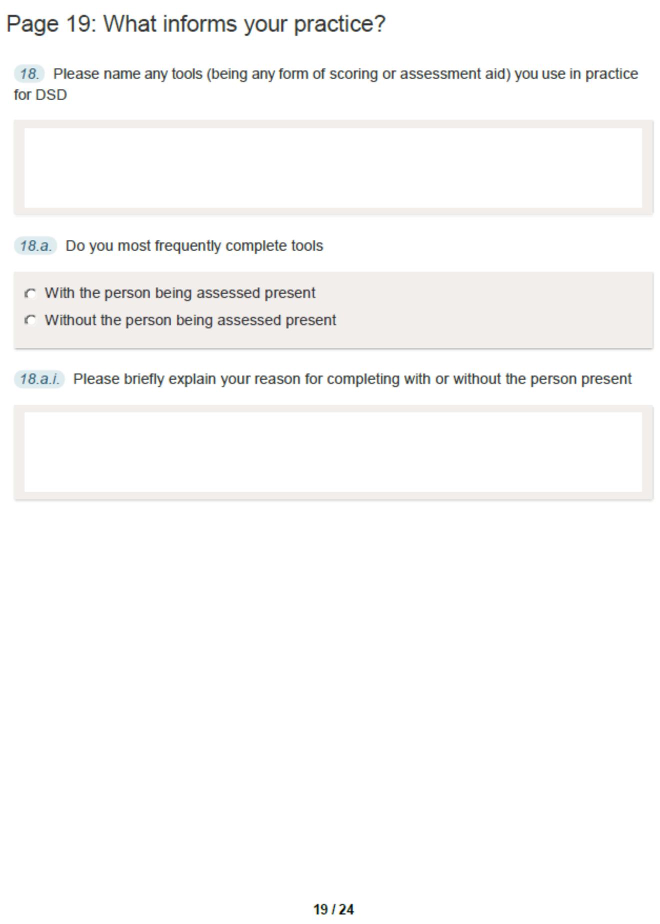

Page 19: What informs your practice?

18. Please name any tools (being any form of scoring or assessment aid) you use in practice for DSD

18.a. Do you most frequently complete tools

○ With the person being assessed present
○ Without the person being assessed present

18.a.i. Please briefly explain your reason for completing with or without the person present

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Page 20: What informs your practice?

19. Consider these statements and choose the answer that most accurately represents **your opinion**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Delirium tools are easy to understand	☐	☐	☐	☐	☐
Delirium tools correctly identify DSD	☐	☐	☐	☐	☐
Delirium tools provide me with enough information to help plan care	☐	☐	☐	☐	☐
Delirium tools take a long time to complete accurately	☐	☐	☐	☐	☐
Often I don't have enough information to complete the tools fully	☐	☐	☐	☐	☐
The person's capacity to understand the questions effects the tools usefulness	☐	☐	☐	☐	☐
The tools cause distress for those being assessed	☐	☐	☐	☐	☐
Delirium tools are useful for people with dementia	☐	☐	☐	☐	☐
The outcome of tools influences my care decisions and plans more than my knowledge of the person	☐	☐	☐	☐	☐

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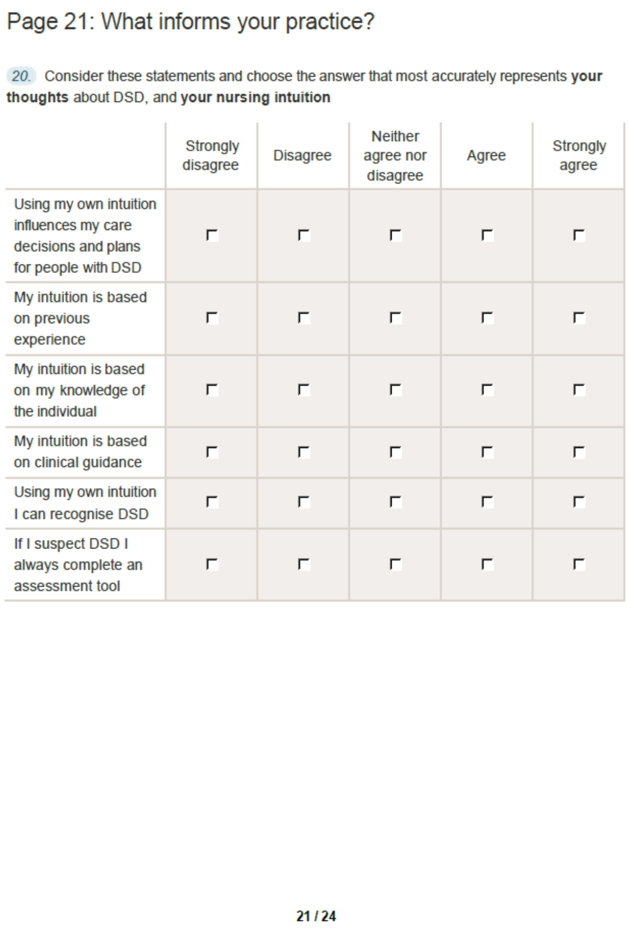

Page 21: What informs your practice?

20. Consider these statements and choose the answer that most accurately represents **your thoughts** about DSD, and **your nursing intuition**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Using my own intuition influences my care decisions and plans for people with DSD	☐	☐	☐	☐	☐
My intuition is based on previous experience	☐	☐	☐	☐	☐
My intuition is based on my knowledge of the individual	☐	☐	☐	☐	☐
My intuition is based on clinical guidance	☐	☐	☐	☐	☐
Using my own intuition I can recognise DSD	☐	☐	☐	☐	☐
If I suspect DSD I always complete an assessment tool	☐	☐	☐	☐	☐

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Page 22: What informs your practice?

21. Please select the answer that most closely fits **your opinion**

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The clinical teams' knowledge of a person is more important than a score or written guidance when considering DSD	☐	☐	☐	☐	☐
Gathering information from friends and relatives is important when considering DSD	☐	☐	☐	☐	☐
Gathering clinical information from tests (inc bloods/urine sample etc) is important when considering DSD	☐	☐	☐	☐	☐
Gathering clinical information from delirium assessment scores is important when considering DSD	☐	☐	☐	☐	☐

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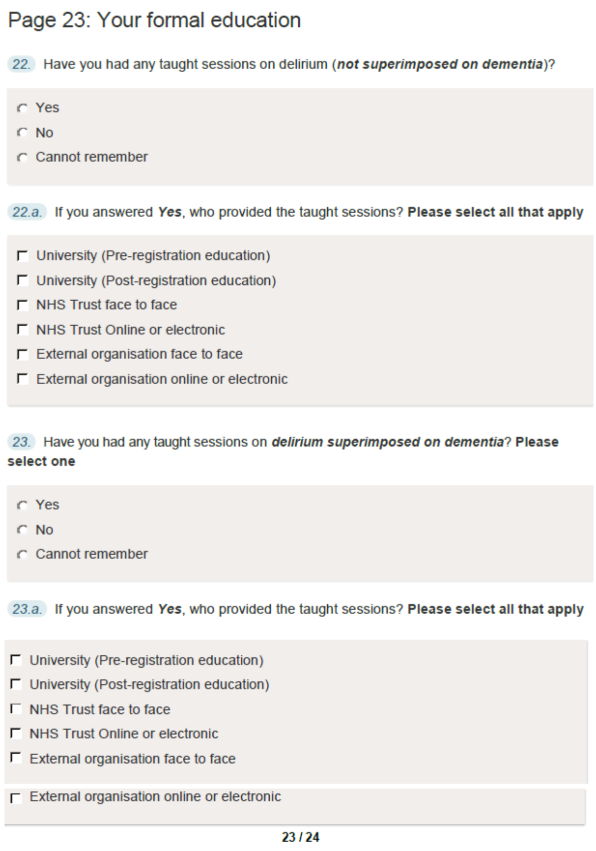

Page 23: Your formal education

22. Have you had any taught sessions on delirium (***not superimposed on dementia***)?

○ Yes
○ No
○ Cannot remember

22.a. If you answered ***Yes***, who provided the taught sessions? **Please select all that apply**

☐ University (Pre-registration education)
☐ University (Post-registration education)
☐ NHS Trust face to face
☐ NHS Trust Online or electronic
☐ External organisation face to face
☐ External organisation online or electronic

23. Have you had any taught sessions on ***delirium superimposed on dementia***? **Please select one**

○ Yes
○ No
○ Cannot remember

23.a. If you answered ***Yes***, who provided the taught sessions? **Please select all that apply**

☐ University (Pre-registration education)
☐ University (Post-registration education)
☐ NHS Trust face to face
☐ NHS Trust Online or electronic
☐ External organisation face to face
☐ External organisation online or electronic

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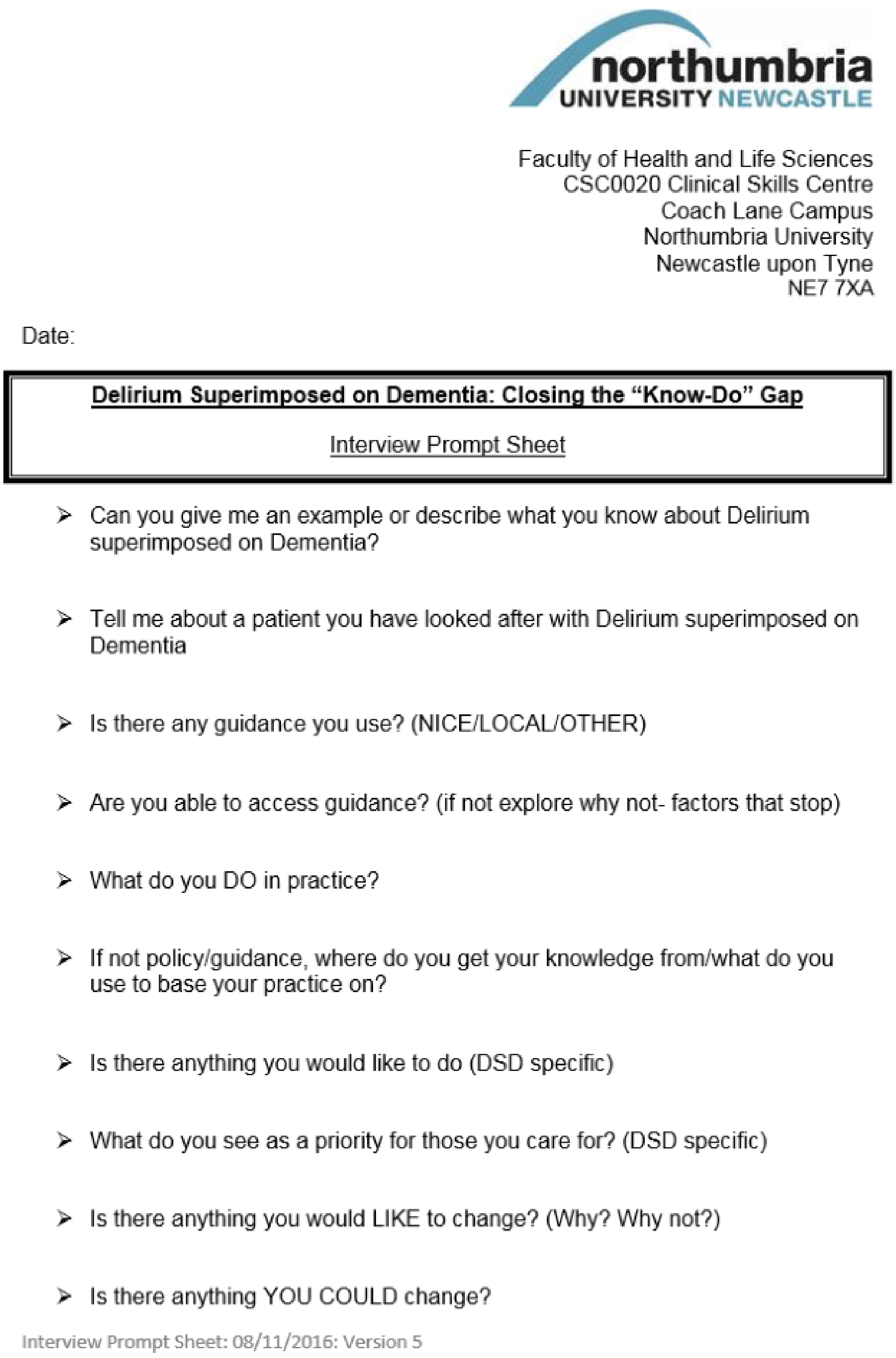
Appendix 9: Interview Prompt Sheet



Faculty of Health and Life Sciences
CSC0020 Clinical Skills Centre
Coach Lane Campus
Northumbria University
Newcastle upon Tyne
NE7 7XA

Date:

Delirium Superimposed on Dementia: Closing the "Know-Do" Gap

Interview Prompt Sheet

- Can you give me an example or describe what you know about Delirium superimposed on Dementia?
- Tell me about a patient you have looked after with Delirium superimposed on Dementia
- Is there any guidance you use? (NICE/LOCAL/OTHER)
- Are you able to access guidance? (if not explore why not- factors that stop)
- What do you DO in practice?
- If not policy/guidance, where do you get your knowledge from/what do you use to base your practice on?
- Is there anything you would like to do (DSD specific)
- What do you see as a priority for those you care for? (DSD specific)
- Is there anything you would LIKE to change? (Why? Why not?)
- Is there anything YOU COULD change?

Interview Prompt Sheet: 08/11/2016: Version 5

- What do you think you need to move “Knowledge” in to working practice?

- Is there anything that helps you in practice?

- Is there anything that doesn’t help?

- Is there anything you feel you need? (Why/what would this do for you/practice/patient?)

- Is there anything else that you haven’t talked about that you would like to?

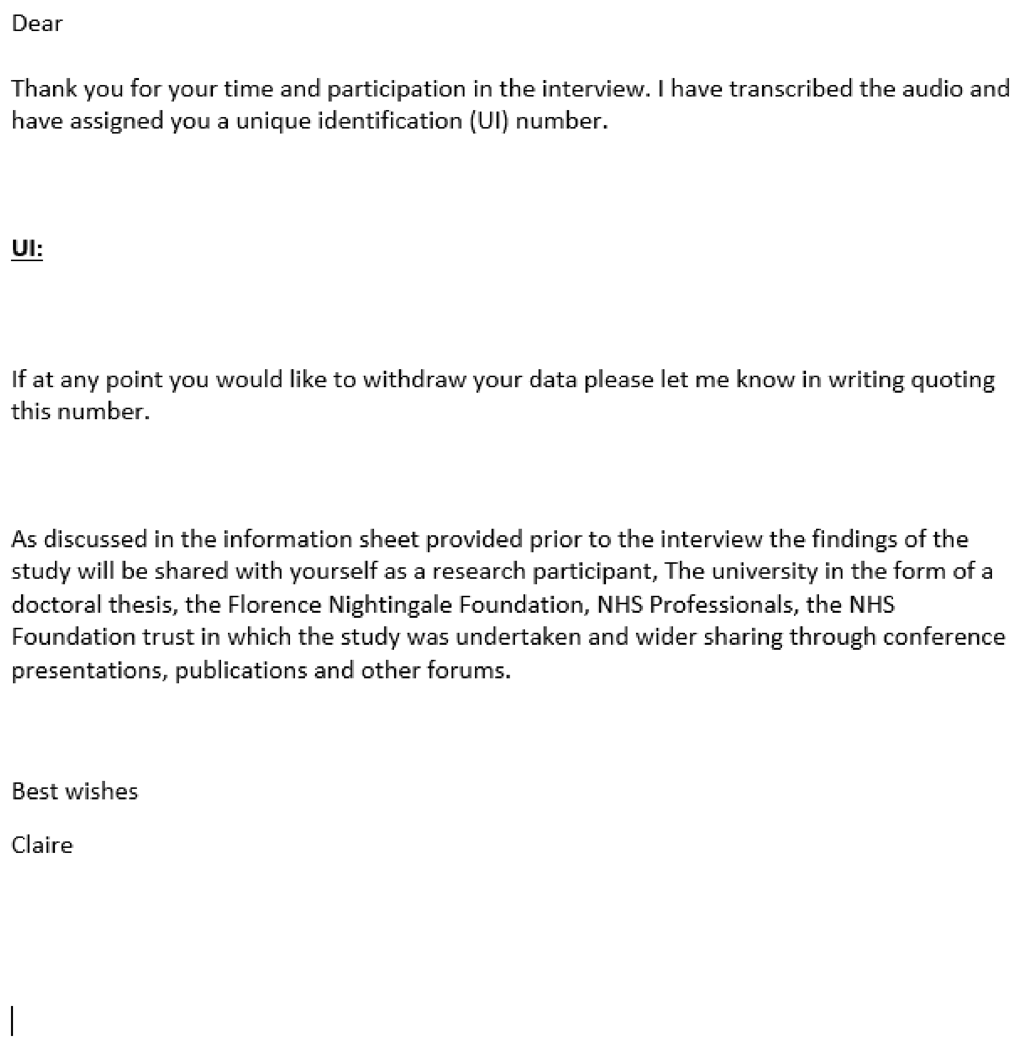
- Do you have any comments or thoughts you would like to share?

Thank you for your time and for the discussion.

The Florence Nightingale Foundation

NHS Professionals

Appendix 10: Unique Identifier Email



Dear

Thank you for your time and participation in the interview. I have transcribed the audio and have assigned you a unique identification (UI) number.

UI:

If at any point you would like to withdraw your data please let me know in writing quoting this number.

As discussed in the information sheet provided prior to the interview the findings of the study will be shared with yourself as a research participant, The university in the form of a doctoral thesis, the Florence Nightingale Foundation, NHS Professionals, the NHS Foundation trust in which the study was undertaken and wider sharing through conference presentations, publications and other forums.

Best wishes

Claire

Appendix 11: Quantification of Qualitative/Open Questions

Quantification of Qualitative/Open Questions: Full set

Q5: Your daily work. Please indicate what type of work you are actually engaged in.....
5.11 Other:
CP05:
Audit regarding Governance, Medication, Infection Prevention and Control etc

CP06:
My role does not routinely involve me in taking obs, samples etc- But maybe it should

CP07:
Careres Groups, F.R.I.E.N.D.S Groups, Literacy Projects, Health Advocacy

40220228:
Development of Formulations

CH2
Manager Roles

Respondent	Theme			
	Non Clinical Roles	Clinical Governance *	Support Roles	Formulation Development
CP05	1	1		
CP06	1			
CP07	1		1	
40220228				1
CH2	1			

*Clinical Governance initially named Organisational Roles- Amended on review with independent researcher.

Q14: The MULTIDISCIPLINARY TEAM and Clinical Environment: In your opinion, where is the most appropriate care setting for someone with DSD?

14.a Other and Additional Comments
CP01:
Whichever care setting is deemed most appropriate to meet an individual's primary needs as caused by delirium

CP02:
Home environment if the person can be managed and does not pose a significant risk to themselves or others

CP03:
A Change of environment can be very disruptive and distressing for someone with DSD

CP06:
The most appropriate should be what meets the person's individual needs at the time

CP07:
Depends on the individual's circumstances and availability of support systems in place. Safety issues are paramount. All aspects to be taken into consideration
Intermediate care only if the carer is struggling to care/manage

40947971:
Depends upon need of any of these things, if manageable at home would be better, dependent upon risk and scope to manage need and behaviour as with any involvement with care services

CH2

Could be a combination of environments depending on person's presentation
It should be looked at holistically

CH11
Stability

CH12
Home environment where they can be treated as moving them into a new surrounding may cause distress

Respondent	Theme			
	Individual Patient Needs	Risk & Safety	Distress	Stability
CP01	1			
CP02	1	1		
CP03			1	
CP06	1			
CP07	1	1		
40947971	1	1		
CH2	1			
CH11				1
CH12			1	

Q18: What Informs Your Practice

18 Please Name any Tools (being any form of scoring or assessment aid) You Use in Practice for DSD

Respondent	Identified Tools									
	MACE	ACE lll	4 AT	CAM	PINCH ME	DEMS	DOSS	Delirium Rating Scale	Delirium Screening Tool	Cornell
CP02	1	1	1							
CP03			1	1						
CP06				1	1					
CP07										
39619216				1	1	1	1			
39630203								1		
39691718				1						
39974881								1		
40193668								1		
40220228									1	
40947971										1
CH9			1							
Total	1	1	3	4	2	1	1	3	1	1

Q18.a.i: Please Briefly Explain Your Reason for Completing With or Without the Person Present

CP01:
Individuals generally at advanced stage of dementia or due to symptoms of delirium are unable/not willing to engage
CP03:
Can be more distressing for a patient and I would rather spend time on therapeutic interventions with a patient

CP06:
Key to involving the person in their care

CP07:
To assess with (if patient not lucid) can be distressing for the patient.
Can educate patient/family member when appropriate time
To assess with can be embarrassing depending on presenting symptoms

39619216*:*
Collaboration and involvement

39691718:
Lack of Capacity

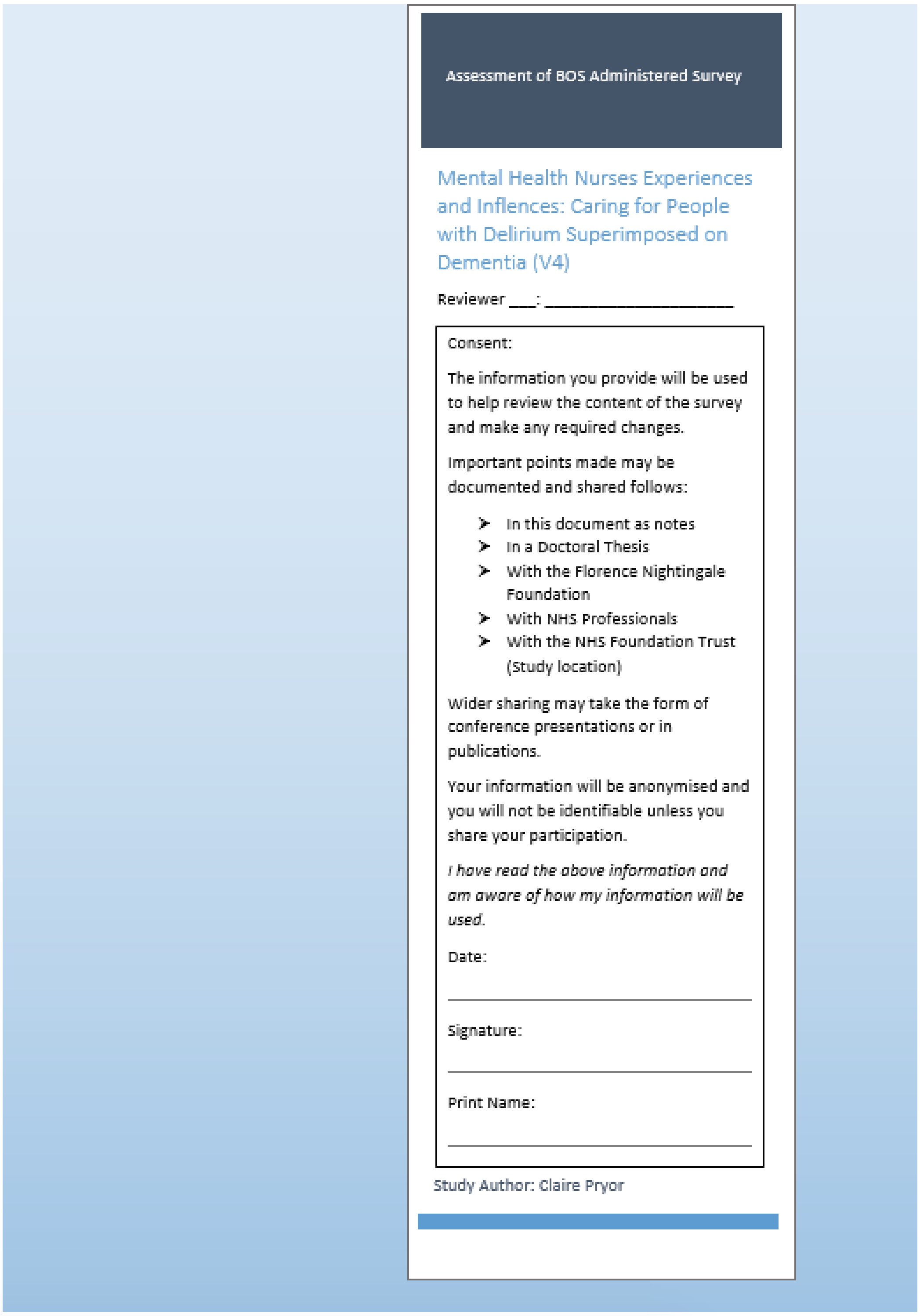
40947971:
Some scope for interaction with patients on this front, largely there is a lack of awareness, capacity to acknowledge symptoms on this unit, predominantly we have patients who are advanced progressively with their dementia. Communication also generally limited, I am considering presently current client group

CH11
Lack of capacity/stress/anxiety

Respondent	With the person present	Without the person present			
	Involvement in own care	Inability to engage	Distress	RNMH Preference for therapeutic activity	Lack of Capacity
CP01		1			
CP03			1	1	
CP06	1				
CP07			1		
39619216	1				
39691718					1
40947971					1
CH11	Indicated “with” person present- decision based on lack of capacity, stress and anxiety				

Appendix 12: Modified Questionnaire Partner Document

This form has been amended for inclusion as an appendix: only one question set is shown for information



Assessment of BOS Administered Survey

Mental Health Nurses Experiences and Inflences: Caring for People with Delirium Superimposed on Dementia (V4)

Reviewer ___: ____________________

Consent:

The information you provide will be used to help review the content of the survey and make any required changes.

Important points made may be documented and shared follows:

- In this document as notes
- In a Doctoral Thesis
- With the Florence Nightingale Foundation
- With NHS Professionals
- With the NHS Foundation Trust (Study location)

Wider sharing may take the form of conference presentations or in publications.

Your information will be anonymised and you will not be identifiable unless you share your participation.

I have read the above information and am aware of how my information will be used.

Date:

____

Signature:

____

Print Name:

____

Study Author: Claire Pryor

Section: ABOUT YOU
Q1: Registration

Is the wording clear?

Is the process of completion clear?

If/Why unable to answer

How did you come up with your answer?

Was it easy or hard to answer?

Can you rephrase this question? Tell me what you think this is asking (paraphrase)

Does this match question intention?

Usability Testing Sheet V1 16/07/2018 CP

Appendix 13 Usability Test Example Feedback Sheet

Section: CONSENT

Participant	Prompts and Comments	
	Is it Clear	*Any Questions*
1	Change finding to *findings* Really clear: data protection and sharing: more than required information	Nil
2	Yes- bullet points break down to digestible chunks	
Action & Rational	1: Added information to indicate part of a study 2: Finding changed to findings	

Section: Your daily work

Q7: Impact on team

Participant	Prompts and Comments						
	Is the Wording Clear	*Is the Process of Completion Clear*	*If/Why Unable to Answer*	*How Did you Come up with Answer*	*Was it Easy or Hard to Answer*	*Can you Rephrase this Question? Tell me What You Think the Question is Asking (Paraphrase)*	*Does this Match the Question Intention*
1	Yes	Yes				Difference between DSD and without	
2					Easy	What is the impact of DSD on colleagues and staff	Yes- especially the bracketed section
Action & Rational	Nil						