An Exploration of Nurse-Led Models of Cancer Care in Ireland: A Mixed Method Study

A thesis submitted in fulfilment of the requirement for the Degree of Master of Science (Research) at the University of Dublin Trinity College

2020

Snehal Prabhukeluskar

Supervisors:

Prof Anne-Marie Brady

Dr Amanda Drury

Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and it is entirely my own work.

I agree to deposit this thesis in the University's open access institutional repository or allow the library to do so on my behalf, subject to Irish Copyright Legislation and Trinity College Library conditions of use and acknowledgement.

I consent to the examiner retaining a copy of the thesis beyond the examining period, should they so wish.

Signed,

Snehal Prabhukeluskar

October 2019

Summary

Background

There has been a proliferation in nurse-led services within cancer care services in Ireland, but such developments have been ad hoc and the roles can vary both within and across services. Changes to nursing regulations have revolutionised the scope of professional nursing practice, increased nurses' autonomy and led to a higher level of advanced nursing practice, with many nurses running clinics and services independent of medical staff. The advent of non-medical prescribing has been a significant milestone, increasing nurses' autonomy, so they are enabled to provide comprehensive and holistic package of care for patients (Stenner & Courtenay 2008; Courtenay 2018). A significant number of nurses are now prescribing independently for patients, which has paved the way for more nurse-led clinics, with the potential for greater continuity and increased choice for patients, as well as meeting government and hospital targets (Stenner & Courtenay 2008; Farrell & Lennan 2013). However, despite advances in nursing practice and improvements in nursing legislation to support it, there is a current lack of clarity around nurse-led models of care, role definitions and agreed minimum competencies for nurse-led models of care, which may confuse patients, the public, and other healthcare professionals. Therefore, this study seeks to explore nurse-led models of cancer care in Ireland to understand current practice relating to nurse-led care.

Design

A sequential explanatory mixed method research design was used in this descriptive study. The first phase of the study involved a national quantitative survey of cancer nurses that explored scope, governance, and infrastructure to clarify the current status of nurse-led models of cancer care. This was followed by qualitative interviews with a sample of 11 volunteers from phase I of the study to explore nurses' perceptions of the benefits and impacts of nurse-led models of care, as well as the challenges and barriers for implementing these models of cancer care.

Findings

The main motives behind the development of nurse-led models of cancer care is to facilitate increased clinical demand, reduce waiting time, ease pressure on clinical service, extend doctors' capacity, and utilize specialist nursing roles to maximise quality of care for cancer patients. There is a wide variety of nurse-led services namely symptom management, treatment, and follow-up care. There is a wide variation in description with regards to nurses, including their grade, qualification, experience, and role description, suggesting different levels of autonomy and clinical practice.

The findings of this study add to the growing body of evidence on the benefits and impact of nurse-led models of care for service users and service providers. Nurses perceive themselves to be providing holistic

and integrated care within nurse-led models of care. The comprehensiveness of nurse-led models and continuity of care offered was seen to improve the patient outcomes and service.

The findings revealed various challenges and barriers to the development and successful implementation of nurse-led models of cancer care. Sustainability of nurse-led service is challenging due lack of provision for of cover for staff absence, lack of administrative support and poor structural planning prior to developing the nurse-led service. Explanations offered not being able to provide an equivalent service was the lack of appropriate trained nurses to provide cover. Nurses also reported a lack of support from hospital management, including nursing management. Nurses perceive the reason for this lack of support to be a lack of understanding of the nurse-led service. Nurses are seeking a structural pathway for the development and implementation of nurse-led models of cancer care.

Conclusion

Nurse-led models of care are an innovative approach to cancer care delivery, providing benefits to the service provider, as well as to the service user. The development of national and structured guidelines for the provision of nurse-led models of cancer care would be beneficial to successfully developing and implementing nurse-led models of cancer care. However, the absence of clear government policies to promote the development of nurse-led services, has contributed to the lack of guidance on scope of practice for nurses working in nurse-led models of care. As such, Planning should consider the logistics of developing a sustainable service including arrangements for cover within nurse-led services.

Acknowledgements

This thesis would not have been possible without the support of number of wonderful people. My sincere thanks to all of them for being part of this journey and making this thesis possible.

My special thanks to the Irish Association of Nursing in Oncology (IANO) and their members who gave their time to complete survey questionnaire and interview process without which this study would not have been possible.

My Supervisor, Professor Anne-Marie Brady, I thank her from bottom of my heart for her continuous support, wisdom and encouragement to complete this process.

My co-supervisor Dr Amanda Drury, I wish to acknowledge and thank her for her guidance and help in every step of this dissertation.

My husband Manoj, for his continuous and unparalleled love, support, constant encouragement and not to forget patience when times got rough are much appreciated and duly noted.

My mum Jayashree for her pride in whatever I do. For giving me opportunities and experiences that have made me who I am.

My forever thanks to my colleague and dear friend Catherine O'Brien, for her constant encouragement and keen interest during the course of this project.

My colleagues from HoPE directorate at St James's hospital: Mairead, Emma, Serena, Noreen and Mijella for their time and a large cup of coffee everytime.

Finally this thesis is dedicated to my constant source of joy and happiness, my kids Sejal and Chinmaya.

Table of Contents

Declaration ii
Summary iii
Acknowledgements v
Table of Contents vi
List of Tables x
List of Figures xi
List of Abbreviations xii
1. Chapter 1: Background and Significance of the study 1
1.1 Introduction 1
1.2 Cancer Care and Service Demands 1
1.3 National and International Perspectives 3
1.4 Nurse-led Models of Care 6
1.5 Summary 8
2. Chapter 2: Literature Review 9
2.1 Introduction 9
2.2 Literature Search Strategy 11
Identification 13
Screening 13
Eligibility 13
Included 13
2.3. Theme 1: Development of Nurse-led Models of Care 31
2.3.1. Professional and educational characteristics of nurses delivering nurse-led models of care 33
2.3.2 Approach used for care delivery of nurse-led models of cancer care 35
2.3.2.1 Nurse-led face-to-face clinics 35
2.3.2.2 Nurse-led Telephone Clinics 37
2.3.2.3 Nurse-led Combined Approach 39
2.3.3 Organisation of Care 40
2.3.4 Infrastructure Required to Support Nurse-Led Models of Care 41
2.4. Theme 2: Activities of Nurse-Led Models of Care 41
2.4.1 Follow-up 42
2.4.2 Symptom Management 42
2.4.3. Treatment Intervention 43
2.5 Theme 3: Outcome analysis of nurse-led models of cancer care 44

2.5.1 Clinical Outcomes 44
2.5.2 Functional Outcomes 45
2.5.3 Health system outcome 46
2.6 Chapter Summary 48
Research Aim and Objective 48
Chapter 3: Methodology Chapter 50
3.1 Introduction 50
3.2 Philosophical Underpinning - Pragmatism 50
3.3 Mixed Methods Research 52
3.3.1 Sequential Explanatory Mixed methods designs 52
3.4 Population and Sampling 54
3.4.1 Study Population 54
3.5 Phase 1: Quantitative Study 55
3.5.1 Phase I Survey 55
Phase 1: Questionnaire Validity and Reliability 58
3.5.1.1 Content Validity 58
3.5.1.2 Phase 1: Pilot Study 60
3.5.1.3 Phase 1: Recruitment 60
3.6 Phase 2: Qualitative Study 61
3.6.1 Development of the Interview Guide 62
3.6.2 Access to Interview Participants 62
3.6.3 Interview procedures 63
3.6.4 Rigor 64
3.6.5 Credibility 64
3.6.6 Transferability 65
3.6.7 Dependability and Confirmability 65
3.7 Integration of Methods 66
3.8 Ethical Considerations 66
3.8.1 Beneficence 67
3.8.2 Respect for persons 67
3.8.3 Informed Consent 68
3.8.3.1 Informed consent for Survey 68
3.8.3.2 Informed consent for Interviews 68
3.8.3.3 Justice 69
3.8.3.4 Confidentiality and Anonymity 69
3.8.3.5 Veracity and Fidelity 70
3.9 Data Analysis 70

3.8.1 Phase 1 Survey 70
3.8.2 Phase 2 Qualitative Data 71
3.8.3 Data integration 73
3.9 Summary 73
Chapter 4: Survey Findings 75
4.1 Introduction 75
4.2 Sample Characteristics 75
4.3 Nurse-led Service 77
4.3.1 Infrastructure 77
4.3.1.1 Administrative Support 77
4.3.3.1 Activities of nurse-led models of care 79
4.3.2 Scope of practice 84
4.3.2.3 Referral Mechanism 85
4.3.5.6 Discharge 87
4.4 Policy/Guidelines/protocol for nurse-led service 88
4.5 Future initiatives 90
4.5 Summary of findings 91
Chapter 5: Qualitative Findings 93
5.1 Introduction 93
5.2 Demographics 94
5.3 Theme 1: Development of nurse-led models of care 94
5.4 Theme 2: Benefits and impact of nurse-led models of care 97
5.4.1 Holistic Care 98
5.4.2 Professional and personal development 101
5.5 Theme 3: Barriers and Challenges of Nurse-led models of care 101
5.5.1 Lack of understanding of the nurse-led concept 102
5.5.2 Undefined Scope of Practice 103
5.5.3 Lack of administrative support 104
5.6 Summary of Findings 108
Chapter 6: Discussion and Conclusion 109
6.1 Introduction 109
6.2 Mapping of nurse-led models of cancer care in Ireland 110
6.3 Factors Influencing Development of Nurse-Led Models of Oncology Care 110
6.4 Scope, Governance and Infrastructure of Nurse-led Models of Oncology Care in Ireland 114
6.4.1 Nursing Roles 114
6.4.2 Training Undertaken in Preparation for Delivering Nurse-Led Models of Care 116
6.4.3 Modes of Delivering Nurse-Led Models of Care 118

6.4.4 Scope of nurse-led models of cancer care 119
6.5 Benefits, Challenges and Impacts of Nurse-Led Models of Oncology Care in Ireland 123
6.5.1 Benefits and outcomes of nurse-led models of cancer care 123
6.5.2 Challenges of nurse-led models of cancer care 126
6.6 Limitations of the study 127
6.7 Future Directions for Development of Nurse-Led Models of Oncology Care 128
6.7 Implication and Recommendation 129
6.7.1 Implications and Recommendations for Policy 129
6.7.2 Implications and Recommendations for Clinical Practice 131
6.7.3 Implications and recommendation for Future Research 131
6.8 Conclusion 132
Appendices 135
Appendix 1: Questionnaire 135
Appendix 2: Personal Correspondence: Request to Adapt Nurse-Led Clinics for Cancer & Palliative Care Questionnaire 152
Appendix 3: Criteria for Measuring Content Validity and Content Validity Score Sheet tool 154
Appendix 4 : Example of CVI Calculation 157
Appendix 5 : Letter of Invitation to Participants 158
Appendix 6 : Participant Information Leaflet for Questionnaire 159
Appendix 7: Reminder letter 161
Appendix 8 :Interview Guide 162
Appendix 9: Participants Information Leaflet for Interview (PIL) 163
Appendix 10: Interview Consent Information Form 171
Appendix 11: Ethical Approval 173
Appendix 12 Data Plan for Phase One 174
Reference 175

List of Tables

Table 1 PEO table to determine the development of the literature search strategy 12
Table 2 Search strategy: Concept Development Table 12
Table 3 Details of studies reviewed 15
Table 4 Demographics 76
Table 5 Absence Cover 78
Table 6 Scope of nurse-led service 79
Table 7 Activities of Nurse-led service 80
Table 8 Frequency of nurse-led services 80
Table 9 Training to equip nurses to deliver nurse-led service 81
Table 10 Audit and Evaluation of nurse-led service 82
Table 11 Functions audited and evaluated 83
Table 12 key performance indicator measured in nurse-led service 83
Table 13 Scope of Practice: Assessment 84
Table 14 Scope of practice: Diagnostic testing 85
Table 15 Scope of Practice: Inward referral to nurse-led service 85
Table 16 Scope of Practice: Outward referral from nurse-led service 86
Table 17 Scope of practice: Prescribing 86
Table 18 Scope of Practice: Decision making 87
Table 19 Scope of practice: Discharge 87
Table 20 Availability of policy/Guidelines/protocol for nurse-led service 88
Table 21 Policy/Guidelines/protocol for nurse-led service 88
Table 22 Frequency of peer review 89
Table 23 Competency Accessor 89
Table 24 Future nurse-led initiatives 90
Table 25 Overview of Main Findings 93
Table 26 Advantage of Nurse-led models of care 97
Table 27 The study aim and objectives 109

List of Figures

Figure 1: Illustration of the flow of information through the review to determine the number of studies identified at each stage using the PRISMA diagram 13

Figure 2 Sequential Explanatory Mixed method design (Adapted from Tashakkori & Teddlie (2010)) 53

Figure 3 Illustrates the survey distribution process 3.6 Phase 2: Qualitative Study 61

Figure 4 Process of thematic analysis (adopted from Braun & Wilkinson, 2003) 72

List of Abbreviations

ANP	Advanced Nurse Practitioner
ADON	*Assistant Director Of Nursing*
CNS	Clinical Nurse Specialist
DoH	Department of Health
EWTD	European Working Time Directives
HSE	Health Service Executive
MDT	Multidisciplinary team
NCNM	The National Council for the Professional Development of Nursing and Midwifery
NCCP	National Cancer Control Programme
NCRI	National Cancer Registry Ireland
NMBI	*Nursing and Midwifery Board of Ireland*
NMSD	*Nursing and Midwifery Service Director*
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
QOL	Quality Of Life
RCT	Randomised Control Trial
RARP	Robotic Assisted Radical Prostatectomy
UKONS	United Kingdom Oncology Nursing Society
WHO	World Health Organisation

1. Chapter 1: Background and Significance of the study

1.1 Introduction

Cancer survival rates are increasing in the western world with modern medicines; as a result, the increasing population requiring conventional cancer-related follow-up places a significant burden on outpatient services. One proposal to address this challenge that has gained momentum over the last decade is that of nurse-led follow-up (Alfano *et al*. 2019; Spellman, Kanatas & Ong 2018; Lai *et al.* 2019). Globally, advanced roles and positions for cancer care nurses, as a constituent part of innovative thinking and healthcare reform, are becoming embedded in both organizational (Bryant-Lukosius 2014; Dowling *et al.* 2013) and institutional thinking (Horrocks *et al.* 2002; World Health Organisation 2015).

This mixed method study will explore current models of nurse-led models of cancer care in Ireland. It will focuses on nurses' scope, governance and infrastructure which underpin nurse-led models of care in the area of oncology nationally. It further investigates factors influencing the development and implementation of nurse-led models of care and the barriers and the challenges nurses face in terms of the development and successful implementation of these models of care. Given the government's initiative to increase nurse-led models of care (Department of Health, Ireland 2017; Hegarty *et al.* 2018), this study is timely and will provide data for policymakers and clinicians with regard to nurse-led models of cancer care.

This chapter sets the context for the study with reference to contemporary national and international policy by first outlining trends in cancer incidence, survival and service demand. It then outlines current developments in the nursing profession including nurse-led models of care.

1.2 Cancer Care and Service Demands

Between 2007 and 2016, the population of adults aged 65 and over in Ireland has increased by one-third (32.8%) (Central Statistics Office 2016). The number of people cancer diagnosed with cancer in Ireland has been increasing for the

past two decades (National Cancer Registry Ireland (NCRI) 2017) and is expected to double by the end of 2045 (National Cancer Registry (NCRI) 2016) for several reasons, including the ageing population.

Similarly, survival rates have been improving as a result of earlier diagnosis arising from greater awareness, implementation screening programmes and improvements in cancer treatment modalities (National Cancer Registry Ireland (NCRI) 2017). Survival rates of the most common cancers such as breast cancer, prostate cancer; lung cancer and colorectal cancer are now higher than 80%, and more people are living with and beyond their cancer diagnoses (National Cancer Registry Ireland (NCRI) 2017). The Combination of increasing incidence and survival rates across all age ranges places increasing pressure on the Irish cancer services to provide 'appropriate care' to people affected by cancer with limited access to oncologists (Drury *et al. 2019*)

The strategy for Cancer Control in Ireland (2006) highlighted the key priorities for Ireland's cancer services (DoHC 2006). An important message arising from this report was to create a single, focused and integrated cancer control programme in Ireland, through the implementation eight centres of excellence. The strategy sought to develop multidisciplinary teams, including nursing teams. The strategy placed emphasis on the development of cancer nursing, reflecting *"the development of cancer nursing roles that reflects recent successful developments in oncology nursing and maximises the potential role that nurse can play in all aspects of cancer care"* (DoHC 2006; p 60).

To support and guide cancer nurses, the National Cancer Control Programme (NCCP) published a Strategy and Educational Framework for Nurses Caring for Patients in Ireland (NCCP 2012) to ensure all clinicians caring for cancer patients in Ireland have the appropriate skills and competencies to deliver quality assured cancer services. Warde et al. (2014) carried out a review of the 2006 National Cancer Strategy and recommended enhancing the scope of practice of cancer nurses to deliver cancer services. More recently, National Cancer Strategy (2017-2026) (Department of Health, Ireland 2017) understands the need to increase staffing in cancer care units due to a current shortage in the oncology workforce, and increasing cancer incidence and complexity of cancer treatment. The strategy further recommends having additional Clinical Nurse Specialists and Advanced Nurse Practitioners in post, and prepared to develop nurse-led

clinics for new patient assessment, oral chemotherapy, follow-up support and survivorship, to ensure appropriate care for cancer patients.

1.3 National and International Perspectives

Internationally, health care professionals' role boundaries are evolving, and nursing role expansion is part of this transformation to provide more effective and sustainable models of healthcare (Bryant-Lukosius, 2014). The terms Advanced practice, Nurse-led models of care/service, nurse-led assessment and nurse-led practice were introduced in nursing profession during 1980s and 1990s (Cable 1995; Redfern *et al.* 2010; Turner 1999). A range of national and international health policies have advocated for nurse-led services (The National Cancer Strategy, 2017; The Health Service Executive Transformation Programme, 2007-2010;The National Taskforce for Medical staffing DOH 2003; (DoHC 2003b); World Health Organization, 2012; International Council for nurses 2012 and an evaluation of the extent and nature of nurse-led services in Ireland (NCNM 2005).

In the USA, a report on future nursing published by the Institute of Medicine (IOM, 2010) recommended the development of nursing practice to contribute to redesigning of health care in the United States. The report proposes substantial changes were needed in terms of workforce planning, policy decision making and infrastructure to facilitate such development. Nurses are encouraged to be pro-active themselves in initiating innovative ways of introducing nurse-led services to provide patient-centred care and quality improvement programs. In Canada, the role of clinical nurse specialist and nurse practitioners are developed to provide nursing leadership in integrated healthcare delivery (Carter *et al.* 2010), In the UK, the National Health Service has widely adopted the concept of nurse-led models of care (Anderson 2010) as reflected in the UK Oncology Nursing Society (UKONS) position statement on nurse-led chemotherapy clinics where it notes the provision of guidelines on skills, prescribing issues, support, audit and monitoring, and financial considerations (Lennan *et al*, 2012).

Kilpatrick *et al.* (2015) have examined the development of evidence briefs in terms of transfer knowledge above advanced practice nursing roles in providers, policy-makers and administrators. The study concludes flexibility in nurse-led

models of care when compared with doctor led model provides interdisciplinary, collaborative approach between health care disciplines including community care and mental health service.

In Ireland, in 2003, the Department of Health and Children (DoHC) investigated the impact on health services of the introduction of European Working Time Directive (EWTD). Under this directive, from the year 2004 average working hours were reduced to 58 hours per week and were reduced to 48hours per week by 2009 (DoHC, 2003a). The National Task Force identified the need for role expansion in nursing as one of the solutions to the manpower constraints caused by the EWTD Early consultations with the nursing workforce regarding proposed role expansion revealed concerns about skill mix, development of policies and protocols, infrastructure and stakeholder support (Peelo Kilroe, 2003; DoH 2015). To help nurses to work within the full range of their scope of practice and to expand their scope according to patient and service need, the Scope of Nursing and Midwifery Practice Framework in Ireland (Nursing and Midwifery Board of Ireland 2015), provides a framework to enable and support changes in the scope of nursing practice.

In the year 2017, a join review done by the Health Service Executives and Nursing and Midwifery Board of Ireland identified national and international trends in the development of nursing profession in terms of continued advancement of nurse prescribing. Further on the DoH Statement of Strategy (2016-2019) outlines strategic priorities to create a more responsive, integrated and person-centred health and social care service. Linked to this priority, the Doh chief nursing officer has identified the need for developing a policy for graduate, specialist and advanced practice. These policy changes support the development of nursing roles.

The expansion of nursing roles in Ireland is demonstrated through the SCAPE study for the National Evaluation of Clinical Nurse/Midwife Specialist and Advanced Nurse/Midwife Practitioner Roles (Begley *et al.* 2010). The study reported that clinical specialist and advanced practitioners have a significant impact on all aspect of healthcare delivery.

There is further evidence across the literature that nurses are taking on more advanced roles across a range of domains (Kimman *et al.* 2010). Nurses are

advancing their practice by introducing nurse-led models of care (Beaver *et al.* 2010) and this model is now firmly established in many specialities such as the COPD outreach programmes and nurse-led services for ambulatory services such as diabetes (Kenealy *et al.* 2004), epilepsy (Higgins *et al.* 2018). The World Health Organisation (2012) quote the Oncology Nursing Society (2009) and note international research in nursing are working towards improving care in terms of managing symptoms, minimising the consequences of cancer treatment, promoting health and quality of life among cancer survivors, and end-of-life issues.

Over two decades ago, the Report of the Commission on Nursing (Government of Ireland, 1998) provided the vision and guiding framework for the development of the nursing profession in Ireland into the 21st century. The report drew attention to the constraints upon the nursing profession, which limited its ability to respond effectively and proactively to the increasingly complex demands of the health services. The Commission recommended that, in future, nurses should take on an additional set of skills and acquire knowledge to ensure increased flexibility and autonomy to expand their scope of practice.

Numerous government policies, reports and reviews over the past two decades have provided direction for the development of nursing profession to respond to the health care need of Irish population by developing clinical nurse specialist roles and advanced practitioner roles (Government of Ireland 1998); A review of Practice Development in Nursing and Midwifery in the Republic of Ireland and the Development of a Strategic Framework (McCormack *et al.* 2011) ; The Strategic Framework for Role Expansion of Nurses and Midwives – Promoting Quality Care (Department of Health and Children 2011).

Furthermore, National Cancer Strategy 2017- 2026 (DoH 2017) priorities the need for integrated patient care to ensure a seamless patient journey. The emergence of specialist training and recognized, advanced practice roles have contributed to a more knowledgeable and skilled nursing workforce in Ireland (Begley *et al.* 2010), prepared to make essential contributions to the development of integrated care via nurse-led models of care.

In the Irish health system, advanced practice roles are differentiated into an advanced nurse practitioner (ANP) and Clinical Nurse Specialist (CNS) roles.

National Council for Nursing and Midwifery (NCNM 2008) provide a clear definition, educational requirements for each role profile. An ANP is a nurse who is an autonomous practitioner, responsible for advanced levels of decision-making, and managing a patient caseload, who demonstrates clinical and professional leadership and advances clinical practice through research (NCNM 2008) whereas The CNS is a nurse who works closely with medical and paramedical colleagues in an area of specialist clinical practice, with an additional remit for education and training, patient advocacy, consultancy and improvement in the quality of patient care through audit and research (NCNM 2008). The importance to continuing cancer education for nurses working within the cancer services has been highlighted by The strategy and Educational Framework for Nursing Caring for People with Cancer in Ireland (Hanan *et al*. 2012) and provided foundation for the development of the National Cancer Education programme for registered nurses working in an inpatient setting in 2017 (Murphy & Mullen 2017).

1.4 Nurse-led Models of Care

Despite the recommendation for nurse-led models of care internationally and nationally, there is no clear definition for the concept of nurse-led models of care. A variety of definitions for nurse-led models of care have been created over time. The term “Nurse-led model of care” has been evident in the literature since the 1980s (Hatchett 2008). In the 1990s, nurse-led models of care became a more specialised area, with more focus on nursing training within academic institutions to provide quality care to patients (Hatchett 2008).

Corner (2003) suggested that nurse-led models of care have two variations; the first, a delegation model, where nurses are delegated to accomplish a specific task which was formally done by doctors. The second model is a comprehensive practice model, where nurses take responsibility patient care, involving more nursing belief and values during care delivery and have autonomy in clinical decision making.

Similarly, Fitzsimmons *et al*. (2005) explain that a nurse-led model of care for chemotherapy administration was viewed cautiously by patients as well as other health care professionals on the basis of it being a “ nurse-doctor substitution model” (*p. 249).*

The National Council for the Professional Development of Nursing and Midwifery (NCNM) in 2005 undertook a scoping review of nurse-led services in nursing and midwifery in Ireland in order to acquire a more definite definition. Unlike the definition proposed by Corner (2003), the NCNM (2005) identified specific activities and characteristics that distinguished nurse-led models of care from nurse-managed or nurse-co-ordinated services.

While nurse co-ordinator as defined by Monas *et al. (2017)* is an advocator for patients and their families and a person for navigating them within a complex health care system.

An NCNM (2005) point out this distinction is vital in terms of emphasis and, indeed, a spirit of interpretation.

> "*by nurses responsible for case management…included comprehensive patient/client assessment…managing a plan of care, clinical leadership and decision to admit or discharge*" (p.7)

Richardson and Cunliffe (2003) propose that the key elements of the nurse-led model of care are autonomy in decision making and independent practice. They summarise that the critical activities of nurse-led care include direct referral mechanism; assessment and technical skills; freedom to initiate diagnostic tests; prescription (to protocol) of medications; increased autonomy and scope for decision making; discharge.

In contrast to previous definitions, Wong & Chung (2006) conducted an exploratory study to define a nurse-led model of care in China using the three aspects of the care: structure, process, and outcome. The study was carried out in two phases. In the first phase, nurses from 34 clinics were interviewed, and in the second phase, 162 clinic sessions were observed in addition to patients (n=162), and physicians (n=16) interviewed. The findings from the study suggest that a nurse-led model of care may be characterised as involving nurses with advanced competency working in a formalised and structured clinic, providing care for patients which encompasses case management, with a holistic approach to assessment and health teaching. Similarly, Hatchett (2008) defines nurse-led models of care as a clinical practice where nurses with a defined patient caseload undertake a patient assessment, have admission discharge and

referral privileges, and provide health-related education, treatment and monitoring, discharge, as well as offering psychological support for patients.

In summary, nurse-led models of care may be defined as a service where the nurse with advanced cancer care knowledge works autonomously within a well-defined and structured model of care, with established guidelines and protocols for the assessment, treatment, and evaluation of patients in their caseload (Shiu, Lee & Chau, 2012). In addition, the nurse provides education and support to the patient and family while working collaboratively within an MDT approach, to enable optimal health outcomes for the patient.

1.5 Summary

The development of “nurse-led models of cancer care” utilising the resources and skills already present in many hospitals with the Clinical Nurse Specialists and Advanced nurse practitioners is widely understood in the research to be both a welcome and positive development. There is now an established body of literature arguing two things; that appropriately trained nurses, such as registered nurses, practise nurses and nurse practitioners can well provide excellent standards of care in comparison to primary care doctors, and secondly that patients can experience equal or even better health outcomes. While government policy seeks to increase nurse-led models of care, the literature reviewed in Chapter 2 will highlight how nurse-led models of care are not always fully understood due to the range of services in place (Hutchison *et al. 2011*), ad-hoc development (Farrell & Lennan 2013), and variability in service design (De Leeuw *et al.* 2013).

2. Chapter 2: Literature Review

2.1 Introduction

Nursing practice has undergone significant development and role expansion in recent decades, with one of the most significant innovations in nursing practice being the introduction of nurse-led care models in the early 1960s (Nevidjon, 2010). The term “Nurse-led models of care” has been evident in the literature since the 1980s (Hatchett 2008). The common characteristics of this model of care is that the nurses provide additional and extremely high standard of care to improve patients’ care (McMahon, 1998). Despite the increased research on nurse-led models of care, a clear and consistent definition across the literature is still lacking (Hutchison *et al.* 2011).

Corner (2000) suggested that nurse-led models of care have two designations, a delegative practice model or a comprehensive practice model. In the delegation model, nurses are allocated a specific task to complete which was, in the past, undertaken by doctors. In the comprehensive practice model, nurses have considerable autonomy in clinical decision making and are given responsibility for an area of care. The National Council for the Professional Development of Nursing and Midwifery (NCNM) in 2005 undertook a scoping review of nurse-led services in nursing and midwifery in Ireland in order to acquire a more definite definition. Unlike the definition proposed by Corner (2003), the National Council for the Professional Development of Nursing and Midwifery NCNM (2005) identified specific activities and characteristics that distinguished nurse-led models of care from nurse-managed or nurse-co-ordinated services as involving:

> “*nurses responsible for case management…included comprehensive patient/client assessment…managing a plan of care, clinical leadership and decision to admit or discharge*” (NCNM, 2005, p.7)

In China, Wong and Chung (2006) conducted an exploratory study to define a nurse-led model of care using the three aspects of care; structure, process, and outcome. The study was carried out in two phases. In the first phase, nurses from 34 clinics were interviewed, and in the second phase, 162 clinic sessions were observed in addition to patients (n=162), and physicians (n=16) interviewed. The findings from the study suggest that a nurse-led model of care

may be characterised as involving nurses with advanced competency working in a formalised and structured clinic, providing care for patients and which encompasses case management, with a holistic approach to assessment and health teaching. Similarly, Hatchett (2008) defines nurse-led models of care as a clinical practice where nurses with a defined patient caseload undertake patient assessment, have admission discharge and referral privileges, and provide health-related education, treatment and monitoring, discharge, as well as offering psychological support for patients. The typical characteristics of nurse-led models of care according to Richardson and Cunliffe (2003) are:

- Direct referral mechanism,
- Assessment and technical skills
- Freedom to initiate diagnostic tests,
- Prescription (to protocol) of medications,
- Increased autonomy and scope for decision making,
- Discharge

In summary, nurse-led models of care may be defined as a service where the nurse with advanced cancer care knowledge works autonomously within a well-defined and structured model of care, with established guidelines and protocols for the assessment, treatment, and evaluation of patients in their caseload. In addition the nurse provides education and support to the patient and family while working collaboratively within an Multi-Disciplinary Team approach, to enable optimal health outcomes for the patient.

In Ireland, under the reform agenda in health care, nurse-led care has been endorsed as a workable solution to enhance the quality of services in an extremely busy health service (Health Service Executive, 2003). Multiple national health policies promote nurse-led services and emphasise the potential for development of the nurse's role to respond to increased clinical demands for cancer care, including the recent National Cancer Strategy (2017-2026), which makes particular mention of the expansion of nurse-led care to deliver oral chemotherapy, patient assessment, survivorship, and follow-up support. The strategy prioritises the expansion of nurse-led services in the future redesign of health care service to maximise the capacity to provide the most efficient quality service for cancer patients, all while reducing medical cost and waiting times (NCNM, 2005; DoH, 2003b).

With this in mind, the current study explores nurse-led models of cancer care in Ireland. Shiu *et al.* (2012) propose that researchers should capture nursing sensitive outcomes for nurse-led care in both cancer care and other service areas, to enable an understanding of the crucial components of nurse-led care and the impact achieved due to the implementation of nurse-led care model. As Gagliardi *et al.* (2011) affirm, good results are not automatically achieved, and as such, this chapter will create an understanding of essential factors in the process and structure of nurse-led models of cancer care to ensure high quality patient care within such models. This chapter reviews literature published between January 2001 and December 2018 and will discuss the literature under the following topics:

- Development of nurse-led models of cancer care
- Infrastructure Required to Support Nurse-Led Models of Care
- Activities of Nurse-Led Models of Care
- Outcome analysis of nurse-led models of cancer care

2.2 Literature Search Strategy

The literature reviewed research conducted on nurse-led models of care in relation to cancer, published between January 2001 and December 2018. An search of the PubMed, CINAHL, Cochrane and the British Nursing Index was undertaken. The reference lists of included papers were searched to identify any additional papers meeting the inclusion criteria. The literature search strategy was informed by the PEOS inclusion criteria for this study (**Error! Reference ource not found.**)**Error! Reference source not found. Error! Reference source not found.**Search terms were identified though the Medical Subject Headings (MeSH) potential search terms corresponded to the major concepts of “nurse”, “cancer”, and “Nurse-led models of care” (**Error! Reference source not ound.**). This ensured that the search concept was closely linked to the study’s overall aim and objectives. In addition, Boolean operators of AND/OR were used to expand or combine the search as necessary for each database.

References were managed using Mendeley. Studies identified via the search strategy were screened for inclusion against the PEOS inclusion criteria in a three-stage process, based on their title, abstract and finally, full text. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist

(Moher *et al.* 2009) outlines the studies excluded at each stage of the screening process (

Figure 1)

Table 1 PEO table to determine the development of the literature search strategy

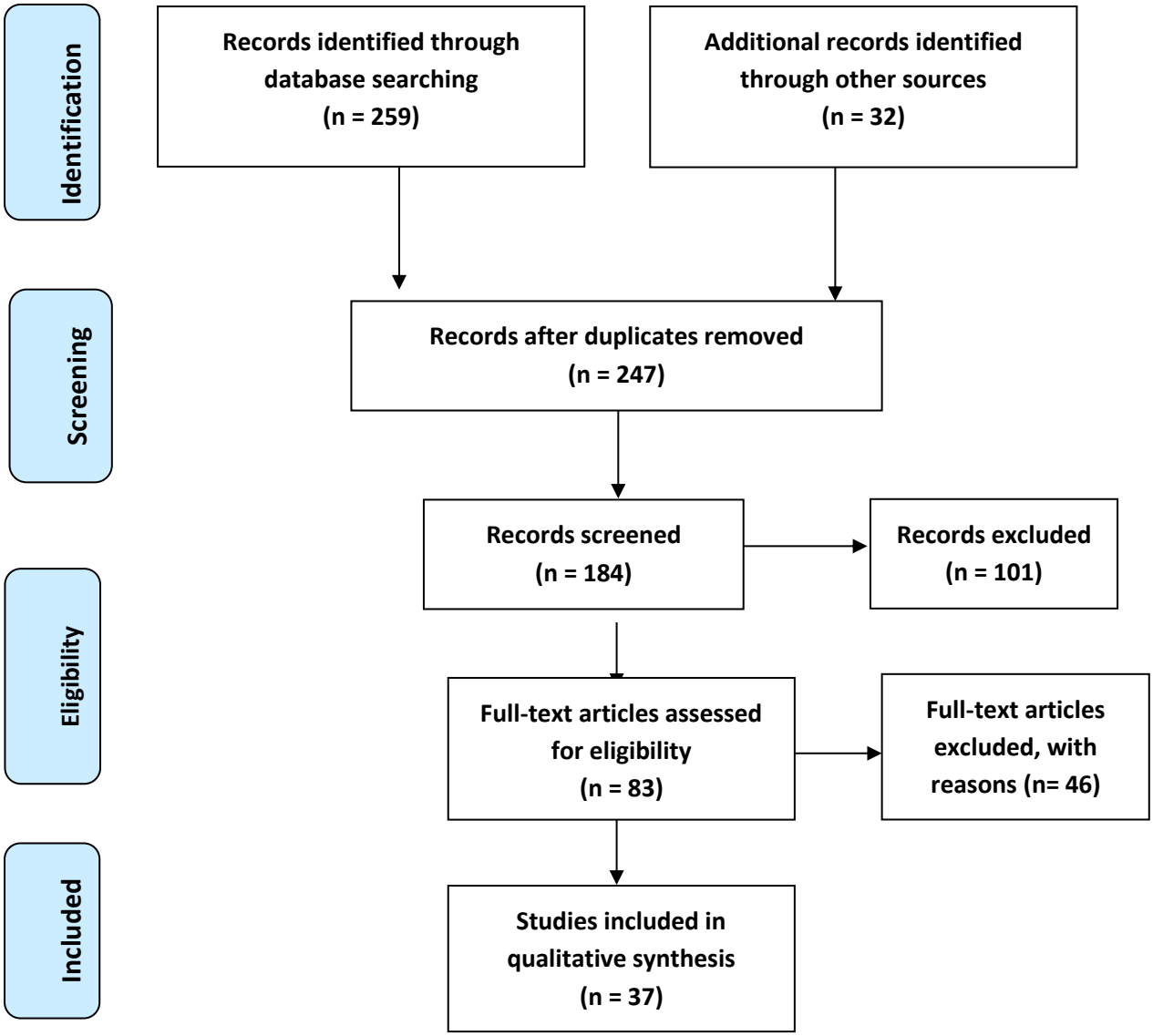
Patients	Cancer patients
Exposure	Nurse-led models of care
Outcome	1. To understand influencing factors on the development of nurse-led models of oncology care. 2. To evaluate evidence for the implementation of nurse-led models of care. 3. To explore outcomes adopted and achieved in nurse-led models of cancer care
Study	Cross-sectional / longitudinal quantitative and qualitative empirical studies

Table 2 Search strategy: Concept Development Table

Search Concept	MESH Term(s)	Search Terms
Nurse	"Nurses" "Nurse Clinicians" "Nurse Practitioner" "Oncology Nursing"	"Nurse" OR "Personnel, Nursing" OR "Nursing Personnel" OR "Registered Nurses" OR "Nurse, on Registered" OR "Nurses, Registered" OR "Registered Nurse" "Clinician, Nurse" OR "Clinicians, Nurse" OR "Nurse Clinician" OR "Nurse Specialist, Clinical" OR "Clinical Nurse Specialists" OR "Specialist, Clinical Nurse" OR "Specialists, Clinical Nurse" OR "Clinical Nurse Specialist" OR "Nurse Specialists, Clinical" "Nurse Practitioner"[Mesh] OR ("Nurse Practitioners" OR "Practitioner, Nurse" OR "Practitioners, Nurse") Oncology Nursing "[MeSH Terms] OR (Nursing, Oncology" OR "Oncologic Nursing" OR "Cancer Nursing" OR "Nursing, Cancer" OR "Nursing, Oncologic" OR "Oncological Nursing" OR "Nursing, Oncological")
Cancer	Neoplasms	neoplasms"[MeSH Terms] OR ("neoplasms" OR "cancer" Neoplasia" OR "Neoplasm" OR "Tumors" Or "Tumor" Or "Cancer" Or "Cancers" OR"Malignancy" OR"Malignancies" OR "Malignant Neoplasms"OR 2Malignant Neoplasm" OR "Neoplasm, Malignant" OR" Neoplasms" OR " Malignant"OR "Benign Neoplasms" OR "Neoplasms, Benign" OR "Benign Neoplasm" OR Neoplasm, Benign")
Nurse-led Models of Care	Nurse-led Clinics; Nursing care Nursing diagnosis Nursing process Nursing services	"Practice Patterns, Nurses'"[Mesh] "Nurses' Practice Patterns" OR "Nurse's Practice Patterns" OR "Nurse Practice Patterns" OR "Nurse's Practice Pattern" OR "Practice Pattern, Nurse's" OR "Practice Patterns, Nurse's" OR "Nurse-Led Clinics" OR "Clinic, Nurse-Led" OR "Clinics, Nurse-Led" OR "Nurse-Led Clinics" OR "Nurse-Led Clinic" "Care, Nursing" OR "Management, Nursing Care" OR "Nursing Care Management" "Diagnosis, Nursing" OR "Diagnoses, Nursing" OR "Nursing Diagnoses""Process, Nursing" OR "Nursing Processes" OR "Processes, Nursing" Services, Nursing" OR "Nursing Service" OR "Service, Nursing" Outcome and Process Assessment" OR "Structure Process Outcome Triad" OR "Donabedian Model" OR "Model, Donabedian" OR "Donabedian Triad" OR

	Model of care	"Triad, Donabedian

Figure 1: Illustration of the flow of information through the review to determine the number of studies identified at each stage using the PRISMA diagram



A total of thirty-seven studies related to nurse-led models of care were identified (Table 3 Details of studies reviewed

). A wide variety of research approaches were adopted across 37 studies, including 8 randomised controlled trials (RCTs), and a quasi-experimental design was adopted to evaluate the effects of nurse-led models of care by three studies; one a systematic review and the remaining pilot studies and satisfaction surveys. The majority of which were undertaken in Europe. Nineteen studies were conducted in the UK (*n*=19*)* (Faithfull *et al.* 2001; Moore *et al.* 2002; Allinson 2004; Booker *et al.* 2004; MacLeod *et al.* 2007; Fletcher & Hornsby 2007; Wells & Ackland, 2008; Cox *et al.* 2008; Beaver *et al.* 2010; Hewett & Howland 2009; Anderson 2010; Collins 2010; Hutchison *et al.* 2011; Guest *et al.* 2012; Craven *et al.* 2013; Casey *et al.* 2017; Farrell *et al.* 2017; Moore 2018; Stanciu *et al.* 2018). Four were conducted in Sweden (Koinberg *et al.* 2004; Dunberger & Bergmark, 2012; Berglund *et al.* 2015; Strand *et al*.2010;). One was conducted in the Netherlands (Van Der Meulen *et al.* 2014) and two in Ireland (Egan & Dowling 2005; Chalabi *et al.* 2014). Four nurse-led models of care were conducted in Australia (Krishnasamy *et al.* 2011; Cox *et al.* 2013; Jefford *et al.* 2013; Birch *et al.* 2016). Three were conducted in Canada (Howell & Watson 2008; Overend *et al.* 2008; Jivraj *et al.* 2018), one from Hong Kong (Lai *et al.* 2017) and one from the USA (n=1) (McCorkle *et al*. 2009) and one systematic review (Lewis *et al.*2009).

Table 3 Details of studies reviewed

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
1. **Moore *et al.* 2002** **Nurse-led follow up and conventional medical follow up in management of patients with lung cancer: Randomised trial**	To assess the effectiveness of nurse-led follow up in the management of patients with lung cancer	UK	1. N=203 lung cancer patients 2. on Follow-up care 3. Open access to nurse-led clinic or telephone follow up vs standard medical follow up	1. RCT	High satisfaction and acceptability with nurse-led. At 3 month interval patients on nurse-led care had less dyspnoea (p=0.03) and improved emotional functioning (p=0.03).Patients had fewer x-rays (p=0.04). More likely to die at home (p=0.04) than in the hospital or hospice. No difference in costs.
2. Koinberg *et al.* 2004 **Nurse-led follow-up on demand or by a physician after breast cancer surgery: a randomized study**	To compare nurse-led follow-up on demand versus physician follow-up after breast cancer treatment with regards to patients wellbeing, satisfaction, access to medical care and medical safety.	Sweden	1.N=264 (*n=131* doctor-led follow-up and n=133 nurse-led follow-up) 2. Follow-up care 3. Nurse-led Follow up care post breast cancer surgery	1. RCT 2. Questionnaire	Medical safety similar in both groups. No statistically significant differences regarding anxiety and depression between groups. nurse-led group had about 450 less visits to the physician but 177 more phone calls to nurses and 88 more visits to the nurse as compared to doctor-led .

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
3. Allinson 2004 **Breast cancer: Evaluation of a nurse-led family history clinic**	To evaluate the effectiveness and acceptability of a nurse-led family history clinic for patients with breast cancer	UK	1.N=59 patients with family history of breast care : 44 (Nurse-led) and 15 (Doctor-led) for patients (at risk of developing breast cancer) with a family history of breast cancer. 2. Family history clinic 3. Nurse-led family history clinic for patients at high risk of developing breast cancer	1. A non-randomised study 2. Two part questionnaire, first part before the consultation and second part after the consultation	100% patient satisfaction . In Nurse led clinical interactions all patients felt they had sufficient time to discuss their concerns and risks, whereas in the doctor-led clinic, 61% felt rushed and no time to discuss concerns and 39% understood their risks better.
4. **Booker et al. 2004 Telephone first Post-intervention follow-up for men who have had radical radiotherapy to the prostate: evaluation of a novel telephone service delivery approach**	To evaluate acceptability of telephone service for post radiotherapy follow up care.	UK	1. N=36 Prostate cancer 2. Follow up care post radiotherapy 3.Nurse-led telephone follow-up care for patients with prostate cancer after radiotherapy.	1. Patient satisfaction survey 2. Survey questionnaire	High level of satisfaction, 97% indicated nurse knew about their treatment and information need was met. Advantage of telephone follow up:- 38% time-saving; 22% convenient; 61% no traveling. Only one patient expressed dissatisfaction with telephone follow up.
5. Faithfull *et al.* 2001 **Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy**	To compare outcomes in terms of toxicity, symtoms experienced, quality of life, satisfaction with care and health care costs, between those receiving nurse-led	UK	1.N=115 (*n*=58 for nurse-led care and *n=57* for conventional medical follow-up) 2. While undergoing pelvic radiotherapy for prostate cancer.	1. RCT 2. Field notes and qualitative comments from satisfaction survey	High satisfaction with nurse-led care (P<0.002). Continuity of care, information needs met. No difference in QOL or

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
	care and a group reciving standard care.		3. Therapeutic support, working with uncertainty, timeliness, enhanced professional autonomy, role flexibility, organizational openness continuity and trust in care		symptom control
6. Egan and Dowling, 2005 **Patients' satisfaction with a nurse-led oncology service.**	To determine satisfaction level of patients attending a nurse-led oncology day ward.	Ireland	1. N=100 cancer patients attending nurse-led oncology day ward 2. Cancer care Nurse-led care for patients attending oncology day ward	1. Quantitative Study 2. Questionnaire	89% satisfaction with the nurse. 65% see the same nurse each time; 13% felt unable to access staff and 15% unsure. 80% felt fully informed; 12% unsure if had any information. 91% satisfaction with skills / attitude of nurses but 12/72 (17%) reported no confidence.
7. Macleod et al. 2007 **A nurse-/pharmacy-led capecitabine clinic for colorectal cancer: result of a prospective audit and retrospective survey of patient experiences**	Evaluate nurse-led and pharmacy-led capecitabine clinic for colorectal patients	UK	1. N=52 colorectal cancer patients 2. While on Oral capecitabine for colorectal cancer patients 3. To introduce Nurse-led/pharmacy-led Capecitabine colorectal cancer service and report patient satisfaction with care.	1.Prospective non-experimental study 2. Patient satisfaction survey questionnaire	More that 85% patients thought the service provision was useful and well organised.

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
8. Fletcher and Hornsby, 2007 Radiotherapy review for patients with breast cancer : a new approach	To assess the effectiveness of new approach where radiographers skills are used to allow a specialist nurse to provide nurse-led models of care.	UK	1. N=57 Breast cancer patients receiving radiotherapy 2. While on Radiotherapy 3. Nurse or radiographer reviews during radiotherapy, determined by patients' completion of a concern checklist.	1. Patient satisfaction survey 2. Survey Questionnaire	Radiographers reviewed patients with concerns about radiotherapy and symptoms (n=39). Nurses reviewed patients with more complex concerns (n=18).100% satisfaction with the service. Optimised use of radiographers' skills and freed up specialist nurse to devote more time to patients. .
9. Wells and Ackland 2008 A study to evaluate nurse-led treatment review for patients undergoing radiotherapy for head and neck cancer	To evaluate a nurse-led clinic for patients undergoing radiotherapy to the head and neck.	UK	1. N=43 head and neck cancer patients receiving radiotherapy. 2. While having radiotherapy for head and neck cancer 3. N= 23 Nurse-led care Vs N=20 Medical-led care during radiotherapy treatment for head and neck patients	1.Non randomised historical control study using Mixed methods approach to data collection 2. Patients completed weekly QOL questionnaire and were asked about experience of support and care. GPs completed a questionnaire about the communication received from the clinic. Checklist used to assess the content of clinic consultation.	Patient value relationship with nurses. More effective management of Oral and nutritional problems. QOL improved, but emotional functioning was higher in medical-led clinics. Small sample size.

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
10.Cox *et al.* 2008, **Nurse led telephone to follow up in ovarian cancer: A psychosocial perspective**	To evaluate the effect of a nurse-led telephone intervention	UK	1. N=52 with ovarian cancer 2.Follow up care 3.Nurse-led follow up for ovarian cancer patients.	1. Satisfaction Survey 2. FACT ovarian QOL questionnaire, plus the satisfaction and experience with follow-up questionnaire	73% preferred nurse-led care. main benefit: patient valued relationship with a nurse, convenience of follow-up over the phone instead of a hospital visit, offered psychosocial support
11. Howell and Watson, 2008 **A mixed method evaluation of nurse-led community based supportive care**	To evaluate a nurse-led supportive care clinical case management program	Canada	1. N=113 2. Supportive care Nurse-led supportive care	1. Mixed method study with triangulation of quantitative and qualitative data was conducted 2. Site visits and semi-structured interview	84% information needs met 92% emotional needs met 88% physical needs met
12. Overend *et al.* 2008, **Evaluation of a nurse-led telephone follow-up clinic for patients with indolent and chronic haematological malignancies: A pilot study**	To determine whether a nurse-led telephone clinic could effectively and safely used to provide follow up patients with haematology malignancies.	Canada	1.N= 45 haematology malignancies patients 2. Supportive care for low-grade and chronic haematological malignancies.	1. Prospective non-experimental pilot study 2. Questionnaire	85% High satisfaction, the convenience of not to travel a long distance (average distance 107km or 2 hours)
13. Hewett and Howland, 2009 **The benefits of a nurse and dietician-led follow-up clinic in head and neck cancer**	To monitor and evaluate the effectiveness of a nurse and dietician-led joint follow-up clinic in head and neck cancer	UK	1. N=12 for first audit and N=13 for second audit of Head and neck cancer patients 2. At any stage of the diagnosis process and before, during or after treatment 3. To provide easily accessible CNS-led	1. Patient satisfaction survey 2. Survey Questionnaire	100% satisfaction with appointment time, directions to the clinics and suitable environment with the joint clinic. 50% patients found verbal information relevant and

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
			and dietetic care. Also psychological support to patients with head and neck cancer and their families.		clear. No second nurse or dietician available to cover the service
14. Mccorkle *et al.* 2009 **Effects of a nursing intervention on quality of life outcomes in post-surgical women with gynaecological cancers**	To assess effect of nurse-led intervention on QOL as assessed by depressive symptoms, uncertainty and distress	USA	1. N=281 Gynaecological cancer patients 2. Post surgery follow-up 3.Nurse-led intervention on quality of life outcomes	1. RCT (Control arm received routine hospital care and intervention arm received 6 month of specialised care from an ANP. 2. Questionnaire	Nurse-led intervention resulted in significantly less uncertainty, less symptom distress and better mental and physical QOL than control group.
15.Molassiottis *et al.* 2009 Effectiveness of a Home Care Nursing Program in the Symptom Management of Patients With Colorectal and Breast Cancer Receiving Oral Chemotherapy: A Randomized, Controlled Trial	To assess the effectiveness of a symptom-focused home care program in patients with cancer who were receiving oral chemotherapy in relation to toxicity levels, anxiety, depression, quality of life, and service utilization	UK	1. N= 164 Cancer patients (110 colorectal and n=54 breast) 2. Treatment phase 3. To provide symptom management for oral therapy patients at home	1. RCT (Control arm received routine hospital care and intervention arm received nurse-led home care program for 18 weeks) 3. Quality of life questionnaire (EORTC-QLQ-C30)	Homecare nurse-led intervention decreases symptom burden and can lead to reduced service utilization (number of inpatients day: control group 167 vs experimental group 57). Toxicity improved after two weeks of chemotherapy. (cycle 1-2 $p<0.001$; cycle 3-4 $P=0.002$, $p= 0.006$) Continuity of care

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
					maintained.
16. Beaver *et al*. 2010 **An exploratory study of the follow-up care needs of patients treated for colorectal cancer**	To explore patient perception of their experiences of follow up care and treatment of colorectal cancer	UK	1. N=27 Colorectal cancer patients 2. Follow up care after completion of current treatment 3. To provide optimal follow-up strategy for colorectal cancer patients including psycho-social and information needs	1.An exploratory qualitative study 2. In-depth interviews	Patients did not receive any information about living with altered bowel function. Nurse specialist plays an valuable role in providing information to patients following hospital discharge. Nurse-led services provide information which are tailored to individuals needs.
17. Anderson, 2010 **The benefits to nurse-led follow-up for prostate cancer**	To evaluate patient satisfaction with nurse-led follow-up initiative for prostate cancer patients.	UK	1. N=46 Prostate cancer patients on follow-up 2. Follow-up care for prostate cancer patients 3. Nurse-led prostatic Specific Antigen (PSA) telephone follow-up clinic	1. Prospective non-experimental study using. Patient satisfaction survey 2. Survey Questionnaire	Overall satisfaction rate of 99% with the telephone follow-up service. 95% patient had confidence in the nurses' professionalism in running the clinic.88% were happy with the

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
					telephone appointment arrangements and 95% stated that the clinic increased the efficiency and convenience of care delivery.
18.Collins, 2010 **Audit of a nurse-led bone marrow biopsy clinic**	To identify patient's experience of a bone marrow procedure performed by the lymphoma clinical nurse specialist in relation to the pain relief used and the quality of the samples obtained	UK	1. N=38, lymphoma patients attending bone marrow biopsy clinic 2. Diagnostic procedure 3. Nurse-led bone marrow biopsy clinic for patients with lymphoma	1. Patient satisfaction Survey 2. Questionnaire	97% of patient satisfaction with nurse-led procedure. Patient had choice of four options of pain relief. 98% of the sample's had a appropriate quality interpretative results. 97% of patients got benefit of information and support when procedure performed by a CNS.
19. Strand *et al.*2010 **Nurse or surgeon follow-up after rectal cancer: A randomized trial**	To compare patient satisfaction, resource utilization and medical safety in patients curatively operated for rectal cancer.	Sweden	1. N=110 Colorectal post-surgery patients (*n*=56 for surgeon follow-up and *n=54* to nurse-led follow-up) 2. Post surgery follow-up 3. Nurse-led models of care to provide follow-up care to patients post colorectal cancer surgery.	1. RCT 2. Satisfaction questionnaire	Patient satisfaction high for nurse-led (9.5) and (9.4) for surgeon; Longer nurse-led consultations (24 vs 15 minutes p=0.001). Nurse took more blood samples taken (29% vs 7% p=0.002). Costs for nurse

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
					consultations were lower, but costs for investigations were higher hence total costs of follow-up did not differ.
20. Hutchison *et al.* 2011 **Overview of nurse-led clinics and their scope of practice**	To identify the type of cancer nurse-led clinics established in one region of Scotland and to establish the scope of clinics and factors that affect development and success.	Scotland	1. N=88 nurse-led clinics 2. For cancer care 3. Nurse-led clinics for cancer care in one region of Scotland	1. Scoping survey 88 nurse-led clinics 2. Questionnaire	51% (n=49) of nurse-led clinics were for treatment; 31% (n=27) follow-up care; 24% (n=21) for symptom management and 14% (n=12) were for diagnostic; Other activities of nurse-led clinics 26%(n= 23) was providing psychological support, pre assessment or PICC line insertion. Perceived benefits of nurse-led services: Continuity of care 31% (n=26) and reduced waiting times. 38% (n=33) had no absence cover and 20% (n=18) had no admin support. Nursing competency was assessed in 70% (n=62) clinics. 48% (n=42) clinics were running for more that five

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
					years but 55% (n=48) were not audited.
21. Krishnasamy *et al.* 2011 **Patient expectations and preferences for follow-up after treatment for lung cancer: a pilot study**	To assess expectation and preferences for follow-up care in a sample of patients who had completed treatment for lung cancer.	Australia	1. N=31 lung cancer patients 2. Post treatment follow-up 3. Nurse-led follow-up care	1.pilot study 2 survey questionnaire	78% of patients supported concept of nurse-led follow-up care.80% focused on care co-ordination, 82% preferred the arrangement beused they knew whom to contact if quesries arise.
22. Dunberger and Bergmark, 2012 **Nurse-led care for the management of side effects of pelvic radiotherapy: What does it achieve?**	To describe what a nurse-led clinic for gastrointestinal side effects after pelvic radiotherapy can achieve.	Sweden	1. N=60 pelvic radiotherapy patients 2. Follow-up care 3. Nurse-led follow-up care for radiotherapy patients	1. Retrospective review of chart 2. Study specific questionnaire	Quality life improved, an important role in the rehabilitation of cancer patients, psycho-social wellbeing
23. Guest *et al.* 2012 **Developing a clinic to meet patient's pre-operative needs**	To evaluate nurse-led preoperative assessment clinic for gynaecological cancer	UK	1.N= 12 patients with gynaecological cancer 2. Preoperative assessment clinic 3. Nurse-led pre-operative assessment clinic for gynaecological cancer	1. Mixed Methods design including Patient Satisfaction survey (n=12) & focus groups with patients (n=5) 2. Survey Questionnaire and	Patients reported their needs addressed. 100% Holistic Needs Assessment useful (N=126 (50%) Focus group: nurse-led clinic reassuring, access to CNS to discuss concerns pre-surgery

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
24. Craven *et al.* 2013 **Is a nurse-led telephone intervention a viable alternative to nurse-led home care and standard care for patients receiving oral capecitabine?**	To explore the usefulness of a nurse-led telephone intervention for supporting cancer patients.	UK	1. N=298 Colorectal patients receiving nurse-led telephone compare with previous data N=164 standard of care 2. Treatment phase 3. Nurse-led telephone support for patients receiving oral anticancer therapy	1. Quasi-experimental study prospective audit 2. Audit and patient satisfaction survey	Reduced toxicity (nurse-led telephone follow-up significantly better than standard care ($p< 0.05$) 93% satisfied with the nurse-led service. 90% felt the information was clearly given in nurse-led service.
25. Cox *et al.* 2013 **Nurse-led supportive care management: A 6-month review of the role of a nurse practitioner in a chemotherapy unit**	To evaluate the oncology nurse practitioner role in a chemotherapy unit.	Australia	1. N=72 patients attending walk-in review to the chemotherapy unit for 6 months 2. On treatment 3. Nurse-led walk-in review	1.Quantitative method 2 Audit	Waiting time to be seen by nurse practitioner (NP)was 5min and investigations or interventions carried out within 30-60 min. Less inpatient admission (*n*=52;60%), NP spent between 10-30minites with most patient.
26. Chalabi *et al.* 2014 **Six-Year Experience of a Nurse-Led Colorectal Cancer Follow-Up Clinic**	To review the experience of a nurse-led colorectal cancer follow-up clinic in a tertiary referral colorectal cancer centre	Ireland	1. N=1125 Post-surgery colorectal cancer patients 2. Follow-up care 3. Nurse-led follow-up care for colorectal patients	1. Service Evaluation 2. Audit	Significantly (almost half) In=407 patients entered nurse-led clinic : reducing the number of patients from medical-led clinics 216 patients actively enrolled in nurse-led clinic.

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
27. Van Der Meulen *et al.* 2014 **The long-term effect of a nurse-led psychosocial intervention on health-related quality of life in patients with head and neck cancer: a randomised controlled trial**	To investigate the effect of the nurse-led counselling on health related quality of life and depressive symptoms of head and neck cancer patients.	Netherlands	1. N=205 head and neck cancer patients (*n*=103) for nurse-led group and (*n*=102) for usual care 2. Treatment phase 3. Nurse-led counselling to improve emotional physical functioning and depressive sypmtoms.	RCT	Significant improvement in emotional and physical functioning (P<0.05) depressive symptoms were better in nurse-led than the control group.
28. Berglund *et al.* 2015 **Nurse-led outpatient clinics in oncology care - Patient satisfaction, information and continuity of care**	To investigate patient's satisfaction with nurse-led clinic and their perception of received information and association between continuity of care and satisfaction with information	Sweden	1. N=866 Cancer patients attending the outpatient clinic 2. Treatment Phase 3. Nurse-led care during cancer treatment	1.Patient satisfaction Survey 2. Two Questionnaire (to measure satisfaction developed for patient-physician outpatient encounter) and (to measure patient's perception of information received European Organization for Research and Treatment of Cancer's Quality of Life Group)	More that 80% of patients reported Waiting time reduced. 84% valued patient-nurse relationship, High satisfaction although a small fraction (*n*=52; 5%)of patients were doubtful if they will recommend nurse-led clinics to a friend.

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
29. Birch *et al.* 2016 **Developing and evaluating Robocare; an innovative, nurse-led robotic prostatectomy care pathway**	To assess patients satisfaction and health care utilization	Australia	1. N=124 between July 2012 and December 2013 2. Follow-up care 3. Nurse-led care to provide adequate information and to manage side effects.	1. Descriptive study 2. Audit	Nurse-led care is safe, high patient satisfaction. Reduced length of stay and admission rates
30. Jefford *et al.* 2016 **A randomised controlled trial of a nurse-led supportive care package (survivorCare) for survivors of colorectal cancer**	To improve psychological distress, supportive care needs and QOL of patients with colorectal cancer.	Australia	1. N= 221 colorectal patients (*n*=110 standard of care) to (*n*=106 SurvivorCare) 2. Follow-up care 3. Nurse-led care for colorectal patient to improve psychological symptoms and for supportive care.	1.RCT 2. QOL questionnaires	Baseline distress and QOL scores were similar to both the groups. Patients in Survivor Care were more satisfied than standard of care group (Significant differences on 10 of 15 items)
31. Casey *et al.* 2017 **Nurse-Led Phone Call Follow-Up Clinics Are Effective for Patients With Prostate Cancer.**	To assess feasibility of nurse-led telephone based clinical assessment and PSA as an alternative for clinic attendance.	UK	1. N=815 stable prostate cancer patients 2. Follow-up 3. Nurse-led clinical assessment and to give PSA results	1.Quantitative 2. questionnaires	87% found service convenient , 77% found it informative 95% preferred telephone-led to avoid coming to the hospital, 53.5% found it reassuring, and 92% felt their information need were met

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
32. Farrell *et al.* 2017 **Are nurse-led chemotherapy clinics really nurse-led? An ethnographic study**	To explore nurses' roles within nurse-led chemotherapy clinics	UK	1. N=61 nurse-led consultation with 13 nurses, N=11 nurses for phase 2 interview in four chemotherapy units/ cancer centres in the UK 2. Treatment phase 3. Nurse-led chemotherapy clinic .	1. Mixed methods study 2. Observation of clinics, Interview with nurses	Four different levels of nurse-led chemotherapy clinics. Disparities between clinic run by chemo nurse and ANP. Medicalisation of the ANP role role in spite of nurse perception of providing holistic nursing care. Reduce autonomy for ANP.
33. Lai *et al.* 2017 **A Nurse-Led Care Program for Breast Cancer Patients in a Chemotherapy Day Center : A Randomized Controlled Trial**	To examine the effects of a nurse-led care program for patients receiving out-patient chemotherapy	Hong Kong	1. N=124 breast cancer patients 2. Treatment phase 3. Nurse-led care for patients receiving outpatient chemotherapy	1. RCT (Control arm received routine hospital care and intervention a, received the nurse-led care plus the routine hospital care) 2. Questionnaires and interviews	Significantly lower distress level from oral problems, fatigue and peripheral neuropathy in intervention arm. Higher satisfaction (P<0.001) level in intervention arm. Intervention arm provided psychological support and build up confidence
34. Moore, 2018 **Nurse-led cancer care clinics: an economic assessment of breast and urology clinics**	To economic evaluation of breast and uro-oncology CNS-led clinics to doctor-led clinics	UK	1. N=338 patients attending a day ward over 50 weeks 2. Treatment Phase 3. Nurse-led cancer care for diagnostic pathway for prostate cancer and supportive discharge of women post breast cancer treatment to enhance	1. RCT 3. Case study, Patient satisfaction Survey	Reduced cost when compared to medical led clinics. Breast Clinic 3 hrs clinic cost reduced to £571.38 in breast compared to 3 hrs physician-led clinic cost.

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
			efficiency and improve patient experience.		Uro-oncology clinic £388.27 compared to Physician led (£891 pounds) . Waiting time reduced, Physician Time saved to take on more complex procedures. Patients are satisfied with care.
35. Stanciu *et al.* 2018 **Trial of personalised care after treatment-Prostate cancer: A randomised feasibility trial of a nurse-led psycho-educational intervention.**	To evaluated the feasibility of a nurse-led psycho-educational intervention to improve the self-management of prostrate cancer survivors.	UK	1. N=305 prostate cancer patients diagnosed 9-48 months ago (N= 48) for nurse-led intervention and (N=47) for control group (Standard of care). 2. Survivorship follow-up care 3. Nurse-led pscho-educational intervention	1. RCT 2. Interview with patients and GPs	Psychological and physical concerns were looked after not the financial one. Nurses take 10hrs of nurse time/ patients with large amount goes in admin work 5hrs/ patients. intervention group identifiifed 50% more symptoms which were not reported in control group.
36. Jivraj *et al.* 2018 **Empowering patients and caregivers with knowledge: The development of a nurse-led gynaecologic oncology chemotherapy education class**	To develop chemotherapy education class for gynaecologic cancer patient	Canada	1. N=538 cancer patients, N= 506 caregivers 2. Treatment phase 3. Nurse-led education for patients and caregiver to understand chemotherapy routine, lower anxiety.	1. Service evaluation	Standardized educational approach for chemotherapy patients. Empowered patients and caregivers with knowledge. Hence decreased patients' anxiety

Author and Title of study	Aim of study	Country	Sample Characteristics 1. Sample Size 2. Disease Phase 3.Delivery of nurse-led models of care	Study Design 1. Study Type 2.Study Instrument	Main Findings
37. Lewis *et al.2009* Nurse-led vs conventional physician-led follow-up for patients with cancer : Systematic review	To evaluate the effectiveness and cost effectiveness of nurse-led follow-up for patients with cancer	N/A	Systematic review of nurse-led vs doctor-led follow-up for patients with cancer	1.Systematic review	Four RCTs: two examined patient initiated follow-up for breast cancer and 2 examined a telephone follow-up for lung cancer and prostate cancer. **Patient satisfaction**: Statistically significant difference between interventional groups: Nurse-led telephone follow-up scored better than those in the conventional follow-up care; Organisation of care (*p*= 0.01), information and advice (*p*=0.01); personal experience of care (*p=0.03) and* satisfaction with care (*p=0.13).* No difference in survival, psychological morbidity or recurrence **Resource use:** The use of radiograph and radiology was higher in the nurse group, compared with conventional follow-up.

2.3. Theme 1: Development of Nurse-led Models of Care

This section of the literature review explores the reasons underpinning development of nurse-led models of cancer care. It will also explore the structure of nurse-led models of care and describe the characteristics of the nurses providing nurse-led services, including their education and training, work experience, and position title.

Seventeen studies were sourced which identify reasons for developing nurse-led models of cancer care. The principal reason for initiating a nurse-led model of follow-up care in colorectal related services was to save time for surgeons and to facilitate increased clinical demand throughout, in addition to relieving service pressures such as waiting times for surgical interventions (Strand *et al.* 2011; Chalabi *et al.* 2014). Similarly, Cox *et al.* (2008) reported that nurse-led models of care developed to ease pressure on clinical services and was incentivised by government targets for service delivery; for example, a suspected cancer patient has to be seen within two weeks of referral. Extending the capacity of, and reducing workload burden for medical doctors, was reported by Anderson (2010) in a non-experimental study done in the UK. Similarly, Chalalbi *et al*. (2014) investigated the six-year experience of a nurse-led colorectal cancer follow-up clinic in Ireland. The clinic was set up to help reduce pressure on the surgeons and colorectal outpatient clinics so that surgeons were able to devote more time and effort to new colorectal patients. Colorectal patients (n=904) had a surgical intervention to treat cancer, and almost half of patients (N=407) were enrolled in a nurse-led clinic post-operatively The study concluded that there was a significant reduction in the surgeon's workload, and the nurse-led clinic was an efficient and effective means of follow-up for this cohort of patients.

A descriptive study by Birch *et al.* (2016) at a cancer centre assessed patient satisfaction, co-ordination of care between MDT, length of stay after surgery and readmission rates for a nurse-led robotic prostatectomy care pathway. The pathway included phone calls from nurses after discharge from the hospital. The majority (85%, *n=99)* of the patients were discharged one day after surgery. Moreover, 98% of patients felt supported as they suggested nurses provided adequate information before surgery. In addition, nurse-led telephone follow-up was thought to reduce hospital visits.

Another study in Australia by Jefford *et al*. (2016) undertook a randomised control, multi-centred trial in response to problems with the existing model of follow-up care for colorectal cancer patients. The existing model of follow-up did not address patients' distress post-surgery, quality of life or unmet needs. The context of this service redesign was to address shortfalls in response to the complex need of colorectal patients, especially after treatment completion. The intervention was an innovative nurse-led model called 'SurvivorCare' designed to provide face-to-face, or telephone nurse-led support to colorectal cancer survivors. The model was developed to improve psychological distress, quality of life (QOL) of colorectal patients and to address patients' needs. Despite the evidence that patients in the SurvivorCare were more satisfied with the care they received, the model did not show any effect on patient's psychological distress..

A number of studies have explored patients' perspectives of nurse-led models of care (Guest *et al.* 2012; Cox *et al.* 2008; Wells *et al.* 2008; Krishnasamy *et al.* 2011; Beaver *et al.* 2010). Guest *et al*. (2012) reported the findings of a satisfaction survey by using a questionnaire and a focus group looking at the holistic needs of patients attending a pre-operative assessment clinic for gynaecological cancer. Although the study highlighted nurse-led clinics provide comprehensive care to the patients (*n*=12) and considered their needs, only 50% (*n*=6) found holistic assessment useful. In addition, the focus group (n=5) noticed that the nurse-led model of care provided a platform for patients to discuss concerns, which provided patients reassurance to alleviates anxiety and fear. However, the findings of Guest *et al.* (2012) are based on a survey of 12 patients and a focus group of five patients, all of whom were attending a pre-assessment clinic for gynaecological cancer; thus the findings may not be representative of nurse-led services for other tumour sites and stages of the cancer trajectory.

Similarly, increased access to health care was a primary motivator for developing nurse-led models of cancer care. Wells *et al.* (2008) undertook a mixed method study to evaluate a nurse-led models of care to support head and neck patients undergoing radiotherapy at a large teaching hospital in Scotland, UK. The incentive for developing nurse-led models of care was to increase ease of access to health care for patients and to provide information and support, in

addition to symptom management for patients undergoing radiotherapy for head and neck cancer.

Cox *et al*. (2008) conducted a pilot study in the UK to evaluate the effect of a nurse-led telephone intervention for Australian women with ovarian cancer on follow up (n=56). The aim of this model of care was to provide holistic care, which covered both the detection of relapse and identification and management of psychological and emotional concerns. Furthermore, in Australia Krishnasamy *et al*. (2011) report in their cross-sectional survey that the main motivation behind developing nurse-led models of care were linked to the patients' preference and expectation of cancer care. The survey reported patient's perceived issues with doctor-led clinics such as difficulty in accessing the clinics, lack of coordination and continuity of care as patients saw different doctor every time. The majority of patients (*n*=21; 78%) preferred nurse-led services when offered as a shared care model.

In summary, it is evident in the literature that nurse-led models of care are mainly developed to address increasingly complex needs of patients, , increase ease of access to quality care for cancer patients, and to relieve workload burden and demand on medical colleagues' pressure on health service and to improve it while using the resources within the health sector.

2.3.1. Professional and educational characteristics of nurses delivering nurse-led models of care

It is difficult to specify the exact professional and educational characteristics of nurses providing nurse-led models of care, as there is considerable variability in the roles described within the reviewed studies. Description of nurses includes their grade, experience and education level, including specialized training to provide nurse-led models of care. A range of role titles associated with nurse-led care models were identified, including:

- Nurse consultant or nurse coordinator in Australia (Gates & Krishnasamy 2009; Jefford *et al.* 2011),
- Nurse practitioner in Australia and America (Cox *et al.* 2013; Mccorkle *et al.* 2009),

- Advanced practice nurse (APN) in America and Hong Kong (McCorkle *et al.* 2009; Lai *et al.* 2017),
- Clinical nurse specialist or specialist nurse in the UK and Ireland (Birch *et al.* 2016; Anderson, 2010; Wells *et al.* 2008; Howell & Watson, 2005, Egan and Dowling, 2005; Chalabi *et al.* 2014) or breast cancer nurse (Wells *et al.* 2008),
- oncology specialist nurse in Sweden (Dunberger & Bergmark, 2012), and
- oncology nurse in the Netherlands (van der Meulen *et al.* 2014).

The details of educational attainment, experience, and training of nurses leading models of care in cancer were reported in few of the studies reviewed (*n*=14). Most of the nurses delivering nurse-led models of cancer care were oncology-trained registered nurses, with a range of clinical experiences. The clinical experience ranged from two to seventeen years (Gates, 2009; Howell *et al.* 2005; Lai *et al.* 2015; Farrell *et al.* 2017). Only one study from Sweden indicated an advanced level of education for two nurses, one with a PhD and another with a Master's Degree (Dunberger & Bergmark, 2012). The aim of the study was to evaluate a nurse-led model of care to provide care for gastrointestinal side effects of pelvic radiotherapy (*n*=60 patients*)*. The study concluded that nurse-led models of care play an important role in improving cancer patients' quality of life and psychosocial wellbeing. Nurse-led service was provided by only two nurses. Even though both the nurses had different levels of university training. both the nurses regardless of their PHD or Master's qualification independently provided the same nurse-led models of cancer care in this service. However, Dunberger & Bergmark (2012) fail to describe if nurses obtained any special training to provide nurse-led models of care, but recommend systematically organising the service and to provide the education and training to healthcare providers to give equal, evidence-based and cost-effective care to cancer patients.

Additional training was commonly undertaken by nurses to equip them to deliver nurse-led models of care. The training was organised depending on the service demand and the nature of the care delivered in the care model. Six studies indicated that the nurses received training before they could deliver nurse-led care (Casey *et al.* 2017; Cox *et al.* 2008; Howell *et al.* 2012; Craven *et al.* 2013; Collins, 2010; and Strand *et al.* 2010). However, few studies described the specific competencies, education and training undertaken in preparation for

leading such services which makes evaluation and comparison of the results of studies difficult.

Studies by Berglund *et al.* (2015) and Egan and Dowling (2005) each highlighted high levels of satisfaction with nurse-led models of care whilst on treatment. Neither study discussed the specific nature of the nursing role, competencies or education and training undertaken to lead such services. Strand et al (2010) was the only RCT study to describe a six-month apprenticeship with colorectal cancer surgeons for nurses to develop competency in clinical examination and sigmoidoscopy for rectal cancer patients. Strand et al (2010) found patient satisfaction for nurse-led intervention was similar to that for the colorectal surgeon, and thus, medical safety was maintained

Although it is suggested nurses receive some specialist training in preparation for leading nurse-led models of care (Casey *et al.* 2017; Cox *et al.* 2008; Howell *et al.* 2012; Craven *et al.* 2013; Collins, 2010; Strand *et al.* 2010) many studies fail to describe the nature of training and evaluation. Of those which describe the education of nurses' providing nurse-led models of care, there appears to be variation in the levels and timing of educational attainment internationally. Thus, there is recognition of the need to systematically organise the education and training of nurses to provide equitable, evidence-based and cost-effective care to cancer patients.

2.3.2 Approach used for care delivery of nurse-led models of cancer care

This theme examines different approaches of nurse-led models of care and timing of appointments to nurse-led services described in 25 studies within this review. While some nurse-led services continue a medical model of care, others developed innovative models of care such as nurse-led telephone clinic for follow up as mentioned above. The delivery of the care varied in the reviewed studies. Face-to-face and telephone approaches were used together or on its own. Some studies took combined approaches.

2.3.2.1 Nurse-led face-to-face clinics

Fifteen nurse-led models of cancer care used a face-to-face approach, including six studies which compared nurse-led models of care with doctor-led care

(Strand *et al.* 2011; Beaver *et al.* 2010; Wells *et al.* 2008; MacLeod *et al.* 2007; Allinson, 2004; Faithfull *et al.* 2001;). Two studies evaluated patient satisfaction with nurse-led models of care delivered face-to-face for bone marrow biopsy (Collins, 2010) and oncology day care setting (Egan and Dowling, 2005). The remaining studies looked at the effectiveness and feasibility of face-to-face nurse led models of care to provide follow-up care (Berglund *et al.* 2015; Cox *et al.* 2013; Van Der Meulen *et al.* 2014; Dunberger and Bergmark, 2012; Chalabi *et al.* 2014;Howell and Watson, 2005).

A randomised control trial (*n*=205) carried out in the Netherlands by Van Der Meulen *et al.* (2013) compared the effectiveness of a face-to-face nurse-led psychosocial interventions on head and neck patients (n=103) or doctor-led care (*n*=102) and concluded that the nurse-led psychosocial intervention was effective and feasible in reducing depressive symptoms ($p<0.05$) in head and neck cancer patients, compared to doctor-led care. Similarly, Faithful *et al*. (2001) conducted a randomised control trial in the UK to compare the effectiveness of nurse-led follow-up care (n=58) delivered face-to-face for prostate cancer patients undergoing pelvic radiotherapy with conventional doctor-led follow-up (n=57). Nurses did express challenges such as obtaining clinic space and recognition for their profile in setting up nurse-led service for radiotherapy. Their vision was to provide care to improve patients' quality of life during radiotherapy through symptom management, providing education on self-care, and psychosocial support. The study concluded that nurse-led models of care provided increased accessibility by adopting an open access policy, where patients were given direct contact with a nurse outside of regular clinic appointments during radiotherapy.

Despite the potential benefits of face-to-face models of nurse-led care in cancer, nurse consultation were at least twice as much time as doctor-led clinics (Wells *et al.* 2008; Allinson *et al.* 2004; Stand *et al.* 2011). The increased time required in nurse-led face-to-face clinics may be the result of more holistic assessments and to address the diversity of patient's needs (Beaver *et al.* 2010) and to provide additional benefits to conventional doctor-led follow-up care and is described in a nurse-led family history clinic where patients are reported of feeling less rushed (Allinson, 2004) and perform a holistic assessment of patients need (De Leeuw et al. 2013) . While the additional time required to

undertake nurse-led models of care have implications for cost and resources in acute care settings, this must be considered in the context of the potential fiscal savings incurred in reducing the workload on the medical workforce in traditional models of care (Farrell *et al.*2017) and the potential benefits to patients resulting from reduced waiting times (Berglund *et al.* 2015). De Leeuw et al. (2013) in their study to compaire nurse-led models of care with doctor led model of follow-up care concluded that both the model of care provide similar medical safery, adequate detection of cancer recurrence and similar health related quality of life.

2.3.2.2 Nurse-led Telephone Clinics

Nine studies provided information on nurse-led models of cancer care using a telephone approach **(**Booker *et al.* 2004; Kimman *et al.* 2010; Moore, 2018; Overend *et al.* 2008; Anderson, 2010; Craven *et al.* 2013; Casey *et al.* 2017; Faithfull *et al.* 2001). The main motivation factor for developing this alternative model of care was to meet the high demands of medical clinics and to offer the best service possible for cancer patients. However, it is not clear from the literature if the origin of this alternative model of care came from doctors, nurses, patients, or hospital management.

The majority of the nurse-led telephone clinics are used mainly for routine follow-up after completion of cancer treatment, which would otherwise have been undertaken by medics in the clinics. This method was commonly used for cancer groups such as prostate cancer, ovarian cancer, and breast cancer. All the studies report that the majority of patients find nurse-led telephone clinics acceptable, safe, and convenient as a method for follow-up care **(**Booker *et al.* 2004; Kimman *et al.* 2010; Moore, 2018; Overend *et al.* 2008; Anderson, 2010; Craven *et al.* 2013; Casey *et al.* 2017; Faithfull *et al.* 2001).

Booker *et al*. (2004) conducted a prospective non-experimental study in the UK to examine the acceptability and feasibility of the nurse-led telephone clinic to patients (n=36) in follow-up after radiotherapy for prostate cancer. The majority (75%, n=27) of patients found telephone follow-up to be as good as face-to-face follow-up, while 8% (n=3) found it better. Only one patient preferred a face-to-face follow-up with the doctor however the reason for his dissatisfaction with telephone clinic is not mentioned. It is also interesting to note that there were two

patients who had no access to a telephone of their own but had a access to a neighbour's phone , arranged to call the hospital at a set time probably from. Barker *et al.* (2004) suggests that reduced need for travel to hospital and the time-saving for patients may have been a significant motivating factor for patients choosing the telephone follow-up method, as some patients had more than 80 miles of travel to reach the hospital for appointments.

Most studies concluded that it was possible to assess patient's physical symptoms over the phone (Casey *et al. 2017*; Craven *et al.*2013*;* Anderson 2010; Booker *et al.*2004).

Casey *et al.* (2017) did a satisfaction survey to assess if nurse-led telephone follow-up clinics are effective for patients with prostate cancer (*n*=815). Nurses used an assessment form to assess patients over the phone. The assessment form asked information about if patient had any urinary symptoms, any bone pain and ECOG score. Further on there is no information on comparison between face-to-face assessments and telephone assessments which raises the question if this assessment is really a holistic assessment or patients self-reporting their symptoms. The study further deemed telephone follow-up is convenient method of care delivery as there is no travelling to hospital, no car parking fees and no waiting time in an overcrowded outpatient clinic. This model of care also benefits the doctors by allowing them to spend more time with patients with complex issue requiring clinical review. There was also financial evaluation of cost saving exercise which showed saving of approximately 15,105 Pounds based on telephone follow-up as opposed to face-to-face attendance at a urology clinic.

Providing reassurance over the phone was considered as one of the important ways of meeting patient's needs. Lai *et al*. (2017) carried out a quasi-experimental study in Hong Kong to provide supportive care for breast and colorectal cancer patients (n=5) before starting chemotherapy. The study found that providing information sessions on the side-effects of chemotherapy before starting chemotherapy and a phone call after the first and second cycle of chemotherapy to discuss any issues the patient might be experiencing is reassuring for patients.

Most studies which evaluated nurse-led telephone clinics concluded they were an acceptable, safe, and convenient method of follow-up care **(**Booker *et al.*

2004; Kimman *et al.* 2010; Moore, 2018; Overend *et al.* 2008; Anderson, 2010; Craven *et al.* 2013; Casey *et al.* 2017; Faithfull *et al.* 2001). Nevertheless, nurse-led telephone clinics are acceptable to patients and are a safe, effective, and cost-saving approach, especially for routine follow-up post cancer treatment.

2.3.2.3 Nurse-led Combined Approach

Of the studies reviewed, seven adopted both face-to-face and telephone approaches to deliver a nurse-led service (Moore, 2018; Birch *et al.* 2016; Stanciu *et al.* 2015; Lai *et al.* 2015; Chalabi *et al.* 2014; Jefford *et al.* 2013; Howell *et al.* 2012). Characteristic of this model, patients were seen in the hospital and given a telephone number to a specialist nurse to contact on demand.

Moore (2018) in the UK, carried out an economic evaluation of breast and urology nurse-led clinics, where nurses took a combined approach to provide care. Nurse specialists provided an end of treatment summary, a holistic needs assessment and information on health and well-being support to patients once cancer treatment was completed. Information about the possible side effects of treatment as well as advice on signs of relapse was also given. The patients had open access to the nurses' telephone contact number and nurses also undertook a planned telephone review of the patient. This approach was found to reduce the anxiety associated with hospital appointments and provided flexibility for patients access support at the time of need.

Similarly, Jefford *et al.* (2013) describes using combined approach for colorectal cancer patients where a nurse-led SurvivorCare initiative to provide education and support colorectal cancer patient survivors comprised a face-to-face end of treatment nurse-led consultation and three subsequent telephone calls. During telephone calls, patients were assessed for psychological distress, unmet needs and quality of life.

While Birch *et al. (2016)* discuss a combine approach used to prepare men for robotic assisted radical prostatectomy (RARP). In this model of care, the robotic nurse specialist used a combine approach for pre and post intervention care. The care protocol used telephone approach to explain procedure over the phone pre-operatively and face-to-face approach for explaining consent for the

procedure, pre-op investigations and to assess any urinary concerns. Telephone approach was used again post operatively every 3 months for duration of one year, 6 monthly until 5 years and annually up to 10 years to discuss any concern or issues.

2.3.3 Organisation of Care

As discussed earlier, the organisation of care in the nurse-led care models were characterised by the duration and frequency of the clinic appointments, which is mainly determined by the time and the nature of the treatment. Overall, for patients on active cancer treatment, nurse-led models of care usually covered the entire treatment duration, with frequency aligned to hospital visits for the treatment. Whereas, for post-treatment or at the end of life situation, frequency of nurse-led model of care depended on patients' need and requirement.

Out of the 36 studies identified, twelve studies provide details of frequency of clinic consultations. Three reported single consultation per treatment (Moore, 2018; Booker *et al.* 2004; Wells *et al.* 2008). Another four (*n*=4) adopted patient initiated follow-up with flexibility in the number of nurse-led consultation depending on a patient's self-identified needs (Stanciu *et al.* 2018; Farrell *et al.*2017; Dunberger and Bergmark, 2012; and Koinberg *et al.* 2004). The remaining three studies reported consultation with nurse-led service until patients transitioned to end of life care pathways or encountered treatment-related complications and needed further consultation with multi-disciplinary team members (Lai *et al.* 2017; Berglund *et al.* 2015; and Faithfull *et al.* 2001).

Wells *et al.* (2008) evaluated a doctor-led review with a nurse-led model of care using a mixed methods approach. The study reported higher frequency and longer consultations in nurse led models of care compared to doctor-led (median 6 vs 4 consultations (p =0.006); 16 vs 4 minutes (p=0.001)). Patients were likely to have shorter waiting times for nurse consultations (2 vs 9 minutes (p=0.001), and longer consultations for nurse-led services (16 vs 4 minutes *p*=0.001) The study suggests nurse-led consultations were longer, as they provide a more holistic consultation including psychological support, nutritional and self-care advice, and systematic assessment toxicities. The authors suggest doctor-led consultations are often more focused upon treating disease and side-effects of

treatment. This is further illustrated by Allinson (2004), where patients felt less rushed in a nurse-led genetic family history clinic. Patients have more time to discuss their concerns, which contrasts with patient's perception of medical clinics.

2.3.4 Infrastructure Required to Support Nurse-Led Models of Care

Infrastructure refers to physical and organisational structures and facilities needed for the operation of nurse-led services. Richardson and Cunliffe (2003) emphases the importance of having adequate infrastructure for nurse-led services. However, the majority of reviewed studies provided no information on infrastructure needed for the nurse-led service. This represents a significant gap in the literature, as such knowledge is necessary to ensure that nurse-led models of care are developed in a sustainable manner. A scoping study of nurse-led clinics by Hutchison *et al.* (2011) in Scotland identified that the one fifth of nurse-led clinics did not have administrative support which resulted in nurse leads doing administrative task and not able to worke at their full potential as an Clinical Nurse Specialist (CNS). Similarly, a scoping study done in the UK by Farrell *et al.* (2017) also found that having no administrative support and not having a clinic space is one of the barriers nurses face while delivering the nurse-led services.

2.4. Theme 2: Activities of Nurse-Led Models of Care

Sixteen studies provided information about the activities of nurse-led models of cancer care. Information about activities within nurse-led models of care were important to understand the nurse's roles within the nurse-led services. While some studies discuss certain aspects of the service, there is a lack of evidence on nurses' perceptions of their roles, what they exactly do in the clinic including the tools they use to assess patients. Three main activities (follow-up care, symptom management, and treatment interventions) were identified within the reviewed studies. Assessment and follow-up care were the most commonly reported nursing activities in the reviewed studies. However, Hutchison et al. (2011) undertook a scoping survey of 88 nurse-led clinics in Scotland, and identified variation in the activities of nurse-led models of care. Of the clinics evaluated by Hutchison et al. (2011), half (51%) were involved in the care and

management of patients in active treatment; one-third (31%) in the follow-up and surveillance of patients after treatment; one quarter (24%) in symptom management during or post-treatment; and 14% were responsible for diagnostic interventions.

2.4.1 Follow-up

The majority of reviewed studies provided limited detail or information on the nurse's role within the nurse-led clinics. Two studies described nurses replacing the doctor to undertake surveillance for recurrence of disease, and to perform clinical examinations usually done by doctors successfully (Baildam *et al.* 2004; Stand *et al.* 2011). Nurses also delivered telephone follow-up clinics to monitor early sign and symptoms of disease recurrence and to reduce the anxiety associated with hospital follow-up (Koinberg *et al.* 2002; Kimman *et al.* 2011).

While these nurse-led models of care provided a replacement for medical models of care, few studies recognised the added value of nurse-led models of care. Moore *et al.* (2002) developed nurse-led and holistic model of care for lung cancer patients to improve complex respiratory symptoms and coordinate care with other disciplines such as the palliative care team. Several studies report nurse-led models of care provide psychological support for patients (Stanciu *et al.* 2018; Hutchison *et al.* 2011; Cox *et al.* 2008). However, there are no details on how nurses undertake such psychological assessment. Although it is evident in the literature that nurse-led models of care offer advantages to patients by giving holistic care and psychological support (Moore *et al.* 2002), how this support is offered is vague, as there are no details available for review.

2.4.2 Symptom Management

The second most common nurse-led activity delivered was for symptom management, both during and after cancer treatment. The symptoms are managed either through face-to-face contact or through telephone consultations. Studies describing nurse-led models of care were commonly reported in radiotherapy services, where symptom management was effective, and patients were satisfied with the service (Faithfull *et al.* 2001; Booker *et al.* 2004; Lee *et al.* 2011; Dunberger and Bergmark; 2012; Wells *et al.* 2011; Fletcher and Hornsby,

2007). Similarly, Molassiotis *et al.* (2009) carried out an RCT to evaluate the effectiveness of nurse-led model of care for symptom management for breast (n=64) and colorectal cancer patients (n=110) who were receiving oral chemotherapy. Patients were randomised to doctor-led care or to nurse-led home care model for 18 weeks. The nurse led service was a proactive approach and was reported to be acceptable and easily accessible to patients as this nurse-led support at home on one standard home visit and reviewed the patient every week over a phone call.

2.4.3. Treatment Intervention

The third nurse-led cancer care activity reported in the literature was in relation to treatment intervention. This model was used for delivering nurse-led care while the patient is in the active cancer treatment phase. Egan and Dowling's (2005) study described patients receiving a nurse-led model of care during chemotherapy treatment in an oncology day ward and nurses provided symptom management and psycho-social care for patients during chemotherapy. The main advantage of nurses providing nurse-led service during treatment is the continuity of care and patients were satisfied with this approach as they were able to build a relationship with the nurse lead (Farrell *et al.2017*; Dunberger *et al.* 2012; Beaver *et al.* 2010; Egan and Dowling, 2005; Wells *et al.* 2008; Faithfull *et al.* 2001). Whilst some of the studies reviewed showed high levels of patient acceptance and satisfaction with nurse-led models of care, no studies compare these outcomes in relation to doctor-led clinics (Farrell *et al.* 2017; Berglund *et al* 2015; Egan and Dowling, 2005).

During radiotherapy, nurses review patients to determine tolerance and assess side-effects to the treatment. However, nurse-led models of care facilitate flexible appointment times which in turns increases early interventions (Faithfull *et al. 2001)* and allows longs and more frequent consultations (Wells *et al.* 2008). Longer consultations with nurses enable patients to receive more information within nurse-led services (Faithfull *et al.* 2001), and facilitates greater communication with GPs to inform them about their patients cancer care (Wells *et al.* 2008). The impact of nurse-led models of care upon for giving sufficient time for patients so they don't feel rushed in the clinic is another consideration evident in the literature, for example in a nurse-led family history clinic (Allinson,

2004). Finally, while in some cases, nurses may adopt a medical model of care within their service, nurse-led consultations result in more holistic care, allowing the patient more time to discuss their concerns, and often result in a perception that nurses understand their needs better when compared with doctor-led consultation (Allinson, 2004).

2.5 Theme 3: Outcome analysis of nurse-led models of cancer care

Outcomes refer to the results or consequences that have an advantage to the patient, or the service due to the provision of health care (De Leeuw *et al.* 2013). The outcomes of nurse-led models of care in the reviewed studies are grouped into clinical outcomes, functional outcomes, psychological outcomes and healthcare system outcomes. Several studies reported high levels of satisfaction with nurse-led models of care (Booker *et al.* 2004; Egan and Dowling, 2005; Williamson, Collinson and Withers, 2007; Overend *et al.* 2008; Anderson, 2010; Craven *et al.* 2013; Lai *et al.* 2017)

2.5.1 Clinical Outcomes

The most common patient outcomes considered in evaluations of nurse-led models of care were symptom management (Lai *et al.* 2015; Van der Meulen *et al.* 2014; Dunberger and Bergmark, 2012; Molassiotis *et al.* 2009; Wells *et al.* 2008, Howell and Watson, 2005), nutrition status (Wells *et al.* 2008); and survival length (lewis *et al.* 2009). A systematic review done by Lewis et al (2009) looked at four RCTs of nurse-led follow-up clinics. The review concluded that there is no difference in the survival or detection of cancer recurrence between nurse-led and doctor-led follow-up. Three studies identified that nurse-led model of care can provide safe clinical practice for breast cancer patients (Beaver et a., 2010; Baildam *et al.* 2004; Koinberg *et al.*2004). These clinical outcomes are to determine the safety and effectiveness of nurse-led models of care, especially where doctors are replaced by nurses in providing follow-up care.

A scoping study done by Hutchison *et al*. (2011) reviewed 88 nurse-led clinics in Scotland. While no information was given on the approach nurses took to deliver care within each clinic, the study identified a wide range of benefits of nurse-led models of cancer care for patients such as continuity of care and reduction in waiting times.

A number of studies also identified patients who were receiving nurse-led care during and after radiotherapy, chemotherapy or palliative care reported lower severity of symptoms, chemotherapy toxicity, and level of distress and had noted improvement in symptoms compared with medical-led care and nurse-led care (Wells *et al.* 2008, Howell and Watson, 2005; Van der Meulen *et al.* 2014; Lai *et al.* 2015; Dunberger and Bergmark, 2012). This could have been because of the increased frequency and duration of consultation within nurse-led service identify patient's symptoms and to support patients with distress (Wells *et al.* 2008).

2.5.2 Functional Outcomes

There is evidence that nurse-led models of cancer care can improve functional outcomes for cancer patients as they relate to the quality of life (QOL), activities of daily living (ADL), and self-care (Howell *et al.* 2005; Van der Meulen *et al.* 2014). Koinberg *et al*. (2004) carried out an Randomised Control Trial (RCT) (n=264) to compare standard medical-led breast cancer follow-up (n=131) to on-demand follow-up within nurse-led models of care (n=133). This hospital-based intervention was provided by an experienced nurse specialist. In a medical-led follow-up, patients were given an appointment four times per year for the first two years and then twice a year for five years and annually thereafter, with annual mammography disease surveillance. In the nurse-led follow-up model of care, the patient was given a scheduled appointment three months post-surgery. The nurse provided information on recurrence, self-care advice, and provided contact details if any concerns or symptoms related to disease reoccurred. Koinberg *et al*. (2004) found an improvement in overall patient's self-management at home after nurses providing self-care advice to the patients. However, there were no statistically significant differences between the groups for quality of life.

Jefford *et al.'s* (2011) Australian study on the feasibility of nurse-led models of care compared psychological distress of post-treatment colorectal patients at baseline and after introduction of nurse-led post-treatment supportive care programme (n=10) and did not find a significant difference in psychological distress. Similarly, several studies show no difference in psychological outcome in comparison to doctor-led clinics (Baildam *et al.* 2004; Lewis *et al.* 2009; Beaver *et al.* 2010; Kimman *et al.* 2011). In contrast, Van der Meulen (2014) found emotional and physical functioning ($p<0.05$) were significantly

improvement in groups that were receiving a nurse-led model of care compared to the doctor-led models of care in their RCT. The reason behind reducing emotional and physical distress within nurse-led model of care was the care was aim to manage the physical, psychological and social consequences of cancer and its treatment. Whereas doctor-led model of care primarily aimed at the detection of recurrences or second primary tumours or to treat complication of treatments**.**

Nurse-led models of care were found to address patients' information needs and by extension, their psychological coping. in an exploratory qualitative study, Beaver *et al.* (2010) explored perception of patients (*n*=27) experience of follow-up care and treatment of colorectal cancer concluded nurse-led follow-up improves patients' information needs, and thus assists patients in coping with cancer. Furthermore, Howell and Watson (2005) conducted a quasi-experimental study to evaluate the impact of a community-based nurse-led model of care for patients (*n=4)* with breast cancer-related lymphoedema in Canada. The nurse provided information, support and manual lymph drainage in patient's home. The study concluded that the nurse led service enhanced continuity of care, communication, trust, and was convenient as the patient avoided travel to hospital. Overend *et al.* (2008) evaluated nurse-led telephone follow-up clinic for patients with hematological malignancies. One of the eligibility criteria for this nurse-led service was for patients who had difficulty in getting to the hospital. The study found it took Average distance from hospital was 107km or up to 2 hours of travel time. Further on, Casey *et al.* (2017), in the UK evaluated a nurse-led telephone follow-up service of stable prostate cancer patients (n=815). The service was found to be convenient (87%) and 95% of the patients preferred telephone-led service to avoid coming to the hospital

2.5.3 Health system outcome

Health system outcomes were mainly concerned with care cost, health service utilisation, and patient's satisfaction with care delivered. Wells *et al.* (2008) reported that radiotherapy patients receiving a nurse-led model of care had several lengthy consultations with the nurse lead. The waiting time for nurse-led clinics was significantly reduced when compared with the medical-led clinic.

Other studies demonstrated surgical cancellations were limited among nurse-led cancer care patients (Fletcher and Hornsby, 2007; Craven *et al.* 2013).

Molassiotis *et al*. (2009) evaluated the health service utilization of patients receiving nurse-led models of care for oral chemotherapy for colorectal (n=110) and breast (n=54) cancer patients, when compared with standard care for 18 weeks. The study revealed GP visits for symptom control was similar in both arms, but the number of inpatient stays was significantly lower in the nurse-led group (*p=0.02).* In considering cost saving to healthcare delivery, there appears to be an assumption that the nurse-led model of care should be less costly than the doctor-led model of care due to the difference in salaries. However, three randomised control trials reported no cost difference between a nurse-led model for follow-up care or doctor-led care (Corner *et al.* 2002; Baildam *et al.* 2004; Strand *et al.* 2011). The explanation for the difference was reported by Strand *et al.* (2010) in an RCT done to compare healthcare resource utilisation nurse led (n=54) with doctor-led (n=56) follow-up for colorectal patients (n=110) post-surgery. The study reported that although the cost for nurse consultations was lower compared to doctor-led consultation, nurses ordered more investigations, which thus increased the cost for the service.

Nurse-led models of care provide coordination of care with other disciplines such as dentist, medical social workers, community health nurse, or general practitioners. Molassiotis *et al.* (2009) and Howell *et al.* (2005) reported that patients receiving nurse-led models of care had fewer visits to other members of the multidisciplinary team. However, an RCT conducted by Well *et al.* (2008) evaluated a nurse-led model of care for early discharge after breast surgery and reported that even though patients were discharged early from hospital, the care was passed on to community nurses. Hence, the workload for community nurses was increased. Furthermore, Hewett and Howland (2009) evaluated the coordination of care within nurse-led models of care reporting that the care was well coordinated, and nurses provided important information about the patients care to the multidisciplinary group. Nursing and dietician activities change according to patients' and service needs.

2.6 Chapter Summary

Thirty-seven studies of nurse-led cancer models of care reviewed in this chapter were published between 2001 and 2018 and were found to serve many diverse cancer diagnoses and stages of the cancer trajectory. Even though most of the studies described the number and position of the nurses, there was a variance in the level of detail of the activities and the organisational aspects of nurse-led care. Multi-method approaches to deliver nurse-led services (telephone and face-to-face or combined) and face-to-face delivery were common approaches utilised in nurse-led care. However, there remains scope for future studies to compare the value of telephone clinics with face-to-face clinics within nurse-led models of care, with particular reference to the effectiveness of patient assessment, and their impact on the psychosocial outcomes of cancer patients. The reviewed studies revealed that the frequency and duration of nurse-led care varies and are primarily determined by patient need and the nature of treatment and stage of illness.

The most common activities of nurse-led models of care were assessment, follow-up care, symptom management and assesment. Several studies reported positive outcomes of nurse-led models; including improvement in quality of life, activities of daily living and self-care. This was in addition to health care service outcomes such as cost savings, reduction in health service utilisation and high patient satisfaction. These findings demonstrate that nurse-led models of care are potentially beneficial to both healthcare institutions and cancer patients. The evidence reviewed does indicate that cancer patients who received nurse-led models of care have greater access to care, with extra hospital visits, were engaged in more regular communication with nurses, and experienced shorter waiting times. However, the quality of the evidence is variable, and there is considerable inconsistency in how the effectiveness is evaluated. Given the variable context of care setting, it can be challenging to compare services. In general, cancer patients welcome the nurse-led models of cancer care and considered nurse-led care to be both acceptable and safe.

Research Aim and Objective

The study aims to explore nurse-led models of cancer care in Ireland,

Objectives:

- Map the current models of nurse-led oncology care nationally in Ireland
- Create an understanding of the scope, governance and infrastructure which underpin nurse-led models of care in the area of oncology nationally
- Explore the perceptions of specialist oncology nurses as to benefits and impacts of nurse-led models of oncology care in Ireland
- Understand the factors influencing the development and implementation of nurse-led models
- Highlight innovations and ideas for the future development of nurse-led models

Chapter 3: Methodology Chapter

3.1 Introduction

This chapter will outline the methodological approach of this study in detail, including the aims and objectives, in addition to a consideration of approaches to, and the rationale for, the methodology used to conduct the study. The philosophical underpinnings of the study will be considered followed by a discussion on mixed methods research design, and its application to this study. The research methods, sampling strategy, data collection, and approach to analysis will be explained. The issues of rigour, validity, and reliability will be discussed, and the chapter will conclude with a consideration of the ethical issues relevant to the study.

To reiterate, the aim of the study is to explore nurse-led models of cancer care in Ireland. The specific five study objectives are to:

1. Map the current models of nurse-led oncology care nationally in Ireland,
2. Create an understanding of the scope, governance, and infrastructure which underpin nurse-led models of care in the area of oncology, nationally,
3. Explore the perceptions of specialist oncology nurses as to benefits and impacts of nurse-led models of oncology care in Ireland,
4. Understand the factors influencing the development and implementation of nurse-led models,
5. Highlight innovations and ideas for the future development of nurse-led models

3.2 Philosophical Underpinning - Pragmatism

The word philosophy speaks to the search for radical wisdom. Research philosophy is a belief or worldview that guides the researcher as to how data about a phenomenon is thought about, collected and analysed (Morgan 2014). It guides the researcher in the selection of specific research methods (Parker, 2005). Ontology can be understood as a philosophical question, that being, what is the nature of reality? It describes the backdrop to how a researcher makes

sense of the world around him or her and, crucially, the methods the researcher employs to identify, collect and then analyse data (Klenke, 2016). Epistemology is how we know what we know? It is concerned with the nature of knowledge and how a research finds way of knowing (Lincolm *et al.*2011). Ontology and epistemology are both important elements of philosophy of knowledge.

This study was undertaken with a pragmatic worldview. Pragmatism is derived from a belief that the end will, ultimately, justify the means; prioritising the outcome of the research study (Morgan, 2014; Creswell & Plano Clark, 2011). Pragmatic methodologists within the field of mixed methods advocate for the use of research methods which may best answer the research questions posed (Morgan, 2014; Creswell & Plano Clark, 2011). Pragmatism is most frequently associated with mixed methods research (Creswell & Plano Clark, 2011). It enables a researcher to choose between different models of inquiry to determine the most suitable method for a particular study and, subsequently, the most practical approach for addressing the research questions, aims and objectives (Bishop, 2015; Willig, 2013).

Creswell (2013), explains that pragmatism is not committed to any one system of reality; therefore this approach enabled the researcher to explore the concept of nurse-led models of cancer care using both qualitative and quantitative methods. This approach may provide a richer understanding of nurses' views on models of cancer care. The quantitative data provided essential information on the types of nurse-led models practised in oncology in Ireland, the roles and responsibilities of nurses providing the service, and the training provided to nurses in preparation for the management and delivery of nurse-led cancer care services. In addition, the qualitative data provided the researcher with further clarification on nurses' view of the experience of developing, managing, and running a nurse-led model of cancer care and potential facilitators and barriers of implementing these services. As a result, integration of quantitative and qualitative results in this study will enhance the overall understanding of the organisation and management of nurse-led models of care in the oncology setting and facilitates the exploration of the perceived benefits of such care in Ireland among specialist oncology nurses. It is, thus, hoped that the research would provide support to the educationalist as well as policymakers in a structured and collaborative way, ultimately improving the current health service.

3.3 Mixed Methods Research

This study used a mixed method approach, providing a comprehensive understanding of nurse-led models of cancer care in Ireland. A mixed methods study involves the collection, analysis and integration of quantitative and qualitative data in a single study (Creswell, 2018). By combing the two methods, the researcher may draw on the strengths of each respective method, overcomes their individual limitations and produce a more comprehensive understanding of a phenomenon (Creswell, 2018).

3.3.1 Sequential Explanatory Mixed methods designs

The current study used a mixed methods explanatory sequential design, guided by Creswell and Plano-Clarke (2011) (Figure 2). Phase 1 consisted of a survey to explore the scope, governance, and infrastructure of nurse-led models to clarify the current status in cancer care. Findings generated from phase 1 of the study informed the development of the interview guide that was used to collect data from a subsample of survey respondents. In Phase 2 of this study qualitative interviews were undertaken to explore nurses' perceptions of nurse-led models of cancer care and to achieve an in-depth understanding of the impact of nurse-led models of care, and the challenges and barriers of developing nurse-led models of cancer care in Ireland. Data from both phases were then integrated with the final analysis stage to provide a complete description of nurse-led models of cancer care in Ireland. The findings of Phase 1 and Phase 2 were analysed separately then integrated and discussed at the end.

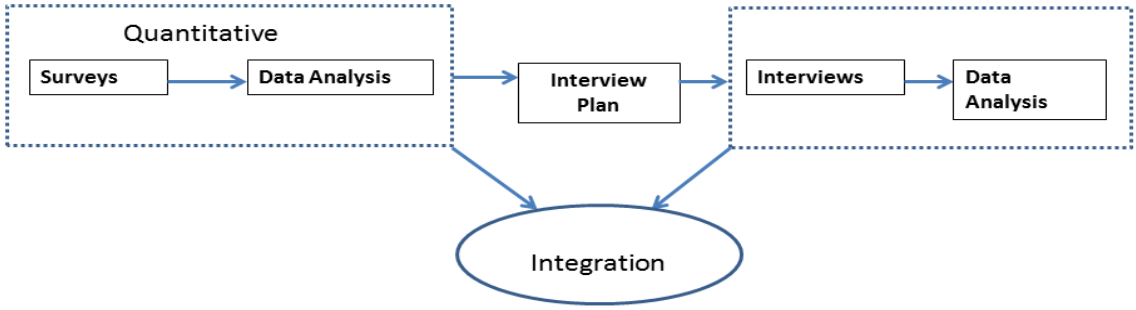
When designing a mixed methods study, priority, implementation, and integration must all be considered (Creswell, 2018). In keeping with Creswell and Plano-Clarke's (2011) , explanatory sequential design, the quantitative phase was undertaken first (timing) and was prioritised (weighting). Integration (mixing of methods) occurred throughout the study within integrated objectives, integrated design, nested sampling, sequential design and integration of findings within the discussion chapter.

The current study is characterised by the quantitative phase survey to gather data from a national sample of nurses working in cancer care, followed by semi-structured interviews with a smaller, purposive sub-sample of survey participants.

Data was collected sequentially, so the initial preliminary analysis could inform the qualitative interviews which were undertaken as landscaping data to gain a fuller, contextual understanding of the barriers and facilitators of nurse-led care in Irish cancer care services.

Survey and interview data were analysed separately; however, equal priority was given to each of the types of data (Thomas & Harden, 2008). The nature of data required to address the research question determined the integration of the quantitative and qualitative data. Both methods were connected and integrated during the interpretation phase of the study.

Figure 2 Sequential Explanatory Mixed method design (Adapted from Tashakkori & Teddlie (2010))



Strengths and Weakness of the Sequential Explanatory Design

An advantage of this design is that a distinct sequential phase of data collection makes it possible for the researcher to enhance understanding of nurse-led phenomena comprehensively (Creswell and Plano Clark, 2011). Consequently, for this particular study, one type of data could have been considered inadequate because “one type of evidence does not tell the entire story” (Creswell & Plano Clark, 2011). In order to capture the concept of nurse-led models of cancer care, the researcher needed to examine the experience of nurses who are working within the services, as well as capture a macro understanding of the status of service in this area through the survey using both the quantitative and qualitative research frameworks. As such, the sequential mixed methods design provided the researcher with the ability to gain a more in-depth understanding of findings revealed from Phase 1: a quantitative study. This two-phase design enabled the

researcher to collect and analyse two different methods separately within a single study, making it practical for the researcher to implement, describe, and report findings (Creswell and Clark, 2010).

Yet, there were some challenges identified in utilising this approach. Indeed, as each phase was conducted separately and performed sequentially, it required extra time and resources for an extensive data collection which is an issue in mixed methods design (Willig, 2010). Consequently, analysis of both quantitative and qualitative data was more time-intensive than the analysis of one type of data on its own (National Research Ethics Service, 2011) and added to the review process and analysis (Willig 2010).

3.4 Population and Sampling

Sampling refers to the potential population from which a researcher may draw participants and respondents (Onwuegbuzie and Leech, 2007). Teddlie & Tashakkori (2010) note that sampling speaks to how a researcher identifies and then selects potential research cohorts. Sampling is generally divided into four categories; these include convenience, purposeful, judgement and random. In the quantitative tradition, sampling attempts to access a representative sample from a population whereby the researcher can generalise from the sample. In the qualitative tradition, there is not an emphasis on attempting to generalise from the narratives of the interviewees. For this study, a nested sampling was utilised.

3.4.1 Study Population

The population for this study was registered nurses involved in cancer care. Nurses were eligible to participate in this study if:

1. they were Registered Nurses, and
2. were working in medical, surgical, and radiation oncology settings

The study population was accessed through the Irish Association for Nurses in Oncology (IANO). The IANO is a non-profit organisation providing a forum for education, training and networking for oncology nurses in Ireland. The IANO has a membership of 217 oncology nurse but does not hold information on the current education or employment details of these members. Therefore, it was not possible to ascertain how many of these nurses were, at the time of

this study, actively providing cancer care to patients. IANO members may be employed in cancer care within the community and private hospital settings, as well as the public sector cancer centres.

3.5 Phase 1: Quantitative Study

3.5.1 Phase I Survey

Newby (2014) defines surveys as a form of quantitative research that targets a defined population and collects data using either questionnaires or interviews to explore the research question. It is a data collection method that asks participants to reply to a defined set of questions (Parahoo 2014) and is a convenient, quick and inexpensive method of collecting information (Jones & Rattray 2010).

For this study, a descriptive survey was undertaken in Phase 1. Surveys gather information of a phenomenon in its natural state without any pre-determined theoretical and philosophical commitment. In addition, this approach was objective, systematic, and repeatable (Girrish & Lathlean, 2015). A large amount of objective information may be obtained efficiently and economically from the survey (Polit & Beck, 2017).

The survey used in this study was based on Hutchison *et al.* (2011), which was developed to evaluate the development of nurse-led activities in cancer and palliative care in Scotland. An online survey was selected as it considered that a large amount of anonymous information could be obtained efficiently and economically from participants nationally (Polit & Beck 2014), Parahoo (2014) warns that online questionnaires tend to have a low return rate. Therefore effort was made to minimise the 'Respondent Burden,' i.e. the time and effort needed to complete a survey (Parahoo 2014).

The survey was tailored for two groups of nurses. The nurses who provided nurse-led services completed the entire survey including sections on infrastructure, scope of practice, audit and evaluation of the service and their perception. The nurses who did not provide nurse-led service were invited to complete the section on demographics and provide comments on their perception of nurse-led models of care. Thus, to filter out the participants to seek

out those who did not provide nurse-led models of cancer care in the questionnaire, the first question was "*Are you involved in the provision of nurse-led models of care?*" If the answer to this question was no, then participants were directed to the end section of the survey, which explored nurses' perceptions of advantages and disadvantages of this model of care.

The questionnaire used in this study was validated by Hutchison *et al.* (2011), with nursing experts working in cancer care. In the Hutchison *et al.* (2011) study, the questionnaire was distributed to 100 clinics, with an 88% response rate across one region of Scotland (Hutchison *et al.* 2011). Permission to modify the questionnaire for use in the current study was obtained from the original author (Appendix 1 & Appendix 2). The instrument was contextualised to the Irish healthcare setting and as such the wording of some items related to nurses' description, job titles, local governance, and management roles was adapted. For example, the UK job classification or banding was substituted with job titles for Irish nursing context such as Clinical Nurse Manager (CNM) or Advanced Nurse Practitioner (ANP). The adapted survey was first reviewed by the researcher's supervision team to determine its relevance to the Irish healthcare context. The questionnaire content validity was subsequently evaluated with a group of specialist and advanced practice nurses who were involved in the provision of nurse-led cancer care services in Ireland and the UK (See Section 3.4.4).

The questionnaire (Appendix 1) was divided into five sections:

- Section 1: Professional demographics
- Section 2: Nurse-led service
- Section 3: Education, training, guidelines and protocols
- Protocols and guidelines,
- Section 4: Scope of practice and competency
- Section 5: Benefits and outcomes of nurse-led models of care

3.6.3.1 Section One: Professional demographic data

Demographic data describing participants' professional characteristics were collected in section one, including the type of hospital in which the participant was employed, professional-grade, highest qualification achieved, years of nursing and cancer nursing experience and time in current position.

3.6.3.2 Section Two: Nurse-led Services

Questions in Section 2 of the survey investigated the infrastructure of nurse-led models of cancer care and included the activities of nurse-led services. These activities were categorised as the administration of cancer treatment, post-treatment review, symptom management, and follow-up care. Additionally, this section evaluated the frequency of the service provided, type of administrative support available, absence cover, referrals pathway and multidisciplinary team involvement and discharge processes.

3.6.3.3 Section Three: Staff Training, Guidelines and Protocols

This section examined additional training undertaken in preparation to provide nurse-led services, which enabled nurses to provide a nurse-led model of cancer care. The questions sought to understand the procedures for the development and review of protocols and guidelines to support service. This included education and training requirements for nurses working in the services. Participants were asked to identify formal guidelines and protocols available to support their practice, including nurse-led assessment, treatment management, symptom management initiating investigations, and the discharge process.

3.6.3.4 Section Four: Scope of practice and competency

This section examined the scope of practice and the competency for the nurses providing nurse-led models of cancer care. The initial question probed the key features of nurse-led models of cancer care (i.e., direct referral mechanisms, responsibility for clinical assessments, autonomy in decision making, freedom to initiate diagnostic tests (e.g. x-rays, blood), admission and discharge rights. At the end of this section, items pertained to the formal assessment of competency to deliver nurse-led services including development and procedures for assessment of competency was explored.

3.6.3.4 Section Five: Benefits and outcomes of a nurse-led model of care

Section five examined the duration of nurse-led service, and formal policies relating to audit and evaluation of the service, including frequency of audit, outcomes of audit, and the use of key performance indicators to evaluate the service. Section five also examined the challenges and benefits of nurse-led models of cancer care and planned developments or innovations in service delivery. However, participants could decline to disclose their place of work. At the end of the survey, participants were given the option to express an interest in participating in follow-up interviews and were asked to provide their email address for the purpose of follow-up correspondence relating to the study.

Phase 1: Questionnaire Validity and Reliability

3.5.1.1 Content Validity

Content validity refers to the capability of an instrument to evaluate the phenomenon under study (Polit and Beck, 2017). It is characterised by face validity and logical validity. As the name suggests, face validity shows that the instrument appears valid “on its face”, whereas content validity is a more complicated process and requires a panel of experts to evaluate the content of the instrument (McGartland *et al.* 2003)

More specifically, validity assesses the degree to which the concept under study is represented by the particular items on the questionnaire (Polit *et al.* 2007). The validity of the questionnaire is often thought to be more important than reliability. A questionnaire needs to be reliable to generate consistent results. However, if the questionnaire does not measure what it is supposed to, it will give inaccurate results which can lead to erroneous conclusions (Grove *et al.* 2013). It is content validity that provides information on the relevance and the clarity of each questionnaire (McGartland *et al.* 2003).

The researcher invited six national and international experts in nurse-led models of care to participate in the content validity evaluation. In the current study, face validity was assessed by a panel six experts in cancer care from Ireland and the UK. Topic experts can provide a logical expert evaluation to determine the

validity of study instruments (Polit and Beck, 2017). Initially, the experts in the field were identified using criteria such as position, experience, knowledge, or a registered nurse working in cancer care for longer than five years. Six experts in nurse-led models of care were identified in Ireland (n=4) and the UK (n=2), all of which had more than five years of experience in cancer care and were involved in the provision of nurse-led services in oncology care. The invitation email included the study instrument (Appendix 1) and content validity score sheet detailing criteria for measuring content validity (Appendix 33). They were asked to consider the relevance and clarity of each question in relation to nurse-led models of care in Ireland (Polit and Beck, 2017), as well as the overall appearance and user-friendliness of the survey, as well as length of time taken to complete the survey.

For this study, the content validity of the items in this questionnaire was assessed based on their relevance to the nurse-led model of cancer care and the clarity of the item's meaning to the expert. The panel of experts were asked to evaluate each question on a four-point scale. A value of four indicated the item was very clear and relevant, with the value of 1 indicating not clear and not relevant. Space was also provided for experts to comment or suggest any ways of improving the instrument. An overall CVI score of greater than 0.80 was evidence of good content validity, according to Lynn (1986) and Yaghmale (2003), who further recommend that if a question receives a low CVI (>0.80), it would need to be revised. Once the expert panel had scored each of the questions for clarity and relevance, an overall score was computed by an average of both the scores (Lynn, 1986; Yaghmale, 2003). The CVI for relevance and clarity was 0.83-1.00, which indicated that the experts found the questionnaire valid (Appendix 1). Appendix 4 gives an example of how CVI for relevance was calculated (Appendix 44).

Experts also recommended adding pharmacist as an answer option for question 19 (other healthcare professionals are involved in the running of the nurse-led services, please provide their job titles). This recommendation informed a minor change made to the questionnaire.

3.5.1.2 Phase 1: Pilot Study

A pilot study is a small-scale version of a study to test the usability and feasibility of a research instrument, recruitment strategies and techniques in preparation for the actual study (Van Teijlingen & Hundley, 2002; Polit and Beck, 2014). The pilot study allows the researcher to test the procedures of the study and identify potential issues which may arise with recruitment and or data collection (Silverman, 2017). If required, the researcher can change or modify the research method accordingly.

The pilot study for the current study was carried out to determine the feasibility of the study and to ensure data collected from the questionnaire was suitable for analysis. It was carried out over one week on 12th October to 19th October 2018. Ten nurses who are members of IANO were randomly selected and invited to participate in the pilot study using the study recruitment protocols outlined in Section 3.4.1. These subjects were excluded from the main study to avoid duplication of data (Van Teijlingen & Hundley, 2002). In addition to completing the questionnaire, pilot study participants were asked to comment on the structure, relevance, and clarity of questions. There was a 70% response rate from the pilot study. No participant provided any comments on the structure, relevance, or clarity of the questionnaire. No issues were identified with recruitment procedures or missing data in the questionnaire.

3.5.1.3 Phase 1: Recruitment

Nurses were recruited through the IANO. An invitation email (Appendix 55) containing an outline of the study purpose, the participant information leaflet for questionnaire (Appendix 66) were distributed to IANO members. The invitation contained a link to the online questionnaire was distributed by the organisation secretary. This email specified a deadline for the return of the survey within two weeks. A reminder letter (Appendix 77) was also sent at the end of week one before the deadline to encourage maximum participation (Rea & Parker 2014).**Error! Reference source not found.** illustrates the survey distribution rocess.

Figure 3 Illustrates the survey distribution process

3.6 Phase 2: Qualitative Study

The purpose of the qualitative interviews is to understand a concept through the eye of others. Semi-structured interviews can describe, explain, and explore a concept from the perspective of participants (Tod, 2015). A semi-structured interview approach was taken for phase 2 of the study. The advantage of interviews in this study was that researcher was able to probe, clarify, and enhance to further explain the quantitative results of Phase 1. In sequential explanatory mixed method designs, the data analysis of the quantitative phase guides the design and data collection of qualitative sampling and data collection (Creswell, 2011). Phase 2 of the study permitted the researcher to interpret the different aspects of the nurses' roles and added greater depth to the quantitative survey findings.

Phase 2 involved a qualitative descriptive qualitative approach. The key features of qualitative descriptive research are its ability to draw from a naturalistic perspective and to examine a concept in its natural state (Sandelowski, 2010). The data collection is usually from individual interviews or focus groups using a topic schedule or guide, which provide a broad insight and rich informative data on the research question (Neergaard *et al.* 2009). The deepness and richness of narrative depth are sought in the qualitative tradition. Bryman (2016) observes

that semi-structured interviews allow for free-flowing conversation but also clear structure to research process when properly planned.

3.6.1 Development of the Interview Guide

An interview guide was formulated to determine the questions before the interview to explore the main findings from phase 1 of the study in greater depth. It offered the researcher a focused structure for the discussion during the interviews but was not followed strictly. This interview guide was based on a preliminary analysis of survey findings discussions supervisors and evidence from the literature (Bryman, 2016) (Appendix 88). While survey explored the infrastructure of nurse-led models of cancer care, researcher wanted to the clarity around how exactly nurses provide the service, what are the challenges and barriers they face to develop nurse-led models of cancer care. In addition, current initiatives around nurse-led models of care and nurses receptiveness of a national pathway for nurse-led models of care. The suitability and feasibility of interview guides and procedures were tested with two of the volunteers from Phase I of the study. It also gave the researcher the opportunity to test audio equipment and become familiar with the system.

3.6.2 Access to Interview Participants

Sampling is an essential aspect of mixed method research (Creswell and Plano Clark, 2017). A purposive sample of volunteers who provided their email address at the end of the Phase 1 survey were invited to participate in Phase 2 interviews. Sandelowski (1995) recommends determining sampling size according to the researcher's judgement. The nested sampling strategy facilitated the identification of information-rich participants, based on survey responses (Sandelowski 1995).

In qualitative research, it is vital to ensure that the sample is representative of the cohort (Polit & Beck, 2014). A maximum variation sampling strategy, as described by Patton (2015), was used to select participants for phase 2 of the study. This strategy facilitates the access of most productive data from a variety of sources to meet the study objectives. The framework for stratification included

representation of all health regions such as from the regional centre or cancer centre, and nursing grades such as staff nurse, CNS, ANP and CNMs. Every attempt was made to select at least one participant who represented these key variations.

Forty percent of survey participants (n=35) indicated their willingness to get involved in the second phase of the study by providing their email addresses at the end of the survey. The researcher sent an email inviting potential participants (n=24) with a letter of invitation and Participants Information Leaflet (PIL) (Appendix 99) for phase 2 of the interview. The letter of invitation stated the aim and objectives of the study and detailed information on the interview process. Eleven nurses responded to the invitation, interviews were arranged at a time of mutual convenience in locations selected by the participant, including the participants' workplace (n=4), hotels (n = 5), and cafes (*n*=2).

3.6.3 Interview procedures

The researcher built rapport with the participants in the emails to arrange the interview. The interviews were conducted over three months starting Dec 2018 and March 2019. The interviews were usually a minimum of 35 minutes to a maximum of 1 hr 30 minutes long. Tod (2015) recommends providing a method through which participants can convey their experience in their own words. In the first two interviews, the researcher found it challenging not to offer opinion during the interviews but resisting this urge became easier with practice; and instead used nods and gestures rather than talking (Tod, 2015). During the interview, the researcher was attentive to ask questions in a non-biased way. Planning the interviews allowed the researcher to decide on what questions to ask, how much time to take, and wording and sequencing of the questions to the participants (Robson & Mccartan, 2016). There is always a risk of potential ambiguity in the spoken word even if data are recorded accurately; hence, consent was obtained in order for the interviews to be audio recorded.

At the start of the interview, the researcher thanked the participant for their time and involvement in phase 2 of the study. Time was also given to read participant's information leaflet (Appendix 99) and sign the interview consent form (Appendix 1010). The participant was reminded of his/her right to stop the interview at any time, should they wish. Once the consent form was signed, all

of the interviews were commenced with the same question: “Tell me about your nurse-led service?” The interview progressed to more specific topics, for example: “explain why the nurse-led clinic was started” or “are there guidelines or a pathway to follow before setting up these clinics?” The purpose of this was to put the participant at ease (Doody & Noonam, 2013).

Open-ended questions were used to allow participants to answer without any restriction, and it facilitated the collection of rich data (Creswell & Plano Clark, 2011). Throughout the interview process, the researcher used probes like nodding the head, repeating back what participants said, and silence to prompt participants to expand on the information (Robson & Mccartan, 2016). Additionally, probes such as a question, “ *Please tell me more about that?*” were used to elicit more in-depth information about their experiences and perceptions of nurse-led services (Tod, 2015). At the end of the interview, the researcher thanked the participants and informed them that once the study was completed, they will be informed of the findings. They were also advised that contact could be made by email if they needed any information.

3.6.4 Rigor

Although qualitative research has always been criticised for lack of objectivity and transparency in the analytical procedures (Rolfe, 2006), every effort was made to ensure standards to maintain rigor. Guba and Lincoln’s (1985) criteria of credibility, transferability, dependability, and confirmability were applied to determine rigor in phase 2.

3.6.5 Credibility

Credibility is used to determine if the interpretation of the respondents’ views matched with the researcher’s analysis (Korstjens & Moser,2018). It relates to the truthfulness of the findings; therefore, direct quotes from participants were used to develop themes to enhance credibility. Lincoln and Guba (1985) recommend member checking as a strong measure of credibility can be formal or informal. Member checking was obtained at the end of the interview where the researcher reviewed and verified what was discussed with each participant and whereby participants actively checked the transcripts themselves and were

permitted to make annotations and revisions. However following member checking, no participant requested changes to their interview transcript.

Another strategy recommended for credibility by Korstjens & Moser (2018) is prolonged engagement with interview participant. This was obtained by asking several distinct questions about nurse-led models of care they provide. Nurses were encouraged to support their views with examples, and follow-up question were asked. Field notes were maintained, and the researcher studied the data until a theme emerged to provide detail information about nurse-led models of cancer care.

3.6.6 Transferability

Transferability is used to determine if the findings of qualitative research can be transferred to other services using nurse-led models of care. In qualitative research, transferability is achieved by providing detailed description of the methods and reality of participants to help other researchers to assess whether the study findings are transferable to for their own settings (Korstjens & Moser,2018). It is recommended to give detail description of the study such as the context in which the study was carried out; it's setting, sample, sample strategy as well as inclusion and exclusion criteria, interview procedure and topic. Hence, section 3.5 gives detail description of phase 2 of the study to let other researchers make the transferability judgement.

3.6.7 Dependability and Confirmability

Dependability is concerned with the stability of data and confirmability is concerned with the objectivity of the research and ensures that interpretations are embedded in findings which is traced to their sources (Lincoln and Guba, 1985). Dependability and confirmability can be verified via an audit trail which includes evidence of the decision-making and of the sequence of data collection and analysis (Sandelowski, 1986). In the current study, dependability and confirmability were achieved by accurately recording the interviews and recording a detailed process of analysis (Jackson & Bazeley, 2018). Qualitative data analysis was undertaken in NVIVO; analytical decisions were recorded

using the coding, memo and annotation functions of NVIVO (Jackson & Bazeley, 2018).

3.7 Integration of Methods

The integration of quantitative and qualitative data is an integral part of mixed methods research (Franz *et al.* 2013). If integration does not happen effectively, it questions the rationale for conducting a mixed methods study (O'Cathain, Murphy & Nicholl, 2007). If integration does happen effectively, it enhances the value of the study (Bryman, 2006a; O'Cathain, Murphy & Nicholl, 2007). Integration for the current study occurred first at design level where study objectives integrated which required data from Phase 1 (quantitative data) to be collected and analysed and the findings from Phase 1 informed phase 2 (qualitative data) data collection and analysis (Ivankova, Creswell & Stick, 2006). Secondly, it occurred at the methods level where an integrated sampling approach was used. The participants who wished to volunteer for the second phase of the study (interviews) were advised to provide their email address at the end of the survey. They were assigned a unique participant ID code, which was then used to link questionnaire and interview data longitudinally, to support the integration of data in line with a mixed methods sequential explanatory design (Fetters, Curry & Creswell, 2013). The findings from phase 1 informed the development of a qualitative interview guide for phase 2. The qualitative phase was designed to clarify, enhance, and further explain quantitative findings, and the findings were discussed together in relation to the literature on nurse-led models of cancer care (Ivankova, Curry & Creswell, 2014) .

3.8 Ethical Considerations

Beauchamp & Childress (2013) identified four core ethical principles they saw as key when carrying out research; autonomy, non-maleficence, beneficence and justice, later developed by a professor of nursing, Parahoo (2014).

Ethical approval for the study was obtained from the School of Nursing and Midwifery Research Ethics Committee (SNMREC) at Trinity College Dublin (Appendix 111). Any research study involving humans is required to comply with the highest standards as mentioned in critical international guidelines or codes

relating to ethical conduct in research including the declaration of Helsinki (DePoy & Gitlin, 2016; World Medical Association, 2013). The Declaration of Helsinki recommends that the research involving human subjects must always give priority to the rights and interests of individuals (World Medical Association, 2013). The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (Nursing and Midwifery Board of Ireland, 2014) principles for the ethical conduct of the research guided this study, including beneficence, respect for human dignity, and justice (Morgan, 2014). Each principle was applied to the current study and is discussed below.

The participant information leaflet informed the individual of the right to withdraw from the study and to stop the interview if any issues occurred.

3.8.1 Beneficence

Beneficence implies that the research should have the maximum benefit with minimal harm or risk for society and participants (Polit & Beck, 2014). In this mixed method study, there was no direct benefit to the participants, other than the contribution of knowledge to the national understanding of nurse-led cancer services, and future education and practice developments for nurse-led models of cancer care in Ireland. The researcher anticipated potential risks of participants becoming distressed and upset during this study; nevertheless, a plan was put in place if this happened. However, this issue did not arise.

3.8.2 Respect for persons

Respect for persons is described as the right to autonomy and self-determination (NMBI, 2014). In a research context, freedom of choice and a person's ability to express his or her opinions are paramount and should be both protected and encouraged (Thomas & Harden, 2008). Indeed, there is a close relationship between autonomy and informed consent (NMBI, 2014). The study was discussed in-depth with each participant, who were given the opportunity to ask questions before signing off consent.

3.8.3 Informed Consent

3.8.3.1 Informed consent for Survey

Informed consent implies that participants and respondents are informed of all aspects of the research process in terms of the various stages and dissemination routes, any potential risks that might arise for them or persons known to them and any rewards including vouchers, gifts or financial remuneration (Declaration of Helsinki, World Medical Association 2013).. The information pack contained the participant information leaflet, which outlined the aims and objectives of the study, and the time commitment required to complete the survey. The participant information leaflet also outlined the potential benefits and risks associated with the study, and the participants' right to decline participation or withdraw from the study at any time. Participants were assured their participation in the study would remain confidential. All participants were provided with contact details for the researcher. The completion and return of the survey were taken as an indication of implied consent to participate in Phase 1 of the study.

3.8.3.2 Informed consent for Interviews

/As with the qualitative dimension to the study, a participant information leaflet outlining the aims and objectives of the study was given to the participants in advance of the interview. Participants were assured their participation in the study would remain confidential and that their personal data would be managed in line with GDPR and Health Research Regulation requirements (General Data Protection Regulations (2018). The participant information leaflet also outlined the potential benefits and risk associated with study, and the participant's right to stop the interview any time or withdraw from the study at any time.

Participants were warned that if they disclosed information during the study that raised concern for the safety of a patient, they were n notified that such information would need to be disclosed to appropriate authorities, such as NMBI or the Director of Nursing of the participants' organisation.

Participants were requested to read and sign two copies of the Phase 2 consent form (Appendix 1010). One copy of the signed consent form was given to the participant for their record, and the other was retained by the researcher.

3.8.3.3 Justice

The principle of justice is concerned with fairness and equality in research procedures and is maintained in the current study. All potential participants received the same information and were treated equally, and all the participants were given equal and fair opportunity to agree or disagree to participate in the study and were treated respectfully regardless of their decision.

3.8.3.4 Confidentiality and Anonymity

The principle of confidentiality and anonymity was observed through the protection of participant's privacy and confidentiality throughout the study (Polit and Beck, 2006). For both survey and interview participants interview, it was made clear in the cover letter that participants' identity will be kept confidential (Appendix 55). All data were stored in keeping with recent General Data Protection Regulation (GDPR) 2018). Confidentiality of data maintained at all stages of the research process No other person had access to the data other than researcher and the supervision team. Participants' identity and any other personal information given during the interviews were removed from the study database and stored separately from the study data. Each participant was allocated a numerical code, pseudonymising their identity. Participants were assured results of the study would be published in a way that individual identities could not be recognised.

In Phase 2 (interviews), it was impossible for the researcher to assure participants of anonymity, as interviews are a communication process involving one-on-one interaction (Streubert & Carpenter , 2010). Participants were assured of confidentiality in the participant information leaflet for interview (Appendix 99). In phase 2 of the study, identifiable information disclosed during interviews was redacted from interview transcripts. Consent forms and the participant database containing identifiable information were stored separately from the survey and interview data. All participants were allocated a pseudonymised numerical code.

The researcher transcribed the data from the interviews. Transcribed data files about the study were stored on an encrypted and password protected computer and were only accessible by the researchers. The hardcopy records were stored securely in the researcher's office in a locked cabinet. Only the researcher had access to this cabinet. The data collected will only be used for the study of a nurse-led model of cancer care and will be retained five years after the completion of the study. After this time, all data will be destroyed by the researcher.

3.8.3.5 Veracity and Fidelity

The ethical principle of veracity deals with truthfulness with research participants; fidelity is concerned with the building of trust with study participants (NMBI, 2014) and necessitates a commitment from researcher to protect participants. To uphold these requirements, potential risks of identification of any malpractice and researcher's duty of care to report any to the director of nursing and or NMBI was disclosed in the participant's information leaflet. Similarly, benefits related to the study to help evaluate the status of nurse-led activities were also disclosed in the participant information leaflet. The researcher had planned to terminate the interview if there were any signs of unnecessary distress to the participants during interview. However, this issue did not arise.

3.9 Data Analysis

Data analysis in mixed method research involves the analysis of both quantitative and qualitative data using an appropriate method of analysis (Creswell & Plano Clark, 2007). A data analysis plan was developed in conjunction with supervisors (Appendix 122). A sequential approach to analysis was undertaken. The survey was analysed first to enable preliminary understanding of findings to inform the interviews for phase 2.

3.8.1 Phase 1 Survey

Data preparation began first by entering the raw data into SPSS to facilitate data analysis. Data were checked and cleaned to ensure the dataset was accurate and complete (Chapman, 2005). For the current study, the data were reviewed

for identifying missing information and for confirming that participants answered each question in the correct format. The responses to the open-ended questions then were organised and categorised to contextualise the statistical data.

To support analysis, categories were grouped together as follows. Nursing grades were categorised as CNM I/II/III, staff nurse, CNS and ANP and candidate ANP. Qualification was categorised as nursing certificate/diploma and degree as one group, postgraduate certificate/diploma as the second group, and MSc as the third group. Experience in nursing profession and time in position were grouped into ≤ ten years and ≥ 11 years for analysis.

Descriptive statistics were generated to explore the characteristics and nursing profile of nurse-led models of cancer care in Ireland. Descriptive statistics is a useful way to describe data in a convenient and informative manner (Polit & Beck, 2010). It allowed the researcher to describe the current status of nurse-led models of cancer care in Ireland comprehensively. Numerical data were described using categorical variables and described using frequencies and percentages. The cross-tabulation function of SPSS was used to determine if there was any association between different groups.

3.8.2 Phase 2 Qualitative Data

A large amount of data was obtained during qualitative data collection which was transcribed within days of the interview. Data were imported into NVivo 12 (2018) software for data management and analysis. NVivo 12 software served as an efficient tool for managing data and maintaining transparency. It also facilitated the researcher to produce a detailed and comprehensive codebook.

Braun and Clarke's (2006) 6 stage framework for thematic analysis was used to facilitate analysis as follows:

Become familiar with the data: at this stage, the researcher familiarises oneself with the data by reading and re-read interview transcripts and field notes multiple times.

Generating Initial Codes At this stage of open coding, extensive initial coding of the interviews was freely generated to further analyse the data from its original chronology into initial non-hierarchical general codes.

Searching for Themes The aim here was to identify the major topic areas discussed in the interviews, including reason for setting up nurse-led service,

challenges, barriers, and how service users and service providers benefited from the service. This involved re-ordering codes identified from phase II and coding in broad topics that could be taken forward to organising them into a framework that made sense to further the analysis of this particular data set, as guided by the research question. This phase also included distilling, renaming, and merging categories to ensure that their definitions accurately reflected coded content.

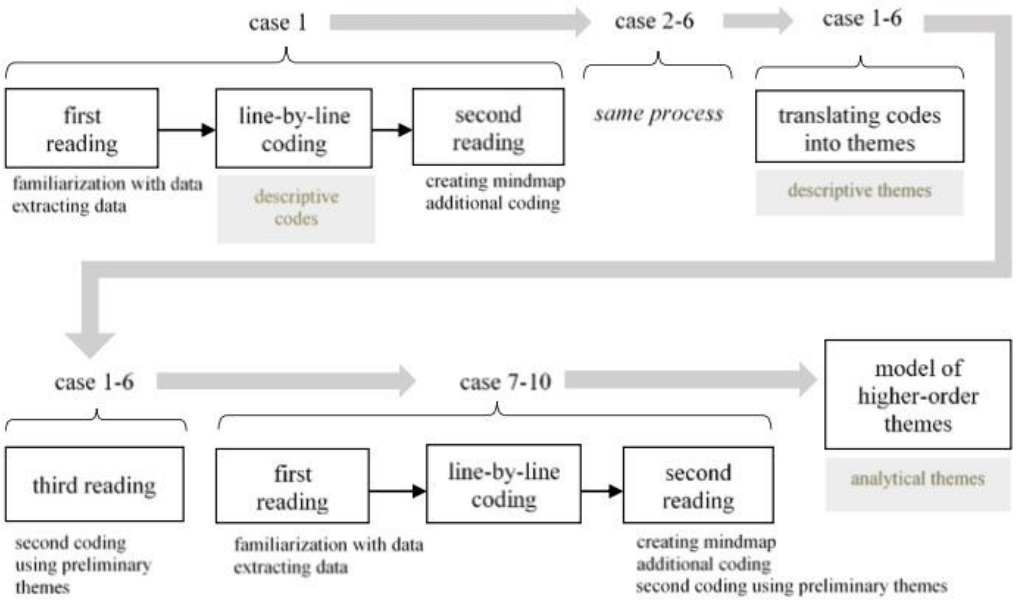
Stage 4 *Reviewing Themes* continued through the coding and organising of the data into sub-categories to offer a more in-depth understanding of the highly qualitative aspects under scrutiny. This involves critically revisiting the data with the identified themes to make sure that the final themes represent the original data.

Phase V: *Defining Themes* involved consolidating codes from all three cycles into three meta themes; nurse-led models of care, benefits of nurse-led models of care, and challenges and barriers of nurse-led models of cancer care.

Phase VI: Write-up involved writing a report on the meta themes and sub-themes and making sense of these in the context of the study question, aims and objectives.

The below figure outlines the process typically undertaken in thematic analysis(Figure 4)

Figure 4 Process of thematic analysis (adopted from Braun & Wilkinson, 2003)



3.8.3 Data integration

The success of a mixed method study lies in careful attention paid to the integration of methods throughout the study (Bryman, 2006; O'Cathain *et al.* 2007). For the current study, the complementary use of survey and semi-structured interviews allowed the study to pose related but different questions in relation to the current status of nurse-led models of cancer care in Ireland. The first as discussed before integration of the methods was exhibited when the survey facilitated access to a purposeful sample for interviews. This approach facelifted the researcher to develop the interview guide and to find explanation for the survey results through interview participants (Greene & McClintock, 1985).

The primary process of integration happened at the interpretation and analysis level where the findings from Phase 1 and Phase 2 were discussed together about the literature on nurse-led models of cancer care (Ivankova, 2014). Further to this, findings from the interview were used to interpret, contextualise, and expand on the survey findings (Teddlie & Tashakkori, 2009). This approach allowed the researcher to understand the depth and breadth of nurse-led models of care, infrastructure required for nurse-led models of cancer care, the scope of practice, training and education, and the motives for starting nurse-led models of care for cancer patients. The integration of both survey and interview findings were done by using Nvivo. The key descriptors from Phase 1 were exported from SPSS into Nvivo, which enabled cross-reference with the Phase 2 analysis. As Nvivo was able to store both quantitative and qualitative data, the researcher was able to pose queries on Nvivo to understand interview findings through cross-checking of quantitative findings. Only when the findings were considered in conjunction with verbal accounts of concern when nurses expressed their fear associated with not being able to provide quality care to cancer patients and issues associated with incomplete follow on care due to insufficient time.

3.9 Summary

This chapter presented a discussion on the methodology of the study. It noted a mixed methods study that used an explanatory sequential design using connected integration with a pragmatic approach to investigate the topic under

review and engage with the study's aim and objectives. A detailed description of the rationale behind using a mixed method design was outlined, and the integration of two different research approaches delineated. A detailed consideration of the ethical consideration for the study was outlined. Finally, the issues relating to sampling, data collection, and data analysis were discussed.

Chapter 4: Survey Findings

4.1 Introduction

This chapter presents the findings generated from the national survey of nurses working in cancer care. A total of 217 questionnaires were distributed to all members of the IANO, and a total of 90 questionnaires were returned, representing a response rate of 41%. All surveys were examined during the data entry process. Three questionnaires were excluded from analysis, as the participants answered only the first 6 questions and did not answer if they were responsible for the provision of a nurse-led service in their organisation. The final sample suitable for analysis was 87 (97%). Forty-nine participants (56%) were responsible for the provision of nurse-led models of cancer care, and completed sections 1, 2, 3, 4, and 5 of the questionnaires (Section 3.4.3). Thirty-eight (44%) nurses were not involved in providing nurse-led models of care and completed Sections 1 and six open ended questions in Section 5, outlining their views on the development of nurse-led models of cancer care. Analysis from open ended question will be integrated in chapter 5 (qualitative findings).

4.2 Sample Characteristics

The following demographic information hospital type, employment grade, education, years of cancer nursing experience and time in the current post, was obtained from participants.

The majority of participants were working in a cancer centre of excellence (*n*= 39; 45%). The remainder worked in regional (*n*=25; 29%) and other hospitals (*n*=23; 26%) providing cancer care. Participants were predominantly clinical nurse specialists (*n*=36; 41%), of whom 24 (49%) provided nurse-led services. Twelve clinical nurses specialists (32%) did not provide nurse-led models of care. Few ANPs/cANPs (*n*=*7*; 15%) responded to the survey; 86% of the ANPs/cANPs (*n*=*6)* provided nurse-led models of care; only one cANP did not provide nurse-led service. The majority of participants achieved the highest qualification of postgraduate certificate or diploma in cancer care (*n*=54; 62%); however, just over half of these (*n*= 30; 55%) provided nurse-led service. A master's degree was held by 28% of participants (*n*=24), while the remaining 10% of the participants (*n*=9) held undergraduate qualifications. A small number

of participants leading nurse-led models of care (*n*=4; 8%) held an undergraduate qualification only. Of those who were not leading nurse-led models of care, one-quarter held a master's degree (*n*=9; 24%).

Table 4 Demographics

		Response of all the nurses		Nurses providing Nurse-led models of care		Nurses not in Nurse-led models of care	
Characteristic		n	%	n	%	N	%
Total		87	100%	49	56%	38	44%
Hospital Type	**Cancer centre of excellence**	39	45%	22	45%	17	45%
	Regional Centre	25	29%	13	27%	12	32%
	Other	23	26%	14	29%	9	24%
Nursing Grade	**Staff Nurse**	19	22%	9	18%	10	26%
	CNM I/II/III	25	29%	10	20%	15	40%
	CNS	36	41%	24	49%	12	32%
	ANP/cANP	7	8%	6	12%	1	3%
Highest Qualification Achieved	**Nursing Certificate/ Diploma/ Degree**	9	10%	4	8%	5	13%
	Postgraduate Certificate /Diploma	54	62%	30	61%	24	63%
	MSc	24	28%	15	31%	9	24%
Cancer Nursing Experience	**≤ 10 years**	26	30%	10	20%	16	42%
	≥ 11 years	61	70%	39	80%	22	58%
Time in Current Position	**≤ 10 years**	59	68%	27	55%	32	84%
	≥ 11 years	28	32%	22	45%	6	16%

There was no significant difference between nurses who provided nurse-led models of cancer care and those who did not, in terms of their grade, qualification, and hospital type. The majority of participants had ≥ 11 years (*n*=61; 70%) of cancer nursing experience. Nurses who had have more than 11 years of cancer nursing experience (*n*=39, 80%) were significantly more likely to provide nurse-led models of cancer care when compared with those who had less than 10 years' experience (*n*=22, 58%); Similarly, the nurses who are working in the current position for less than 10 years (*n*=32; 84%) were less likely to provide nurse-led models of cancer care when compared with nurses

who are in the current position for more than 11 years (*n*=22; 45%). Most of the participants (*n*=28; 57%) reported the nurse-led services they have been providing have been running for ≤ 5 years, with the remaining (n=21;43%) established for more than 6 years (**Error! Reference source not found.**).

4.3 Nurse-led Service

Nurses who were not involved in the provision of nurse-led services did not answer this section of the questionnaire. Therefore, the proportions reported in this section relate to the proportion of participants providing nurse-led models of care(*n*=49;56%).

4.3.1 Infrastructure

4.3.1.1 Administrative Support

Nurses were asked to report on the administrative support available for the nurse-led service they provide. More than half of the participants (n=27; 55%) participants had no administrative support. The nature of the administrative support varied. Four-fifths of participants (n=18; 81%) got patients' medical/nursing notes delivered before clinic, whereas only 41% (n=9) received support for recording clinic statistics. Participants from the regional centre (n=7; 54%) more frequently reported receiving more support when compared with participants working in the cancer centre of excellence (n=9; 41%) or other centres (n=6; 42%). ANP/cANP (n=4; 67%) had most administrative support and staff nurses (n=2; 22%) had the least support. The ANP/ cANP had administrative support for patient's medical and nursing notes delivered after the clinic (n= 4; 100%), while 75% (n=3) of ANP/cANP had administrative assistance to obtain patients medical/nursing notes before staring clinics and transcribe the letters. One ANP/CANP (n=1; 25%) got support to record clinic statistics.

4.3.1.2 Absent Cover

Nurses were asked to report the arrangements for nurse-led service if the nurse lead is absent. In this survey, 22 (44%) responded that a full equivalent service was provided in the event of the nurse lead being absent. Participants from

cancer centre of excellence were more likely to report their service had cover for their absence (*n*=12; 54%) compared to regional (*n*=5; 23%)) or other hospitals (*n*=5; 23%). In the absence of the nurse lead, nurse-led services were most often covered by a CNS (*n=13; 54* %) (Table 5).

Table 5 Absence Cover

Absent cover from	Type of hospital					
	Cancer centre of excellence (N=12)		Regional Centre (N= 5)		Other (N=5)	
	n	%	n	%	n	%
CNS (N=13; 59%)	5	42%	3	60%	5	100%
Doctor (N=4; 18%)	3	25%	1	20%	0	0%
Another nurse (N= 5; 23%)	4	33%	1	20%	0	0%

When nurse-led services were not covered, patients were booked into the next available nurse-led clinic (*n*=14; 56%) or booked into a consultant-led clinic (*n*=11; 44%). The primary reason cited for not having a full equivalent cover (*n*=27; 55%) in the absence of the nurse lead was that no appropriately trained nurse was available when the lead is absent (n=12; 44%). The other reasons were that the patients are rescheduled for the next available nurse-led clinic (n=8; 30%) and there are not enough nursing staff (*n*=7; 26%) to provide cover in the absence of nurse lead.

4.3.1.3 Scope of Nurse led service

Nurses were asked to report on the scope of their nurse-led service. Just over 50% of participants had responsibility for clinical assessment (n=22; 56%) and had autonomy in decision making (n=22; 56%). Most of the ANP/CANP (n=44; 66%) were able to refer patients to other MDT members whereas less than half of CNS participants (n=11; 46%) were able to refer directly to other MDT members (Table 6)

Table 6 Scope of nurse-led service

Scope of nurse-led service	Nursing Grade							
	ANP/CANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
	N	%	n	%	n	%	n	%
Direct referral mechanisms to other MDT member (N=18; 46%)	4	66%	11	46%	2	20%	1	11%
Clinical assessments (N=22; 56%)	3	50%	12	50%	4	40%	2	22%
Autonomy in clinical decision making (N= 20; 51%)	3	50%	12	50%	3	30%	2	22%
Diagnostic tests (e.g. x-rays) (N=15; 37%)	2	33%	10	42%	3	30%	0	0%
Admission rights (N=5; 13%)	1	17%	4	17%	0	0%	0	0%
Discharge rights (N=7; 18%)	2	33%	5	21%	0	0%	0	0%

4.3.3.1 Activities of nurse-led models of care

Participants were asked to identify the nurse-led activities provided within their services. Some of the participants reported to provide more than one activity within nurse-led models of cancer care. Symptom management (n=36; 73%), follow-up care (n=34; 69%) and post-treatment review (n=33; 67%) were the most common activities reported by participants within nurse-led models of care. Participants also reported having other nurse-led activities (n=37; 76%) including nurse-led psychological support, nurse-led clinical trial assessment, and nurse-led assessment for oral chemotherapy.

Just over 80% of the CNS (*n*=20) provided nurse-led care for symptom management and post-treatment review and 75% (*n*=18) provided nurse-led follow-up care. While there was a variation in nursing grade and activities of nurse-led service, ANPs/cANP were the only group who consistently provided nurse-led follow up care (*n*=6; 100%).(Table 7)

Table 7 Activities of Nurse-led service

		Type of Hospital					
		Cancer centre of excellence N=22		Regional Centre N=13		Other N=14	
		N	%	N	%	N	%
Activities of NURSE-LED Service	Administration of Cancer Treatment (N=26; 49%)	12	46%	9	35%	5	19%
	Post Treatment Review (N= 33; 67%)	15	45%	10	30%	11	33%
	Symptom Management (N=36; 73%)	16	44%	11	31%	9	25%
	Follow-up care (34; 69%)	17	50%	9	26%	8	24%
	Other Activities (N= 37; 76%)	18	49%	11	30%	8	22%

Across all sites, nurse-led services were most commonly provided on a daily basis (n=36; 73%). **(**Table 8)

Table 8 Frequency of nurse-led services

Frequency of nurse-led service	Hospital Type					
	Cancer centre of excellence N=22		Regional Centre N=13		Other N=14	
	N	%	N	%	N	%
Daily (N=36; 73%)	12	55%	11	85%	13	92%
Weekly (N=9; 18%)	7	32%	2	15%	0	0%
Fortnightly (N=2;4%)	2	8%	0	0%	0	0%
Monthly (N=2;4%)	1	5%	0	0%	1	8%

4.3.1.4 Training

Nurses were asked to report the education and training they received in preparation for providing nurse-led cancer services. Just over 50% of participants (n=26) stated they received some kind specific education or training to equip them to deliver nurse-led care, 43% of participants (n =21) indicated they did not receive any specific training or education, with the remaining 4% (n

= 2) were unsure if they received any training or education. While all of the ANPs had their ANP certification completed, they also had to complete clinic-specific training. Participants who were CNS and staff nurse grade received specific training such as physical examination module, nurse prescribing course as well as self-directed learning and clinic-specific training. (**Error! Reference source ot found.**)

Table 9 Training to equip nurses to deliver nurse-led service

	Nursing grade							
Additional Training	**ANP/CANP N=6**		**CNS N=24**		**CNM I/II/III N=10**		**Staff Nurse N=9**	
	N	%	N	%	N	%	N	%
Physical examination module (N= 14;1 6%)	**6**	**100%**	**8**	**33%**	**0**	**0%**	**0**	**0%**
Prescribers course (N=9;18%)	**6**	**100%**	**2**	**8%**	**0**	**0%**	**1**	**11%**
ANP Certification (N=6;12%)	**6**	**100%**	**0**	**0%**	**0**	**0%**	**0**	**0%**
Self-directed learning (N=12;24%)	**6**	**100%**	**1**	**4%**	**5**	**50%**	**0**	**0%**
Clinic-specific training (N=38;76%)	**6**	**100%**	**13**	**54%**	**10**	**100%**	**9**	**100%**

4.3.1.5 Multidisciplinary involvement

Nurses were asked to report the involvement of multidisciplinary team members in the nurse-led service they provided. One-third of the participants reported their service had multidisciplinary involvement (*n*=27; 55%), including pharmacist (*n*=8; 30%), dietician (*n*=6; 22%), and medical consultants (*n*=5; 19%). The regional centre and other centres providing cancer care did not have a radiation oncologist working in their MDT team while cancer centre of excellence had one radiation oncologist (11%). Similarly, occupational therapy (*n*=1; 8%) was a part of Multi-disciplinary team only in regional centre.

Thirty-six Participants (73%) providing nurse-led models of care reported having autonomy to refer patients to other services. They primarily initiated outward referral to a dietician (*n*=34, 69%). The CNS was the only group of nurses who referred to all of the members of a multi-disciplinary team.

4.3.1.6 Audit and evaluation of nurse-led service

Nurses were asked to report on the audit and evaluation of the nurse-led service. The majority of nurse-led services (n=21; 43%) were not subject to formal audit or evaluation of the service and further twenty-four percent of the participants (n=12) were not aware if there was any formal audit or evaluation of the service. The remaining 33% (n=16) were audited, and participants working in cancer centres of excellence were most likely to report that their service was audited and evaluated (n=8; 50%). (Table 10)

Participants reported the clinical indicators, activities and patient outcomes that were audited and evaluated formally or informally. The number of patients attending the nurse-led service was the most frequently evaluated indicators (*n*=22; 49%), followed by patients' satisfaction rate (*n*=16; 33%). While accuracy of diagnostic skills (*n=2;* 4%) and prescribing pattern (n=2; 4%) were less frequently evaluated indicators. centres (Table 11)

Table 10 Audit and Evaluation of nurse-led service

Audit and Evaluation (n=16)		**Cancer centre of excellence (n=8; 50%)**		**Regional Centre (n=4;25%)**		**Other (n=4;25%)**	
		n	%	n	%	n	%
Frequency of Audit and evaluation	**Every 2 years (N=3; 19%)**	1	12%	2	50%	0	0
	Annually (N=9; 56%)	5	63%	1	25%	3	75%
	Never (N=1; 6%)	0	0	0	0	1	25%
	Other (N=3; 19%)	2	25%	1	25%	0	0

Table 11 Functions audited and evaluated

Function audited/evaluated	Type of Hospital					
	Cancer centre of excellence N=22		Regional Centre N=13		Other N=14	
	N	%	n	%	N	%
Number of patients (n= 22; 45%)	10	45%	7	32%	5	23%
Patients Satisfaction (*n*=16; 33%)	6	37%	6	37%	4	26%
Waiting times (*n*=13; 27%)	7	54%	4	31%	2	15%
Symptoms management (*n*=7; 14%)	4	57%	2	28%	1	14%
Quality of Life (*n*=6; 12%)	4	67%	2	33%	0	0%
Frequency of Referral (*n*=5; 10%)	3	60%	2	40%	0	0%
Anxiety level (*n*=3; 6%)	1	33%	1	33%	1	33%
The accuracy of referral back to the medical team (*n*=3; 6%)	1	33%	2	67%	0	0%
The accuracy of diagnostic skills (*n*=2; 4%)	1	50%	1	50%	0	0%
Prescribing pattern (*n*=2; 4%)	0	0%	2	100%	0	0%

Participants specified the following key performance indicators (KPIs) which are currently being measured in the nurse-led service. Nurses providing nurse-led models of cancer care reported that they measure KPIs mainly for waiting times (*n*=11; 22%), patients' satisfaction (*n*=9; 18%), quality of life (*n*=5; 10%), and symptoms management (*n*=4; 8%). (Table 12)

Table 12 key performance indicator measured in nurse-led service

Key performance indicators	Type of Hospital					
	Cancer centre of excellence N=22		Regional Centre N=13		Other N=14	
	n	%	n	%	n	%
Waiting times (*n*=11; 22%)	5	45%	3	27%	3	27%
Patients Satisfaction (*n*=9; 33%)	3	33%	5	56%	1	11%
Quality of Life (*n=5*; 10%)	2	40%	2	40%	1	20%
Symptoms management (*n=4*; 8%)	2	50%	1	25%	1	25%

4.3.2 Scope of practice

The participants were asked to report how they evaluate their scope of practice in relation to six criteria, namely assessment (Table 13), diagnostic testing (Table 14), referral mechanism in and out of the nurse-led service (Table 15Table 15, Table 16) , prescribing Table 17Table 17, decision making (Table 17Table 18) and discharge (Table 19).

4.3.2.1 Assessment

Scope of practice for assessment was determined if participants undertook holistic nursing assessment verbally or with physical examination focusing only of tumor group or a full physical examination. The level of nursing assessment changed according to the nursing grade. The majority of participants providing nurse-led services undertook holistic nursing assessment verbally, including symptom assessment (n=35; 71%). Physical assessment was mainly done by ANP's (n=6; 100%) either only focusing on tumour groups or full physical examination with clinical assessment. (Table 13)

Table 13 Scope of Practice: Assessment

Nursing grade		ANP/CANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Scope of Practice: Assessment	**Holistic nursing assessment (verbal) including symptom assessment (n=35;71%).**	0	0%	16	67%	10	100%	9	100%
	Holistic assessment and physical examination/clinical assessment focusing only on tumour group (n=5;10%).	2	33%	3	13%	0	0%	0	0%
	Holistic assessment with full physical examination/clinical assessment (n=9;18%).	4	67%	5	20%	0	0%	0	0%

4.3.2.2 Diagnostic testing

Most of the participants (*n*=30; 61%) reported diagnostic tests such as CT scans or x-rays were initiated by doctors within the nurse-led service. A small number

(*n*=4; 8%) reported other arrangements with doctors where the nurse recommends the diagnostic test after reviewing the patient and doctor orders it with the radiology department. (Table 14)

Table 14 Scope of practice: Diagnostic testing

Nursing grade		ANP/CANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	%	N	%	N	%	N	%
Scope of Practice: Diagnostic Testing	Initiated by doctor (n=30;61%).	1	17%	14	58%	7	70%	8	89%
	Requested by Nurse (n=15;31%).	4	67%	8	33%	2	20%	1	11%
	Other (n=4;8%).	1	17%	2	8%	1	10%	0	0%

4.3.2.3 Referral Mechanism

Participants reported most of the referrals to and from nurse-led services were made internally by doctors (n= 26; 53%). All of the ANP/cANPs (n=6;100%) got referral to their service internally within the organisation either from the doctor or from other discipline whereas twelve percent of the CNS (n=3)and forty percent of CNMI/II/III (n=4) got referral from external sources as well internal sources. (Table 15 and Table 16).

Table 15 Scope of Practice: Inward referral to nurse-led service

Nursing grade		ANP/CANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	%	N	%	N	%	N	%
Scope of Practice: Inward referral to nurse-led service	Internal from doctor (n=26;53%).	3	50%	13	54%	5	50%	5	56%
	Internal from doctor or other discipline (n=15;31%).	3	50%	8	33%	1	10%	3	33%
	External and internal sources (n=8;16%).	0	0%	3	12%	4	40%	1	11%

Table 16 Scope of Practice: Outward referral from nurse-led service

Nursing grade		ANP/cANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	%	N	%	N	%	N	%
Scope of Practice: Outward referral from nurse-led service	Referred by doctor (n=33;67%)	2	33%	13	54%	9	90%	9	100%
	Referred by Nurse (n=12;25%).	4	67%	7	29%	1	10%	0	0%
	Other (n=4;8%).	0	0%	4	17%	0	0%	0	0%

Error! Reference source not found.

4.3.2.4 Prescribing

The majority of nurses working within nurse-led service reported that they were not a registered prescriber (n=38; 78%). Five participants reported they were a registered prescriber but prescribed infrequently (10%). Six participants were registered prescribers, prescribing regularly (12%). ANP was the only group where all participants reported prescribing regularly (*n*=5; 83%) or when needed (*n*=1; 17%). (Table 17).

Table 17 Scope of practice: Prescribing

Nursing grade		ANP/cANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	%	N	%	N	%	N	%
Scope of Practice: Prescribing	Not a prescriber (n=38;78%).	0	0%	22	87%	9	90%	8	89%
	Registered prescriber but infrequently prescribe (n=5;10%).	1	17%	2	8%	1	10%	1	11%
	Registered prescriber and prescribe regularly (n=6;12%).	5	83%	1	4%	0	0%	0	0%

4.3.2.5 Decision making

The majority of participants reported that clinical decision-making within their service was made with the permission of a doctor (*n*=32; 65%). One-quarter of participants reported autonomous clinical decision-making (*n*=12) within the nurse-led service. ANP's were more likely to report autonomy in clinical decisions (*n*=5; 83%) compared to other grades. (Table 18)

Table 18 Scope of Practice: Decision making

Nursing grade		ANP/cANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	%	N	%	N	%	N	%
Scope of Practice: Decision making	With permission from doctor (n=32;65%)	0	0%	18	75%	8	80%	5	56%
	In discussion with doctor (n=5;10%)	1	17%	0	0%	1	10%	4	44%
	Autonomous (n=12;25%)	5	83%	6	25%	1	10%	0	0%

4.3.5.6 Discharge

When discharging a patient from the nurse-led service, fifty-five percent of the participants (n=27) reported that they had to refer patients back to the doctor for discharge. Thirty-five percent reported that they were allowed to discharge from the nurse-led service (n=17); a small number of participants (n=5; 10%) indicated that they could discharge patients from the hospital. Participants ANPs/cANPs (n=3; 50%) and CNSs (n=2;8%) were the only professional grades that could discharge patients from the hospital **Error! Reference source not found.**(Table 9).

Table 19 Scope of practice: Discharge

Nursing grade		ANP/CANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	%	N	%	N	%	N	%
	Refer back to doctor (n=27;55%)	1	17%	13	54%	7	70%	6	67%

Scope of Practice: Discharge	**Discharges from nurse-led service (n=17;35%)**	2	33%	9	38%	3	30%	3	33%
	Discharges from hospital (n=5;10%)	3	50%	2	8%	0	0%	0	0%

4.4 Policy/Guidelines/protocol for nurse-led service

The majority of participants (*n*=39; 80%) reported that their practice was informed by existing policies, protocols, or guidelines for nurse-led services. Nurses working in regional centres (*n*=11; 84%) and cancer centres of excellence (*n*=18; 81%) were more likely to report having policies, guidelines and protocols to guide for nurse-led services and in compared to other hospitals (*n*=10;71%).(Table 20).

Participants were asked to report what types of guidelines were available for the nurse-led service. The most common guidelines available for nurse-led services related to monitoring of blood tests (*n*=28; 72%), followed by toxicity and symptom management guidelines (*n*=25; 64%). Few participants reported having guidance available on absence cover when the nurse lead was absent (*n*=5;12.8%). Table 21(Table 20).

Table 20 Availability of policy/Guidelines/protocol for nurse-led service

Hospital Type	**Cancer centre of excellence N=22**		**Regional Centre N=13**		**Other N=14**	
Total	N	%	N	%	N	%
Available Policy/Guidelines/protocol for nurse-led service (N= 39; 80%)	18	81%	11	84%	10	71%

Table 21 Policy/Guidelines/protocol for nurse-led service

Policy/Guidelines/protocol for nurse-led service	**N**	**%**
Guidance on monitoring required e.g. blood tests	28	72%
Guidance on toxicity/side-effect and symptom management	25	64%
Inclusion/Exclusion Criteria for patients cohort	23	59%
Process for referral to the service	23	59%
Parameters for treatment without medical review	22	56%
Guidance on administration of treatment	22	56%

Guidance on nurse-led assessment	22	56%
Education and Training Requirement	21	54%
Guidance on criteria and process for referral back to the consultant	19	49%
Guidance on evaluation of parameters e.g. booking of CT scans and X-rays	17	44%
Competency Requirement	15	38%
Guidance on process for discharge from nurse-led service	10	26%
Clerical and Secretarial Support	6	15%
Absence Cover	5	12.8%

Participants asked to report frequency of peer review of policies, guidelines and protocols. Most of the participants (*n*=14; 74%) reported that policies were reviewed by their peers in the organisation every 2 years. Eighty-three percent of the participants (*n*=6; 43%) cited that a peer review of the service was done by the ANP/CNS within the organisation (
Table 22).

Table 22 Frequency of peer review

Frequency of peer review		Every 6 months		Annually		Every 2 years	
		N	%	N	%	N	%
Total		3	16%	2	11%	14	74%
Reviewer	**Management Team**	2	67%	0	0%	4	29%
	ANP/CNS	1	33%	0	0%	6	43%
	NPDU	0	0%	2	100%	4	29%

Only thirty-seven percent of the participants (n=18) reported formal assessment of their competencies to provide nurse-led service. Competencies for ANPs (n=6; 100%) were assessed by a doctor, while others nursing grades reported their competence was assessed by a clinical nurse specialist (n=12; 67%). **Error! eference source not found.**(**Error! Reference source not found.**).

Table 23 Competency Accessor

Nursing grade		ANP/CANP N=6		CNS N=24		CNM I/II/III N=10		Staff Nurse N=9	
		N	%	N	%	N	%	N	%
Competency accessor (n=18; 37%)	Doctor (n= 6; 33%)	6	100%	0	0%	0	0%	0	0%
	Nursing peer (n=12;67%)	0	0%	8	66%	2	17%	2	17%

4.5 Future initiatives

Participants were asked to report the future initiatives under development or in place in their organisation for nurse-led services.

Thirty-one participants reported that there were some kind of initiatives for further development of nurse-led services in their organisation (36%). Participants (*n*=15;48 %) from cancer centre of excellence reported more nurse-led initiatives under development within their organisations, compared to those (*n*=11; 35%) from regional centres. The most nurse-led initiative under development at the moment is nurse-led models of care for oral chemotherapy (Table 24)

Table 24 Future nurse-led initiatives

Future initiatives N= 31	Hospital Type: Cancer centre of excellence N=22		Regional Centre N=13		Other N=14	
Total	N	%	N	%	N	%
Pre-assessment clinic (N= 4; 13%)	2	50%	2	50%	0	0%
Oral chemotherapy clinic (N=11; 35%)	6	55%	4	36%	1	9%
Survivorship clinic (N=5; 16%)	3	60%	1	20%	1	20%
Telephone Clinic (N=6; 19%)	2	33%	1	16%	3	50%
ANP-led Service (N=5; 16%)	3	60%	2	40%	0	0%

4.5 Summary of findings

The results show that the survey captured a variety of participants with different grades, education, and hospital type. The analysis of nurses providing nurse-led services demonstrates that nurses lead a range of services such as administration of cancer treatment, post-treatment review, follow-up, symptom management, and other activities such as support clinics. Most of these services were provided on a daily basis.

It is of concern that half of the participants reported they did not have administrative support, which meant administrative work was undertaken by the nurse leading the service which, in turn, resulted in other aspects of the nurse-led service not being fulfilled. Furthermore, participants reported that a particular challenge in developing a nurse-led service in the first instance was the lack of administrative support.

Half of this sample did not have any absence cover. The primary reason given for not having any absence cover and no equivalent service being provided was the lack of an appropriately trained nurse. Wherever service was not covered, patients were either booked into the next available nurse-led clinic or consultant-led clinics, with the majority of referrals to nurse-led service made by consultants; Nurses primarily referred to only dieticians. CNS was the only group that made a referral to all the members of the multidisciplinary team.

Half of the nurses leading the service had service-specific specialist training and education. All of the ANPs reported having policy, guidelines, and protocols to direct their service, but this type of structure was not consistently available to other nursing grades. Most of these protocols provided guidance on monitoring, surveillance and symptom management.

The majority of nurse-led service had common features and activities including direct referral mechanisms, clinical assessment, and freedom to initiate diagnostic tests., Again, there was variation in levels of autonomy in clinical decision-making of participants. Arrangement for formal assessment of competence was commonplace and arranged locally; ANP competence was assessed by physicians, while other grades' reported competency assessment being undertaken by the clinical nurse specialist. The majority of participants (*n*=28; 57%) were working in services that had been running for less than 5 years.

Key performance indicators included numbers of patients, waiting times, patients' satisfaction, quality of life, and symptoms management prescribing and referral pattern, and the accuracy of diagnostic skills. The multidisciplinary team approach was the most commonly cited perceived system benefit, followed by the continuity of care. Lack of administrative support within the nurse-led service was the most commonly cited challenge to the nurse-led service.

There are several innovative practices and types of nurse-led services, especially in Cancer centre of excellence, for example a pre-assessment clinics, oral chemotherapy clinic, survivorship clinics, and telephone follow up clinics. In a few places, nurses are developing an ANP-led service.

Chapter 5: Qualitative Findings

5.1 Introduction

This chapter presents the qualitative findings of the study generated from the eleven interviews of cancer care nurses with knowledge or experience of nurse-led models of cancer care and includes responses to the open-ended items (n=87) included in the survey. The demographics of participants are first illustrated and are followed by the interview findings under the following three themes: development of nurse-led models of cancer care, benefits and impact of nurse-led models of cancer care, and the challenges and barriers of nurse-led models of cancer care. An overview of the main findings is illustrated in Table 25 below.

Table 25 Overview of Main Findings

Codes	Categories	Themes
1. Overcrowded clinics 2. Increased cancer patients 3. Ad hoc development	Service need	Development of Nurse-led Models of Care
1. More one to one time for patients 2. The long waiting list for procedures 3. Increased clinic waiting times	Patient need	
1. Integrated care 2. Holistic Care 3. Waiting time reduced 4. Medication compliance 5. Continuity of care	Improved patient outcomes and experience	Impact and Benefits of Nurse-led Models of Care
1. Medical clinic pressure reduced 2. MDT approach	Increased demand for cancer services	
1. Working to full CNS potential	Personal and Professional Development	

1. Ad hoc development 2. Lack of facilitators 3. Clinic Space 4. Lack of Clerical support 5. Nursing Shortage	Infrastructure and planning	Challenges to Nurse-led Models of Care
1. Confusion around the nurse-led concept 2. Not a defined scope of practice	Lack of understanding of the concept of nurse-led care	
1. Lack of training, education and guidance for N/L models of care 2. Lack of information on Roles and responsibilities	Guidance/training and facilitation	

5.2 Demographics

Eleven nurses participated in the interviews: seven Clinical Nurse Specialists (CNSs), three staff nurses, and one Advanced Nurse Practitioner (ANP). Of those, seven worked in cancer centres of excellence and four in regional centres. The majority of interviewees had undertaken a postgraduate certificate or diploma in cancer care (*n*=7; 64%). Three participants held a Masters degree (27%)) and 1 (9%) held either a nursing certificate, diploma, or degree. Three nurses had less than ten years of experience post graduation; the remainder (*n*=8) had 10 or more years of experience and as might be expected were predominantly CNS's/ANP, and had with more than 11 years of experience in oncology(*n*=8; 73%). . Almost two-thirds of interviewees had worked in their current position for less than ten years (*n*=7; 64%) The demographics that relate to the open-ended responses to the survey are reported in chapter 4 (Table 4)

5.3 Theme 1: Development of nurse-led models of care

The literature illustrates that nurse-led models of care are characterised as services in which a nurse with advanced cancer care knowledge works autonomously within a well-defined and structured model of care, which includes guidelines and protocol for the assessment, treatment, and evaluation of patients in their caseload. The nurse provides education and support to the patient and family while working collaboratively within an MDT approach, to enable optimal health outcomes for the patient.

The evolution of nurse-led models in cancer care has been precipitated by both health professional and system demand and a number of factors influenced the set-up and the demand for the development of nurse-led service.

All respondents agreed there is a requirement for change in healthcare service delivery to meet demand from an increased number of cancer patients. However, the development and provision of nurse-led models of care has largely come about in an ad hoc fashion throughout the Irish health service in the different geographical regions.

With the increasing number of cancer patients in treatment, the caseload of cancer related services and outpatient clinics are increasing. This commonly results in overruns on scheduled clinics and impacts patient flow and work patterns.

> *NL019 : "Clinics were getting busy; sometimes the last patient could be seen seven after 6 o'clock. Day ward staff had to stay back if unscheduled admission ".*

The majority of participants reported the development of nurse-led services were initially influenced by the need to ease pressure from overcrowded medical clinics. However, there was a growing recognition within services of the increased potential of Clinical Nurses Specialist roles to effectively utilise the role to its maximum potential to assess, treat and manage cancer patients.

All of the participants expressed the need for a specific framework for nurse-led models of cancer care. Participants considered that the framework would provide a national standardised pathway in Ireland, providing information on nurses' roles, skills, and responsibilities. It would also facilitate the development of guidelines for education, with competency requirements further benefitting the sustainability of services.

> *NL019 : "…a framework for nurse-led cancer care giving information about roles and responsibilities. Also it will help top management to understand the concept".*

The setup of a nurse-led service was also informed by the model of care delivery from different countries.

NL084 "..She (Pharmaceutical Representative) gave us the information on nurse-led anti-cancer oral therapy clinics which were already established in the UK."

Furthermore, participants acknowledged the increased pressure on health services such as cancer services and radiology services. Another explanatory reason for development of nurse-led service was to improve the quality and timeliness of cancer care services to patients. For example, the nurse-led PICC insertion service was established after identifying a gap that the radiology department was too busy to insert PICC lines on time.

NL032 "…They (Xray department) could not accommodate us and chemo was getting held or postponed because the patient had poor access. We saw the gap in the service".

Another influencing factor for the development of nurse-led service was to advance a holistic approach to service delivery. Participants related that the main focus of doctor-led clinics is disease management and treatment plans. Therefore, patients did not get any time to discuss any other issues of concern to them.

NL005 "..Medics are under pressure just to complete their clinics, they mostly would look at any signs of disease and they plan treatment. They do not have time to talk about other issues unless the patient specifically brings it out".

A greater flow and access to information was an unmet patient need that informed the development of nurse led services. Participants recognised a need for patients to have timely access to appropriate & accurate information and guidance on cancer diagnosis and treatment.

NL032 "...Patient needed proper information, especially when they are overwhelmed with a cancer diagnosis."

To conclude, development of nurse-led models of care has come about in an ad hoc fashion. The main motives behind the development of nurse-led models of cancer care is to facilitate increased clinical demand, reduce waiting time, ease pressure on clinical service, extend doctors' capacity, and utilize specialist

nursing roles to maximise quality of care to provide support on information and guidance regarding cancer diagnosis and treatment for cancer patients.

5.4 Theme 2: Benefits and impact of nurse-led models of care

The main advantage of nurse-led models of cancer care as reported by phase 1 questionnaire participants are summarised in Table 26 Overall, participants reported nurse led services provided a more comprehensive holistic and integrated approach to care, which was of benefit to patients. The comprehensiveness of nurse-led models was seen to improve service outcomes such as continuity of care, waiting times and clinic efficiency. Patient information needs were enhanced through such innovation and as nurses were more attuned to patient treatment needs they were able to influence patient outcomes such as medication compliance. Nurse-led models of cancer care also extend professional opportunities and advancement and nurses were able to develop personally and professionally in their careers.

NL032 "...It makes you aware of latest changes in the practice as well as doing nurse-led clinics is a plus point to have on the CV."

Table 26 Advantage of Nurse-led models of care

Advantages of nurse-led models of care	***Nurses responses***	
Characteristic	***n***	***%***
Total	***11***	***100%***
Holistic Care	**3**	**27%**
Improves patients' outcome and service	**11**	**100%**
Reduction in waiting time	**9**	**82%**
Patients information needs	**8**	**73%**
Improved medication compliance	**4**	**36%**
Ease medical clinics pressure	**10**	**91%**
Personal and Professional development	**5**	**45%**

5.4.1 Holistic Care

Participants described the distinct holistic care offered by nurses with attention to psychological and social support. Support is offered informally by talking to patients about their clinical care, as well as everyday concerns.

> *NL022: "…not only symptom management but we look at the patient as a whole, we provide holistic care, I would chat with them, make them comfortable, if they have any issues at home as well if any family member who is not able to cope with the diagnosis, we discuss information about coping strategies with them and their family member".*

In response to patient need, participants also influenced and advanced referral patterns to other members of the multidisciplinary team for example Psycho-oncology, palliative care, and occupational therapy. They saw themselves as facilitators of access to care for patients, signposting services and sources of support within the multi-disciplinary team.

> *NL032 "….I assess patient, and according to need, I refer them to different specialities."*

Since the introduction of a nurse-led service, participating nurses reported that it has a demonstrable impact on integrated care. In comparing nurse-led models of care with doctor-led care, participants remarked upon the ability to deliver holistic and integrated care in contrast to the treatment and surveillance focus of doctor led care. During treatment visits, nurses avail of opportunities to discuss other health-related issues with the patient and coordinate care with other multi-disciplinary team members. Participants further reported that this model of care also allowed them to provide information about the management of side effects, health promotion, as well as the importance of self-care and medication compliance.

> NL038: *"…See with medics, patients used to be in and out within 10 minutes because doctors are concerned about the disease and how a patient is tolerating the treatment. However, when we are assessing the toxicity to communicate with patients, many times we talk about self-care, weight management and health promotion like smoking cessation. Patients are not rushed so they have time to talk to us, tell us about any concern they might have at home"*

Skilled nurse assessment during patient visits can detect social support issues that may affect physical health as illustrated in the following:

> *NL038: "…Yesterday I had this elderly gentleman coming in for radiation, losing weight, so when I started enquiring about his diet and all. Finally, he told me that he gets chipper every night because he does not know how to cook and his wife is not able to, and also does not have any family nearby for household chores."*

Continuity of care is perceived as one of the main advantages of the nurse-led service. Patients are receiving care from one person rather than meeting a different person each time, and this was seen as a crucial element in enhancing the therapeutic relationship between a health professional and patient. Increased and timely access to services was another benefit of the nurse-led service. The unique quality of the nursing assessment was evident in responses with reports of the ability of nurses to respond to the holistic needs of patients. Patients were also well placed to ensure timely referral to other services such as psych oncology, social workers, physiotherapy, and palliative care teams.

> *NL059 "….We look at the patients as a whole, they see one person at all times, they (patient) know you, they connect…share their anxiety, doubts and any concerns with you more freely, according to their needs we make references to a different speciality. It is more important to catch it on time, so it is an important part. We keep a record of references made to different specialities, so it is quite remarkable".*

The care for the patient is timely and flexible during acute phases of illness, for example, sepsis or toxicity management while on cancer treatment. Another feature of responses included reports of encounters over the telephone being commonplace, with troubleshooting and assessment of need reported to affect patient outcomes positively.

> *NL059 "….They have our direct number, they can ring us, for out of hours can go to in-patient ward but from Monday to Friday, they ring us with any problem. I see it as making emergency care more accessible; they do not have to wait and is attended to immediately.*

Participants remarked on the difference in the nurse-patient interaction during clinical contact. Nurses emphasised the importance of looking after patients' information needs, especially in the era of information technology where multiple sources of information are available, which can be confusing for patients.

NL050 "…..When the clinic was first started, but the main reason was to help patients with medication compliance and to assess medication toxicity, side effects, Provide them with information about when to take the tablet, how to assess toxicity, when to seek help was important…especially when you have GOOGLE doctor around."

Participating nurses noted medication compliance had increased after the introduction of nurse-led models of care for oral anti-cancer therapy. Participants also emphasised that medication compliance in oral anticancer treatment is essential for effective use of cancer treatment.

NL084 *"…anticancer oral medication is for life, and they have to take them till it is working on them or there is toxicity which patients can't tolerate. We keep a close eye on medication compliance. You get so attached that you know everything is happening in their life. Also, they have our direct number to call if they have any query or any issue at all. Patients are happy; they get to see us all the time and there compliance with oral tablets is 100%. "*

Participants also highlighted that taking less complex patients out of doctor-led clinics facilitated release of medical time to care for other complex cases.

NL084 "…Medics can take on more complex cases, we do not want to take on their roles, but once we have the skills and knowledge we can take on less complicated patients…likes of oral chemotherapy patients".

This development of nurse-led clinics has further contributed to a reform and change agenda in health service delivery and enabled role development in the context of effective workforce management.

NL050 "…. It is an excellent way of providing efficient and quality service to patients. There is no point having funding available if it does not come to these types of initiatives.

Nurse-led models of care contribute to enhancing the integration of care in a multi-disciplinary team approach. Key to this is the effective and timely communication between nurses and other health professionals, with an impact on the quality of service and the patient experience.

NL059 "…we talk to other members of the team like physio, occupational therapy to make sure patient has all the support they need".

Patients are more accepting of nurse-led models of care. A high percentage of patient satisfaction was also noted, with patients giving more preference to seeing a nurse in the clinic rather than a doctor.

> *NL005 "…However, patients enjoy it. They are happy. They keep asking us if they need to see consultants on DAY 1*(Before starting a new treatment cycle) *at all."*

5.4.2 Professional and personal development

Career satisfaction and progression was a common theme in the findings. Participants cited personal and professional development as benefits of nurse-led service. Job satisfaction, increased autonomy, and empowerment were three indirect impacts of the professional development associated with nurse-led models of cancer care.

> *NL005 "…..Well, there is no doubt that it has contributed to the nursing profession. I feel that I am using my knowledge and skills to provide care and making a difference; it is quite empowering".*

Individual commitment also influenced the development of services, with some nurses expressing willingness to undertake additional training and education in their own time.

> *NL005: "……We need more bodies!! Too many patients and not enough nurses!! Even when we are trying to train to learn new skills, we do it in our own time."*

5.5 Theme 3: Barriers and Challenges of Nurse-led models of care

Participants reported various difficulties and barriers to the development and successful implementation of nurse-led models of care, such as lack of understanding, the undefined scope of practice, lack of clerical support, lack of clinic space, and lack of education, training and guidance. Nine participants reported a lack of training, education and guidance for nurse-led models of cancer care, eight noted lack of understanding of nurse-led concepts, a further eight noted the scope of practice is not quite defined, six reported lack of clerical support and five noted a lack of clinic space.

5.5.1 Lack of understanding of the nurse-led concept

Participants reported a lack of understanding from management and other health providers as a substantial challenge to the operation of nurse-led models of care. The lack of support and sometimes resentment from nursing colleagues was a concern in some instances. Spending time in nurse-led clinics can mean, in turn, that nursing staff are not available in the clinical area and this can be interpreted negatively by colleagues.

NL019: "….. See another problem is even if I am working in the office unless I am in day ward doing clinical work, others (Day-ward nurses) think I am just dossing".

Participants expressed concern that hospital management may not have a clear understanding of nurse-led models of cancer care and may consider it more as a substitute doctor model of care. This leads to nursing management, giving less priority to nurse-led service undermining the sustainability of service. As a result, nursing management may be easily predisposed to cancellation of the nurse-led service in the event of resource challenges for example chemotherapy unit is busy or nurse shortage due to sick leave.

> *NL018 "….She (Assistant Director Of Nursing) is not against nurse-led clinics but doesn't support the idea of doing medics work when nurses are busy. She is the first one to say cancel the clinic if someone is sick or even when day ward is a bit busy."*

Some of the participants were concerned with varying degrees of support from the medical consultants. Service development, in many instances, has arisen due to established nurse-doctor relationships, and there can be reluctance by medical colleagues to extend support to nurse colleagues they are not familiar with. As a result, the service is not easily replicable or transferrable across services. This Inconsistency in the arrangement was also in evidence within individual services or departments.

> *NL032"…We are two CNS working within the unit but what I struggle with is only because of a colleague has worked more with a consultant, he is happy to give her caseload...he has made that very clear to us. I feel if we have a protocol and scope of practice defined, it should not matter."*

5.5.2 Undefined Scope of Practice

Scope of practice for nurses working within nurse-led models of cancer care is changing and evolving with rapid developments of health service roles. It is influenced by the development of roles within nurse-led models of care and is sometimes guided by protocols. However, there is strong evidence of discrepancy across the service. While the majority of participants have protocols to deliver the nurse-led service guiding their scope of practice, some of the services do not have formal protocols.

> *NL019 "…we have a protocol for nurse-led Herceptin clinic; it gives us information on how to assess the patient before chemo, toxicity management…..but then my colleagues do nurse-led symptom management clinic where there is no protocol as such yet, she kind of does anything and everything which is floating".*

Indeed written protocols are potentially limited with some participants highlighting that while they give information about the clinical management of cancer patients, there is no clear guidance or direction on title or role of nurses. As a result, there can be variance in the way nurses work within one nurse-led service.

For example, a participant working with a title of staff nurse may perform very similar duties to nurse-led services to a CNS, and this may result in uncertainty regarding the scope of practice.

> *NL038 "…I have a CNS working with me, we assess patients and according to the protocol I grade the toxicity. The protocol also gives information on the grade of toxicity and medication to prescribe. CNS with me has a prescribers course, but I don't have it so when I am alone, I have to ask one of the medics to prescribe. I make sure I carry the protocol with me to show it them (Doctors) as I would not want anyone to question my pin".*

Participants also highlighted the confusion about protocols in the context of the scope of practice within nurse-led models of cancer care. While a consultant is aware of nurse's clinical expertise and capabilities, consultants overlook the restriction of patient's selection criteria within the protocol and may ask nurses to take some of their responsibilities to request X-rays or prioritising a CT scan with the radiology department as a favour instead of following the protocol. This was

seen as a consequence of the fact that the nurse-led services are still at the early stage of the development.

> *NL019 "….Consultant is well aware of our capabilities but still they keep asking for favours… then we must go back write it down in the protocol and then should be able to develop the role"*

5.5.3 Lack of administrative support

The physical and administrative structures to support nurse-led services were a dominant concern for many participants. Another concern was the lack of office and clinical space and access to information technology. Many described the lack of planning and competing demands on rooms as they have to "fight for the room". This is further compounded by the perceptions that doctors are prioritised for room allocation.This affects the ability of nurses to provide a consistent service and valuable clinical time is diverted to the completion of administrative tasks.

> *NL059 "… Yes we do have clerical support but very limited. It is a struggle all the time. You want to type letters, get charts, ring admissions office or collect some data for nurse-led service. Some will do it, some will say its not in their job profile…. I now "realise that when we started this initiative, we never got them involved. We just presumed that they will do it because they did for consultants. It's not the case"*

There were examples of satisfaction with secretarial/administrative support provided, but these have come about as a result of substantial negotiation at a local level

> *NL019" … 100% dedicated to us but we have a person getting charts for the clinic, doing appointment and posting letters. Initially, we didn't have any but then we had to fight for it. We have some help now*

There was concern expressed regarding the willingness of administrative staff to support nurse-led clinics. Nurses were frequently frustrated with not having enough support from administrative staff. Service limitation was commonplace among respondents with reports of difficulties in securing the collection of charts collecting and entering data, scheduling and dictation.

NL019 "…..*They (administrative staff) think they are only for consultant!! When we ask for help, for example preparing for the clinic, scheduling appoinments or some help with data entry, their common comment is that " That is not my work"*

NL007 "…..They (administrative staff) think they are only for consultant!! When we ask for help, for example preparing for the clinic, scheduling appoinments or some help with data entry, their common comment is that " That is not my work"

Participants attributed a lack of secretarial support to administrative staff not understanding the concept of nurse-led models of cancer care. Nurses adopt strategies to overcome administrative barriers by not segregating lists for doctor-led clinics and nurse-led clinics. Hence, administrative staff had an illusion that they were still collecting charts for doctors.

NL005 " ….They (Secretaries) point black refused to help us with typing letter, they will pull the chart for the medical clinics but not for nurse-led clinics. To avoid this we don't segregate out list so they pull all the charts. I am like these are consultants' patients, if I don't review them they will go back to consultant's clinic and they will type the letters anyway then."

It was also evident that nurses are devoting considerable time to collect and capture data on their activity. This is to a large extent due to the limitations of digital systems and limited visibility of nurse-led activity. However, it is also complicated by restrictive work practices among administrator grades of staff. As a result, nurses are commonly keeping records of their own patients, typing referrals letters to other health professionals, or collecting their own data.

NL019: " …I take one day for office work to collect data on how many nurse-led we did, number of referral in and out of the nurse-led service, findings etc. this can be easily captured by the clerical staff not all of it at least some of it. but they (Clerical staff) won't do it for us...they will do it for consultants, but if we have a nurse-led list they will not do it...it can be quite frustrating. Especially with new technology, it is just a click"

5.5.4 Structure and support for nurse-led models of cancer care

Concern was also expressed as to the clarity of purpose and structure of nurse-led services. Nurse-led services were not sustainable if they produced additional

supervision burdens as in this example below where a nurse lacked the requisite confidence in her clinical decision making which presented risk to the sustainability and consistency of service delivery.

> *NL022: "…I know the last nurse-led project they tried did not work because the nurse was in and out of the consultant room so much that he decided to review the patients himself. That what I will be worried about".*
>
> *Nl022: "….I did not find much guidance around the competencies for nurse-led models of care."*

Participants highlighted that developing the role within nurse-led service was problematic because of difficulties in accessing relevant education and skills training. In places where education or training was provided, CNS did not have anyone to cover their clinic and found it difficult to take time away from the clinical work.

> NL005: *"……We need more bodies!! Too many patients and not enough nurses!! Even when we are trying to train to learn new skills, we do it in our own time.*

5.5.5 Guidance

Most of the nurses reported that they found little or no guidance when setting up nurse-led services and developed their protocols and had to convince the hospital management to support the nurse-led model of care.

> *NL044: "….Yes, we developed our protocol, we initially got no help or support to develop it. We had to sale to stakeholder to buy into it".*

Other participants took a shared care approach to access information and guidance from others in their field adopting protocols from other specialities or other countries to meet local need.

> *NL022: " ….The bone-marrow co-ordinator working with us is from XXX and already has a nurse-led clinic established in her hospital. So we are taking information from that".*

The support of clinics within organisations was influenced by success in other areas with examples such as epilepsy noted.

Nl047: "…We have a nurse-led epilepsy clinic here. So got a few pointers from them".

The absence of a formal and precise government policy providing guidance on organisational and governance structures for delivering the nurse-led services was seen as a barrier to sustainability and detracts negatively from the clinical time of staff of nurses intact.

NL052: "…People in HSE needs to provide a structure like if anyone is doing nurse-led clinics to have a clinic space or secretary, We don't need one per clinic but at least having a provision of one secretary per unit for nurse-led clinics… Else all I feel I am doing is administrative work!!"

Tensions between nurses and consultants were also challenging. Nurses reported comfort in protocols to clarify the boundaries of the scope of practice. The participants expressed concern that some activities may be outside scope and, in some instances, medical colleagues may not fully understand the constraints of nursing practice

Nl012: *" … The consultant I work with is always pushing us to take on the new patients and task, but it's not in the protocol and that what I find it difficult as it will be me who is answerable to the NMBI….It is his word against mine. We tell him that we have to work with the protocol, but he just does not get it."*

While participants develop their protocols and have set pathways for referring patients to nurse-led clinics, in many areas the boundaries of scope were still fluctuating and often dependent upon the consultant they are working with, and acceptance by other health care professionals. Thus, referrals from nurses were not uniformly accepted by medical colleagues and practice in this regard was often inconsistent within and across organisations and departments.

NL038: "…Sometimes it all goes down to who is the service provider….last week I had to refer this lady to a dermatologist in the hospital, but he rang my consultant to say he will not accept a refer because it came from me!! And we have XXX (another dermatologist) *who is happy to accept referral from us…What do you say to that"*

5.6 Summary of Findings

It is clear from the findings of this qualitative analysis that the development of nurse-led models of cancer care is at an early developmental stage when one compares this to other more established medical models. The study confirmed the ad hoc development of nurse-led models of cancer care. While participants suggested patients appreciate having a defined and approachable point of contact, and doctors articulated valuing support with their increasing workload; currently, there are differences in the interpretation of nurse-led models of cancer care in Ireland.

It is clear from the findings that nurse-led models of care are being developed in response to health services and patient's need and it is further evidence that these models of care have an enormous contribution to quality patient care through treatment management, symptom management, and education.

Many benefits of nurse-led services have been highlighted in the findings including, as examples, the provision of more holistic, timely and accurate care, continuity of care, access to healthcare and reduction in waiting time. However, nurses working within nurse-led services face complex challenges, for example, absence of formal guidance on nurse training, & competencies, variance in governance and infrastructure and shortfalls in administrative support. Nursing roles and job titles, infrastructural and administrative support require more strategic consideration and detailed planning before starting a nurse-led service.

Chapter 6: Discussion and Conclusion

6.1 Introduction

This study has sought to establish the current status of nurse-led models of cancer care in Ireland. As discussed in Chapter 2, there is currently little empirical research examining the development of nurse-led models of cancer care within the Irish context. The approach used was a mixed method study.

Survey and interview findings were assessed sequentially and findings are now integrated within this discussion chapter to provide a comprehensive understanding of nurse-led models of cancer care in Ireland. The results of the study are discussed in relation to the study objectives and within the context of literature in the field (Table 27). The factors influencing the development and characteristics of nurse-led services are considered. The evaluation, outcomes, and nurses' perception of their impact on service, and its benefits for service users are discussed. The barriers and challenges to implementation of nurse-led models are discussed with consideration of the National Cancer Strategy (2017) and the potential for standardising care delivery. Participants' expectations for future development of nurse-led services are discussed with attention to professional career development opportunities for nurses. The strengths and limitations of this study will be also reported. The chapter will conclude with implications for health policy and clinical practice with recommendations for future research.

Table 27 The study aim and objectives

Study aim	**To explore the nurse-led models of cancer care in Ireland**
Study Objectives	1. Map the current models of nurse-led oncology care nationally in Ireland. 2. Create an understanding of the scope, governance and infrastructure which underpin nurse-led models of care in the area of oncology nationally. 3. Explore the perceptions of specialist oncology nurses as to benefits and impacts of nurse-led models of oncology care in Ireland 4. Understand the factors influencing the development and implementation of nurse-led models. 5. Highlight innovations and ideas for the future development of nurse-led models

6.2 Mapping of nurse-led models of cancer care in Ireland

The findings from the study showed considerable variability in nursing activities, roles, training and academic qualifications undertaken in preparation for the delivery of nurse-led services. Almost half, forty-nine percent of the participants across Ireland, reported to have actively involved in providing nurse-led models of cancer care. Similar to the literature findings, this study reported variation in nursing grade from staff nurse grade to an ANP grade who provided nurse-led models of cancer care. While in the literature there is evidence that CNS/ ANPs can provide effective and safe models of nurse-led care (Collins. 2010; Guest *et al*. 2012; Moore 2018; Mccorkle *et al.* 2009), there is no specific mention of staff nurse grade providing nurse-led models of cancer care in literature reviewed.

Consistent with other research, participants in this study believed that nurse-led models of cancer care can provide a promising alternative to conventional models of care, which have placed a major burden on health services due to increasing cancer occurrences. Findings uncovered nurses responded to this burden by developing nurse-led service such as symptom management (n=36; 73%), Follow-up care (n=34; 69%) or task specific nurse-led service for example nurse-led PICC insertions service. This is in contrast to a mapping survey done in Scotland by Hutchison *et al.* (2011) where they found 51% of the nurse-led service were involved in care and management of cancer patients on active treatment and only 31% were providing follow-up care. Many recent studies endorse using nurse-led model of follow-up care for meeting patient's needs and to provide easily accessible care (Strand *et al*. 2010; Beaver *et al.* 2010; Hewett and Howland 2009; Jefford *et al.* 2016). Furthermore, interview participants illustrate their perception of using nurse-led models of cancer care for symptom management is not limited to clinical care but in providing holistic care with attention to psychological and social support.

6.3 Factors Influencing Development of Nurse-Led Models of Oncology Care

Nurse-led models of cancer care have been developed in Ireland in response to patient and service need. The National Council for Professional Development of Nursing and Midwifery (NCNM) evaluation report on nurse-led models of care in

nursing and midwifery in 2005 identified only one nurse-led model of cancer care in Ireland. This study has identified forty-nine nurses who articulated they were providing nurse-led models of care in the context of the Irish cancer services. This demonstrates a substantial increase in nurse-led models of cancer care in Ireland since the 2005 NCNM report. The NCNM (2005) evaluation report concluded that the development of nurse-led models of care in Ireland was influenced by health policies, changing nature of the nursing practice and the need to develop innovative model that meets patients need. More recently, Chalabi *et al* (2014) also reported introducing the nurse-led service to deal with increased numbers of colorectal cancer patients after new development of centres of excellence in the Irish health service under NCCP where we have seen an increase in rectal cancer patients in 8 tertiary referral centres. In addition, recent report on integrated care for older person programmes focuses on nurse-led models of care to provide holistic care to older patients (HSE 2016). Longpre & Dubois (2017) also recommended the development of nurse-led services that can provide care for prevention, self management and disease modification.

Within this study, participants reported nurse-led models of care were developed primarily to respond to the health services to facilitate increased clinical capacity and to meet patient's need, which is in line with the international development of similar initiatives (Allinson 2004;Beaver *et al.* 2010; Strand *et al.* 2011; Farrell *et al.*2017). Participants suggested the nurse-led models of care which they provided facilitated increased clinical capacity, prolonged waiting times, ease pressure on clinical services and extend the capacity of and reduce workloads for doctors. Nurses articulated that nurse-led models of care could be further developed to provide a defined and approachable point of contact for cancer patients.

Participants suggested developing the models with strict protocols and policies using maximum potential of a Clinical Nurse Specialist role to assess, treat and manage cancer patients. Consistent with the study done in the UK by Farrell *et al* (2017), participants from this study also are looking for guidance on developing nurse-led service. A national framework to facilitate developments of competencies, training and role profile of a nurse to standardise nurse-led models of cancer care in Ireland would be helpful. A recent policy on the

Development of Graduate to Advanced Nursing and Midwifery Practice recommends developments of nursing roles to provide nurse-led care to respond to patient need. The policy provides with the appropriate credentialing pathways, education and training and cultural change with managerial support (DoH 2019). The report gives four recommendation to develop a critical mass of Advanced Practitioners.

The first recommendation is to provide Advanced Practitioners with prescriptive authority for diagnostic and referral pathways and appropriate treatment to facilitate the provision of full episode of care. A robust governance and accountability structure also need to be in place to oversee the development and implementation of advanced practice. Similarly, proposed national framework for nurse-led models of cancer care should develop critical mass of nurses working in nurse-led models of cancer care. The role description and title of the role nurse including training and education required needs to be described. A similar robust governance and accountability structure needs to be put in place to oversee the development and implementation of nurse-led models of cancer care.

A second recommendation is to monitor patients outcomes to ensure Advanced practice meets demand. Similarly, within the proposed national framework, there needs to be a mandatory requirement that new services implement standardised metrics/KPIs to audit the service against. Framework should provide guidelines on the domains of mandatory metrics/KPIs.

A third recommendation is to streamline the education pathway for graduates to advanced nurse practitioners. The proposed national framework should give framework for education and training required to equip themselves to provide nurse-led models of care.

The fourth recommendation is to evaluate service impact, outcomes and impact of the activity; The proposed framework should also evaluate the impact to assess the success of the model.

Interestingly, four-fifths of participants reported that their service was underpinned by existing policies and protocols or guidelines for nurse-led models of care. Nurses considered such policies central to the development of autonomous and effective nurse-led services which responded to the increasing

demand placed on cancer services by the growing population of people affected by cancer. Participants reported that the policies and protocols guiding their services provided essential guidance on operational processes, criteria for medical assessment, onward referral & consultation and diagnostic procedures. However, nurse-led services were also uniquely informed by nursing work, and participants stated that nurse-led services often provided a more comprehensive assessment of the psychosocial aspects of care compared to medical-led models of care.

This echoes with the position statement by the UK Oncology Nursing Society (UKONS) regarding the unique importance of nurse-led services in the provision of holistic care and family support (Lennan et al., 2012). Also, a recent study by Drury *et al.* (2019) found that access to a named nurse was associated with more positive emotional well-being among colorectal cancer survivors, while access to a named doctor was associated with more positive quality of life overall. However, a key issue highlighted by this study was the fact that colorectal cancer survivors were primarily receiving healthcare within the public healthcare system, where cancer care follow-up is predominantly nurse-led; therefore access to a named doctor may provide additional support influencing overall quality of life outcomes. Nevertheless, the findings of the Drury *et al.* 2019 study lend support to the findings of this study, highlighting the potential positive impact of nurse-led services on colorectal cancer survivors' emotional well-being.

Similar to international trends, nurse-led models of care described within this study were most frequently involved in follow-up care (Berglund *et al.,* 2015; Cox *et al.,* 2013; Van Der Meulen *et al.,* 2014; Dunberger and Bergmark, 2012; Chalabi *et al.*, 2014; Howell and Watson, 2005). Farrell (2015) suggests the under-utilisation of nurse-led models of care in acute cancer care may be related to the acute and medicalised needs of cancer patients which characterise this phase, including prescribed medicines and supportive therapies. However, in the current study, survey findings showed 73% of the participants were engaged in providing nurse-led models of care for symptom management. Participants in the interviews explained that nurses who lead services for acute symptom management were guided by service protocols with clear criteria for escalation of care to medical staff.

6.4 Scope, Governance and Infrastructure of Nurse-led Models of Oncology Care in Ireland

6.4.1 Nursing Roles

A scoping study by Hutchison *et al.* (2011) in Scotland identified wide variation in nursing roles and titles across nurse-led clinics delivering nurse-led models of cancer care. Similarly, the findings from this study found significant variation between the nurse's roles, requisite qualifications, grades and experience of nurses' which contributes to disparity in autonomy and clinical practice across nurse-led services in Ireland. The variability in nurse-led models of care in Ireland reflects the historical ad hoc development and evolution of nursing roles, more generally, within cancer care services. Participants reported to have undertaken similar activities across different grades, for example, nurse-led models for symptom management was provided by 80% of the CNS (*n=20)* and 55% of staff nurses (*n=9).* Participants from the interviews reported that this inconsistency has produced confusion and has come about due to the more localised arrangement and protocols which do not feed into a national perspective. This represents a long-standing concern highlighted by the NCCP (2012) *Strategy and Educational Framework for Nurses Caring for People with Cancer in Ireland* about disparities in nurse-led services among different nursing grades undertaking similar specialist roles both within and across hospitals.

Findings from the study showed variation in the scope of practice between ANP and CNS or Staff nurses within nurse-led models of cancer care. Begley *et al.* (2014) describes the role of ANPs as to provide improved service delivery, greater clinical and professional leadership, developing education curricula, conducting research with clear governance and accreditation structure. Cowman *et al* (2010), evaluated the role of the clinical nurse specialist in cancer care, and concluded that clinical nurse specialist is central to the patient journey and a key person in providing quality care. The quality care is achieved by providing patient support in the form of advice, skills, education, organisation of care and referrals and follow-up (Cowman *et al.* 2010). CNSs provide a personalised approach to nurse-led models of follow-up care ensuring holistic care is delivered to the patients (Moore 2018). The findings of Collins (2010), Guest *et al.* (2012) and

Farrell et al. (2017) demonstrate that ANPs and CNSs both provide quality care to the cancer patients.

O'Connell *et al. (2014)* has outlined very clearly the differences between decision making capabilities of both CNSs and ANPs. CNSs assess the stable, predictable situation and make decisions which are predominantly task-focused. They suggest the most appropriate course of action in recurrent situation (Within the protocol), however the ultimate decision-making capability lies with medical team. ANPs on the other hand, have the capability to adapt to constantly changing environments where they remain creative and flexible in their responses to changing situations. They use clinical reasoning on a case by case situational bases to enable 'wise' action by selecting best choices for treatment in specific situation. In this way they demonstrate autonomous clinical decision-making capabilities.

However, ANPs are regulated by the national framework for advanced practice requirements and standards (NMBI 2017). The domains of competence for ANPs are articulated clearly in the document and are adopted from national body NMBI (2015). This document clearly defines ANP's scope of practice and NMBI requirement to regulate practice policies, procedure, protocols and guidelines (Begley *et al.* 2013). The expanded scope of practice for ANPs incorporates the interpretation and application of advanced nursing theory and research, higher level decision-making and autonomy in practice, which are consistent with their education level and clinical experience. On the other hand, the nurses and clinical nurse specialist who expand their role must adopt to the associated responsibilities (Furlong & Smith 2005) and responsibility to facilitate the role expansion lies with the local management, including access to further education, allocation of necessary resources, policy development and assessment of competency (Fealy *et al.* 2014). This could be one of the reasons for lack of consistency with scope of practice and responsibilities among different nursing grades providing nurse-led models of cancer care.

Hutchison *et al.* (2011), in their recent overview of nurse-led cancer clinics in Scotland, specifically recommended that true definition of nurse-led clinic requires a ANP's level of autonomous decision making capability. However, the participants from this study have described how clinical nurse specialist with the use of appropriate protocols, policies and specialised training are able to work

within their scope of practice to provide nurse-led models of cancer care such as follow-up care, nurse-led PICC insertion service as well as nurse-led assessment service and information service. The scope of nurse-led clinic is determined by the level of clinical complexity of the patient cohort. Hence, a consistent governance structure for nurse-led models of care in terms of policies and procedure to provide knowledge, skills and attributes required for providing standardised nurse-led services regardless of role profile and hospital type is necessary needs to be in place.

6.4.2 Training Undertaken in Preparation for Delivering Nurse-Led Models of Care

Most of the participants (62%) from the study reported to have undertaken either postgraduate certificate or diploma in cancer care and 31% of participants had achieved their MSc however there were small amount of participants who provided nurse-led models of care but had only primary nursing degree. This variation is also seen in the literature where a two nurses, one with master's degree and another nurse with PhD independently provided same model of nurse-led care for gastrointestinal side effects of pelvic radiotherapy (Dunberger & Bergmark, 2012). While there was no difference in the care delivered by a Msc qualified nurses and PHD holder, there is a clear need to specify university qualification for nurses who want to provide nurse-led models of care.

Similarly, the majority (*n*=45; 92%) of nurses in this study delivering nurse-led models of care had undertaken specialist oncology education at postgraduate level; the level of education varied, and included Postgraduate Certificate, Postgraduate Diploma, and most commonly, Master's level. This was evident from the studies done by Howell and Watson (2008) in Canada and Lai *et al.* (2015) in Hong Kong, The high uptake of specialist oncology education at postgraduate level might be the reflection of the substantial investment in postgraduate education in the Irish health services and has ensured nurses working with cancer patients have completed specialised cancer education (NCCP, 2012; DoH 2019).

Findings from the study indicated while cancer nursing education is important for nurses working in cancer care, it does not sufficiently prepare nursing staff to deliver nurse-led models of care. Specific training for nurses to assume

advanced practice roles and deliver nurse-led services is essential to ensure nurses develop the necessary expertise to provide safe and acceptable nurse-led services to patients. These findings reflect those of previous studies conducted in the UK (Wells *et al*., 2008; Allinson, 2004; Craven *et al.,* 2013). Several studies have highlighted the nature of training nurses received specific to the services they would deliver. Strand et al. (2010) described nurses receiving training in clinical examination and sigmoidoscopy to prepare nurses to deliver a nurse-led model of follow-up care to patients following colorectal surgery. Similarly, Collins (2010) describes training nurses received from the medical colleagues to perform bone marrow biopsy.

Within the current study, just 50% of participants (*n*=26) received specific clinical training to equip them to deliver nurse-led models of care. Interview participants expressed difficulty accessing relevant education and skills training within the clinical setting In particular, participants found it difficult to take time away from the clinical work, as nurse-led services did not have cover for the nurse lead's absence.

Interview participants reported advanced nurse practitioners undertook structured university-based modules on research, prescribing course and specialist advanced practice to equip them deliver a nurse-led service. In contrast, clinical nurse specialists and staff nurses evolved into roles delivering nurse-led service; much of their training in preparation for delivering nurse-led services was self-directed or locally arranged skills training such as training for PICC insertion. Interviewees suggested this informal, ad hoc training may fall short of the expertise required for the delivery of safe and acceptable nurse-led models of care; this was a significant concern among clinical nurse specialists within this study.

There is a notable absence of a formal competency framework and/or guidance for nurse-led models of care in Ireland. In 2017, the National Cancer Strategy (2017-2026) recommended development of nurse-led services within cancer care. The current study's findings showed that while nurses undertake a wide range of nurse-led models of cancer care, there is no proper structure for the competency assessment of a nurse working within nurse-led models of cancer care. Indeed, as the domains of competence leading to registration as an

Advanced Nurse Practitioner are adapted from NMBI 2015. The competency assessments for Advanced Nurse Practitioners is conducted by either by an advance nurse practitioner or a medical consultant, while for Staff Nurses and Cinical Nurse Specialists, competency assessment is undertaken by peers, which raises the additional concerns about the validity of competency assessments within these groups. In lieu of this, it is important to ensure standardised policies and formal competency assessment structures are in place for all nurses who plan to deliver nurse-led services to ensure appropriate governance and competency in advance of implementation (Hutchison *et al.,* 2011).

6.4.3 Modes of Delivering Nurse-Led Models of Care

There are many approaches to nurse led services internationally including face-to- face approaches (Strand *et al*., 2011; Beaver *et al*., 2010b; Wells *et al*., 2008; Allinson, 2004; Faithfull *et al*., 2001; MacLeod *et al.,* 2007; Williamson, Collinson and Withers, 2007, Collins, 2010); and telephone or virtual approaches (Booker *et al.,* 2004; Kimman *et al.,* 2010; Moore, 2018; Overend *et al.,* 2008; Anderson, 2010; Craven *et al.,* 2013; Casey *et al.,* 2017; Booker *et al.,* 2004; Faithfull *et al.,* 2001). Birch *et al.* (2016) suggests nurse-led models of cancer care are developed to more effectively use health service resources by developing nurse-led telephone clinic for follow-up care. However, the current study demonstrates Irish nurses are primarily using a combination of face to face and virtual contact to deliver nurse-led models of care for symptom management and assessment of need as a combined approach but not as a standalone approch, similar to those in use in other jurisdictions (Molassiotis *et al.,* 2009; Howell *et al.,* 2012; Jefford *et al.,* 2013; Chalabi *et al.,* 2014; Lai *et al.,* 2015; Birch *et al.,* 2016; Moore, 2018; Stanciu *et al.,* 2015).

Nurses perceive this combined approach as the optimal model for nurse-led patient care; providing a mix of structured management and support, while facilitating timely access to support for patients to address unmet needs between scheduled appointments and reduces unnecessary hospital appointments. The policies highlight potential benefits of nurse-led models of cancer care delivered in this way, including reduced waiting times, increased capacity, and opportunities to deliver quality nursing care for cancer patients (DOHC, 2006;

NCCP, 2012). Participants reported that they are looking at nurse-led telephone service as an opportunity to further develop the care, especially for follow-up care. It is evident in the literature that nurse-led telephone clinics are increasingly used as an alternative model for providing nurse-led models to provide follow-up care to cancer patients and are proven to be safe and effective **(**Booker *et al.* 2004; Kimman *et al.* 2010; Moore, 2018; Overend *et al.* 2008; Anderson, 2010; Craven *et al.* 2013; Casey *et al.* 2017; Faithfull *et al.* 2001). The NCCP oncology medication safety review (2014) recommended to have a telephone triage policy. All the hospitals providing cancer care now have a standardised telephone triage tool kit adopted from UKONS is in use which can be used when providing nurse-led telephone models of care. Nurses might not feel confident to assess patients over the phone while providing nurse-led models of cancer care.

A national guidelines which would form the basis of nurse-led telephone model of care with appropriate training and education will be necessary. The recent development in General Data Protection Regulations (2018) might further have implication on having this type of service which needs to be taken into consideration during development phase. It is also difficult to put emphasis on amount of work nurse-led telephone model of care can generate (Blackberry *et al.* 2013). A creative way of capturing data to evaluate the workload of the nurse while providing nurse-led telephone service will be essential.

6.4.4 Scope of nurse-led models of cancer care

The majority of Participants (*n=39;* 80%) in this study reported that the scope of practice for nurse-led models of cancer care is often confined to a protocol. Most of the protocols provided information on blood monitoring and treatment, toxicity and symptom management as well as guidance on escalation of care to medics in case of emergency. The majority of participants reported their nurse-led service had majority of the common features such as direct referral mechanism, assessment skills, freedom to initiate diagnostic test, prescribing were confined to protocol of medications, discharge and scope for decision making authority as discussed by (Richardson and Cunliffe 2003).

Previous studies suggest clear protocols underpinning nurse-led services may positively impact nurses' autonomy within such services. Birch *et al (2016*) introduced a protocol-driven nurse-led service for robotic assisted radical

prostatectomy pathway. The care pathway provided guidance for clinical nurse specialist to deliver pre-operative multidisciplinary education session, postoperative phone support and for long term nurse-led phone call follow-up. The nurse-led service was successful with up to 96% of patients reporting high confidence in knowledge of the clinical nurse specialist about the disease and treatment. similarly, Jefford *et al* (2016) gave details of a protocol to provide nurse-led follow-up care for colorectal patients. where protocol was developed by experts and key stakeholders to provide nurse-led supportive care program called SurvivorCare. This intervention was tailored for individual patient's needs.

Within the current study, there was variation in the levels of autonomy for clinical decision making of nurse-led model of care. Fifty-one percent of the participants (*n=20)* reported to have various degree of autonomy in clinical decision making. The variation in the levels of autonomy appeared to be influenced by nurses roles, experience, training. This variation is consistent with the findings from the literature where greater autonomy is evident in nurse-led models of cancer care for treatment where nurses are able to prescribe if needed (Wells *et a*l. 2008) or autonomy for clinical decision making within the protocol (Lewis *et al.* 2006). Gagnon *et al.* (2010) defines clinical decision-making as an essential part of autonomy.

Findings from this study suggest the majority of participants (*n=39;* 80%) reported that their autonomy for decision making is limited to the agreed protocols to deliver the nurse-led service, however, sixty-five percent of participants leading nurse-led services in this study reported decisions within their services required endorsement or permission of a doctor, despite their being protocol in place. In addition, nurse's individual perception may also influence their autonomy, for example nurses' confidence in their clinical skills and decision making in clinical practice.

Clearly, the variation in the nurse's autonomy in clinical practice is an important issue in terms of providing nurse-led models of care to benefit cancer patients. The findings from the current survey also demonstrated the complexity around discharging practice for Irish nurses, similar to that of Scottish nurses providing nurse-led models of care (Hutchison *et al.* 2011). The current survey found that only 18% of nurses at Advanced Nurse Practitioner and Clinical Nurse Specialist

grade were able to discharge patients from the hospital, and the large majority required permission from a doctor before discharging. Interviewees found it discouraging especially when they perceived themselves to be competent to make discharge decisions, but as decisions to discharge patients was not specified in the protocol, they needed doctors to discharge patients from the hospital, contributing to delays in patient discharge.

Potential delays in discharge could also arise where protocols for nurse-led services were not accepted within practice. Interview participants reported that even when nurses had the scope to refer patients to other disciplines, there were occasions where another expert could refuse to accept a nursing referral. As nurse-led services continue to develop, there must be cross-organisational and interdisciplinary recognition of an agreement to abide by the policies and practices surrounding nurse-led care. Furthermore, nurses will develop experience and expertise within their roles; and as nurses achieve the competencies required to assume additional roles and expand their practice within existing nurse-led services, provision should be made within governing policies to expand the activities of the service where there is opportunity to benefit the patient, the nurse, and the organisation.

Within this study, there was a recognisable difference in the role of a clinical nurse specialist, staff nurse, and advanced nurse practitioner within nurse-led models of cancer care. The significant difference was in the nature of nurse's clinical practice. For example 56% of the participants reported to be able to clinically assess patients and 22% of the participants were able to prescribe. However, despite these differences; they all were providing nurse-led services under the umbrella of nurse-led models of care. Although interviewee expressed understanding the importance of having prescribing rights within nurse-led models of care, of the 22% who were reported being able to prescribe, advanced nurse practitioners were the only group who reported prescribing regularly. However, advanced nurse practitioners are expected to undertake prescribers training within the formal structure for MSc Nursing Advanced Practice (Nursing and Midwifery Board of Ireland, 2017). The limited number of nurses engaged in prescribing is surprising, given the recent drive from HSE to support role expansion by introducing nurse medication and x-ray prescribing (NMBI, 2016). However, one of the features of nurse-led service as discussed in the literature is

prescription to protocol of medication (Richardson and Cunlife 2003; Farrell *et al.* 2017). Hence. nurse-led protocol prescription may be a means to enhance capacity for prescribing within nurse-led services provided by staff nurses and clinical nurse specialists.

The findings from this study revealed that the majority of nurses undertook a holistic approach to assessment including evaluation of symptoms. Interestingly, advanced nurse practitioners were more likely to report undertaking full physical examination of patients, this again is likely due to the core module of advanced health assessment within MSc in Advanced Practice in accordance with Advanced Practice (Nursing) Standards and Requirements (NMBI 2017).

Sixty-eight percent of the survey participants reported to provide direct telephone contact details to the patients enrolled in the nurse-led models of cancer care. The participants perceived this mode of communication was means for continuity of care as patients were able contact nurse whenever there was a need, Furthermore, the participants from this study reported that they undertook a multi-disciplinary approach to provide continuity of care within their nurse-led models of cancer care. The literature suggests nurse-led models of care provide holistic, streamlined, and integrated care to patients to facilitate better communication with other healthcare workers and to improved patient health outcomes. The potential for improved patient outcomes was reflected in interview findings, where nurses described using assessment tools to carry out a comprehensive assessment of patient's symptoms and to develop understanding of the patient's life, such as their diet arrangements and family support. Use of assessment tools are also evident in the study done in Canada to evaluate community-based treatment programme for lymphedema (Howell and Warson, 2008) which contributed to provision of safe and effective care within nurse-led models of cancer care.

There is evidence in the literature that nurses may waste resources though over use of diagnostic testing and may be reluctant to prescribe (Loftus & Weston 2001). However, the findings from the current study suggests there is limited scope for nurses to initiate diagnostic testing in nurse-led models of cancer care. Most of the participants (*n*=34; 69%) were dependent on doctors to initiate diagnostic testing such as CT scans and X-rays. This was discussed at length in

the interview where nurses reported they ordered the test, but doctors still need to approve what the nurse is doing. This dependability causes delays in the patient care. Furthermore, the findings from this study shows that referrals to nurse-led models of care are mainly made by doctors; however, interviewees suggest the process of nurse-led referrals are also influenced by a professional relationship built on trust and confidence between doctors and nurses. This is an important issues while developing nurse-led models of care since extending nurse's roles in this way has implication for patients and the service. It creates a lack of clarity and understanding regarding the nurses' role and scope of practice. This indicates that greater transparency is needed for nurse-led models of cancer care, including a framework for role development and on-going training for clinical practice.

6.5 Benefits, Challenges and Impacts of Nurse-Led Models of Oncology Care in Ireland

This section explores key challenges and barriers to the implementation of nurse led models of cancer care in Ireland. Specifically, it comments on the promising alternative of nurse-led models of care, it notes lack of service audits; issues around continuity of care; the importance of engaging with patients; job satisfaction amongst nurses, and concludes with need for standardisation of nurse-led models of care.

6.5.1 Benefits and outcomes of nurse-led models of cancer care

The participants from the study reported nurse-led models of cancer care can provide a more comprehensive holistic and integrated approach to care, which is of benefits to patients. Most participants (*n=16; 33%)* reported carrying out patient satisfaction surveys for the nurse-led models of cancer care they provide, and interview participants suggested that patients expressed high levels of satisfaction with nurse-led models of care within these surveys. They suggested patient satisfaction was often linked to high quality care, communication and continuity of care. These findings are consistent with previous studies which report high levels of patient satisfaction with nurse-led models of cancer care (Wong and Chung 2006; Desborough *et al*. 2011). However, patient satisfaction surveys may be biased by socially desirable responses (Muller *et al.* 2015) as

these patients rely on the nurses to provide their care and may not tell if they are not happy with service they received. Also, surveys tend to be closed hence, the patients will only answer the questions they are asked and may miss out on the questions about the difficulties patients are experiencing.

In line with the literature review, the current study's findings showed that nurses evaluate nurse-led models of care for clinical outcomes, which have an impact on patient satisfaction, access, and outcomes. Continuity of care was the most commonly cited benefit in the provision of nurse-led models of cancer care (Hutchison *et al.* 2011; Anderson 2010; Berglund *et al.* 2015; Birch *et al.* 2016). Interviewees also spoke about how continuity of care was maintained in nurse-led services as patients had one defined point of contact rather than meeting a different person each time and this was seen as a crucial element in enhancing the therapeutic relationship between a health professional and patient. The findings from the literature also suggest that patients are satisfied with nurse-led models of cancer care as they were able to build a relationship with the nurse lead (Farrell *et al.2017*; Dunberger *et al.* 2012; Beaver *et al.* 2010; Egan and Dowling, 2005; Wells *et al.* 2008; Faithfull *et al.* 2001). Similarly, Molassiotis *et al.* (2009) evaluated nurse-led models of cancer care for oral chemotherapy, and found the high compliance with oral chemotherapy and a significantly lower number of patients were admitted to hospital for treatment-related toxicity from the nurse-led models of care. correspondingly, participants in the current study described how nurses influenced increased medication compliance for patients on oral chemotherapy after the introduction of nurse-led models of care.

Another benefit evident in the literature for nurse-led model of follow-up care was that it provide opportunities to give patients useful information. Once patients had knowledge on what was normal and what could be expected during their cancer journey, it helped them cope with cancer more effectively (Beaver *et al.* 2010). Patients receiving information needs intervention show less anxiety than the patients on standard follow-up care (Beaver *et al.* 2006) which appears that information may be a key factor to relieve cancer patient's anxiety and psychological distress. Similarly, Within this study, interview participants reported providing information support within nurse-led models of cancer care. Participants reported to be providing information according to patients need. For example, information was provided on patient's disease, diagnosis, treatment

schedule, side effects of the treatment. Information regarding follow-up care and survivorship care was also provided. Participants recognised that nurse-led model of cancer care can be used effectively to meet patient's information needs especially in the era of information technology where multiple sources of information can be both misleading and confusing.

Furthermore, Interview participants in this study suggested creative ways of looking after information needs within the nurse-led models of cancer care by utilising hospital resources more efficiently and effectively. For example, providing information over the phone about patient's diagnosis and treatment, preassessment of patients before starting treatment, symptom management. An evaluation of a nurse-led robotic prostatectomy care pathway by Birch *et al.* (2016) found a nurse-led multidisciplinary pathway provides a well-planned and structured information to cancer patients undergoing robotic prostatectomy and patients information need before, during and after surgery is met which may have impact on lowering hospital resources. Thus, nurse-led model of care need to provide well planned and structured information.

The findings of Chalabi *et al.* (2014) suggested that, in addition to the relieving increasing clinical pressure and saving surgeons time, nurse-led models of cancer care were able to reduce waiting times for cancer patients. similarly, Interview participant from this study also reported that by taking responsibility for the care of patients with less complex needs, nurse-led care provides a means to reduce physician workload, and increase capacity among physicians to care for patients with more complex medical needs.

Several studies have evaluated clinical outcomes within nurse-led models of care (Molassiotis *et al.* 2009; Wells *et al,* 2008, Howell and Watson, 2005; Van der Meulen *et al.* 2014; Lai *et al.* 2017; Dunberger *and Bergmark*, 2012); psychological outcomes (Jefford *et al*. 2011; Baildam *et al*. 2004; Lewis *et al*., 2009; Beaver *et al*. 2009; Kimman *et al*. 2011); functional outcomes related to quality of life, activities of daily living (Howell *et al.,* 2005; Bakitas *et al.* 2009; Van der Meulen *et al.* 2014), and healthcare system outcomes (Fletcher *et al.* 2007; Craven *et al.* 2013). Within this study, nurse-led services in cancer centres were more likely to be subject to audit on an annual or 2-yearly basis (16%). Just one third of survey participants (n=16; 33%) reported that their service was

audited, evaluating healthcare system outcomes such as patient number (45%) patient satisfaction (33%) and waiting times (27%). During interviews, participants explained that service was not audited because there was no compulsion for auditing the service as well as there is no standardised metrics available for auditing. This indicates a need for a mandatory requirement for nurse-led services should have standardised metrics, set key performance indicators to audit the service. The proposed framework might provide guidelines on the domains of mandatory metrics and key performance indicators.

6.5.2 Challenges of nurse-led models of cancer care

The findings from the current study reported nurses' frustration as a result of several barriers, all of which were directly or indirectly related to a perceived lack of support and resources for the development and implementation of nurse-led models of cancer care. Inadequate administrative and managerial support were the most frequently articulated barriers in delivering nurse-led models of cancer care, reflecting findings of Hutchison *et al.* (2011) and Farrell *et al.* (2017). Richardson and Cunliffe (2003) emphasise the importance of having adequate infrastructure for nurse-led services. Future development of nurse-led models of cancer care was a significant recommendation of the National Cancer Strategy (2017). However, delivery of nurse-led models of care are challenged by poor resourcing of services. Interview participants suggest that limited administrative and management support affect delivery of care for cancer patients. An Australian study undertaken by Wilkinson & Daly (2012) to evaluate reasons for non-attendance at nurse-led wellness services and highlighted the importance of administrative structures for scheduling routine appointments and to send reminders about patients appointments. It provided evidence that administrative support is necessary for successfully implementing nurse-led models of care. When explored further, interview participants suggested that poor understanding of nurse-led models of care among administrative staff contributed to a reluctance to provide support for such services. This suggests that more awareness needs to be created among other health care workers to understand the concept of nurse-led models of cancer care.

Another barrier to implementation of nurse-led models of cancer care discussed by interview participants was that of poor infrastructure. Common frustrations

included the lack of availability of clinic rooms for nurse-led models of care, and prioritisation of clinical space for physician-led activities. This reflects the findings of two studies completed 16 years apart in the UK (Faithful *et al*. 2001; Farrell *et al.* 2017). This is indicative that for last 16 years nurse-led models of cancer has been developing without having proper structures and resources to ensure sustainability of nurse-led models of care.

Another concern participants reported was undefined scope of practice. Common barrier include some participants confining their practice to a protocol however there is no guidance or direction on nursing title or role. As a result, there is a variance in the way nurses work within one nurse-led service and interview participants confirmed that the absence of role description causes conflicts. This was very much evident in the literature where very little information on role description for a nurse-led service. This shows a need for a structural support to develop a standardised role description for nurses working in nurse-led models of cancer care.

6.6 Limitations of the study

Several limitations must be considered in reviewing and interpreting the results. Participants were recruited though Irish Association of Nurses in Oncology. The IANO has a membership of oncology nurses but does not collect information about the current education or employment details of these members. Therefore, the sample may not be representative of the population of nurses providing nurse-led cancer care in Ireland as it is not possible to ascertain how many of these nurses were, at the time of this study, actively providing cancer care to patients. Furthermore, those who self-selected to participate in the survey and interviews may be motivated by a strong interest or motivation in nurse-led models of care and may affect the generalisability of the findings of the study. While many findings from the survey are corroborated by the qualitative findings, self-report measures were used for both the variables.

Another limitation of the study to the generalisability of findings specific to Irish context because of the sample size.

This study explored the current status of nurse-led models of cancer care in Ireland from a nursing perspective exclusively. As such, it does not examine

perspectives of nurse-led models of cancer care from other health care workers such as administrative staff, doctors, and other allied health care professionals which may affect the implementation and sustainability of nurse-led models of care. Therefore, findings of the study must be interpreted with awareness of this limitation. Furthermore, the findings are limited to the context of nurse-led cancer services in the Irish context.

6.7 Future Directions for Development of Nurse-Led Models of Oncology Care

The second National Cancer Strategy was published in 2006 discussed and outlined the future direction of cancer care services in Ireland (Warde *et al.* 2014). The report endorsed positive development in oncology nursing and development of nurse-led models of cancer care to enhance patient care. The NCCP and the HSE Office of the Director of Nursing and Midwifery Services (ONMSD) developed a partnership to identify and advise on priorities for cancer nursing nationally which developed a Strategy and Educational Framework for Nurses Caring for People with Cancer in Ireland. The framework recommended further development of nurse-led models of cancer care to enhanced patient need (National Cancer Control Programme 2012).

It is evident from the study that there are already many developments in nurse-led models of cancer care in Ireland. The diversity and variety in the nurse-led models of cancer care suggest that nurses are able to respond to patients need in Ireland. Furthermore, survey findings showed that the thirty-six percent of the study participants reported future initiatives either planned or under development for nurse-led models of cancer care The most of the nurse-led initiative under development at the moment is nurse-led models of care for oral chemotherapy (35%); survivorship clinic (16%) and innovative use of telephone approach to provide nurse-led service.

The recent NCCP report on acute sector cancer survivorship services in the Irish context puts emphasis on survivorship and changes in follow up care provision (Hegarty *et al.* 2018). Nurse-led models of cancer can provide care to cancer survivors by improving patients' experiences, their quality of life, psycho-social well-being and communication. When developing such a models, it is important

to provide appropriate training and associated skills. Despite the limitations of the study, it provides valuable information for actions required to support existing nurse-led services and for new developments.

6.7 Implication and Recommendation

6.7.1 Implications and Recommendations for Policy

Despite the fact that current nurse-led models of cancer care are ad hoc and lack clear standards and policy, there is, none the less, some merit in further developing certain aspects referred to in the literature and in regional and local articulations, including nurse-led follow-up care and nurse-led model of care for assessment.

The findings from the study showed the inconsistency in nursing grade, education and training. It is recommended to develop a national framework to bring a standardised approach to these models of care. The national framework will provide guidance on role description, education requirement of nurse providing nurse-led models of care, protocol requirement and the process of establishing nurse-led models of care, depending on the individual service need. Furthermore, the DoH and NMBI should take responsibility to agree upon and promote a shared philosophy of nurse-led models of cancer care, with universally agreed nurse-led models of care concepts. The shared philosophy needs to be inclusive of wider nurse-led models of care in general nursing practice, and the impact needs to be measurable.

Current Cancer strategy (2017-2025) recommends increased use of nurse-led models of cancer care; however, without clear guidance informing development of these models, inconsistent and ad hoc approaches to development and implementation of nurse-led modes of care will continue. Clear policy directives are required to endorse a standardised national framework for nurse-led models of cancer care in Ireland. The current study will facilitate comparisons of different nurse-led models of cancer care in Ireland to ensure greater standardisation and fewer disparities between nurse-led models.

The survey findings from this study showed wide variation between nurse's grade, title, roles and their education and training. There was a distinct lack of

clarity between the nurse's title and their roles and responsibilities. While the development of nurse-led services was initially influenced by the need to ease pressure from overcrowded medical clinics, there was a growing recognition within service to increase Clinical Nurse Specialist roles to effectively utilise the roles to its maximum potential to assess, treat and manage cancer patients. The proposed national framework will provide a standardised pathway in Ireland, providing information on nurses' roles, skills and responsibilities. It would also provide guidelines for education, with competency requirements for sustainability of service. While developing the framework it will be advisable to collaborate with academic leaders regarding a planned training programme with prescribing and clinical assessment skills for nurses who are interested in providing nurse-led services, to provide optimum care within nurse-led models of cancer care.

The findings from the study showed variation in level of nurses autonomy for nurse-led models of cancer care. The autonomy for clinical decision in some cases was limited to agreed protocols however there were variation in the content of the protocols. To ensure standardisation of practice, and consistency of autonomy of nurse-led services within and between organisations, the NCCP and Department of Health must consider the development of directives and policies guiding the implementation of nurse-led services in collaboration with key stakeholders in organisations delivering cancer care in Ireland. Such directives and policies must complement the proposed national framework for nurse-led models of care, and be supported by the development of service development tools and template to guide implementation of standardised models of nurse-led cancer care in Ireland.

It was evident from the findings of the study that while nurses undertook wide variety of nurse-led activities, a formal structure for competency assessment for nurse-led models of cancer care is available for ANPs providing nurse-led models of care, but the same is not available for CNSs and Staff nurses working in nurse-led models of cancer care. This raises further concern about validity of existing competency tools within these groups. The national framework for nurse-led models of cancer care must incorporate competency assessment guidelines to support standardised competency assessment for various nursing grades responsible for the delivery of nurse-led models of care.

Nurses from this study suggested they provided more holistic care to patients, with greater as continuity of care, lower waiting times and clinic efficiency. However, there was a little evidence of formal evaluation of these services. Therefore, it is difficult to measure impact of these models of care. Given recent recommendations from National cancer strategy 2017-2025 (Department of Health 2017) to introduce more nurse-led models of care, it is important to evaluate impact of these services. The proposed national framework may issue guidance to address these needs, with core service metrics/KPIs for audit.

6.7.2 Implications and Recommendations for Clinical Practice

The barriers for the development and successful implementations of nurse-led models of cancer care were factors such as lack of infrastructure, administrative support and absence cover. The management do not always support the nurse-led models of cancer care and might give preference to doctor-led clinics hence clinic room might always be allocated first for doctor-led clinics. The reason for lack of absence cover was because of the lack of an appropriately trained nurse and lack of administrative support was because administrative staff may not understand the concept of nurse-led models of cancer care and may take it as extra work. Lack of awareness about the nurse-led concept was also seen in other disciplines where they refused to take on the referrals originated in nurse-led service. Hence, it is recommended to increase awareness of nurse-led models of care concept among disciplines, as well as other health care workers by engaging both in an early stage of the development of nurse-led service.

6.7.3 Implications and recommendation for Future Research

- As there is an evidence of increase nurse-led models of cancer care in Ireland, there is a need to explore the impact of nurse-led services in cancer care on patients outcomes, cost-benefit of implementing nurse-led services in Irish health context.
- As this study looked at perception of nurses about nurse-led models of cancer care, there is a opportunity to explore perception of other professional to ascertain external barriers.
- As this research has been limited to cancer nursing, there is scope to extend this to other areas of nurse practice to explore the extent to which

the issues that have been uncovered in this study may be mirrored elsewhere in the medical system.

Efforts should be made to disseminate learning from implementation of nurse-led services in Ireland to support development in the field.

6.8 Conclusion

This study has expanded the understanding of current status of nurse-led models of cancer care in Ireland. This study provides a benchmark of current nurse-led models of cancer care in Ireland and a comprehensive understanding of the factors affecting their development and success. It is clear from the study findings that the development of nurse-led models of cancer care is at an early developmental stage when compared with other more established medical models. While development of nurse-led models of cancer care is in an ad hoc fashion in response to health service need and patient's need, this model of care provides a defined and approachable point of contact for patients and doctors value support with their increasing workload.

Within these models of cancer care in Ireland, nurses are providing a range of services such as administration of cancer treatment, post treatment review, follow-up care, symptom management and providing information clinics. However there is wide variation regarding nurses titles, roles, responsibilities and education and training which has caused considerable confusion.

Furthermore, training and education varied considerably within nurses working in nurse-led models of cancer care. The majority of nurses had received specific training to equip themselves to provide nurse-led models of cancer care, however there was variability in the nature of academic education. While most of the nurses providing nurse-led models of cancer care had obtained postgraduate certificate or diploma in cancer care or MSc, there were small number of participants with primary nursing degree who also provided nurse-led models of care. A variation in the levels of autonomy within nurse-led models of cancer care was also seen which appeared to be influenced by nurses roles, experience and training. However, autonomy in clinical decision making was limited to the agreed protocols, there were cases where protocol overtook endorsement or permission of a doctor in some cases. While nurses undertook wide range of

nurse-led models of cancer care, a formal structure for competency assessment for nurse-led models of cancer care is not available intended for CNSs and Staff nurses working in nurse-led models of cancer care. This raises further concern about validity of existing competency tools within these groups.

Nurse-led models of cancer care are reported to provide effective and quality efficient care and are potentially beneficial to both healthcare institutions and cancer patients. Health care delivery within Irish cancer services is evolving and influenced by increased prevalence of cancer in an aging population, increased clinical demand associated with constrained resources, developments in treatment and increased survival among those living longer with cancer. The Irish nursing workforce has responded by adopting clinical activities which were previously undertaken by the doctor and acquiring new clinical skills to deliver nurse-led models of cancer care. However, nurses are frustrated by the lack of resources to support sustainability of service such as infrastructure and administration support. Nurses are looking for guidance and standards for nurse-led models of cancer care. The introduction of a national framework with national guidelines for training and evaluation of nurse-led models of cancer care will provide a transparency for nurses and for other health care professional. More structured planning and objective evaluation of service needs, with the provision of active endorsement and participation from support staff, is required for the successful implementation and sustainability of these care models.

Appendices

Appendix 1: Questionnaire

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Introduction

Thank you for taking the time to participate in this survey. You have been asked to take part in this study of nurse-led models of cancer care in Ireland because you are involved in the provision of nurse-led services.

Your responses will assist in documenting the current status of nurse-led cancer services in Ireland.

The survey should take less than 20 minutes to complete.

If you have questions or comments, please contact Snehal Prabhukeluskar at 0863662123 or sprabhuk@tcd.ie

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 1 - About You

The questions in this section are all about your experience and the organisation you work in.

For each question please tick the ONE BOX that best describes your answer.

*** 1. In which type of hospital are you employed?**

- ◯ Centre of Excellence
- ◯ Regional Centre
- ◯ Other (please specify)

*** 2. What is your employment grade?**

- ◯ Advanced Nurse Practitioner
- ◯ Advanced Nurse Practitioner Candidate
- ◯ Assistant Director Of Nursing
- ◯ Clinical Nurse Specialist
- ◯ Clinical Nurse Manager III
- ◯ Clinical Nurse Manager II
- ◯ Clinical Nurse Manager I
- ◯ Staff Nurse
- ◯ **Other (please specify)**

*** 3. How many years of professional nursing experience do you have?**

- ◯ 0-5yrs
- ◯ 6-10yrs
- ◯ 11-15yrs
- ◯ 16-20yrs
- ◯ more than 20yrs

*** 4. What education have you undertaken? (Please tick all that apply and specify speciality wherever applicable)**

- ☐ Nursing Certificate
- ☐ Nursing Diploma
- ☐ Nursing Degree
- ☐ Postgraduate Certificate (Speciality)
- ☐ Postgraduate Diploma (Speciality)
- ☐ Master's Degree, (Speciality)

Other (please specify speciality)

*** 5. How many years of cancer nursing experience do you have?**

- ◯ 0-5 yrs
- ◯ 6-10 yrs
- ◯ 11-15 yrs
- ◯ 16-20 yrs
- ◯ More than 20 yrs

*** 6. How long have you been working in your current position?**

- ◯ 0-5 yrs
- ◯ 6-10 yrs
- ◯ 11-15 yrs
- ◯ 16-20 yrs
- ◯ More than 20 yrs

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 2 - Nurse-Led Service

The questions in this section are about your responsibilities in this service

For each line please tick the ONE BOX that best describes your answer to each question.

*** 7. Are you responsible for the provision of nurse-led services in your organisation?**

- ◯ Yes
- ◯ No

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 2 - Nurse-Led Service

*** 8. Please specify the type of nurse-led services provided in *your* organisation? (Tick all that apply)**

- ☐ Administration of cancer treatment
- ☐ Post-treatment review
- ☐ Symptom management
- ☐ Follow-up care
- ☐ Other (please specify)

*** 9. What are the activities of the nurse-led service*you* provide? (Tick all that apply)**

- [ ] Administration of cancer treatment
- [ ] Post-treatment review
- [ ] Symptom management
- [ ] Follow-up care
- [ ] Other (please specify)

*** 10. How often do you operate nurse-led clinics/services?**

- ○ Daily
- ○ Weekly
- ○ Monthly
- ○ Other (please specify)

*** 11. Is there administrative support for the nurse-led clinic service?**

- ○ Yes
- ○ No

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

12. If yes, what type of administrative support is provided?

- [ ] Patient medical/ nursing notes delivered before clinic
- [ ] Patient medical/nursing notes collected after clinic
- [ ] Letters transcribed
- [ ] Recording of clinic statistics
- [ ] Other (please specify)

* 13. **Is a full equivalent service provided when the nurse lead is absent e.g. due to sickness, holiday etc?**

- ◯ Yes
- ◯ No

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

14. If the nurse lead is absent, who provides this service? (Please tick all that apply)

- ☐ Clinical Nurse Specialist
- ☐ Doctor
- ☐ Another Nurse
- ☐ Other Health Care Professional

If Other Nurse or Other Health Care Professional (Please specify their grade)


Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

15. What happens when the nurse who leads the clinic is absent?

- ◯ Patients are booked into the next available nurse-led clinic appointment
- ◯ Patients are booked into consultant/registrar's medical clinic
- ◯ Other (please specify)

16. **Why is a fully equivalent service not provided?**

- ○ Not required, patients come to next available nurse-led clinic
- ○ There is no appropriately trained nurse available when the lead is absent
- ○ Other (please specify)

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 2 - Nurse-Led Service

* 17. **Where do the referrals for the nurse-led service originate from? (Tick all that apply)**

- ☐ Medical Consultant
- ☐ Advanced Nurse Practitioner
- ☐ Clinical Nurse Manager
- ☐ Patient self-referral
- ☐ Other (please specify)

* 18. **Are there any other healthcare professionals involved in the running of the nurse-led service?**

- ○ Yes
- ○ No

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 2 - Nurse-Led Service

* 19. **If any other healthcare professionals are involved in the running of the nurse-led service, please provide their job titles.**

- [ ] Not applicable
- [ ] Physiotherapist
- [ ] Dietician
- [ ] Radiation Oncologist
- [ ] Medical Oncology Physician
- [ ] Surgical Oncologist
- [ ] Occupational Therapist
- [ ] Social Worker
- [ ] Other (please specify)

* 20. **In the nurse-led service, who can the nurse refer patient to? (Tick all that apply)**

- [ ] None
- [ ] Physiotherapist
- [ ] Not applicable
- [ ] Psycho-oncologist
- [ ] Community Nurse
- [ ] Radiation Oncologist
- [ ] Complementary Therapist
- [ ] Radiation Therapist
- [ ] Dietician
- [ ] Social Worker
- [ ] Medical Oncology Physician
- [ ] Speech Therapist
- [ ] Occupational Therapist
- [ ] Surgical Physician
- [ ] Other (please specify)

* 21. **In the nurse-led service, can you discharge the patient from the service? (Discharge can mean from the hospital or after each consultation that the nurse was providing)**

- ( ) Yes
- ( ) No
- ( ) Don't know

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 3 -Staff Education, Training, Guidelines and Protocols

The questions in this section are about education, training, and the guidelines and protocols which equip and support nurses to provide a nurse-led cancer services.

For each question please tick the ONE BOX that best describes your answer.

*** 22. Have you received specific education or training to equip you to lead this service?**

- ◯ Yes
- ◯ No
- ◯ Don't know

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 3 -Staff Education, Training, Guidelines and Protocols

*** 23. Can you describe the training or education you have undertaken?**

*** 24. Are there specific policies, protocols or guidelines which inform your scope of practice within this nurse-led service?**

- ◯ Yes
- ◯ No
- ◯ Don't Know

Other (please specify)

* 25. **Do these policies/ protocols/ guidelines include guidance on education & training requirements?**

Yes No

* 26. **Do these policies/ protocols/ guidelines include guidance on competency requirements?**

Yes No N/A

* 27. **Do these policies/ protocols/ guidelines include guidance onclerical and secretarial support for the service?**

Yes No N/A

* 28. **Do these policies/ protocols/ guidelines include guidance on absence cover?**

Yes No N/A

* 29. **Do these policies/ protocols/ guidelines include guidance on eligible patients (inclusion/exclusion criteria)?**

Yes No N/A

Other (please specify)

* 30. **Do these policies/ protocols/ guidelines include guidance on process for referral to the service?**

Yes No N/A

* 31. **Do these policies/ protocols/guidelines include guidance onnurse-led assessment?**

Yes No N/A

* 32. **Do these policies/ protocols/ guidelines include guidance oncriteria and process for referral back to consultant?**

Yes No N/A

* 33. **Do these policies/ protocols/ guidelines include guidance on parameters for treatment without medical review?**

Yes No N/A

* 34. **Do these policies/ protocols/ guidelines include guidance on administration of treatment?**

Yes No N/A

* 35. **Do these policies/ protocols/ guidelines include guidance on toxicity/side-effect/symptom management?**

Yes No N/A

* 36. **Do these policies/ protocols/ guidelines include guidance on monitoring required e.g. blood tests?**

Yes No N/A

* 37. **Do these policies/ protocols/ guidelines include guidance on evaluation parameters e.g. booking of CT scans, X-rays?**

Yes No N/A

* 38. **Do these policies/ protocols/ guidelines include guidance on the process for discharge from nurse-led service?**

Yes No N/A

* 39. **Do these policies/ protocols/ guidelines include guidance on audit / evaluation of the nurse-led service?**

Yes No N/A

* 40. **Are these policies/ protocols/ guidelines reviewed by peers in your organization?**

Yes No

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 3 -Staff Education, Training, Guidelines and Protocols

* 41. **If Yes, what is the frequency of the peer review process for policies/ protocols/ guidelines in your organization?**

- ◯ Every 6 months
- ◯ Annually
- ◯ Every 2 years

Other (please specify)

* 42. **Who reviews the policies/ protocols/ guidelines in your organization?**

- ☐ Management Team
- ☐ Clinical Nurse Specialist/Advanced Nurse Practitioner leading the service
- ☐ National Practice Development Programme
- ☐ Other (please specify)

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 4 - Scope of Practice and Competency

The questions in this section are about your scope of practice for the provision of nurse-led services.

For each question please tick the ONE BOX that best describes your answer to each question.

* 43. **In your nurse-led service, is there (Choose all that apply).**

- ☐ Direct referral mechanisms
- ☐ Responsibility for clinical assessments
- ☐ Autonomy in decision making
- ☐ Freedom to initiate diagnostic tests (eg x-rays, bloods)
- ☐ Autonomy to directly admit patients to in-patient service if required
- ☐ Autonomy to discharge patients

* 44. **Please describe the nature of your patient assessment.**

- ◯ Holistic nursing assessment (verbal) including symptom assessment
- ◯ Holistic nursing assessment and physical examination/clinical assessment focusing only on tumor group
- ◯ Holistic nursing assessment with full physical examination/ clinical assessment

* 45. **Please tell us how patients are referred to your nurse-led service.**

- ◯ Internal from doctor
- ◯ Internal from doctor or other discipline
- ◯ External & internal sources

* 46. **Please describe how diagnostic testing are arranged in your nurse-led service.**

- ◯ Initiated by doctor only
- ◯ Initiated by nurse
- ◯ Other (please specify)

* 47. **Please describe how referral for other consultation arranged.**

- ◯ Referral by doctor only
- ◯ Referral by nurse
- ◯ Other (please specify)

* 48. **Please describe your scope of practice relating to prescribing.**

- ◯ I am not prescribing
- ◯ I am a registered prescriber but I prescribe infrequently
- ◯ I am a registered prescriber and I regularly prescribe
- ◯ I am not a registered prescriber but I prescribe within agreed protocol

* 49. **Please describe about your scope of practice relating to clinical decision making about changes in patient care.**

- ◯ With permission from doctor
- ◯ In discussion from nurse
- ◯ Autonomous

* 50. **Please tell us about your practice relating to discharge.**

- ◯ I must refer back to doctor for discharge
- ◯ I can discharge from nurse-led service only
- ◯ I can discharge from hospital

* 51. **Are nurses involved in the service subject to formal assessment of competence?**

◯ Yes ◯ No

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 4 - Scope of Practice and Competency

* 52. **If nurses involved in the service are subject to formal assessment of competence, who is the formal assessor of the competency?**

◯ Clinical Nurse Specialist ◯ Doctor (please specify grade)

please specify

* 53. **Have you developed your own core competencies?**

◯ Yes ◯ No

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 4 - Scope of Practice and Competency

* 54. **If you have developed your own core competencies, could you please specify the competencies you use?**

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 5 Benefits and Outcomes of Nurse-led Models of Care in Oncology Settings

The questions in this section are about the benefits and outcomes that may be anticipated from nurse-led model of care.

For each line please tick the ONE BOX that best describes your answer to each question.

* 55. **How long has this nurse-led service been running?**

◯ </=1year ◯ 2-5 years ◯ >6 years

* 56. **Has a formal audit or evaluation of this service been undertaken?**

◯ Yes ◯ No ◯ Don't Know

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 5 Benefits and Outcomes of Nurse-led Models of Care in Oncology Settings

* 57. **If a formal audit or evaluation of this service been undertaken, please provide details:**

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 5 Benefits and Outcomes of Nurse-led Models of Care in Oncology Settings

* 58. **How often is an audit or evaluation of this nurse-led service undertaken?**

- ○ Never
- ○ Annually
- ○ Every 6 months
- ○ Every 2 years
- ○ Other (please specify)

* 59. **What outcomes do you audit/evaluate? (please tick all that apply)**

- ☐ Patient satisfaction
- ☐ Symptom management
- ☐ Numbers of patients
- ☐ Prescribing patterns
- ☐ Waiting times
- ☐ Frequency of referral back to medical staff
- ☐ Anxiety levels
- ☐ Appropriateness of referral back to medical staff
- ☐ Quality of life
- ☐ Accuracy of diagnostic skills
- ☐ Other (please specify)

* 60. **Have the following Key Performance Indicators (KPIs) been measured in this nurse-led service? (please tick all that apply)**

- [ ] Patient satisfaction
- [ ] Numbers of patients
- [ ] Waiting times
- [ ] Anxiety levels
- [ ] Quality of life
- [ ] Symptom management
- [ ] Prescribing patterns
- [ ] Frequency of referral back to medical staff
- [ ] Appropriateness of referral back to medical staff
- [ ] Accuracy of diagnostic skills
- [ ] Other (please specify)

* 61. **What do you think the benefits of nurse-led service are?**

* 62. **What do you think the challenges of nurse-led service are?**

* 63. **Are there any new nurse-led service initiatives under development in your organization?**

- ◯ Yes
- ◯ No

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Section 5 Benefits and Outcomes of Nurse-led Models of Care in Oncology Settings

* 64. **If yes, Please describe what is proposed or being developed?**

* 65. **Do you have any other comments about the nurse-led services in your organization?**

66. **Which cancer centre are you working in?**

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

Phase two of this project will involve interviews with nurses that are providing nurse led care so that we may fully understand the work you are doing. If you are interested in taking part, please provide your email address so that we can contact you to arrange an interview.

Thank you for taking the time to complete this questionnaire

Exploring Nurse-Led Models Of Cancer Care In Ireland: Nursing Perspectives

67. **Enter your email address please.**

Appendix 2: Personal Correspondence: Request to Adapt Nurse-Led Clinics for Cancer & Palliative Care Questionnaire

From: Hutchison, Cathy [RETRACTED]
Sent: Wednesday, August 01, 2018 6:58 AM
To: Prabhukeluskar, Snehal
Subject: RE: Nurse-Led Clinics

Hi Snehal

No problem at all. Hope your study goes well.

Best wishes

Cathy

From: Prabhukeluskar, Snehal [RETRACTED]
Sent: 31 July 2018 15:42
To: Hutchison, Cathy
Subject: [ExternaltoGGC]RE: Nurse-Led Clinics

Dear Cathy,

Thank you so much for sharing the research instrument with me a few months ago. My research study is progressing slowly but steadily.

I am seeking your permission to use the questionnaire for my study of "Nurse-led Model of Care in Cancer Services". As you suggested in your previous email, I will have to make few amendments to some of the items to ensure they are appropriate to the Irish healthcare services.

I formally request your permission to use the instrument and adapt it as appropriate to contextualise to the Irish healthcare services.

Thank you in advanced for your assistance with this matter

Yours's Sincerely,

Snehal Prabhukeluskar,

From: Hutchison, Cathy [mailto: [RETRACTED]
Sent: 31 January 2017 07:57
To: Prabhukeluskar, Snehal
Subject: RE: Nurse-Led Clinics

Dear Snehal

Have attached as requested. You'll see from some of the questions that it is a bit dated, but hopefully some of it will be of use.

Kind regards, Cathy

From: Prabhukeluskar, Snehal [mailto: RETRACTED]
Sent: 27 January 2017 10:26
To: Hutchison, Cathy
Subject: Nurse-Led Clinics
Dear Cathy,
I am a student, currently undertaking Masters in Trinity College Dublin, Ireland. I am planning to research current state of Nurse-Led clinics in Ireland. There has been no review of Nurse-Led Cancer Care activities in recent times.
It was interesting to read your review on Nurse-Led clinics and I was very impressed with the 88% response rate you received. I wonder if you will be happy to share your questionnaire with me please.
Kind Regards,
Snehal Prabhukeluskar,

Appendix 3: Criteria for Measuring Content Validity and Content Validity Score Sheet tool

You are invited to provide feedback on the validity of the enclosed questionnaire to assess the scope, governance and infrastructure underpinning nurse-led models of care in oncology settings in Ireland.

The objectives of the study are:

- To map nationally the current models of nurse-led oncology care in Ireland.
- To create understanding of the scope, governance and infrastructure which underpins nurse-led models of care in oncology.
- To explore the perceived benefits and impacts of nurse-led models of oncology care in Ireland among specialist oncology nurses.
- To understand the factors influencing the development and success of nurse-led models of care.
- To inform innovations in the future development of nurse-led models of medical care.

I would appreciate if you could evaluate the validity of the questionnaire for this study within the following criteria:

1) Relevance: - Is this item relevant to the phenomena under study?
2) Clarity: Is the item clearly worded?

Your expertise and contribution to this study will support the development of a robust and relevant questionnaire, aiding a comprehensive evaluation of nurse-led oncology services in Ireland. Please find below content validity tool and the questionnaire attached (Appendix 1)

Content Validity tool:

Relevance: **1** =Not relevant **2**= Question needs some revision
3= Relevant but need minor revision **4**= Very relevant

Clarity: **1** = Not clear **2**= Question needs some revision
3= Clear but need minor revision **4**= Very Clear

Question	Relevance	Clarity	Comments
1.	1 2 3 4	1 2 3 4	
2.	1 2 3 4	1 2 3 4	
3.	1 2 3 4	1 2 3 4	
4.	1 2 3 4	1 2 3 4	
5.	1 2 3 4	1 2 3 4	
6.	1 2 3 4	1 2 3 4	

7.	1 2 3 4	1 2 3 4	
8.	1 2 3 4	1 2 3 4	
9.	1 2 3 4	1 2 3 4	
10.	1 2 3 4	1 2 3 4	
11.	1 2 3 4	1 2 3 4	
12.	1 2 3 4	1 2 3 4	
13.	1 2 3 4	1 2 3 4	
14.	1 2 3 4	1 2 3 4	
15.	1 2 3 4	1 2 3 4	
16.	1 2 3 4	1 2 3 4	
17.	1 2 3 4	1 2 3 4	
18.	1 2 3 4	1 2 3 4	
19.	1 2 3 4	1 2 3 4	
20.	1 2 3 4	1 2 3 4	
21.	1 2 3 4	1 2 3 4	
22.	1 2 3 4	1 2 3 4	
23.	1 2 3 4	1 2 3 4	
24.	1 2 3 4	1 2 3 4	
25.	1 2 3 4	1 2 3 4	
26.	1 2 3 4	1 2 3 4	
27.	1 2 3 4	1 2 3 4	
28.	1 2 3 4	1 2 3 4	
30.	1 2 3 4	1 2 3 4	
31.	1 2 3 4	1 2 3 4	
32.	1 2 3 4	1 2 3 4	
33.	1 2 3 4	1 2 3 4	
34.	1 2 3 4	1 2 3 4	
35.	1 2 3 4	1 2 3 4	
36.	1 2 3 4	1 2 3 4	
37.	1 2 3 4	1 2 3 4	
38.	1 2 3 4	1 2 3 4	
39.	1 2 3 4	1 2 3 4	
40.	1 2 3 4	1 2 3 4	

41.	1 2 3 4	1 2 3 4	
42.	1 2 3 4	1 2 3 4	
43.	1 2 3 4	1 2 3 4	
44.	1 2 3 4	1 2 3 4	
45.	1 2 3 4	1 2 3 4	
46.	1 2 3 4	1 2 3 4	
47.	1 2 3 4	1 2 3 4	
48.	1 2 3 4	1 2 3 4	
49.	1 2 3 4	1 2 3 4	
50.	1 2 3 4	1 2 3 4	
51.	1 2 3 4	1 2 3 4	
52.	1 2 3 4	1 2 3 4	
53.	1 2 3 4	1 2 3 4	
54.	1 2 3 4	1 2 3 4	
55.	1 2 3 4	1 2 3 4	
56.	1 2 3 4	1 2 3 4	
57.	1 2 3 4	1 2 3 4	
58.	1 2 3 4	1 2 3 4	
59.	1 2 3 4	1 2 3 4	
60.	1 2 3 4	1 2 3 4	
61.	1 2 3 4	1 2 3 4	
62.	1 2 3 4	1 2 3 4	
63.	1 2 3 4	1 2 3 4	
64.	1 2 3 4	1 2 3 4	
65.	1 2 3 4	1 2 3 4	
66.	1 2 3 4	1 2 3 4	
67.	1 2 3 4	1 2 3 4	
68.	1 2 3 4	1 2 3 4	

Thank you

Appendix 4 : Example of CVI Calculation

Questions	Expert						CVI Ratio	CVI
	#1	#2	#3	#4	#5	#6		
In which type of hospital are you employed?	4	4	4	4	4	4	6/6	1
What is your employment grade?	4	4	4	4	4	4	6/6	1
If nurses involved in the service are subject to formal assessment of competence, who is the formal assessor of the competency?	4	4	2	4	4	4	5/6	0.83

Appendix 5 : Letter of Invitation to Participants

RE: Research Study: An exploration of nurse-led model of cancer care in Ireland.

Dear Colleague,

I am a Clinical Nurse Manager II in Cancer Clinical Trial's Department at St. James's Hospital, Dublin and a part-time student of the Master of Science in Nursing at Trinity College Dublin. As part of the requirements for this programme I am undertaking a research study to explore nurse-led models of cancer care in Ireland. I hope to use the findings of this study to map nurse-led oncology services nationwide, and to provide understanding of the scope, governance and infrastructure underpinning nurse-led models of care in oncology. It will also explore provider's perceptions of the benefits and impacts of nurse-led models of cancer care in Ireland and the factors influencing the development and success of this type of care.
All nurses who provide nurse-led model of care in twenty-six cancer centres which administer systemic anti-cancer therapy have been contacted about this study. Your agreement to participate in this study would greatly increase the value of this study.

A copy of the participant information sheet is attached to this email. Please find link to the survey questionnaire here: https://www.surveymonkey.com/r/nurse-led_study

It will take 15-20 minutes to complete this questionnaire. Participation in the study is voluntary. All information that you provide in the questionnaire will be confidential.

This study is undertaken in fulfilment of the Master of Science in Nursing. All work is supported by my research supervisors, Professor Anne-Marie Brady and Ms Amanda Drury. Ethical approval for this study has been obtained from the School of Nursing and Midwifery Research Ethics Committee, Trinity College Dublin.

Should you have any queries regarding any aspect of this study, please feel free to contact me by email at **sprabhuk@tcd.ie**, or by phone at 0863662123.

Thank you in advance for your participation.

Yours sincerely,

_____

Snehal Prabhukeluskar

Appendix 6 : Participant Information Leaflet for Questionnaire

Research Title	**An exploration of nurse-led models of cancer care in Ireland.**
Educational Institution	**Trinity College Dublin, Dublin**
Researcher	**Snehal Prabhukeluskar, Clinical Nurse Manager II, Cancer Clinical Trials Office, St James hospital**
Researcher Contact Details	**Address: Cancer Clinical Trials Office, St James's Hospital** **Email: sprabhuk@tcd.ie** **Phone: 01 4103755/0863662123**

Invitation to Participate in a Research Study

You have been invited to take part in a questionnaire for the study of nurse-led models of cancer care in Ireland because you are currently running a nurse-led service. Before you consent to take part in the study, it is important that you understand why the research is being conducted and what the research involves. Please take time to read this Participant Information Leaflet carefully and feel free to contact the researcher using the contact details provided above at any time for further information about the research study.

What is the purpose of this study?

The research aims to explore to explore nurse-led models of cancer care in Ireland. The aim of the research is to document the current status of nurse-led cancer services in Ireland, understanding the impacts, benefits and the factors that affect the development and success of nurse-led models of patient care. A secondary aim of this study is to gain insight to the governance and infrastructure of nurse-led models of care in oncology settings.

Why have I been invited?

As an experienced professional providing cancer care and services, your knowledge of the service and opinions regarding the status, impacts, benefits and development of nurse-led cancer services is important. You may also be invited to participate in follow-up interview.

Do I have to take part?

No, participation in this study is entirely voluntary and you are free to withdraw your consent to participate at any time without explanation. Consent is implied by completion and return of the questionnaire. Once the questionnaire is returned, it is not possible to withdraw from the study.

What will happen if I participate?

Data will be collected online using a survey questionnaire. The questionnaire will take between 20 and 30 minutes to complete. At the end of the survey, you will

be invited to provide your contact details if you wish to participate in follow-up interviews. I will contact you within 3 months to arrange an interview at a time and a place of your convenience.
If you provide details to be interviewed, please note that your identity will only be known to the researcher and that you will be allocated an ID code which will link your survey and interview.

Confidentiality and Data Protection

The questionnaire data will be anonymous. No names and address will be collected from the survey except for those who will volunteer to provide your names and address to take part in Phase II (Interview Phase) of the study. Only if you volunteer for interview, you will be allocated a numerical code which will be stored separately to your name. The results of this study will be published; however no identifying information will be included in such publications.

Benefits to participants

Your participation will help evaluate the status of nurse-led activities in Ireland.

Risks to participants

During surveys and interviews you may give some information that raises concern about potential risk or harm to patients. I would like to remind you that it is my duty of care to report any malpractice to the appropriate authority such as NMBI or the Director of Nursing of the your organisation.

Also there is a potential issue of possibly identifying your identity from your survey as your email addresses will be collected on the last page of the questionnaire to allow you to get involved in the second phase of the study. To avoid this issue, I will separate email address from the questionnaire data to maintain your confidentiality.

Please remember that Should you be adversely affected by any aspect of this research, you may obtain support from your organisations occupational health department or the employee assistance programme available from your employer.

Compensation

You will not receive payment for participation, also please note that the researcher is covered by clinical indemnity insurance.

Ethical Approval

This study has obtained ethical approval from the School of Nursing and Midwifery Research Ethics Committee, Trinity College Dublin, Dublin 2.

Appendix 7: Reminder letter

RE: Research Study: An exploration of nurse-led model of cancer care in Ireland.

Dear Colleague,

I am writing to you regarding the current study exploring nurse-led model of cancer care in Ireland.

This is a gentle reminder asking you to please complete the survey questionnaire using https://www.surveymonkey.com/r/nurse-led_study by 18th November 2018.

If you have already returned your questionnaire, I would like to take this opportunity to thank you for your reply.

I would like to remind you that your participation in this study is voluntary. Confidentiality will be maintained at all points of research process.

Should you have any queries regarding any aspect of this study, please feel free to contact me by e-mail at sprabhuk@tcd.ie

Thank you in advance for your time and participation.

Your sincerely,

Snehal Prabhukeluskar

Appendix 8 :Interview Guide

A qualitative exploration of nurse-led model of oncology care. The interview will be semi-structured, however additional questions may arise from observation of clinical practice and responses may also generate other questions.

Questions in *italics* could be used to initiate the interview and explore areas of interest:

1. *How describe how your nurse-led oncology clinic set up initially?* (Governance, Any SOPs, Pathway Guidance)
2. *Can you speak about your motive for setting up the nurse-led model of care initially?*
3. *Can you describe how the care was delivered before the clinic was established?*
4. *Can you tell me about any substantial changes that have occurred since you adopted this type of model?* (Prompt Example)
5. *Can you describe the impact of your nurse-led model of care?*
   • Impact on patients, staff and service delivery
   • impact of the clinic on nursing practice (Competency/scope of practice and workload
6. *Can you tell me about the challenges you faced?*
7. *Can you tell me about how you think the service might be further developed or improved?*
   • Funding, support, implication
   • Future developments / plans
8. *Can you tell me about your perception of the impact of standardised national pathway for developing nurse-led care would be beneficial to you? IF yes, why do you think so*? (Explore perceptions)
9. *Are there any other thoughts that you have around nurse-led that you would like to share?*

Appendix 9: Participants Information Leaflet for Interview (PIL)

Title of Study: An exploration of nurse-led models of cancer care in Ireland.

Research Team:

Principal Investigator	Snehal Prabhukeluskar, Clinical Nurse Manager III, National Coagulation Centre, St James Hospital Email: sprabhuk@tcd.ie Phone: 01 4103755/0863662123
Supervisor	Professor Anne-Marie Brady, School of Nursing and Midwifery, Trinity College Dublin, The GAS Building, 24 D'Olier Street, Dublin 2, D02 T283. Ph: 01-8963004. E-mail: abrady4@tcd.ie
Co-Supervisor	Dr Amanda Drury, School of Nursing and Midwifery, Trinity College Dublin, The GAS Building, 24 D'Olier Street, Dublin 2, D02 T283. Ph: 01-8964164.
Educational Institution	Trinity College Dublin, Dublin

Data Control & Protection:

Data Controller:	Trinity College Dublin
Joint Data Controller, Trinity College Dublin:	Snehal Prabhukeluskar, Clinical Nurse Manager III, National Coagulation Centre, St James Hospital **Email:** sprabhuk@tcd.ie **Phone:** 01 4103755/0863662123
Data Protection Officer, Trinity College Dublin:	Ms Jennifer Ryan, Data Protection Officer, Secretary's Office, Trinity College Dublin, Dublin 2, Ireland. **E-mail:** dataprotection@tcd.ie
Data Processor	Snehal Prabhukeluskar, Clinical Nurse Manager III, National Coagulation Centre, St James Hospital **Email:** sprabhuk@tcd.ie **Phone:** 01 4103755/0863662123

Introduction

Thank you for your participation in the Nurse-led Models of Care in Ireland survey and your willingness to get involved in second phase of the study. You are being invited to participate in an interview as part of the study of nurse-led models of cancer care in Ireland because you expressed an interest in being interviewed during the survey phase of the study.

As an experienced professional providing cancer care and services, your knowledge of the service and opinions regarding the status, impacts, benefits and development of nurse-led cancer services is important.

Who is organising and funding this study?

This evaluation study is being coordinated by Ms Snehal Prabhukeluskar, under the supervision of Professor Anne-Marie Brady and Dr Amanda Drury. This study is not funded.

Participation:

Before you consent to take part in the study, it is important that you understand why the research is being conducted and what the research involves. Please take time to read this Participant Information Leaflet carefully and feel free to contact the researcher using the contact details provided above at any time for further information about the research study. This is process is know as 'Informed Consent'.

Your participation in this study is entirely voluntary, and you are free to withdraw your consent to participate at any time without explanation.

Why is this study being done?

The research aims to explore nurse-led models of cancer care in Ireland. The aim of the research is to document the current status of nurse-led cancer services in Ireland, understanding the impact and benefits of such services and the factors that affect the development and success of nurse-led models of patient care. A secondary aim of this study is to gain insight to the governance and infrastructure of nurse-led models of care in oncology settings.

What will happen to me if I agree to take part?

If you choose to participate in second phase of the study to explore nurse-led models of cancer care in Ireland, you will be asked to participate in a face-to-face interview will be arranged at a time and in a place convenient to you. Prior to the interview, you will be asked to read and sign informed consent for the interview.

Once consent is signed, we will proceed with a semi-structured audio-recorded interview. The interview will be based on the objectives of this study and guided by the phase one qualitative results.

Interviews will last between 20 to 30 minutes and will be digitally recorded and transcribed. Please note that you can only withdraw from the study up until the point where the interview data is merged for analysis. I anticipate this will take place by March 2019.

What are the benefits of the study?

There are no direct benefits to you from participating in the study. We hope that information gained from your participation will help evaluate the status of nurse-led activities in Ireland. This information will help to improve the service.

What are the risk of the study?

During interview you may provide information that raises concern about potential risk or harm to patients. If this happens, interview will be stopped and any potential risks will be reported to the appropriate authority. I would like to remind you that it is my duty of care to report malpractice to the appropriate authority such as NMBI or the Director of Nursing of your organisation.

Should you be adversely affected by any aspect of this research, you may obtain support from your organisations Occupational Health Department or Employee Assistance Programme.

There is also a potential issue of identifying your identity from your survey as your email addresses will be collected on the last page of the questionnaire to allow you to get involved in the second phase of the study. To avoid this issue, you will be allocated a numerical code which will be stored separately to your name. The results of this study will be published; however, no identifying information will be included in such publications.

Will it cost me anything to take part?

We do not anticipate that participation in this study will incur any financial costs to you. You will not receive payment for participation.

Data Protection and Confidentiality

What is the purpose of processing my personal data?

As an experienced professional providing cancer care and services, your knowledge of the service and opinions regarding the status, impacts, benefits and development of nurse-led cancer services is important.

What is the legal basis for processing my personal data?

We are carrying out this research in the public interest and will process personally-identifiable and sensitive personal data for scientific research purposes under Articles 6(1)(e) and 9(2)(j) of the General Data Protection Regulations (2018). This means that we will use your data in the ways needed to conduct the research study.

Is this study confidential?

Confidentiality will be maintained at all stages of the research. No other person will have access to the data other than researcher. Your identity and any other personal information given during the interviews will be removed and stored separately from the data and each interviewee will be allocated a numerical code which will be stored separately to your name. All results will be published in a way that individuals cannot be recognised. Interviews will be digitally recorded and transcribed. If you wish to avail a copy of your transcript, I can arrange a copy to be sent to you.

Who will have access to my personal data?

Any personally-identifiable information we have about you and your participation in this evaluation will only be available to the researcher to monitor, audit and facilitate data collection processes.

Pseudonymised information collected from you will be viewed by the researcher and the supervision team for the purpose of research and audit. This means your data will be referred to by a unique participant number rather than by name. Personally-identifiable information will be stored separately and referred to by your unique participant number

Will the data I provide be used for future research studies?

The information will only be used for the purpose of this research and will not be shared with third parties.

How long will my personal data be stored for?

Once the data has been analysed and reported, the researchers will anonymise electronic study datasets to minimise the risk of a data breach. Personally-identifiable information, such as your unique participant number will be removed from the dataset, so that data cannot be linked back to you. All interview recordings will be destroyed once they have been transcribed. Hardcopy data collected for the purposes of this study will be retained for a minimum period of five years after completion of the study. The researcher will take responsibility for data destruction.

Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. The actual recording will be kept in researcher's office in a locked cabinet in Trinity College Dublin.

All electronic data saved in password-protected computer files stored on encrypted hard drives. These hard drives will be stored in the researcher's offices in the School of Nursing and Midwifery, Trinity College Dublin.

Can I withdraw from the study?

You have the right to withdraw from this study at any time. You will be able to do this by contacting Snehal Prabhukeluskar via email at sprabhuk@tcd.ie .

What happens to my data if I withdraw from the study?

Should you wish to withdraw from the study, we will destroy any personally-identifiable information about you.

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

What are my data protection rights as a research participant?

As a participant of this research study, you have a number of rights under data protection regulations:

1. You have the right to access to all personal information held about you by the researcher.
2. You have the right to change or request deletion of personally-identifiable information held about you for the purpose of this research, including your name, address or contact information.
3. You have the right to move, copy or transfer your personal information to organisations or services in a readable format.
4. You have the right to restrict or object to the processing of personally-identifiable information.

You can exercise any of these rights by contacting Snehal Prabhukeluskar via email at sprabhuk@tcd.ie

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter via email at: dataprotection@tcd.ie.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful, you have the right to lodge a complaint with the Data Protection Commissioner at: https://www.dataprotection.ie/.

Ethical Approval

This study has obtained ethical approval from the School of Nursing and Midwifery Research Ethics Committee, Trinity College Dublin, Dublin 2.

Indemnity:

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

Further information:

If you need any further information, or if anything in this document is unclear, please contact Snehal Prabhukeluskar at 0863662123 or sprabhuk@tcd.ie who would be happy to discuss any of this information with you.

Next Steps:

Having read this information, you must decide if you would like to take part the second phase of the study to explore nurse-led models of cancer care in Ireland.

If you agree to participate in the study, we would ask you to sign the Consent statement below to approve the following:

- The interview will be recorded and a transcript will be produced
- The transcript of the interview will be analysed by **Snehal Prabhukeluskar** as research investigator
- The participants will be allowed to access the interview transcript
- Any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymized so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify yourself is not revealed
- The actual recording will be kept in researcher's office in a locked cabinet in Trinity College Dublin.
- No identifiable data or material will be retained after the study is completed and no material will be used in future unrelated studies without further specific permission being obtained

By signing this form, I agree that;

1. I am voluntarily taking part in this project. I understand that I don't have to take part, and I can stop the interview at any time
2. The transcribed interview or extracts from it may be used as described above
3. I have read the Information sheet
4. I don't expect to receive any benefit or payment for my participation
5. I can request a copy of the transcript of my interview and may make edits I feel necessary to ensure the effectiveness of any agreement made about confidentiality
6. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

_____

Printed Name

_____

Participants Signature
Date :

Statement of Principal/Co-Investigator's Responsibility*:*

I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

_____

Researchers Signature
Date :

Appendix 10: Interview Consent Information Form

Research Title	**An exploration of nurse-led models of cancer care in Ireland.**
Educational Institution	**Trinity College Dublin, Dublin**
Researcher	**Snehal Prabhukeluskar, Clinical Nurse Manager II, Cancer Clinical Trials, St. James's Hospital**
Researcher Contact Details	**Address: Cancer Clinical Trials Office, St James's Hospital** **Email: sprabhuk@tcd.ie** **Phone: 014103755/ 0863662123**

The research aim is to explore nurse-led models of cancer care in Ireland. The aim of the research is to document the current status of nurse-led cancer services in Ireland, understanding the impacts, benefits and the factors that affect the development and success of nurse-led models of patient care. A secondary aim of this study is to gain insight to the governance and infrastructure of nurse-led models of care in oncology settings.

The interview will take 20 to 30 minutes and will be tape recorded. You have the right to stop the interview or withdraw from the interview at any time.

Should you be adversely affected by any aspect of this research, you may obtain support from your organisation's occupational health department or the employee assistance programme available from your employer.

Should you disclose incidents of poor practice, the researcher is obligated to report such disclosure to the appropriate authority. Thank you for agreeing to be interviewed as part of the above research project. Ethical procedures for academic research undertaken from Trinity College Dublin require that interviewees explicitly agree to being interviewed and how the information contained in their interview will be used. This consent form is necessary for us to ensure that you understand the purpose of your involvement and that you agree to the conditions of your participation.

Would you therefore read the accompanying information sheet and then sign this form to certify that you approve the following:

- The interview will be recorded and a transcript will be produced
- The transcript of the interview will be analysed by **Snehal Prabhukeluskar** as research investigator
- The participants will be allowed the access to the interview transcript
- Any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymized so that you cannot be identified, and care will

be taken to ensure that other information in the interview that could identify yourself is not revealed

- The actual recording will be kept in researcher's office in a locked cabinet in Trinity College Dublin.
- No identifiable data or material will be retained after the study is completed and no material will be used in future unrelated studies without further specific permission being obtained

By signing this form, I agree that;

1. I am voluntarily taking part in this project. I understand that I don't have to take part, and I can stop the interview at any time

2. The transcribed interview or extracts from it may be used as described above

3. I have read the Information sheet

4. I don't expect to receive any benefit or payment for my participation

5. I can request a copy of the transcript of my interview and may make edits I feel necessary to ensure the effectiveness of any agreement made about confidentiality

6. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

_____

Printed Name

_____

Participants Signature
Date

_____

Researchers Signature
Date

Appendix 11: Ethical Approval

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Snehal Prabhukeluskar
Cancer Clinical Trial's Office,
St James's Hospital,
Dublin

14th September 2018

Study title:

"An exploration of nurse-led models of cancer care in Ireland"

Dear Snehal Prabhukeluskar,

I am pleased to inform you that your study has been granted Chair approval from the School of Nursing and Midwifery Research Ethics Committee.

Yours sincerely,

Dr. Gabrielle McKee
Acting Chair of School of Nursing and Midwifery Research Ethics Committee

Scoil an Altranais agus an Chnáimhseachais
Dámh na nEolaíochtaí Sláinte,
Coláiste na Tríonóide,
Baile Átha Cliath,
Ollscoil Átha Cliath,
24 Sráid D'Olier.
Baile Átha Cliath 2, Éire.

School of Nursing and Midwifery
Faculty of Health Sciences,
Trinity College Dublin,
The University of Dublin,
24 D'Olier Street,
Dublin 2, Ireland.

+353 1 8962692
nursing.midwifery@tcd.ie
nursing-midwifery.tcd.ie

Appendix 12 Data Plan for Phase One

Objective	Data Analysis Question	Survey item(s)	Thesis section
1. To map nationally the current models of nurse-led oncology care in Ireland.	Explore type and frequency of nurse-led activities,	Q8, 9, 10 Q 14-22 Activities of nurse-led clinic variable	Current activities/ models of nurse-led cancer care in Ireland
2. To create an understanding of the scope, governance and infrastructure which underpins nurse-led models of care in oncology.	Explore administrative support, service cover and Referral system Scope:- Autonomy	Q11, 12 to q22 Q23 to q42 Q43 to 54 Administrative support Service cover Referral pathway MDT involvement	Scope, Governance and infrastructure of nurse-led models of cancer care
3.To explore the perceived benefits and impacts of nurse-led models of oncology care in Ireland among specialist oncology nurses.	Benefits and challenges of nurse-led clinic	Q43 to q63	Benefits, challenges and impact of nurse-led models of care as per service providers
4. To understand the factors influencing the development and success of nurse-led models of care.	Understand the effect of demographic (experience, education, type of institution) on variables relating to conduct of nurse-led clinics	Demographic items: Section 1: Q1-6 Conduct of nurse-led clinics variables: Q 8, 9, 10	e.g. "Factors Influencing the Development and Success of Nurse-led Models"
5.To inform innovations in the future development of nurse-led models of cancer care.	Future Innovation	Initiatives under development Q63,64	Innovation and activities of future development of nurse-led models of cancer care

Reference

Alfano et al.. 2019. Building Personalized Cancer Follow-up Care Pathways in the United States: Lessons Learned From Implementation in England, Northern Ireland, and Australia. *American Society of Clinical Oncology educational book.* **39**(Jan), 625-639.

Allinson et al.. 2004. Breast cancer: evaluation of a nurse-led family history clinic. *Journal of Clinical Nursing.* **13**(6), 765-766.

Anderson, B. 2010. The benefits of nurse-led telephone follow-up for prostate cancer. *British Journal of Nursing* ***19***(17), 1085-1090.

Baildam et al.. 2004, Nurse-led surgical follow-up clinics for women treated for breast cancer- a randomised controlled trial, *European Journal for Cancer care* **8**(3),136-138

Beauchamp, T.L & Childress, J.F (2013). Principles of Biomedical Ethics. (7th ed.). New York: Oxford University Press.

Beaver et al.. 2006. An exploratory study of the follow-up care needs of patients treated for colorectal cancer. *Journal of Clinical Nursing*. **19**(1), 3219-3300.

Beaver et al.. 2010. Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurses. *Journal of Clinical Nursing*. **19**(19-20), 2916-2924.

Begley *et al..* (2010). An Evaluation of Clinical Nurse and Midwife Specialist and Advanced Nurse and Midwife Practitioner Roles in Ireland (SCAPE). National Council for the Professional Development of Nursing and Midwifery in Ireland, Dublin.

Begley *et al..* (2013) Policy-makers' views on impact of specialist and advanced practitioners roles in Ireland: the Scape study. *Journal of Nursing Management* **22**, 410-422.

Berglund et al..(2015). Nurse-led outpatient clinics in oncology care–Patient satisfaction, information and continuity of care. *European Journal of Oncology Nursing*, **19**(6),724-730.

Birch et al.. 2016. Developing and evaluating Robocare; an innovative, nurse-led robotic prostatectomy care pathway. *European Journal of Oncology Nursing*. **21**(1), 120-125.

Bishop, F.L. 2015. Using mixed methods research designs in health psychology: An illustrated discussion from a pragmatist perspective. *British Journal of Health Psychology.* **20**(1), 5-20.

Blackberry et al.. 2013. Effectiveness of general practice based, practice nurse led telephone coaching on glycaemic control of type 2 diabetes: the patient engagement and coaching for health (PEACH) pragmatic cluster randomised controlled trial. *British Medical Journal.* **(347),** 278-290

Booker et al.. 2004. Telephone first post-intervention follow-up for men who have had radical radiotherapy to the prostate: Evaluation of a novel service delivery approach. *Journal of Oncology Nursing*. **8**(4), 325-333.

Braun, V & Clarke, V. 2006. Using thematic analysis in psychology. *Research in Psychology*. **3**(2), 77-101.
Bryant-Lukosius, D. (2014). Back to the Future: Advancing the Global Evolution of Advanced Practice Nursing. Keynote address. International Council of Nurses, *Nurse Practitioner/Advanced Practice Nurse Network Conference.* Helsinki.

Bryman, A (2016). *Social research methods*. (5th ed.). United Kingdom: Oxford university press.

Bryman, A. 2006. Integrating quantitative and qualitative research: how is it done? *Qualitative Research*. **6**(1), 97-113.

Burns, N, Grove, S & Gray, J (2013). The Practice of Nursing Research: Appraisal, Synthesis, and Generation of Evidence. (7th ed.). Missouri: Elsevier Saunders

Cable S. 1995. Minor injuries clinics: dealing with trauma. *British Journal of Nursing.* **4**(20),1177–1182.

Carter et al.. 2010. The role of nursing leadership in integrating clinical nurse specialists and nurse practitioners in healthcare delivery in Canada. *Canadian Journal of Nursing Leadership* **23**(1),167-188.

Casey et al.. 2017. Nurse-Led Phone Call Follow-Up Clinics Are Effective for Patients with Prostate Cancer. *Journal of Patient Experience*. **4**(3), 114-120.

Central Statistics Office (2016): Census 2016. Retrieved from: https://www.cso.ie/en/census/

Chalabi et al.. 2014. Six-Year Experience of a Nurse-Led Colorectal Cancer Follow-Up Clinic. *Surgery Research and Practice*. **14**(1), 1-6.

Chapman A.D. (2005) Principles and Methods of Data Cleaning Primary Species and Species Occurrence Data. Report for the Global Biodiversity Global Faculty, Copenhagen. Retrieved from: https://www.gbif.org/document/80528/principles-and-methods-of-data-cleaning-primary-species-and-species-occurrence-data on 5/1/2019

Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives (2014). Retrieved from: https://www.nmbi.ie/NMBI/media/NMBI/Code-of-Professional-Conduct-and-Ethics-Dec-2014_1.pdf on 24 March 2019.

Collins, J & Howland, D. 2010. Audit of a nurse-led bone marrow biopsy clinic. *Cancer Nursing Practice*.**9**(4),14-19.

Cormack, D (2013). The research process in nursing. (6th ed.). New York, United States: John Wiley & Sons Inc.

Corner. 2003. The role of nurse-led care in cancer management. *Lancet Oncology*. **4**(10), 631-636.

Courtenay, M. (2018). An overview of developments in nurse prescribing in the UK. *Nursing Standard*. **33**(1), 40-44.

Cowman et al..2010. Stroke and nursing home care: a national survey of nursing homes. *BMC Geriatrics.* **10**(4), 102-109

Cox et al.. 2008. Nurse-led telephone to follow up in ovarian cancer: a psychosocial perspective. *European Journal of Oncology Nursing*. ***12***(5), 412-417.

Cox et al.. 2013. Nurse-led supportive care management: A 6-month review of the role of a nurse practitioner in a chemotherapy unit. *Australian Health Review*. **37**(5), 632-635.

Craven et al.. 2013. Is a nurse-led telephone intervention a viable alternative to nurse-led home care and standard care for patients receiving oral capecitabine? Results from a large prospective audit in patient with colorectal cancer. *European Journal of Cancer Care*. **22**(10), 413-419.

Creswell J. and Plano-Clark V.L. (2007). Designing and Conducting Mixed Method Research. Sage Publications, Thousand Oaks.

Creswell, J. W. and Clark, V. L. (2010). Designing and Conducting Mixed Methods Research. (2nd ed.). London: Sage publication.

Creswell, J.W & Plano Clark, V.L (2011). Designing and Conducting Mixed Methods Research. (2nd ed.). London: Sage publication.

Creswell, J.W & Plano Clark, V.L (2013). Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. (4th ed.). London: Sage publication.

Creswell, J.W (2018). Designing and Conducting Mixed Methods Research. (3rd ed.). USA: Sage publication.

Cusack, M. and Taylor, C., 2010. A literature review of the potential of telephone follow-up in colorectal cancer. Journal of Clinical Nursing, 19(17/18), 2394-2405.

De leeuw et al.. 2013. Nurse-led follow-up care for cancer patients: what is known and what is needed. Supportive Care in Cancer. 21(9), 2643-2649.

Department of Health (1998), Report of the Commission on Nursing: A blueprint for the future. Government Publications: Dublin

Department of Health (2017) National Cancer Strategy 2017-2026. Retrieved from http://health.gov.ie/wpcontent/uploads/2017/07/NationalCancer-Strategy-2017-2026.pdf

Department of Health and Children (2011) Strategic framework for role expansion of nurses and midwives: Promoting Quality Patient Care, The Stationery Office: Dublin

Department of Health and Children (2011) Strategic framework for role expansion of nurses and midwives: Promoting Quality Patient Care The Stationery Office: Dublin

Department of Health and Children (DoHC) (2001) Quality and Fairness-A health system for you, Executive Summary, Dublin

Depoy, E & Gitlin, N.L (2016). Introduction to Research: Understanding and Applying Multiple Strategies. (5th ed.). USA: Elsevier Saunders.

Desborough et al..2011. Nurse-led primary healthcare walk-in centres: an intergrative literature review. *Journal of Advanced Nursing*. **68**(2), 248-263

DoHC (2003b) Report on the National Task Force on Medical Staffing: The challenge for nursing and midwifery, a discussion paper, Dublin

DoHC (2006): Department of Health and Children: A Strategy for Cancer Control in Ireland. Dublin.

Doody, O & Noonam, M. 2013. Preparing and conducting interviews to collect data. *Nurse Researcher*. **20**(5), 28-32.

Dowling et al.. 2013. Advanced practice nursing: A concept analysis. *International Journal of Nursing Practice.* **19**(1), 131-140.

Drury, A, Payne, S & Brady, A.M. (2019). Identifying associations between quality of life outcomes and healthcare-related variables among colorectal cancer survivors: A Cross-Sectional Survey Study. *International Journal of Nursing Studies*. doi: https://doi.org/10.1016/j.ijnurstu.2019.103434

Dunberger and Bergmark et al.. 2012. Nurse-led care for the management of side effects of pelvic radiotherapy: what does it achieve? *Current opinion in supportive and palliative care.* **6**(1), 60-68.

Effectiveness of general practice based, practice nurse led telephone coaching on glycaemic control of type 2 diabetes: the Patient Engagement And Coaching for Health (PEACH) pragmatic cluster randomised controlled trial. *British Medical Journal.* **347,** 275-278

Egan, M & Dowling, M. 2005. Patients' satisfaction with a nurse-led oncology service. *British Journal of Nursing*. **14**(21), 1112-1116.

Faithfull et al.. 2001. Evaluation of nurse-led follows up for patients undergoing pelvic radiotherapy. British Journal of Cancer. **85**(12), 1853-1856.

Farrell et al.. 2017. Are nurse-led chemotherapy clinics really nurse-led? An ethnographic study. *International Journal of Nursing Studies*. **69**(1), 1-8.

Farrell, C & Lennan, E. 2013. Nurse-led chemotherapy clinics: issues for the prescriber. *Nurse Prescribing*. **11**(7), 353-358.

Fealy G., Casey M., Brady A. M., Hegarty J., Kennedy C., McNamara M., O'Reilly P., Prizeman G., and Rohde D. (2014) National Review of the Scope of Nursing and Midwifery Practice Framework. Dublin, Nursing and Midwifery Board of Ireland.

Fetters, M.D, Curry, L.A & Creswell, J.W. 2013. Achieving integration in mixed methods designs-principles and practices. *Health Services Research*. **6**(2), 2134-2156.

Fitzsimmons et al..(2005). Nurse-led models of chemotherapy care: mixed economy or nurse-doctor substitution? *Journal of Advanced Nursing*, **50**(3). 244-252.

Fletcher et al.. 2007. Radiotherapy review for patients with breast cancer: a new approach. *Cancer Nursing Practice*. **6**(4), 35-40.

Furlong E, & Smith R (2005) Advanced nursing practice: Policy, education and role development. *Journal of Clinical Nursing.* **14** (9) 1059-1056.

Gagliardi, A.R, Dobrow, M.J & Wright, F.C. 2011. How can we improve cancer care? A review of interprofessional collaboration models and their use in clinical management. *Surgical Oncology*. **20**(3), 146-154.

Gagnon et al..2010. Nurse autonomy in cancer care. *cancer Nursing*. **33**(3), 21-28.

GDPR. 2018. General Data Protection Regulation (GDPR).Retrieved from: https://www.itgovernance.eu/blog/en/the-gdpr-understanding-the-6-data-protection-principles on 15 March 2019.

Girrish, K.L.J & Lathlean, J (2015). The Research Process in Nursing. (7th ed.). UK: John Wiley & Sons Inc.

Government of Ireland (1998) Report of the Commission on Nursing Government Publications: Dublin.

Greene, J & Mcclintock, C. 1885. Triangulation in evaluation: Design and analysis issues. *Evaluation Review*.**9**(5), 523-545.

Greene, J & Mcclintock, C. 1885. Triangulation in evaluation: Design and analysis issues. *Evaluation Review*.**9**(5), 523-545.

Guest, A & Howland, D. 2012. Developing a clinic to meet patients' pre-operative needs. *Practice Development*. **11**(3), 25-29.

Hanan, T., Laffoy, M. and Wynne, M. (2012) A Strategy and Educational Framework for Nurses Caring for People with Cancer in Ireland. National Cancer Control Programme in partnership with the HSE Office of Nursing and Midwifery Director.

Hatchett, R.(2008) Nurse-led clinics: 10 essential steps to setting up a service. *Nursing Times.* **104**(4), 62-64.

Health Service Executive (HSE) (2017) Cancer Services: Welcome to the National Cancer Control Programme retrieved from https://www.hse.ie/eng/services/list/5/ cancer/ on 10th August 2018.

Hegarty J et al.. (2018) Acute Sector Cancer Survivorship Services in the Irish Context. National Cancer Control Programme; Dublin.

Hewett, J & Howland, D. 2009. The benefits of a nurse and dietitian-led follow-up clinic in head and neck cancer. *Cancer Nursing Practice*. **8**(2), 23-28.

Higgins et al..(2018). Rising to the challenge: Epilepsy specialist nurses as leaders of service improvements and change (SENsE study). *Sezure: European Journal of Epilepsy,* **63,** 40-47.

Horrocks et al.. 2002. Systematic review of whether nurse practitioners working in primary care can provide equivalent care to doctors. *British Medical Journal*. **324**(7341), 819-823.

Howell, D& Watson, M. 2008. Evaluation of a pilot nurse-led community-based treatment programme for lymphedema. *International Journal for Palliative Nursing*. **11**(2), 62-70.

Hutchison et al.. 2011. Overview of nurse-led clinics and their scope of practice. *Cancer Nursing Practice*. **10**(9), 29-36

Institute of Medicine (2010): Report on future of nursing, retrieved from http://www.nap.edu/catalog.php?record_id=12956 on 28th December 2018.

Ivankova, et al. 2006. Using Mixed-Methods Sequential Explanatory Design: From Theory to Practice. **Field methods**. **18**(1), 3-20.

Ivankova, et al. 2014. Implementing quality criteria in designing and conducting a sequential QUAN → QUAL mixed methods study of student engagement with learning applied research methods online. *Journal of Mixed Methods Research* .**8**(1), 25-51.

Jackson, K & Bazeley, P (2018). Qualitative Data Analysis with Nvivo. (3rd ed.). London: Sage publication.

Jefford et al.. 2011. Development and pilot testing of a nurse-led post treatment support package for bowel cancer survivors of the role of a nurse practitioner in a chemotherapy unit. *Cancer Nursing*. **34**(3), 1-10.

Jivraj et al.. 2018. Empowering patients and caregivers with knowledge: The development of a nurse-led gynaecologic oncology chemotherapy education class*. Canadian Oncology Nursing Journal*. **28**(1), 4-7.

Jones M. & Rattray J. (2010) Questionnaire design. In The Research Process in Nursing, 6th edn. (Gerrish K. & Lacey A., eds), Wiley-Blackwell, Oxford.

Jones M. & Rattray J. (2010) Questionnaire design. In The Research Process in Nursing, 6th edn. (Gerrish K. & Lacey A., eds), Wiley-Blackwell, Oxford.

Kenealy et al.. (2004). Diabetes care: practice nurse roles, attitudes and concerns. *Journal of Advanced Nursing*, **48** (1), 68-75

Kilpatrick et al.. 2015. Development of evidence briefs to transfer knowledge above advanced practice nursing roles in providers, policy-makers and administrators. *Canadian Journal of Nursing Leadership*. **28**(1), 11-23.

Kimman et al.. 2010. Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer. *BMC Cancer*. **10**(1), 174-184

Kimman, et al…2011. Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer. *BMC cancer*, **10**(1), 174-176.

Koinberg et al.. 2002. Breast cancer patients' satisfaction with a spontaneous system of check-up visits to a specialist nurse. *Scand Journal of Caring Science*. **17**(1), 209-215.
Kostjens, I & Moser, A. 2018. Practical guidance to qualitative research. *European Journal of General Practice.***24** (1), 120-124.

Kostjens, I & Moser, A. 2018. Practical guidance to qualitative research. *European Journal of General Practice.***24** (1), 120-124.

Krishnasamy et al.. 2011. European Journal of Oncology Nursing Patient expectations and preferences for follow-up after treatment for lung cancer: A pilot study*. European Journal of Oncology Nursing.* **15**(3), 221-225.

Lai et al.. 2017. A Nurse-Led Care Program for Breast Cancer Patients in a Chemotherapy Day Center. *Cancer Nursing*. **38**(5), 36-45.

Lai et al.. 2019. A Nurse-Led Care Program for Breast Cancer Patients in a Chemotherapy Day Center. *Cancer Nursing*. **42**(1), 20-34.

Lennan, E. (2012) Best practice in nurse-led chemotherapy review: a position statement from the United Kingdom Oncology Nursing Society. *Ecancermedicalscience.***6**, 263-264.

Lewis et al.. 2009. Nurse-led vs conventional physician-led follow-up for patients with cancer: a systematic review. *Journal of Advanced Nursing* .**65**(4), 706-723.

Lincoln, Y.S & Guba, E.G (1985). Naturalistic Inquiry. Beverley Hills CA: Sage publication.

Loftus, L & Weston, V. 2001. The development of nurse-led clinics in cancer care LINDA. *Journal of Clinical Nursing*. **10**(1), 215-220.

Lynn, M.R. 1986. Determination and quantification of content validity. *Nursing Research*. **35**(6), 382-385.

Macleod et al.. 2007. A nurse-/pharmacy-led capecitabine clinic for colorectal cancer: Results of a prospective audit and retrospective survey of patient experiences. *Journal of Oncology Nursing*. **11**(3), 247-254.

Mccorkle et al.. 2009. Effects of a nursing intervention on quality of life outcomes in post-surgical women with gynecological cancers*. Psycho-oncology*. **18**(1), 62-70.

Molassiotis et al.. 2009. Effectiveness of a Home Care Nursing Program in the Symptom Management of Patients With Colorectal and Breast Cancer Receiving Oral Chemotherapy: A Randomised, Controlled Trial. *Journal of Clinical Oncology*. **27**(36), 6191-6198.

Monas et al.. (2017). The oncology nurse Coordinator: role perceptions of staff members and nurse coordinators. *Israel Journal of Health Policy Research,* **6**(1), 78-86.

Moore et al.. 2002. Nurse led follow up, and conventional medical follow up in the management of patients with lung cancer: a Randomised Trial. *British Journal of Cancer*.**325**(7373), 1145-1167.

Moore et al.. 2018. Nurse-led cancer care clinics: an economic assessment of breast and urology clinics. *Cancer Nursing Practice*. **17**(1), 34-41.
Morgan, D (2014). Integrating Qualitative and Quantitative Methods: A Pragmatic Approach. (1st ed.). London: Sage publication.

Muller at al..2015. Validation of the adherence barriers questionnaire-an instrument for identifying potential risk factors associated with medication-related non-adherence. *BMC Health Service Res. **15***(8), 153-155

Murphy. H., and Mullen, L. (2017) Evaluation of the national cancer education programme: Registered nurses working in an inpatient setting. National Cancer Control Programme in partnership with the HSE Office of Nursing and Midwifery Director.

National Cancer Control Programme, 2012. A strategy and educational framework for nurses caring for people with cancer in Ireland (Report). Health Service Executive (HSE).Ireland.

National Cancer Control Programme, 2017. Evaluation of National Cancer Education Programme: registered nurses working in an inpatient setting (Report). Health Service Executive (HSE).

National Cancer Registry Ireland (2016) Cancer in Ireland 1994-2014: Annual Report of the National Cancer Registry. NCR, Cork, Ireland.

National Cancer Registry Ireland (2017). Cancer in Ireland 1994-2015 with estimates for 2015-2017: Annual Report of the National Cancer Registry. NCR, Cork, Ireland.

National Council for the Professional Development of Nursing and Midwifery (NCNM) (2005). An evaluation of the extent and nature of nurse-led/midwife-led services in Ireland. Retrieved from http://hdl.handle.net/10147/44772 on 8 August 2018.

National Council for the Professional Development of Nursing and Midwifery (2008). Framework for the Establishment of Clinical Nurse/Midwife Specialist Posts 4th Edition. NCNM: Dublin.

National Research Ethics Service (2011), Does my project require review by a Research Ethics Committee? Retrieved form http://www.nres.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=134016 (Accessed Sept 10th 2019).

National Research Ethics Service (2011), Does my project require review by a Research Ethics Committee? Retrieved form http://www.nres.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=134016 on Sept 10th 2019.

Neergaard et al.. 2009. Qualitative description-the poor cousin of health research? *BMC Medical Research Methodology.* **9**(1), 52-58.

Nevidjon et al.. 2010. Filling the gap: development of the oncology nurse practitioner
workforce. *Journal of oncology practice*. **6**(1), 2-6.

Newby, P (2014). Research Methods for Education. (2nd ed.). New York: Routledge.

Nursing and Midwifery Board of Ireland (2016). Collaborative Practice Agreement Guidance for Nurses and Midwives with Prescriptive Authority. 4th Edition. Dublin: Nursing and Midwifery Board of Ireland.

Nursing and Midwifery Board of Ireland, 2015. Scope of Nursing and Midwifery Practice Framework published by the Nursing and Midwifery Board of Ireland.

O'Connell et al..2014. Beyond competencies: using a capability framework in developing practice standards for advanced practice nursing. *Journal of Advanced Nursing*. **70**(12), 2728-2735

O'Cathain, A, Murphy, E & Nicholl, J. 2007. Integration and publications as indicators of 'yield' from mixed methods studies. *Journal of Mixed Methods Research.* 1(2), 147-163.

Oncology Nursing Society 2009–2013 Research Agenda. Pittsburgh, ONS, 2009 retrieved from: http://www. ons.org/media/ons/docs/research/2009–02013onsresear chagendaexecutivesummary.pdf on 7th August 2018.

Onwuegbuzie, A. J., & Leech, N. L. (2007). Sampling Designs in Qualitative Research: Making the Sampling Process More Public. *The Qualitative Report*, **12**(2),238-254. Retrieved from https://nsuworks.nova.edu/tqr/vol12/iss2/7 on 14 March 2018.

Overend et al.. 2008. Evaluation of a nurse-led telephone follow-up clinic for patients with indolent and chronic hematological malignancies: A pilot study. *Canadian Oncology Nursing Journal*. **18**(2), 64-68.

Parahoo, K. (2014). Nursing Research: Principles, Process and Issues. (3rd ed.). UK: MacMillan Education.

Parker, I. (2005) Qualitative Psychology: Introducing Radical Research. Open University Press, Maidenhead.

Patton, M (2015). Qualitative Research and Evaluation Methods: Integrating Theory and Practice. (4th ed.). United States: Sage publication.

Polit et al.. 2007. Is the CVI an acceptable indicator of content validity? Appraisal and recommendations'. *Research in Nursing & Health*. **30**(4), 459-467.

Polit, B & Beck, C (2017). Nursing Research: Principles and Methods (Nursing Research: Principles & Practice). (10th ed.). USA: Wolters Kluwer.

Polit, D.F & Beck, C.T (2014). Essentials of Nursing Research: Appraising Evidence for Nursing Practice. (8th ed.). Philadelphia: Lippincott Williams & Wilkins.

Rea, L.M & Parker, R (2014). Designing and Conducting Survey Research: A Comprehensive Guide. (4th ed.). San Francisco: John Wiley & Sons Inc.

Redfern et al.. 2010. An exploration of personal initiative theory in the role of consultant nurses. *Journal of Research in Nursing* . **15**(5), 435-453.

Richardson, A & Cunliffe, L. 2003. New horizons: the motives, diversity and future of 'nurse led' care. *Journal of Nursing Management.* **11**(2), 80-84.

Robson, C & Mccartan, K (2016). Real World Research. (4th ed.). United States: John Wiley & Sons Inc.

Rolfe, G. 2006. Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*. **53**(3), 304-310.

Sandelowski, M. 1986. The problem of rigor in qualitative research. *Advanced Nursing Science*. **8**(3), 27-37.

Sandelowski, M. 2010. What's in a name? Qualitative description revisited. *Research in Nursing & Health*. **33**(1), 77-84.

Shiu, A.T, Lee, D.T & Chau, J.P. 2012. Exploring the scope of expanding the advanced nursing practice in nurse-led clinics: a multiple case study. *Journal of Advanced Nursing.* ***68***(8), 1780-1792.

Shiu, A et al..2011. Exploring the scope of expanding advanced nursing practice in nurse-led clinics: a multiple case study, *Journal of Advanced Nursing*, **68**, 8, (1780-1792).

Silverman, D (2017). Doing Qualitative Research. (5th ed.). UK: Sage publication.

Spellman, J & Kanatas, A. 2018. Early experience of a nurse-led clinic in a tertiary centre. *British Journal of Oral and Maxillofacial Surgery*. **56**(4), 338-339.

Spellman, J, Kanatas, A & Ong, T.K. 2018. Early experience of a nurse-led clinic in a tertiary centre. *British Journal of Oral and Maxillofacial Surgery* . **56**(4), 338-339.

Stanciu et al.. 2018. Trial of personalised care after treatment—Prostate cancer: A randomised feasibility trial of a nurse-led psycho-educational intervention. *European Journal of Cancer Care*. **17**(1), 1-11.

Stenner, K & Courtenay, M. 2008. The role of inter-professional relationships and support for nurse prescribing in acute and chronic pain. *Journal of Advanced Nursing*. **63**(3), 276-283.

Strand et al.. 2011. Nurse or surgeon follow-up after rectal cancer: A randomized trial. *Colorectal Disease*.**13** (9), 999-1003.

Streubert , S.H & Carpenter , D (2010). Qualitative research in nursing: Advancing the humanistic imperative. (5th ed.). Philadelphia: Lippincott Williams & Wilkins.

Tashakkori, A & Teddlie, C (2010). Mixed Methods in Social & Behavioral Research . (2nd ed.) . California: Sage publication.

Teddlie, C & Tashakkori, A (2009). Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in the Social and Behavioral Sciences. London: Sage publication.

Thomas, J & Harden, A. 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology.* **8**(1), 45-55.

Tod, A. 2015. Interviewing. In: Gerish, A & Lathlean, J eds. The research process in nursing. Oxford: Wiley-Blackwell, 387-400.

Turner, M., 1999. Involvement or over-involvement? Using grounded theory to explore the complexities of nurse-patient relationships. *European Journal of Oncology Nursing* **3**(3), 153-160.

Van Der Meulen et al.. 2014. Long-term effect of a nurse-led psychosocial intervention on health-related quality of life in patients with head and neck cancer: A randomised controlled trial. *British Journal of Cancer*. **110**(3), 593-601.

Van tenijlingen, E & Hundeley, V. 2002. The importance of pilot studies*. Journal of nursing education*. **16**(4), 33-36.

Walliman, N & Tashakkori, A (2018). Research Methods: The Basics. (2nd ed.). New York: Routledge.

Warde, P., de Koning, H. and Richardson, A. (2014) National Cancer Strategy 2006: a Strategy for Cancer Control in Ireland: Evaluation Panel Report. Retrieved from https://health.gov.ie/wp-content/uploads/2015/05/FinalEvaluation-Panel-Report-of-NationalCancer-Strategy-2006.pdf on 10th August 2018

Wells et al.. 2008. A study to evaluate nurse-led on-treatment review for patients undergoing radiotherapy for head and neck cancer*. Journal of Clinical Nursing*. **17**(11), 1428-1439.

Wilkinson, J & Daly, M. 2012. Reseon for non-attedance: audit findings from a nurse-led clinic. *Journal of Primary Health Care,* **4** (1), 39-44.

Willig, C & Wendy, S.R (2017). Qualitative Research in Psychology. (2nd ed.). California: Sage publication.

Willig, C (2010). Introducing qualitative research in psychology: Adventures in theory and method. (2nd ed.). Maidenhead: Open Univercity Press.

Willig, C (2013). Introducing qualitative research in psychology . (3rd ed.). United Kingdom: McGraw-Hill Education.

Wong, F.K & Chung, L.C. 2006. Establishing a definition for a nurse-led clinic: structure,
process, and outcome. *Journal of Advanced Nursing*. **53**(3), 358-369.

World Health Organisation (2012) Enhancing nursing and midwifery capacity to contribute to the prevention, treatment and management of noncommunicable diseases, Geneva. Retrieved from https://www.who.int/hrh/resources/observer12.pdf

World Health Organisation. (2015). *Health Workforce 2030: A Global Strategy on Human Resources for Health*. Geneva: WHO. Retrieved from http://www.who.int/hrh/resources/glob-strat- hrh_workforce2030.pdf?ua=1

World Medical Association (2013) “Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects”. *JAMA*. **310**(20): 2191-2194

World Medical Association (2013) Declaration of Helsinki: Recommendation Guiding Medical Doctors in Biomedical Research Involving Human Subjects. World Medical Association, Helsinki.

Yaghmale, F. 2003. Content validity and its estimation. *Journal of nursing education*. **3**(1),133-135.