THE ALZHEIMER SOCIETY of IRELAND

Briefing document on the case for Dementia Clinical Nurse Specialists in Acute Settings

Contents

1. Executive Summary 3
2. Introduction 4
3. Literature Review 7
4. Methodology 13
5. Results & Discussion 15
6. Concluding Remarks 25
7. Key Recommendations 28
8. References 30

Appendix 1 – Methodology (expanded) 35
Appendix 2 – Study Documentation 38

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1. Executive Summary

Aims and objectives: This report explores the case for further investment in Clinical Dementia Nurse Specialist roles in acute settings, providing insight into the value of this role, a thorough analysis of the enablers and barriers to implementation and recommendations for a national rollout.

Background: Extended stays and adverse events can mean that hospital admissions are both challenging and costly for people with dementia, and patient experiences and outcomes can often be poor. Internationally, Dementia Clinical Nurse Specialist (CNS) roles have been identified as having the potential to enhance care quality, reduce excess stays and reduce cost. However, the evidence base for these roles in an Irish setting is currently limited due to the small number of active posts and the relatively recent introduction of such roles. We sought to provide a practical understanding of the Dementia CNS role by qualitatively exploring the utility and scope of the role, and the challenges and enablers associated with role to underpin the case for further funding.

Methods: A brief literature review encompassed national and international perspectives, including grey literature (Reports, Strategies, Action Plans) and research studies around international best practice in dementia care. Qualitative data was also collected to understand the current status quo concerning the dementia nurse specialist role and the complexities and challenges of providing dementia care in the acute setting. A broad range of stakeholders was consulted, including Clinicians, Nurses, and other Health and Social Care Professionals, involved in delivering dementia care, alongside patient advocacy group members, board members, members of the public affected by dementia, and family carer representatives.

Results: International evidence indicates that the dementia clinical nurse specialist undertaking a clearly defined role can significantly benefit people with dementia in hospitals and their carers. This is further emphasised by the qualitative evidence gathered for this report, which suggests that current CNS roles are beneficial to patients and family carers and further investment should be prioritised. Consideration needs to be given to the wide range of 'demands' on the CNS, with the suggestion of in-built flexibility to the job description to allow local prioritisation of needs.

Conclusions: Both the literature and qualitative insight gathering identified several key areas where the clinical nurse specialist role can positively impact the dementia patient in the acute setting. These include improving patient experience in hospital, better supporting family carers, enhancing communication, and decreasing adverse outcomes.

2. Introduction

Large numbers of older people are admitted to hospitals with dementia annually, with recent research from Ireland and the UK placing this figure at over 30% of admissions in over 70s (Timmons *et al*., 2015; Briggs *et al*., 2017). National and international research confirms that admission to an acute hospital can be both distressing and disorientating for the person with dementia and is often associated with a decline in their cognitive ability, levels of functioning, and quality of life (Bracken-Scally *et al.,* 2020; Ryan, 2013). People with dementia have complex needs, and their outcomes are often poorer than those without dementia. Admission to an acute setting can be both traumatic and debilitating for people with dementia and their families, with delayed discharge and adverse events common (Pierce, 2014). Internationally, Dementia strategies place acute hospital care as a critical objective. Many countries, including England, Scotland, Finland, Northern Ireland, Norway, and Australia, recommend specialist care for the person with dementia within this setting (Fortinsky, 2014). It is estimated that there are currently almost 65,000 people living with dementia in the Republic of Ireland. This number is expected to triple in the next 20 years, with many expected to require hospital admission each year (Cahill, 2012). The cost of acute hospital care for people with dementia in the Republic of Ireland in 2016 was almost €22 million (Timmons, 2016), with the current annual figure estimated at closer to €28 million. People living with dementia are a vulnerable population who experience substantially more extended hospital stays and require more nursing resources than similar patients without dementia (Mukadam, 2011; Rosvik, 2020). They are more likely to experience adverse events, including dehydration, falls, and malnutrition, and are more likely to be readmitted (Sampson, 2012).

The role of a Clinical Dementia Nurse Specialist can provide substantial input in the acute hospital setting to improve the hospitalisation experience for people affected by dementia and their families (Elliot & Adams, 2011; Griffiths *et al.,* 2015). An Irish scoping review of the CNS role in acute care found that a Dementia Clinical Nurse Specialist undertaking a clearly defined role can significantly benefit people with dementia in a hospital (Griffiths *et al*., 2015).

Results and recommendations from the most recent HSE National Clinical Audit on Dementia (iNAD2, 2020) reflect the need for specialist expertise in dementia care where the role of specialist staff is specifically highlighted:

> *"There should be suitably qualified and trained staff available within the hospital to support and advise on optimum dementia care within the hospital; this includes a wider team of dementia champions and one or more dementia specific roles. These latter roles should not be limited to nursing posts only"*

There are currently a limited number of Dementia Clinical Nurse Specialist roles in Ireland. However, the success of specialist nurses in other fields suggests that there is an opportunity for specialists in dementia to support the delivery of high-quality and safe care in hospitals (Doody & Bailey, 2011). The job description for the HSE-funded Clinical Dementia Nurse Specialists addresses many of the objectives and aims of national service delivery concerning the management of people with dementia within acute hospitals. The Dementia CNS role is specifically aligned to the targets of care for people living with dementia in multiple national clinical programmes and strategies such as the Integrated Care Programme for Older People, National Dementia Strategy, and the Irish National Dementia Audits. The roles also encompass key recommendations within the Slaintecare Action Plan in relation to improving safe, timely access to care, and promoting health & well-being, alongside the streamlining of care pathways, from prevention to discharge.

The aim of the CNS role is to deliver care in line with the five core concepts set out in the Framework for the Establishment of Clinical Nurse/Midwife Specialist Posts. The concepts are

- Clinical Focus
- Patient/Client Advocacy
- Education and Training
- Audit and Research
- Consultation

Encompassing these core concepts, the main specific focus areas of the nurse specialist role include: direct and indirect care; developing policies, pathways, and screening tools for use by hospital staff; detailed care planning and signposting of services; facilitating dementia training for other staff, as well as research and clinical audit of dementia services.

The literature highlights how focusing on these core areas can significantly impact the hospital experience for patients and that the potential return on investment from even modest reductions in length of stay can be high (Jokiniemi, 2023; Doody, 2021). This is further supported by the National Clinical Audit on Dementia- iNAD2 (Bracken-Scally *et al.,* 2020), where detailed recommendations for the provision of quality, safe, and accessible clinical care in the acute setting describe the use of specialist staff and appropriate training as key enablers.

The Dementia CNS remit also sits well alongside the core principles contained in the recently published draft Model of Care for Dementia. The MoC addresses the needs of all people with suspected dementia or living with dementia, and sets out pathways of care that are underpinned by the following key areas – citizenship, person-

centred approaches, integration, personal-outcomes and timeliness. The Dementia CNS and other specialist staff are important for the successful implementation of the MoC with the concepts of Clinical Focus, Advocacy, Education, Research and Consultation vital for the delivery of an integrated, person centred and timely clinical service.

This paper involved a brief review of relevant literature, policy, and evidence relating to international best practices on the role of dementia nurse specialists alongside qualitative data collection in the form of interviews and focus groups with key stakeholders to assess the benefits and challenges of the role, operational and logistical facilitators as well as barriers and considerations for further rollout. This mixed method approach identified several critical themes from the literature and the qualitative fieldwork, each of which is further explored with supporting quotes. A series of summary recommendations are also proposed.

3. Literature Review

An overview of the literature focusing on key challenges in dementia care identified several areas where Dementia Clinical Nurse Specialists can affect the most impact. The literature review is framed around the core concepts set out in the Framework for the Establishment of Clinical Nurse/Midwife Specialist Posts which was used to inform the Dementia CNS job description.

These include:

- Clinical Focus
- Advocacy and Signposting
- Education and Training
- Research and Audit
- Consultation

4.1 Evidence for Clinical Focus

International evidence suggests that the CNS role should have a strong patient focus and subscribe to the overall purpose, functions, and ethical standards of nursing within the Dementia care setting, participating in both direct and indirect care (Røsvik,2020). Direct care comprises assessing, planning, delivering, and evaluating care to the patient and family carer. In contrast, indirect care relates to activities that influence and support the provision of direct care. The literature also indicates that CNS roles can significantly assist in the provision of best practice and optimal care delivery to dementia patients (Fulton, 2019; Hennelly, 2017). The CNS role should provide a leading function in initiating and facilitating the implementation of evidence-based interventions that optimise the outcomes for people with dementia across the health service, particularly in acute settings (Abbott, 2022; Fulton, 2021, Spencer, 2013). These interventions often include multidisciplinary programmes of care, strategies for case finding and screening for dementia, and programmes focusing on patient safety, such as fall prevention and readmission reduction through redesigning care delivery. Clinical nurse specialists are also critical in planning, designing, and implementing care and treatment plans and protocols to optimise patient outcomes.

Consensus on the areas of patient care that can deliver the most impact in acute settings is currently mixed, but there is a body of expertise relating to the role of specialist nurses in developing strategies for communicating effectively with people with dementia (Spencer, 2013) alongside advising on many aspects of environmental design that are likely to improve the experience of older people in an acute setting (Brook, 2019 & Goldberg, 2014). Within the context of the provision of clinical care, there is a broad range of identified areas where the CNS can improve the hospitalisation experience for the dementia patient, and these include; improving

assessment services, identifying dementia-specific risk factors in the hospital environment alongside individual indicators of distress, providing dementia specific support, consultation, and assessment in settings such as A&E, clinic, ward and pre and post-operative units (Griffiths 2015; Dewing & Dijk, 2016) all of which can all be enormously beneficial. The CNS's role in reviewing medication and the timely referral to liaison psychiatry and other allied health services is also key.

4.2 Evidence for Advocacy and Signposting

The CNS role involves communication, negotiation, and representation of the patient and their values and can be instrumental in supporting the decision-making process in collaboration with other healthcare workers and dementia supports. The responsibility of the CNS to offer signposting and support for patients and families to allow people living with dementia to navigate their journey in an empowering and dignified manner is essential (Jeavons, 2018; Hagan, 2020; Larkin, 2022) The Dementia CNS has a significant function in the promotion of health literacy for clients, liaising with multidisciplinary teams and supporting people living with dementia to understand their condition and planned treatments so that they can participate in decisions about their health needs in an informed and supported manner. All the evidence points to the essential role of nurse specialists in developing and supporting the concept of advocacy, particularly in relation to patient participation in decision-making, thereby enabling informed choice of treatment options (Jokiniemi, 2021).

Patient-centered care is the cornerstone of providing excellence in dementia care, with the nurse specialist playing a huge part in empowering the patient and in maintaining the privacy, dignity, and confidentiality of the patient and their family. The CNS can help establish, maintain, and improve collaboration and cooperation between Acute Services, Primary Care and Voluntary Organisations and are ideally placed to proactively challenge any interaction which fails to deliver a quality service to patients (De Flon, 2012; Hughes, 2019).

A study from the UK (Elliot & Adams, 2011) evaluated the role of the dementia clinical nurse specialist an acute hospital setting. The main priorities and focus areas identified included staff training on dementia alongside advocacy and signposting of good quality information for people with dementia and their family carers, thereby improving the hospitalisation experience for people with dementia. This analysis describes the importance of a 'Person-Centred' approach when caring for people living with dementia, especially in a hospital setting. This involves valuing and respecting the dignity of people with dementia and treating them as individuals, and trying to see the world from the perspective of the person with dementia. The nurse specialist is essential to this person-centred approach, in that their specialist training and knowledge can enable any behaviour or procedure that do not respect these values to be challenged, such as inappropriate

sedation or restraint. The CNS plays a vital role in creating a dementia aware environment, as well as developing policies and pathways to care for these vulnerable patients.

4.3 Evidence for Education & Training

Elliot & Adams (2011) describe the critical role of the Dementia CNS in education and training, while the literature also suggests that nurse specialists sustain clinical competence in patient management by keeping up-to-date with relevant research to ensure the implementation of evidence-based practice (Doody, 2022). It is essential that the CNS role involves a remit for education and training, including both structured and impromptu educational opportunities to facilitate staff development and patient/service user education (Palmer, 2014). CNS roles are integral to the education and training of other staff within acute settings (Schindel Martin, 2016). This is both in relation to assessing the educational needs of dementia care provision across staff groups, as well as in the design, delivery, and evaluation of staff education material. The CNS plays an important part in the implementation of evidence-based interventions that optimise outcomes for people with dementia across the health services, alongside introducing best practices to colleagues through collaboration and participation in patient care (Fulton, 2021).

The majority of nursing and care staff have only a basic understanding of the complexities of caring for dementia patients and do not exhibit the specialist knowledge and skills required (Tadd, 2011). Targeted evidence-based training around dementia care contributes positively to patient experience at all levels, from basic awareness training for the majority of staff who come into contact with people with dementia, to more comprehensive training for qualified staff and others who frequently provide care. This is further supported by the recommendations of iNAD2 in relation to the importance of staff education and training.

> *"Each acute hospital has responsibility for developing a training and knowledge strategy to ensure all staff receive training in dementia awareness and that a cohort of staff receive more in-depth dementia training.*

The Dementia CNS is critical in the provision of educational interventions that are multi-faceted, focused and supplemented by additional supervision to deliver the best outcomes. Tailored feedback on performance is found to be the most effective way to support change in professional behaviour and improvement of patient outcomes (Ivers, 2012). With that in mind, the role of the dementia CNS in education provision should focus on providing educational opportunities that include role modelling best practice to colleagues through collaboration and participation in patient care, alongside audits of practice and individualized feedback to non-specialist staff. The CNS also has a role in helping patients and their families understand their healthcare needs in relation to dementia and its effect on other health conditions and treatments (Chick, 2012) The provision of appropriate information

and other supportive interventions to people living with dementia and their families should increase their knowledge, skill, and confidence in managing their dementia, thus empowering them to actively participate in the management of their condition.

4.4 Evidence for Research & Audit

Audit of current practice and the evaluation of improvements in the quality of patient care are essential requirements of the CNS role. The use of evidence-based research to inform both service delivery and clinical practice is an crucial tool with any outcomes of audit and/or research important to improve and develop service provision and care pathways for Dementia patients (Kinley, 2019; Smith, 2019; Sykes, 2023).

The CNS role should also guide the assessment of the effect of education and training programmes and support change through audits of practice and individualized feedback. Establishing and maintaining a register of patients and a record of clinically relevant data aligned to national KPIs may be useful, alongside conducting multi-disciplinary audit and research. However, it is essential to balance having a practical clinical audit function within the role and the over-collection of metrics and data that may not be useful for improving service delivery.

The crux of a specialist role is in the identification, analysis, dissemination, and integration of sound clinical evidence into the field of dementia care, thus contributing to improved service planning through the use of audit data and specialist knowledge. Audit results and research findings can help to identify areas for quality improvement in collaboration with nursing/midwifery management and MDT colleagues both in the acute and community settings (Begley, 2015).

4.5 Evidence for Consultation

Inter and intra-disciplinary consultations across both sites and services are recognised as critical functions of the CNS role. This consultative role also can contribute to improved patient management as well as better societal awareness of dementia (Martin, 2020). The contribution of a nurse specialist in dementia in supporting and enhancing care provision for dementia patients in acute settings is paramount. The CNS provides leadership in clinical practice and acts as a resource and role model for specialist practice with other staff, contributing to the development of clinical standards and guidelines for dementia care and using their specialist knowledge to support and enhance clinical practice for dementia patients within their service.

In developing collaborative working relationships with local MDT colleagues and in engaging and planning community support, a more person-centered care pathway is achievable. (Cheong, 2021; Rutten, 2021) The consultation function also involves liaison with other health service providers in the development and ongoing

delivery of the National Clinical Programme model of care for Dementia, to improve service delivery and outcomes for patients accessing dementia services in acute settings.

The evidence also suggests that simple changes to the hospital environment can greatly improve the hospital experience for dementia patients and potentially have a huge impact on patient satisfaction (Grey, 2018). The Dementia CNS is instrumental in providing consultation on appropriate environmental and infrastructure change in order to deliver improved dementia care.

4.6 Budgetary Considerations

For illustrative purposes, a simple scenario is presented based on the assumption of placing one CNS in every acute hospital (not including maternity or paediatric, n=35).

We propose a clinical nurse specialist at level 5 on the HSE pay scale for nurse specialists (mid-range) and include pension, income tax and average annual training costs. The potential annual cost of providing thirty-five dementia nurse specialists to have one whole time equivalent per acute setting, is less than €3 million.

Annual salary CNS (mid-scale, L5)[1]	€59,597
Annual cost (inc pension and income tax)[2]	€77, 923
Annual Training Costs[3]	€2,000
Annual Salary and Training Costs [4]	€80,000
Number of acute hospitals	35
Total annual Budget required	€2,800,000
Recommended # of cases per CNS [5]	300
Cost of annual admissions of patients with dementia[6]	€28,000,000

1 HSE Pay scale CLINICAL NURSE SPECIALIST (GENERAL): 55,248 - 65,316 (9 points)

2 Pension estimated @20% plus 11.05% PRSI etc.

3 Based on NMBI average annual CPD cost (5 days training and 1 conference attendance)

4 Rounded up for illustrative purposes

5 Royal College of Nursing, 2010 & Elliot 2011

6 Extrapolated from figures in Timmons, 2016

4.7 Summary

The role of specialist nurses in providing improved care for people with a variety of long-term conditions is well documented (Doody, 2021; Fulton 2021). The depth and breadth of the CNS role covers many areas of

impact in dementia care provision, including direct care, consulting with other staff, and supporting education and practice development.

The benefits of nurse specialist input can be far-reaching with the potential impact to improve patient outcomes, family satisfaction and health economic burden. The provision of quality care to people with dementia in hospital presents a significant challenge; however, the Dementia CNS role is a critical element in the ongoing drive to improve Dementia services. The success of specialist nurses in other fields presents an opportunity for specialists in dementia care to support their nursing colleagues and others in delivering high-quality and safe care. (Comiskey, 2014; Sanchez-Gomez, 2019). These opportunities involve improved care coordination and communication within the hospital team and with people with dementia and their carers.

While detailed metrics for current roles are not yet available, there exists significant evidence in the literature to indicate that these roles can deliver substantial improvements for people with dementia and their family carers in acute settings. The qualitative evidence also describes the positive impact of specialist nurses in supporting and improving the care of people with dementia and the impact of such care in improving the hospital experience. Previous research (Royal College Nursing, 2010; Elliot & Adams, 2011) indicates that there should be at least one whole-time equivalent dementia specialist nurse for every 300 hospital admission for people with dementia per year. It is vital to understand the wide range of potential 'demands' on the CNS and the impact this could have on any measurable benefit to the patients they care for. Strategic goals and quantifiable KPIs are important, and prioritisation should take place in conjunction with existing stakeholders, resources, and services to avoid isolation and duplication.

4. Methodology

The first component of this initiative comprised of a desk based rapid review of relevant literature, policy and evidence relating to international best practice on the role of dementia nurse specialists. The literature was examined within the framework of the five core competencies of the CNS role, and evidence for each element was presented. The desk-based analysis also included a summary of the budget requirement to roll out Dementia Nurse Specialist roles in every acute hospital in the Republic of Ireland.

This second part of this initiative sought to capture the experience of staff, patients' and family carers around the role of Dementia CNS in acute settings. The aim of this insight gathering was to build knowledge around the role and utility of Dementia CNS in Ireland. Patient and staff knowledge is central to improving clinical service delivery and this initiative provides a voice to those who have had direct experience of dementia care in acute settings, and may be helpful in supporting the future development of dementia services. We sought to understand how the CNS role is currently working, the perceived benefits of the role, and how to build on it from the perspective of key stakeholders. It is hoped that the insights generated from this engagement may assist policymakers to steer policies in a direction that is rooted in how people experience the CNS role in practice and how they understand the perceived benefits and positive impact.

The qualitative approach to insight gathering utilised a combination of interviews and focus groups. We established lines of communication with key stakeholders, as identified with the ASI team in the stakeholder mapping process for scheduling of meetings and set up a series of online meetings. The insights gathered from the stakeholder engagement phase were examined and collated to reflect the depth and breadth of information. The gathered data was collated to build a robust evidence base for the value and utility of the role of nurse specialists in dementia care.

It is important to note that the themes and findings from this report should be read as qualitative insights from a limited number of interviews. The sample was drawn from a range of settings and experiences but is based on volunteers and is relatively small. The inclusion of the patient/service users' voice is to bring a practical sense of how they experienced dementia care in an acute setting. We have presented these personal accounts as suggestions for what is working well and what could be improved based on their feedback.

The staff interviewed, who are working within the hospital system, similarly expressed where they see the CNS role as being useful and, in some cases, where they would like to see improvements made. We do not see this

research as an assessment of the success of current posts but more as an opportunity for patients and staff to share their views and experiences, to outline what they see as important and what could be focused on in the future to improve dementia care in acute settings. The data and views collected provide empirical evidence as to the success of the current roles and reinforces the need for expansion of the role and further investment into Dementia Clinical Nurse Specialists.

5. Results & Discussion

6.1 Themes Identified

Interviews and focus groups were reviewed in depth to identify indicative themes that illustrate attitudes and behaviours that currently are held by patients and staff around the dementia CNS role. Patient experiences tended to be more emotive and personal, while staff interviews were generally more focused on broader systems and staff support. While not exhaustive, the views were captured from a wide variety of sources that have direct experience of dementia care in acute settings or are involved in the treatment and care of dementia patients or work in the surrounding care systems.

The interviewing took place during the Spring of 2023, but many of the patient stories related to a timeframe where COVID-19 was prevalent (2020-2022). This may have impacted the ability of staff to communicate with both patients and family members and as such, impacted the care experience in hospital. Overall, the team spoke to 26 people, 15 patients or families of patients, and 11 staff who are involved in the delivery of dementia care within their role as healthcare workers.

The range of themes that emerged is included in table 1. To indicate the frequency of a theme, we have used a descriptive approach that would be suitable for both the patient and staff interviews. Where most of the interviews mentioned a theme, we have marked it under “All/Most,” and this language is used in the report. If 2-3 patients or staff mention a theme or issue, we mark this as “some,” and where only one person mentions something, we will say “one person” or “one interviewee.” In the case of staff, while one person may mention a theme, it may still be worth noting, given their expertise or broader knowledge of the system.

Table 1: Summary of Themes & Frequency

Participant Group	Theme	Sub-theme & Frequency
Staff	Clinical Focus	● Breadth of CNS job description could be refined -**ALL** ● Flexibility required to prioritise focus areas for local requirements -**MOST** ● Role of allied health in acute setting to assist support of patients -**SOME** ● Prioritisation of hands-on care and effective communication vital -**MOST**
Staff	Education & Training	● Improved education and training of non-specialist staff essential -**ALL** ● Specialist roles can cause siloing of responsibility in some settings and deskilling of general staff -**SOME**
Staff	Dementia Awareness	● Societal awareness of dementia is poor -**MOST** ● Impact of hospitalisation on dementia patients, often very negative -**ALL** ● Burden on carers and families -**ALL**
Staff	Existing Infrastructure	● Size and type of acute setting can impact the effectiveness of the role -**MOST** ● Locally available supports impact care -**MOST** ● Simple environmental changes can improve hospital experience- **MOST**
Staff	Community Support	● Importance of integrated working / Liaison and support back to the community - **ALL** ● Workable link to GPs/Nursing homes etc. -**SOME**
Staff	Environmental Changes	● Improvements to environment -make acute setting safer and more dementia friendly -**MOST** ● Simple changes to infrastructure can have a considerable impact- **MOST**

Patient	Advocacy & Support	• Signposting and support a vital tool for empowering patients and carers -**ALL** • Specialist support needed to discharge home no worse than on admission -**MOST** • Provision of supportive care that considers dementia diagnosis -**MOST**
Patient	Specialist Care	• Dementia patients are unique and acute care needs to reflect this- **ALL** • Dedicated infrastructure and staff who understand the complexities of the condition -**SOME**
Patient	Education & Training	• Prioritise education and training of non-specialist staff to ensure respect and dignity at all times -**ALL** • Staff awareness, useful tool to empower patients and families -**SOME**
Patient	Communication	• CNS is effectively a translator for the dementia patient -**SOME** • With understanding comes empathy, a person-centered approach is essential **-MOST**
Patient	Practical Help	• Role of CNS in providing practical support around self-care, mealtimes, medication, environment -**SOME** • Planned vs emergency admissions bring different challenges – **SOME**
Patient	Acute environment	• Dementia-friendly initiatives to assist patient experience -**MOST** • Many issues arise from the hospital environment itself, but simple changes could greatly alleviate this -**MOST**

6.2 Discussion of results

The evidence from our qualitative data gathering exercise was examined to explore how the role of the dementia clinical nurse specialist in the acute setting impacts on people living with dementia and their family carers.

Thematic analysis of the interviews was performed and several dominant themes emerged, which are very much in line with those emerging from the literature. We have included some quotes from the interviews as relevant and have anonymized the responses to protect the identities of the participants.

6.2.1 Clinical Focus & Breadth of Role

The CNS role was seen as an overwhelmingly positive support for staff, patients and family support networks.

> *"Having access to a dedicated CNS meant less stress and less worry for us knowing that mum had someone who knew how to help her"*

> *"The CNS changed the whole trajectory of my husbands care, and the impact was so significant, it just turned everything around"*

> *"The CNS is a vital role as so many issues arise with dementia patients from just being in hospital, a specialist support can really help us all to have a better understanding on how to clinically managed the dementia patient in the most appropriate way"*

For the maximum impact and benefit to patients, the concept of flexibility and autonomy in the role is seen as important, so that hospital teams can identify local needs and gaps in service and supports in order to prioritise key focus areas for attention. This type of pragmatic approach allows acute settings to refine and tailor the scope of the role to the scale and complexity of the individual hospital setting, taking into account other available supports and services.

The CNS can then draw on existing mechanisms and interventions known to have a beneficial effect in improving patient and family experiences, thereby optimising patient outcomes, including reducing length of stay and preventing adverse events. The clinical focus of the role should concentrate on the more complex cases, thereby facilitating non-specialist upskilling and creating improved awareness around best practice in dementia care. Their reduced capacity to deliver one-to-one patient care must be explicitly recognised.

It is essential to be mindful of the potentially wide range of 'demands' on the Dementia CNS and the potential that are too overburdened to have any measurable benefit. This must be understood and mitigated by clearly defining the scope of the role locally. Strategic goals must be clear, the appropriate levers of action identified and the required structures must be in place to facilitate success.

> "*The more people trained in dementia care can only be of benefit to the dementia patient; however, while the potential impact of the CNS role is huge, I would argue that it needs a singular focus and appropriate support"*

> *"One individual cannot plus 15 holes, there is just so much to do and we need to prioritise areas in order to have the most impact"*

Local flexibility can help mitigate the perceived challenge concerning the breadth and scope of the role. Some staff felt that the current scope is too broad and may negatively influence the potential impact of such roles. The five core components of Clinical Focus, Advocacy, Consultancy, Education & Training, and Research & Audit involve multiple tasks and priorities, and local ranking and prioritising of such tasks could be important while taking into account other available staff, supports and services.

6.2.2 Education & Training

The importance of improved education and training of non-specialist staff was identified as a critical area, and the role of the Dementia CNS in this is seen as essential to this. The hospital environment is especially detrimental to the dementia patient, and staff awareness on managing and caring for this vulnerable population is generally low.

> *"We have an aging population, but we don't really know how to care properly for our older citizens; the nurse specialist could play a vital role in changing this and improving awareness of how the dementia patient has different needs."*

> *"The art of effective communication with a person living with dementia and their carers is a vital tool in our care arsenal. If we as nursing staff can communicate effectively, it can be far-reaching."*

> *"We need to train and upskill our non-specialist staff on how to communicate effectively with the dementia patient; it is the most important quality, the science you can teach."*

The dementia CNS is perceived as the gatekeeper of dementia care with a significant role in educating staff, developing improved pathways, and increasing awareness. In relation to education and training, it is important that specialist roles do not cause siloing of responsibility in some settings, whereby deskilling of non-specialist staff can occur, so it is particularly important that continuous training and professional development is prioritised. Additionally, the limitations of educational interventions must be acknowledged so that increased awareness and behaviour change are delivered via role modelling practices and the provision of targeted feedback on performance to non-specialist staff.

> *"It is a bit like infection prevention control; you don't want the responsibility to lie solely with the dementia CNS; we all need to be able to manage the dementia patient."*

From the patient's perspective, the education piece is important for the development of person-centered care and to ensure respect and dignity at all times.

> "*Some staff are not patient or understanding, and it was so distressing for me to leave my mum in that environment."*

> *"I have had really amazing support on my journey so far from people who truly understand my condition".*

> *"The CNS saved my husband, and the impact of her support enabled him to come home to me and not to a nursing home; I will never forget that.* "

6.2.3 Dementia Awareness / Specialist Care

Societal awareness of dementia is generally poor and there is little understanding of the condition and the impact of hospitalisation on the dementia patient. There is a huge burden on carers and families of those living with dementia, particularly when they are admitted to an acute setting. The impact of the pandemic further exacerbated this issue as visiting was severely impacted.

The role of the CNS in increasing awareness of how best to assist patients with dementia is paramount. Dementia patients are unique and acute care needs to reflect this by providing dedicated infrastructure and staff who understand the complexities of the condition.

"Dementia patients in the hospital need to be seen as special; they have complex needs and need specialist understanding and specialist care."

"Who is advocating for the person with dementia when their carer is not with them? They cannot advocate for themselves; they need help."

A dedicated and skilled practitioner who can advise and support staff in caring for dementia patients is crucial. The impact of this is potentially far-reaching and improves the experience for the patient, their families, and the wider community.

"*Having someone there who understands his condition when I'm not there to be his voice, I worry so much when I'm at home and away from him. If the CNS can help all the staff to understand his needs better, that would be amazing."*

6.2.4 Acute Setting

There has been huge strides and advances in the provision of dementia care in the last 10 years due to both targeted clinical focus and planning, alongside investment on foot of the national dementia strategy and expansion of the integrated care programme. Geographical inequities in service provision, both in the acute and community setting, still remain, but green shoots are appearing.

"Rural communities used to be seen as at a huge disadvantage, but thankfully over the past 10 years, things have improved drastically; both acute and community services recognise the need for specialist staff, which can mean a wider team of dementia champions, alongside dementia specific roles"

The utility of dedicated dementia CNS roles in acute settings can assist in the implementation of dementia-friendly initiatives to assist patient experience. This is particularly evident in more peripheral settings where locally available allied health supports such as access to physiotherapy, OT, and dietician support can be less accessible than in larger hospitals.

"*The size and type of acute setting can impact the effectiveness of role, in larger more well-resourced sites although the caseload is higher there is greater access to support services, and so we need to be mindful of this".*

Better integration of CNS roles with community support and effective communication could help improve the impact and reach of the service, embedding the role as a vital tool for dementia care.

6.2.5 Dementia Friendly Infrastructure

Simple changes to the hospital environment can greatly improve the hospital experience for dementia patients and potentially have a huge impact on patient satisfaction. The CNS plays an important role in implementing such changes.

> "*The nurse specialist can help other staff become aware of the small changes to the hospital environment that can make a huge difference to patients with dementia in acute care."*

> *"Simple things like clear signage, removal of clutter, softer lighting, less noise, colour coding of doors, etc. all can have a huge impact, and they are cheap and easy to implement."*

We can make the acute setting safer and more dementia friendly with simple, effective, and practical changes that do not require huge budgets or staffing to implement. Nurse specialists have been instrumental in implementing this type of practical support around changes to infrastructure, resulting in vastly improved experiences for the dementia patient.

> *"Just having a dedicated space in the ED for people presenting with cognitive issues; doors, signage, white-boards where basic information can be communicated."*

> *"I've had really good support, especially when I've been admitted to hospital for other medical stuff. The CNS in the hospital I attend has gone over and above to make sure I'm understood……. its simple things like a whiteboard beside my bed with all my details "*

6.2.6 Community Liaison

To have the maximum impact, the dementia CNS in acute hospitals needs to coordinate their efforts and integrate their service with existing services, both in the hospital and community. The importance of integrated working and liaison and support back to the community cannot be underestimated, including developing workable links on discharge back to GPs/Nursing homes, local Dementia advisors etc.

Ireland has a well-developed network of community support and services for dementia. Medicine and psychiatry for older people, and existing liaison services, are crucial resources, as are other community-

based services such as memory assessment clinics and integrated care pathways. Rather than just direct follow-up with patients or family carers, the CNS can help families to understand how to access the correct support on discharge. It is not suggested that the CNS takes on an additional role in the area of community care coordination but rather acts as a gatekeeper to help signpost to appropriate community services to ensure a successful handover.

It is important to avoid isolation and duplication, and roles should be developed in conjunction with stakeholders, taking into account available resources and services.

> **"***We need a singular service that is connected across all areas of persons care, so it is important to consider where these CNS roles sit within the wider acute and community service."*

> *"The Dementia CNS can be a champion of excellence in dementia care, helping the patient to live well for longer and helping to understand what may be needed on discharge"*

6.2.7 Advocacy & Support

Signposting and support are both vital tools in the package of care for patients living with dementia. This is both for the patients themselves and for their families and carers. The provision of supportive care that fully takes into account the dementia diagnosis, particularly in the presence of other medical issues, can be highly impactful. The dedicated nurse specialist can serve as a dementia champion in the acute setting, helping to provide a holistic person-centred approach to dementia care.

> *"Specialist support for the dementia patient in hospital can be really powerful in making sure that the person is discharged home no worse than on admission."*

> *"It would be great to have access to someone who knows my condition, my diagnosis, my history, and how this can make any stay in the hospital challenging."*

6.2.8 Communication

Both staff and patients overwhelmingly flagged the issue of communication as a potential barrier to excellence in dementia care. The dementia CNS plays a huge role in overcoming the challenge of poor communication for staff, patients and families.

"*If you think about it, the nurse specialist is effectively a translator for the dementia patient; we speak a different language and often need someone who truly understands our condition to translate…..to help our voice to be heard.*"

Effective communication facilitates understanding and empathy for the person living with dementia so that a person-centered approach can be taken to empower patients and families on their journey. Having specialist staff who understand the complexities of the condition and who can effectively communicate and provide supportive care is a crucial tool in improving and enhancing communication strategies for the dementia patient. The Dementia CNS has the skill, expertise and aptitude to take on the translator role and to advocate and communicate appropriately for the dementia patient in hospital.

"The CNS can act like an interpreter to tell the patients story with empathy and compassion so that we understand, as often their voice is not heard"

"CNS support was so empowering for me, someone who understood me and my challenges and who could help me access the care that I needed"

6. Concluding Remarks

The literature review and qualitative data collected has clearly demonstrated the value and utility of the Dementia CNS role for people with dementia in hospital. Given the complexity of the management of dementia care, a multidisciplinary approach is often required, particularly during an acute admission where people living with dementia may require access to a number of specialist services. The Dementia CNS can provide appropriate support and advice on optimum care and how to assist and manage patients with dementia in an acute setting. Based on hospital-level INAD-2 data, Dementia-specific nurse specialist roles are crucial to improve the provision of dementia care and in the implementation of other national guidelines relating to acute hospital dementia care. If the benefits of specialist support addressed even only a fraction of the potential adverse issues of hospitalisation, such as excess stays, readmissions, falls, etc, a very significant return on investment could be obtained.

> "*The cost of resourcing a CNS role is much cheaper in the long run than the cost of dementia care in the acute setting, a cost which will continue to rise with our aging population."*

Investment in Dementia CNS roles could have a significant impact on patient experience, staff retention and of course the obvious financial impact of reducing adverse events associated with extended hospitalisation of the dementia patient.

> "*The CNS who understands the nuances of dementia care can help get the patient home in at least as good a condition as on admission, enabling them to live well for longer."*

The role of the Dementia clinical nurse specialist is well supported from a practical point of view, especially from the patient/ family carer perspective.

> "*The CNS was so kind; they had huge awareness of my husband's dementia need and provided such compassionate care. It had a hugely positive impact on his recovery from surgery".*

However, it is important to understand that this point of view can potentially be skewed by other negative experiences of the health system.

> *"We must be cautious of interpreting or over-relying on positive feedback from families, as it often comes on foot of a negative experience in other settings"*

The introduction of a number of senior nursing roles at the hospital group level to coordinate quality improvement around dementia care is thought to be an additional positive step in the roadmap for Dementia services. This senior clinical leadership will further embed and enable the CNS roles in supporting the education of non-specialist staff and developing care standards across the service.

Careful consideration needs to be given to the number of CNS required within the acute setting to have maximum impact. A Royal College of Nursing 2010 report suggests a target caseload of 300 patients per year, and this is reiterated by the work of Elliot & Adams (2011), however, the size and complexity of the acute setting should also be considered.

> *"I think you could argue that larger tertiary centres with 25-bed ICUS could have multiple CNS roles; they can see around 1500 known dementia admissions annually, so, in reality, it is even more, whereas some units are too small to warrant a full-time nurse specialist, but they could share a resource with another peripheral site."*

> "*We also need to think about diagnostic pathways and how dementia is presenting in acute settings, many patients are already diagnosed on admission, but there are many situations where patients are going under the radar as staff are not recognising the condition; I think this is really where the CNS can help.*"

The evidence base suggests that much of the benefit for patients results from the active identification of cases, thereby initiating appropriate care. However, if cases are identified, and specialist care is not forthcoming due to a lack of awareness or understanding, then less can be achieved for the patient. The CNS is integral to ensuring that any treatment takes into account the dementia diagnosis so that care is delivered in an appropriate and supportive manner.

There is some suggestion of a need to move beyond a broad job description towards a more specific 'role' with a narrower scope and a more clearly defined range of services to facilitate the practical needs of people with dementia (Wood, 2020; Sanchez, 2019). Flexibility around the role in different acute settings and locations may be critical to successful implementation in that Urban vs. Rural, Tertiary Centres vs. Peripheral Hospitals may have different requirements for dementia support within acute service provision. The ever-growing patient population with dementia in many hospitals also suggests that a single Dementia CNS will be unlikely

to make a difference for all patients with dementia within the setting, and serious consideration needs to be given to where the CNS sits alongside other available dementia supports and services.

In conclusion, this research identified several key areas where the clinical nurse specialist role can positively impact the dementia patient in the acute setting. These include improving patient experience in hospital, better supporting family carers, enhancing communicating and decreasing adverse outcomes. This is further emphasised by the qualitative evidence gathered for this report, which suggests that current CNS roles are beneficial to patients and family carers and further investment should be prioritised.

7. Key Recommendations

Both the literature and the qualitative data gathered for this exercise present a strong case for further investment in Dementia CNS roles. While no formal KPIs are available to date to measure the impact of the Dementia CNS role from a health economic perspective, there is sufficient qualitative evidence to suggest that nurse specialists working in the acute setting deliver substantial benefits for people with dementia and their family carers. This is further consolidated by international best practice as described in the literature. Following on from this insight gathering exercise, several key recommendations are proposed to maximise on existing investment in current roles and suggesting further investment in additional roles to develop dementia services and deliver excellence in care for people living with dementia and their families.

Recommendation 1: Invest in Dementia Clinical Nurse Specialist roles.

The role of the CNS in improving patient care and the overall hospital experience for people living with dementia is clear. The evidence collected from this exercise presents a comprehensive view of the practical experience of healthcare staff, patients and family support networks in relation to these roles and demonstrates a strong case for further investment in these important roles.

Recommendation 2: Prioritise the delivery of person-centred care.

Provision of specialist care that focuses on the needs of the individual and is delivered by the right professional at the right time should be prioritised to develop a more person-centred care approach. Advocacy and Consultation are essential elements in the provision of excellence in Dementia care and the CNS play a huge part in ensuring that the person living with dementia is viewed and treated as an individual with dignity and respect, and that their autonomy and personhood is at the centre of all care provision.

Recommendation 3: Invest in at least one Dementia Clinical Nurse Specialist for every 300 hospital admissions

The increasing population of patients with dementia in many hospitals suggests that in larger sites a single specialist nursing role with a dementia remit may be insufficient to make a measurable difference to all patients. International evidence suggests that one CNS be provided for every 300 hospital admissions of people with dementia per year, which suggests that sharing of roles in smaller acute settings and adding additional supports to larger sites should be considered.

Recommendation 4: Prioritise education and training in dementia care.

The CNS plays a vital role in the provision of educational and training to staff in order to support improved dementia services. Education of non-specialist staff to support behaviour change and improved dementia awareness is crucial and should comprise of role-modelling and provision of targeted feedback on performance.

Recommendation 5: Provide a flexible approach to the Dementia Clinical Nurse Specialist role.

Scope within the CNS role alongside local autonomy to prioritise key areas of need, based on existing infrastructure is essential. The CNS can positively impact the hospital journey for Dementia patients at multiple touchpoints in the acute setting. Capacity within the job description to prioritise local areas of focus is important to deliver best practice care for dementia patients.

Recommendation 6: Ensure that the Dementia Clinical Nurse Specialist roles are supported through structure and cooperation for ongoing measurable success.

It is important to address where the CNS roles sit within the wider dementia service in the acute setting. The introduction of senior nursing roles at the hospital group level to coordinate quality improvement around dementia care is thought to be an additional positive step in the roadmap for Dementia services. This senior clinical leadership will further embed and enable the CNS roles in supporting the education of non-specialist staff and developing care standards across the service.

Recommendation 7: Fully integrate and embed the Dementia Clinical Nurse Specialist role within existing services for dementia patients.

The Dementia CNS is integral to the provision of appropriate support and advice on optimum care and on how to assist and manage patients with dementia. The role of the CNS in ensuring care in hospital is delivered in a coordinated and integrated way should be further developed and refined taking care not to silo the responsibility to a single individual. A nurse specialist who is fully embedded within dementia services, supports and staff can effect the most change and benefit the most patients in acute settings.

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Appendix 1 – Methodology (expanded)

Methodology Framework

The methodology utilised for this project applied research, strategic design, and project management processes in three key stages: SCOPE, COLLECT & EXECUTE.

Phase 1 – Scope

An initial introductory meeting took place with the ASI team to agree on the project methodology as per the tender. It was agreed at this point that the project target was to speak to around 20 patients and staff and that this would be based on a best endeavour approach. The final number achieved was 11 staff interviews and two focus groups with patient/family carers totalling 15 participants. The kick-off meeting outlined approaches to recruitment, which would be in line with these guidelines and international best practice and are fully compliant with all ethical and GDPR (General Data Protection Regulation) considerations. At the kick-off meeting the ASI team outlined what staff interviews should be targeted, and some suggestions were made for specific expert interviews. The ASI team provided contacts of patients and family carers for a series of focus groups, all of whom are part of the ASI patient advocacy community.

The study team worked closely with the ASI Team to develop all relevant study documentation which is included in Appendix 2. Input from the ASI team facilitated the creation of a short patient information note outlining the project and why their participation was valued. The team also agreed a semi-structured interview guide, which was used to guide the conversation and outlined some key topics where information or experiences was sought. The guide was used to support rather than lead conversations and the interviewee's perspective and experience were the key guide in the conversations.

Phase 2 – Collect

Interviews and focus groups were conducted with staff and patient volunteers on MS teams. The discussion guide was designed to explore perceptions, experience and knowledge of the dementia CNS role, as well as obtain data to contribute depth and detail to an understanding of the context of the information obtained. Prior to interviews, all patient participants were asked to sign a consent form to be interviewed, a copy of which is in Appendix 2. This consent form outlines the purpose of the research and explains the format of the interviews. External support bodies were nominated to offer post-interview liaison and support as required.

The interviews were largely conducted online due to the preference of interviewees. In total, 26 participants took part in online sessions, with an average interview length of around 40 minutes. With the permission of

participants, the interviews were recorded via the relevant platform, and electronic transcripts were created. As per our GDPR agreement, all interview data is kept for the duration of the project and up to a maximum of three months.

Phase 3 - Execute

This study adopted a data analysis methodology based on the principles of thematic analysis. Thematic analysis is a qualitative data analysis method that involves reading through a data set, in this case notes from the interviews conducted, and identifying patterns in meaning across the data to derive themes. This meant that the thematic analysis emerges from what is being said and can be compared to predefined categories. Topics that are outside of the predefined themes were also included and built iteratively as the interviews progressed (deFarias, 2020). Initial coding was undertaken by the primary interviewer in the form of identifying key themes emerging during the interview and then on review of the recorded interview. A second member of the team reviewed the notes and themes identified by the interviewer, and together they created a list of key themes identified for both the patient and staff interviews.

The initial themes were listed, and then as subsequent interviews were undertaken the interviewer would identify consistent themes across patient or staff interviews. The interviewer also identified quotes or story elements that reflected or supported the theme. Once the interviews were complete, the team captured the key themes in a coding framework and tested them against all the interview data to identify how prevalent the theme was and if it was supported or contradicted by other data. We did not use a template for data capture; our approach focused on being interviewee led. The range of themes that emerged is included in Table 1. To indicate the frequency of a theme, we have used a descriptive approach that would be suitable for both the patient and staff interviews. Where most of the interviews mentioned a theme, we have marked it under “All/Most,” and this language is used in the report. If 2-3 patients or staff mention a theme or issue, we mark this as “some,” and where only one person mentions something, we will say “one person” or “one interviewee.” In the case of staff, while one person may mention a theme, it may still be worth noting, given their expertise or broader knowledge of the system.

In the case of this study, the very disparate nature of patient versus staff data led to separate coding. There were consistent themes emerging from the coding of both sets of data, with some small subthemes based on personal experience. These were very much aligned with the themes from the literature and those associated with the core functions of the role. On the staff side, the varying roles of the staff interviewed led to a variety of themes emerging and not all had the same level of supporting quotes or experiences. We highlighted themes that emerged based on what the interviewee felt was significant and based on their expertise and

knowledge of the area. In the case of the staff interviews, the content is relatively objective in nature. The prevalence of themes highlighted in the thematic analysis is a small sample and should be seen as indicative and not a formal evaluation of current roles. We have included quotes from the insight-gathering interviews and focus groups to emphasise any points that arose and were supported by a number of patient comments or experiences.

Appendix 2 – Study Documentation

Discussion Guide for Patients & Carers

Development of a briefing document on Case for Clinical Dementia Nurse Specialists in acute hospitals

Introduction

Hi my name is Liz Tully and I am part of the Xenon research team tasked by the ASI to examine service users experiences and understanding of the role of Clinical Dementia Nurse Specialists in acute settings. We want to accurately capture practical experience and personal perspectives so that we can improve Hospital care for people affected by dementia and better communicate hospital care needs with policymakers. Thank you so much for taking the time to talk with me today. Our session should take around 50 minutes.

Are you ok with me recording our chat? This is so I can make sure that we capture your opinions accurately, and so that I can concentrate more fully as you share your experience. The recording will only be used by our team for the purposes of this work, and will be destroyed afterwards.

All responses are confidential. When we report the insights from this session, we remove all names any personally identifiable information from the insights. We want to hear your personal story so please be as open as you want. If you feel uncomfortable at any stage you can leave the session.

Introduction to the topic

The Alzheimer Society of Ireland (ASI) is the leading dementia-specific service provider in Ireland, working across the country in the heart of local communities providing dementia-specific services and supports and advocating for the rights and needs of all people living with dementia and their carers.

The value of Clinical Dementia Nurse Specialists and the need for further investment has been widely highlighted by frontline staff, advocacy group members and members of the public affected by dementia. The ASI is committed to evidence-based advocacy and wishes to develop a deeper understanding of the value, costs, enablers, and barriers to investment in these roles and has commissioned Xenon Health Solutions Ltd (XHS) to produce a briefing document that explores the case for further investment in Clinical Dementia Nurse Specialist roles.

We want to chat with you today to better understand your personal experience of being a carer for someone with dementia who has been in hospital and the associated challenges and supports available.

It is really important for us to accurately capture your experience so that we can improve how we do things and find better ways of supporting carers and people living with dementia, particularly during hospital admissions.

Starting the session

I can see that you have already signed the consent form, thank you for that.
As I mentioned earlier, we'll be recording the session. We will start recording now.

Questions

Have you any questions so far? If you have any questions during the session please let me know.

Participant Details

Can I start by asking each of you to tell me a bit about yourself and your role ?

Story Capture

We would like to capture your experience of caring for a person living with dementia who have undergone a hospital admission.

We also want to capture your understanding of the role of clinical dementia nurse specialists in acute settings and to tell in your own words the benefits of any interactions you may have had.

We want to understand what you learned from your experience and what advice you would give family, friends and other people moving forward.

We want to capture your story accurately during this session, so I may ask some questions as you tell your story just to clarify the details, and understand what you are sharing.

In your role as a carer, have you had any direct interactions with a dementia CNS?

Would you like to share with us your experience in your own words?

(Listen out for or Probe on this at the end, let them lead)

- When did this take place ?
- Can you talk us through your journey?
- What was the value and impact of this interaction ?

For those who have not had direct experience and I appreciate the current roles are very new, so what do you think are the key supports such a role provides?

- Key Therapeutic work (interventions)
- Sharing information about dementia and carer issues
- Advanced assessment skills
- Preventative and health promotion
- Ethical and person centred care
- Balancing the needs of the carer and the person with dementia
- Promoting best practice

What are the main perceived value of such a role for carers?

- Main benefits/enablers

What do you think are the main expected impacts of such roles?

- Reduced LOS
- Reduced readmission
- Reduced falls

What are the main barriers/obstacles?

- Any challenges you envision?

Reflective questions

We're coming to the end our session now, and I just want to take a moment to reflect on the things we've discussed.

Are you happy that you have had an opportunity to share your experience accurately?

Is there anything that we discussed today that you'd like to talk about more?

Thank You

Thank you, this has been really informative, thank you for your time.

Your insights into the value of Clinical Dementia nurse specialists will be really helpful in informing best practice and developing future plans for acute settings.

PLAIN LANGUAGE STATEMENT & CONSENT FORM

Development of a briefing document on Case for Clinical Dementia Nurse Specialists in acute hospitals

Introduction

The Alzheimer Society of Ireland (ASI) is the leading dementia-specific service provider in Ireland. The ASI works across the country in the heart of local communities providing dementia-specific services and supports and advocating for the rights and needs of all people living with dementia and their carers. Our vision is an Ireland where people on the journey of dementia are valued and supported.

The value of Clinical Dementia Nurse Specialists and the need for further investment has been highlighted across The ASI's grassroots (i.e., frontline staff, advocacy group members, board members, and members of the public affected by dementia). The ASI is committed to evidence-based advocacy and wishes to develop a deeper understanding of the value, costs, enablers, and barriers to investment in these roles.

The ASI is commissioning Xenon Health Solutions Ltd (XHS) to produce a briefing document that explores the case for further investment in Clinical Dementia Nurse Specialist roles to provide The ASI with evidence and information to inform future advocacy activities.

We plan to speak to healthcare professionals, family carers and people living with dementia. Gathering the opinions and views from a wide range of stakeholders will help us to understand more about the potential impact of Clinical Dementia Nurse Specialists, and the barriers and facilitators to investment in these roles.

What does your participation mean and how will your information be used?

It is really important for us to accurately capture your experience and perspective so that we can improve Hospital care for people affected by dementia and better communicate hospital care needs with policymakers.

Data Retention

We will record each session for the purposes of analysing the results. The recording will only be used by the XHS team for the purposes of this work, and will be destroyed afterwards. All responses are confidential. When we report the insights from this session, we will remove all names and any personally identifiable information.

Potential Risks

Potential risks may include anxiety and distress arising from the topics discussed, misrepresentation or identification of participants. To mitigate these risks we have identified appropriate supportive follow up (if required) and will provide written information signposting to this information. We are adhering to the highest standards of confidentiality and data protection. Participation is entirely voluntary and written informed consent will be sought from each individual.

Benefits of Participation

Sharing your perspectives will help us to understand more about the potential impact of dementia nurse specialists in hospital settings. The data collected will be really helpful in informing best practice and supporting The Alzheimer Society of Ireland with their advocacy work.

Consent to participate – please tick box

• I voluntarily agree to take part in this research study.	
• I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind.	
• I have had the purpose and nature of the project explained to me and I have had the opportunity to ask questions	
• I understand that I will not benefit directly from participating in this research.	
• I agree to my interview being recorded.	
• I understand that all information I provide will be treated confidentially.	
• I understand that in any report my identity will remain anonymous. This will be done by changing my name and disguising any details of my interview which may reveal my identity or the identity of people I speak about.	
• I understand that if I inform the researcher that myself or someone else is at risk of harm they may have to report this to the relevant authorities - they will discuss this with me first but may be required to report with or without my permission.	
• I understand that signed consent forms and original audio recordings will be retained by XHS on a secure password protected server for six months and only members of the project team will have access to these records.	
• I understand that under freedom of information legalisation I am entitled to access the information I have provided at any time while it is in storage as specified above.	
• I understand that I am free to contact any of the people involved in the research to seek further clarification and information. ○ Point of contact – Dr Liz Tully, XHS ■ Email - liztully@xenonhealthsolutions.com ■ Telephone – 0876898144	

Please sign below if you consent to participate and to the data capture sessions being recorded.

PRINT NAME _____

SIGNATURE _____

DATE _____

THANKS VERY MUCH!
XENON HEALTH SOLUTIONS LTD