

Exploring and informing the provision of nutrition advice to patients with cancer and healthcare professionals, with a focus on cancer survivorship

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General Declaration

This PhD by published work consists of:

- Fourteen lead-authored articles in refereed journals
- One published conference abstract.

They were published in the period 2018-2023. None have been submitted for any other degree or diploma by me or any other person. I can confirm that single-authored publications are based on my own independent work and that my contribution to jointly authored publications is as indicated in Table 1.1.

I spent time as a research scholar at Tufts University, Boston, United States of America (USA) in 2018, which led to the development and pilot of a nutrition intervention (Nutricare). Therefore, the research presented in this thesis took place in both Ireland and the USA. This has been clearly indicated throughout the thesis.

I confirm that the word count of this thesis is less than 20,000 words ($\pm 10\%$), excluding the title page, contents, acknowledgements, abstract, abbreviations, headings, tables, figures, appendices, and references.

Table 1.1 Papers included in this thesis and contributions of the candidate.

Thesis chapter	Publication number	Reference	Study method(s)	Nature and extent of candidate's contribution	Citations (google scholar 27.09.23)	Presentations arising
1.4	1	Keaver L., O'Callaghan N., LaVertu AE., Semple CJ., Hughes CM., Hanna JR., Ryan L. (2023). Experiences of cancer patients in receiving dietary advice from healthcare professionals and of healthcare professionals in providing this advice-a systematic review. <i>Journal of Cancer Survivorship</i> . https://doi.org/10.1007/s11764-023-01359-4	Systematic review	Study conception and design, Prospero registration, assessing papers, data extraction, data analysis and interpretation, drafting and critical revision of manuscript	0	
2.2	2	Keaver L., O'Meara C., Mukhtar M., and McHugh C (2018). Providing Nutrition Care to Patients with Chronic Disease: An Irish Teaching Hospital Healthcare Professional Study, <i>Journal of Biomedical Education</i> , vol. 2018, Article ID 1657624, 7 pages. https://doi.org/10.1155/2018/1657624	Quantitative - Survey	Study conception and design, ethical approval, data entry, data analysis and interpretation, drafting and critical revision of manuscript	22	
2.3	3	Keaver L., Connolly P., Richmond P. (2021). Providing nutrition advice in the oncology setting: A survey of current practice, awareness of guidelines and training needs of Irish healthcare professionals in three hospitals. <i>European Journal of Cancer Care</i> . Jul;30(4):e13405. https://doi.org/10.1111/ecc.13405	Quantitative -Multicentre survey	Study conception and design, ethical approval in three hospitals, recruited HCPs in hospitals to assist with survey distribution, data entry, analysis, and interpretation, drafting and critical revision of manuscript	11	Sligo University Hospital Annual Research Conference November 2020, Sligo Ireland -one of two chosen oral speakers. Irish Nutrition and Dietetic Research Symposium, March 2021, online (presentation).
2.4	4	Keaver L. (2021). Irish cancer patients and survivors have a positive view of the role of nutritional care in cancer management from diagnosis through survivorship. <i>Irish Journal of Medical Science</i> 190(4):1387-1390. https://doi.org/10.1007/s11845-020-02488-w	Quantitative-Survey	Study conception and design, ethical approval, data collection, data entry, data analysis and interpretation, drafting and critical revision of manuscript	10	Irish Nutrition and Dietetic Research Symposium, March 2021, online (presentation).
2.5	5	Keaver, L., Richmond, J., Rafferty, F., and Douglas, P. (2023), Sources of Nutrition Advice and Desired Nutrition Guidance in Oncology Care: Patient's Perspectives.	Quantitative-Multicentre survey	Study conception and design, ethical approval recruited HCPs in hospitals to assist	1	Irish Nutrition and Dietetic Research Symposium, March 2021, online (presentation).

		Journal of Human Nutrition and Dietetics; 36: 434– 442. https://doi.org/10.1111/jhn.13111		with survey distribution, data entry, analysis, and interpretation, drafting and critical revision of manuscript		
2.6	6	Keaver L., Walsh L., Callaghan H., and Houlihan C. (2020). Nutrition Guidance for Cancer Patients and Survivors- A review of websites of Irish Healthcare and Charitable Organisations and Cancer Centres. European Journal of Cancer Care, 29(2):e13216. https://doi.org/10.1111/ecc.13216	Review	Study conception and design, implemented search strategy and applied inclusion criteria, data collection, data analysis, drafting and critical revision of manuscript	14	FENS, Dublin, Ireland, September 2019 (poster). Irish Nutrition and Dietetic Research Symposium, March 2021, online (presentation). Irish Showcase of the European Association for the Federation of Dietitians Conference, October 2021, online (presentation).
2.7	7	Keaver L., Loftus A., Quinn L. (2021). A review of iPhone and Android apps for cancer patients and survivors: assessing their quality, nutrition information and behaviour change techniques. Journal of Human Nutrition and Dietetics 34(3):572-584. https://doi.org/10.1111/jhn.12857	Review	Study conception and design, implemented search strategy and applied inclusion criteria, data collection, data analysis, drafting and critical revision of manuscript	10	Irish Nutrition and Dietetic Research Symposium, March 2021, online (presentation). Irish Showcase of the European Association for the Federation of Dietitians Conference, October 2021, online (presentation).
3.2	8	Keaver L., O’Callaghan N., Houlihan C., LaVertu A.E., Ding S., Zhang F.F. (2022). Evidence-based Nutrition Guidelines for Cancer Survivors in Europe- A Call for Action. European Journal of Clinical Nutrition, 76(6):819-826. https://doi.org/10.1038/s41430-021-01036-8	Meta-epidemiological	Study design, document review, data extraction and interpretation, drafting and critical revision of Manuscript	6	FENS, Dublin, Ireland, September 2019 (poster)
3.3	9	Keaver L., O’Callaghan N., Douglas P. (2022). Nutrition and weight related issues in Irish Cancer Survivors indicate a need for provision of nutrition advice and intervention from credible sources. BMJ Nutrition, Prevention & Health; https://doi.org/10.1136/bmjnph-2022-summit2022.15	Quantitative-Survey	Study conception and design, data analysis and interpretation, drafting and critical revision of Abstract	0	NNedPro Symposium July 2021 – online (presentation). Irish Showcase of the European Association for the Federation of Dietitians

						Conference, October 2021, online (presentation).
3.4	10	Keaver, L., Huggins, MD., Chonaill, DN., O'Callaghan, N. (2023). Online nutrition information for cancer survivors. <i>J Hum Nutr Diet</i> ; 36 (2), 415-433 https://doi.org/10.1111/jhn.13095	Review	Study conception and design, implemented search strategy and applied inclusion criteria, assessed quality, readability, and usability of the websites, extracted nutrition content, data interpretation, drafting and critical revision of Manuscript	3	International Society for Behavioural Nutrition and Physical Activity Annual Conference, Arizona USA, May 2022 (poster).
4.2	11	Keaver, L., Yiannakou, I., Folta, S., & Zhang, FF. (2020). Perceptions of Oncology Providers and Cancer Survivors on the Role of Nutrition in Cancer Care and Their Views on the "NutriCare" Program. <i>Nutrients</i> . 12. https://doi.org/10.3390/nu12051277	Qualitative - Interviews/focus groups	Study conception and design, ethical approval, conducted focus groups, transcription, thematic analysis, drafting and critical revision of manuscript	19	Irish Nutrition and Dietetic Institute Research Symposium, January 2019, Dublin Ireland (poster). Irish Society for Clinical Nutrition & Metabolism conference, March 2019, Dublin Ireland (poster). International Society for Behavioural Nutrition and Physical Activity Annual Conference, Prague, Czech Republic, May 2019 (presentation). Irish Showcase of the European Association for the Federation of Dietitians Conference, October 2021, online (presentation).
4.3	12	Keaver, L., Yiannakou, I., Zhang, F.F. (2020) Integrating Nutrition into Outpatient Oncology Care—A Pilot Trial of the <i>NutriCare</i> Program. <i>Nutrients</i> , 12, 3590. https://doi.org/10.3390/nu12113590 .	Pilot intervention	Study conception and design, ethical approval, ran pilot and delivered all sessions, data entry, data analysis and interpretation, drafting and critical revision of	4	Irish Nutrition and Dietetic Institute Research Symposium, January 2019, Dublin Ireland (poster).

				manuscript		<p>Irish Society for Clinical Nutrition & Metabolism conference, March 2019, Dublin Ireland (poster).</p> <p>International Society for Behavioural Nutrition and Physical Activity Annual Conference, Prague, Czech Republic, May 2019 (presentation).</p> <p>Irish Showcase of the European Association for the Federation of Dietitians Conference, October 2021, online (presentation).</p>
5.2	13	Keaver L., O'Callaghan N., McHugh C (2022). What should the role of doctors be in the provision of nutrition advice - a qualitative study, International Journal of Health Promotion and Education, https://doi.org/10.1080/14635240.2022.2153230	Qualitative - Focus groups	Study conception and design, ethical approval, conducted focus groups, thematic analysis, drafting and critical revision of manuscript	0	
5.3	14	Keaver, L, O'Callaghan, N, Douglas, P. (2023). Nutrition support and intervention preferences of cancer survivors. J Hum Nutr Diet; 36 (2), 526-539. https://doi.org/10.1111/jhn.13058	Mixed method – survey and focus groups	Study conception and design, ethical approval, data collection, data entry, data analysis and interpretation, drafting and critical revision of manuscript	7	International Society for Behavioural Nutrition and Physical Activity Annual Conference, Arizona USA, May 2022 (poster).
5.4	15	Keaver L., Douglas P., O'Callaghan N. (2023). Perceived Barriers and Facilitators to a Healthy Diet among Cancer Survivors: A Qualitative Exploration Using the TDF and COM-B. Dietetics, 2(1), 123-139; https://doi.org/10.3390/dietetics2010010	Qualitative- Focus groups	Study conception and design, ethical approval, thematic analysis, drafting and critical revision of manuscript	1	

Abstract

Nutrition is an important component of supportive care for those with cancer. It is recognised by international nutrition societies that nutrition interventions can improve weight status, reduce length of hospital stay and improve quality of life, amongst other benefits for cancer patients. Despite this, nutrition is not always included as a standard part of cancer care.

This research encompassed a systematic review to identify healthcare professionals' (HCPs) experiences of providing and patients' experiences of receiving nutrition advice in the oncology setting, supplemented by largely quantitative explorations of current practices locally and nationally. Narrowing the focus to cancer survivorship, an extensive review of available European guidelines to guide clinical practice for HCPs was explored, alongside online nutrition resources likely to be found by cancer survivors when searching online. Following on, an intervention (*Nutricare*) was designed using the 5-model and piloted in oncology clinics in the United States of America. Finally, the Irish context was explored in depth, using qualitative and mixed-methods methodologies to aid the adaption of *Nutricare* for Ireland.

The findings presented contribute important insights into the provision of nutrition advice in oncology settings, with implications for knowledge translation efforts. Those with cancer would welcome guidance, however, it should be practical, specific, timely, consistent, and ideally from a dietitian. HCPs recognise the importance of nutrition but need support in the provision of this advice. Interventions addressing these needs are required, however, no one intervention mode or type was identified as preferred. The *Nutricare* intervention could be adapted for the Irish healthcare setting using findings from this research. Recent European and International position papers have called for nutrition interventions that are multidisciplinary and person-centred with input from both HCPs and patients to ensure appropriateness. The knowledge presented in this thesis will help inform the design and adaption of future nutrition interventions.

Key words: nutrition; oncology; cancer; nutrition advice; patient-centred; nutrition intervention

Acknowledgements

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I have to acknowledge both Professor Ivan Perry and Professor Richard Mattes as the individuals who inspired a career in research, opened doors to amazing opportunities and had faith in my ability to undertake complex research while still a student. I will be forever grateful for the world you introduced me to.

To my colleagues at the Atlantic Technological Institute who have consistently supported and encouraged me to undertake this process. Your belief in me has helped no end in getting me to this point.

Pauline Douglas, you are a god among dietitians! You helped me to see how these ‘random’ pieces of work could actually tell a coherent story. For that and your friendship I will be forever grateful. I will return the favour for you when you undertake this process with your amazing body of work. And to Niamh, our fabulous master’s student! Working with you has been such fun. You are so talented, and your work has made a real difference to those with cancer. You should be so proud. I look forward to our future collaborations and research trips!

Prof Fang Fang Zhang thank you so much for believing in me enough to host me in Tufts University in 2018. That opportunity and our continued collaborations have allowed for the production of a large part of this body of work and continue to excite and inspire me.

To my supervisory dream team (Prof Cherith Semple, Prof Ciara Hughes, Dr Jeffrey Hanna and Dr Lisa Ryan), thank you for all your help, guidance, and support in undertaking this process. You have been amazing and have made this experience so enjoyable and for that I will be forever grateful. It was no easy feat to compile this body of work into a thesis nor was it easy I am sure for you to get your head around everything so quickly! I have loved learning from and working with you and I hope this is the start of many more collaborations. Thank you so very much for being so supportive throughout this year. The work that you all do is

inspirational and has had and continues to have a pivotal and important impact on so many lives.

To all my co-authors who I have learnt so much from and to all those who took part in this research -thank you.

To Jean, my writing buddy and friend, I am so happy that we got to undertake this journey together. Our writing sessions kept me motivated and ensured I got to the end of this process! Thank you so much for the chats, the support, and the encouragement throughout. I look forward to graduating together and seeing what the next chapter holds for us both! No doubt it will involve copious amounts of chocolate!

To the most amazing friends who have kept me sane this last year, thank you! I am so lucky to have you in my life. Máire, Aoife, Meave, Eva, Allison in particular – you have looked out for me, supported me, and motivated me for years but especially this last 12 months. Thank you for being my tribe.

Finally, a special thanks to my family for their continued support while I chose to undertake yet another challenge! And to Darren for encouraging me to stay focussed on this no matter what the day or occasion. Thank you for being such an amazing fiancé and for letting me prioritise this PhD for the last 12 months. I love you and this thesis is dedicated to you.

"For presenting yourself on this battlefield, I give you thanks"

William Wallace

Notes on terminology

Cancer survivor - the term cancer survivor was coined in 1985 by Mullans who recognised the distinct needs of those with cancer post-treatment (Mullan, 1985). Not everyone with cancer however ‘accepts’ the term (Park et al., 2009) with some feeling that it is stigmatising (Surbone et al., 2013). Despite this, many others embrace the term and see it as an essential component of their identity (Deimling et al., 2007; Park et al., 2009; Cheung and Delfabbro, 2016). For the purpose of this thesis, ‘cancer survivor’ is defined as those post primary treatment, who are not palliative (Institute of Medicine and National Research Council, 2006; O’Connor and Donnelly, 2019).

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List of abbreviations

AHPs	Allied Healthcare Professionals
ATU	Atlantic Technological University
BCTs	Behaviour Change Techniques
BCW	Behaviour Change Wheel
CPD	Continuous Professional Development
ESPEN	European Society for Parenteral and Enteral Nutrition
FGLS	Flesch-Kincaid Grade Level Score
FRES	Flesch-Kincaid Reading Ease Score
GLIM	Global Leadership Initiative on Malnutrition
GP	General Practitioner
HCPs	Healthcare professionals
IPDAS	International Patient Decision Aid Standards Tool
IrSPEN	Irish Society for Parenteral and Enteral Nutrition
MARS	Mobile App Rating System
MIND	Mediterranean-DASH Intervention for Neurodegenerative Delay
MMAT	Mixed Methods Assessment Tool
MRC	Medical Research Council
NACP	Nutrition Assessment for Cancer Patients
NIHR	National Institute for Health Research
NIS	Nutrition Impacts Symptoms
NNEdPro	Need for Nutrition Education Project
PPI	Patient and Public Involvement
ROADMAP	nutRition knOWledge AttituDes and coMpetence in heAlthcare Professionals
SMART	Specific, Measurable, Achievable, Realistic and Timely
SR	Systematic Review
SUH	Sligo University Hospital
TDF	Theoretical Domains Framework
UK	United Kingdom
USA	United States of America

WCRF World Cancer Research Fund

Chapter one: Introduction and overview

This introductory chapter provides an overview of my research journey to the point of starting the PhD experience, the role of nutrition in cancer care, and the framework which has been applied to this overall body of research. Finally, the aims and objectives will be summarised, and the thesis structure outlined.

1.1 Background

This thesis showcases the research journey I have undertaken over the last five years. I had thought about and abandoned the idea of a PhD many times since graduating from my undergraduate degree in Dietetics in 2011. On graduation, I worked clinically, initially in a local community hospital developing policies and protocols, and then in the National Rehabilitation Hospital. I missed research but lacked the conviction to commit to a PhD programme and so I undertook a master's in public health at University College Cork. This changed my career direction slightly and I undertook a three-year public health nutrition fellowship with Safefood (sponsored by Ulster University). During this time, I missed research and contact with patients and research participants, but still lacked the belief to commit to a full-time PhD programme.

I started lecturing at the Atlantic Technological University (ATU) in 2016 (then the Institute of Technology Sligo) which is conveniently located across the road from Sligo University Hospital (SUH). This presented an opportunity to get back to clinical nutrition and expand my research skills, to advocate for evidence-based practice through research. I was interested in better understanding doctors' and nurses' knowledge of, and confidence in providing nutrition advice. At that time, there was a lack of available dietetic positions, a legacy from hiring embargos in previous years. I had felt while working clinically that in some clinical areas there was a lack of appreciation for nutrition, despite its important role in many conditions. Where there appeared to be awareness and interest amongst clinical teams, I felt there was a lack of knowledge from healthcare professionals (HCPs) other than dietitians about what guidance to provide patients with. In some situations, I experienced HCPs providing inaccurate information to patients.

I wanted to use my knowledge and skills to make a difference in practice and identified an opportunity to better understand and inform HCPs' delivery of nutrition advice. Through personal family experience of cancer, I became interested in learning more about the role of nutrition in the management and treatment of cancer. At the same time, I was undertaking data collection onsite at Sligo University Hospital exploring general nutrition knowledge of HCPs. Through conversations with HCPs, I became aware of the particular lack of nutrition provision and support for those with cancer.

I became very interested in the work that was being conducted nationally in the area of nutrition and oncology, and quickly learnt the benefits of good nutrition for those with cancer. After attending a fascinating keynote talk on cancer cachexia and sarcopenia at the Nutrition Society conference in 2015 (Ryan et al., 2016), I knew that nutrition and cancer was the research area for me. Becoming more familiar with the area, I identified that while there was limited international research addressing nutrition needs and access to advice for those with cancer, equally there was limited national data to inform practice.

This presented an opportunity to marry my two interests – that of nutrition knowledge and practices of HCPs with enhancing understanding, and ultimately improving access to nutrition guidance for those with cancer. As my research progressed, my interests further narrowed, to that of cancer survivors. I knew that were I ever to undertake a PhD, it would need to be a topic I was enthralled by, and where I genuinely believed I could make a difference. It has taken several years to get to this point, but the work that is presented in this thesis embodies my contributions and continued efforts in this field.

Throughout the work presented I have endeavoured to include the perspectives and practices of both those with cancer and HCPs to better allow for the development of nutrition resources that will be feasible, acceptable, and useful in the oncology setting.

1.2 Nutrition and oncology

Nutrition is an important component of supportive care throughout the cancer experience. This has been illustrated in Figure 1.1. and discussed in more detail in subsequent paragraphs.

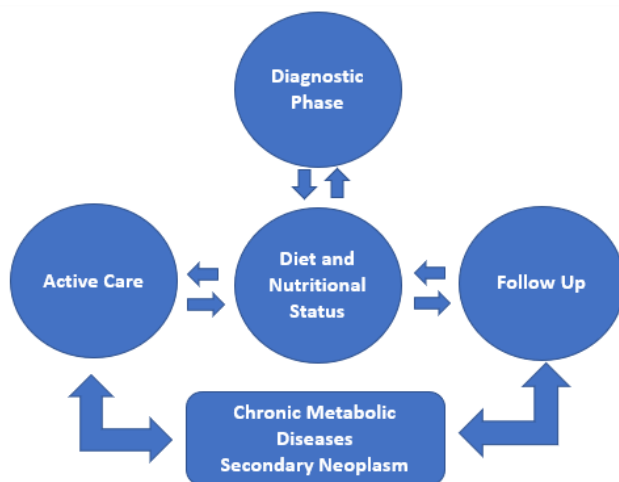


Figure 1.1 Nutrition and Cancer adapted from Rosti et al. (2020)

Inadequate nutrition can impact tolerance to treatment, increase duration of hospital stays and decrease survival rates (Thompson et al., 2017; Reber et al., 2021). It can contribute to weight loss, which in conjunction with cancer cachexia and sarcopenia, leads to loss of muscle tissue, which can impact on physical function, tolerance to treatment (da Silva Dias et al., 2022) and quality of life (Polański et al., 2017; Martin et al., 2020; Xiao et al., 2020). Weight loss during cancer treatment can negatively impact survival (Lu et al., 2014). This can often be overlooked in those who are overweight or obese, increasing risk for these individuals (Ryan et al., 2016).

Malnutrition is prominent in those with cancer. In 2019 a global consensus around core diagnostic criteria for malnutrition in adults in clinical settings were released – the GLIM criteria (Cederholm et al., 2019). This criterion consists of 3 phenotypic criteria (non-volitional weight loss, low body mass index, and reduced muscle mass) and 2 etiologic criteria (reduced food intake or assimilation, and inflammation or disease burden). To diagnose malnutrition at least 1 phenotypic criterion and 1 etiologic criterion should be present. Currently available malnutrition data is not always available or comparable, due to the use of different tools e.g. GLIM, Body Mass Index (BMI), Subjective Global Assessment (SGA). Current data suggests rates between 30 and 60% (Pressoir et al., 2010; Hébuterne et al., 2014; Muscaritoli et al.,

2017b; Tobert et al., 2018), but rates can be significantly higher in some cancers e.g. 85% in pancreatic cancer (Poulia et al., 2022). Nutrition impact symptoms (NIS) can occur as a result of the cancer itself or the treatment and include fatigue, dry mouth, sore mouth, pain, gastrointestinal issues, taste and smell changes. These NIS can impact dietary intake, detrimentally impacting nutrition status and weight-loss (Deftereos et al., 2021) as well as survival (Anandavadivelan et al., 2018).

Cancer survivors have their own unique nutrition issues to contend with. NIS, in particular fatigue can persist (Vistad et al., 2007; Jones et al., 2016). Some survivors e.g. breast cancer survivors who undergo chemotherapy can experience weight gain (Gross et al., 2015). This can be due to a combination of changes in dietary habits as well as side-effects of treatment e.g. steroids, chemotherapy-induced menopause, reduced physical activity and cancer-related fatigue (Anderson et al., 2021). Cancer survivors are also more likely to develop cardiovascular disease than the general population (Strongman et al., 2019; Yu et al., 2022). Therefore, a focus on healthy diet and weight management is important in this cohort (World Cancer Research Fund/American Institute for Cancer Research, 2018b).

Nutrition intervention can improve outcomes, reduce length of hospital stays, assist in successful completion of treatment, reduce NIS and improve weight status (Ravasco et al., 2005; Caccialanza et al., 2020; van der Werf et al., 2020; Bargetzi et al., 2021; Prado et al., 2022). Access to nutrition support can positively impact on quality of life in cancer care (Marín Caro et al., 2007; Sonneborn-Papakostopoulos et al., 2021). The importance of nutrition as part of cancer care has been recognised by many international societies with recommendations for nutrition care to guide clinical practice and improve patient outcomes. This includes the American Society of Clinical Oncology (Ligibel et al., 2022), the European Society for Clinical Nutrition and Metabolism (Muscaritoli et al., 2021a) and the American Society of Parenteral and Enteral Nutrition (McKeever, 2021). In addition, cancer survivors are recommended to follow the World Cancer Research Fund (WCRF) recommendations for cancer prevention (World Cancer Research Fund/American Institute for Cancer Research, 2018b).

Despite this, access to nutrition advice for those with cancer is disparate, in part due to a lack of access to dietitians (Irish Nutrition and Dietetic Institute, 2019; Trujillo et al., 2019). The average dietitian-to-patient ratio in oncology outpatient clinics in the United States of America (USA) has been estimated to be 1:2308 (Trujillo et al., 2019); while in Ireland the ratio has

been estimated to be 1:4500 (Irish Nutrition and Dietetic Institute, 2019). In the absence of availability of dietitians, it is important that other HCPs recognise that they have a role to play as nutrition care is a multidisciplinary responsibility (British Association for Parenteral and Enteral Nutrition, 2007). However, despite positive attitudes towards nutrition, research has demonstrated a lack of confidence, knowledge of, and competency to deliver nutrition advice among non-dietetic HCPs (Crowley et al., 2015c; Keane et al., 2021; Conway et al., 2022; Kelly et al., 2022). Those who cannot access nutrition support within the healthcare system will look elsewhere to address this need, often leading to conflicting and unsupported evidence (Sullivan et al., 2021). It is crucial that those living with cancer receive evidence-based, appropriate advice to support them on their cancer journey (Arends et al., 2017).

Patients are experts of their own condition and can help us understand their needs, concerns, and preferences for nutrition support (Karazivan et al., 2015). HCPs can help understand and guide how integration of patients' needs and preferences can be best supported in the clinical setting (Tringale et al., 2022). For these reasons, developing strategies for integrating nutrition into oncology care should include the perspectives of both those living with cancer and HCPs (Kelly et al., 2021).

1.3 Aims and objectives.

The aims of this PhD research are twofold: (1) to contribute towards current knowledge on the provision of nutrition advice to those with cancer; and (2) to develop and pilot an intervention designed to improve provision of nutrition advice in healthcare settings.

The specific objectives are to:

1. Identify current practice and experiences of delivering (HCPs) and receiving (those with cancer) nutrition advice.
2. Assess what nutrition guidelines for cancer survivorship are available to HCPs to guide implementation into practice.
3. Assess what nutrition information is available for patients with cancer and cancer survivors through commonly accessed sources.
4. Devise and evaluate an intervention to address the gaps observed in current practice by aims one to three.

5. Expand the Irish evidence-base to help inform the adaption of the intervention developed in aim 4.

1.4 Thesis structure

This thesis has been undertaken according to the requirements of Ulster University for the award of a PhD by previously published works. The main body of the thesis comprises four distinct, but linked chapters. Each chapter is contextualised and discussed in relation to recent advances in the field. The published studies will be discussed in the context of other literature, as well as any recent advancements in policy and practice at a national, European, and international level.

A PDF of all published papers is included in Appendix 1. A list of additional research published by the candidate during the timeframe (2018-2023) has been included in Appendix 2.

An overview of the research design for this thesis has been included in Figure 1.2.

Aim: 1) to contribute towards current knowledge on the provision of nutrition advice to those with cancer; and 2) to develop and pilot an intervention designed to improve provision of nutrition advice in healthcare settings.

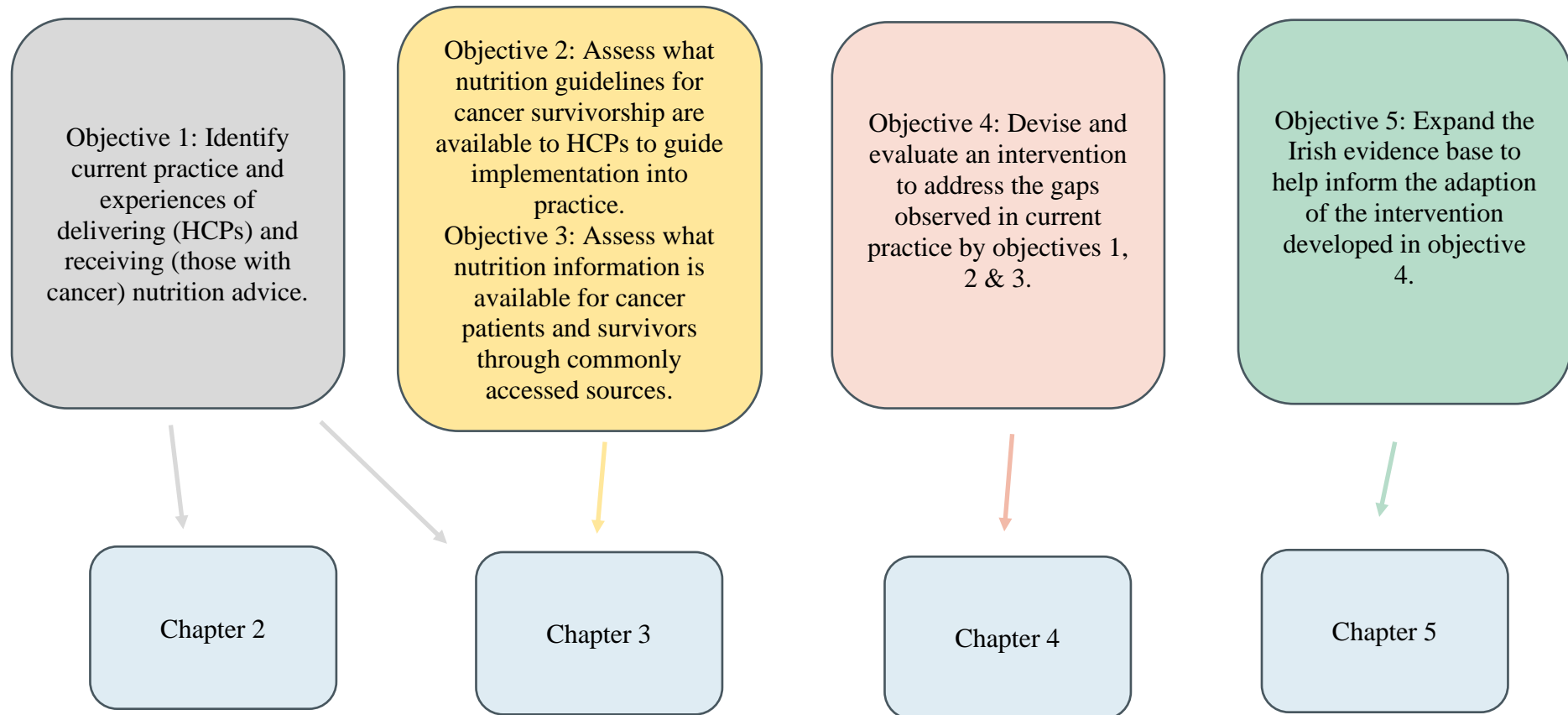


Figure 1.2 Research Design Overview

1.5 Framework

The work presented in this thesis has been viewed through the lens of the Medical Research Council (MRC) framework for the development and evaluation of complex interventions (Figure 1.3) (Skivington et al., 2021). The MRC framework is designed to aid researchers in selecting and applying appropriate methods when developing and evaluating complex interventions (Skivington et al., 2021; Guastafarro and Pfammatter, 2023). The MRC framework advocates for the use of theory and incremental stepped approaches, leading to interventions that are more likely to be successful (Skivington et al., 2021). During evaluation the contributions of different components to the overall effectiveness of the intervention will also be easier to elucidate (Skivington et al., 2021). There are four phases within the MRC framework: development or identification; feasibility; evaluation; and implementation. The work presented in this thesis is set within the development and feasibility phases of the MRC framework. Within each phase there are six common core elements: considering context; developing and refining programme theory; engaging stakeholders; identifying key uncertainties; refining the intervention; and economic considerations (Skivington et al., 2021).

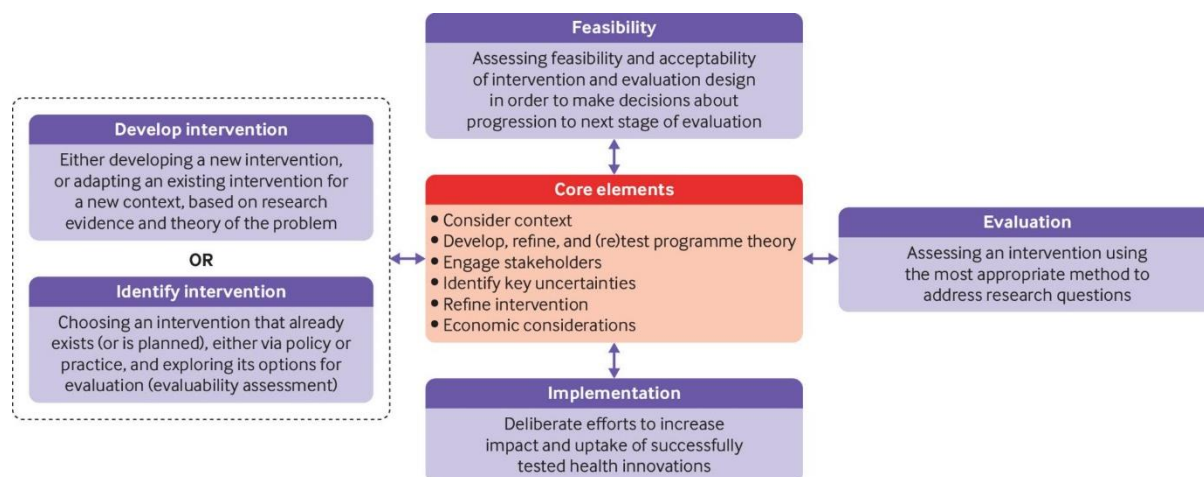


Figure 1.3 MRC framework for developing and evaluating complex interventions (Skivington et al., 2021)

Studies presented in chapters 2, 3 and 4 are situated in the development phase. Specifically, they involve identifying the evidence base; engaging with patients with cancer and cancer survivors, and oncology HCPs; operationalising findings into intervention development; and engaging with stakeholders to determine intervention acceptability.

The pilot study presented in chapter 4 is situated in the feasibility phase, presenting evidence on the acceptability, recruitment, and retention of a novel nutrition intervention (in the USA). Chapter 5 aims to further add to the evidence-base, and the adaption of the nutrition intervention for use in another country (Ireland); therefore, situated in the development phase of the MRC framework. Each chapter has been mapped to the phases of the MRC framework and the relevant MRC core elements in Figure 1.4 below.

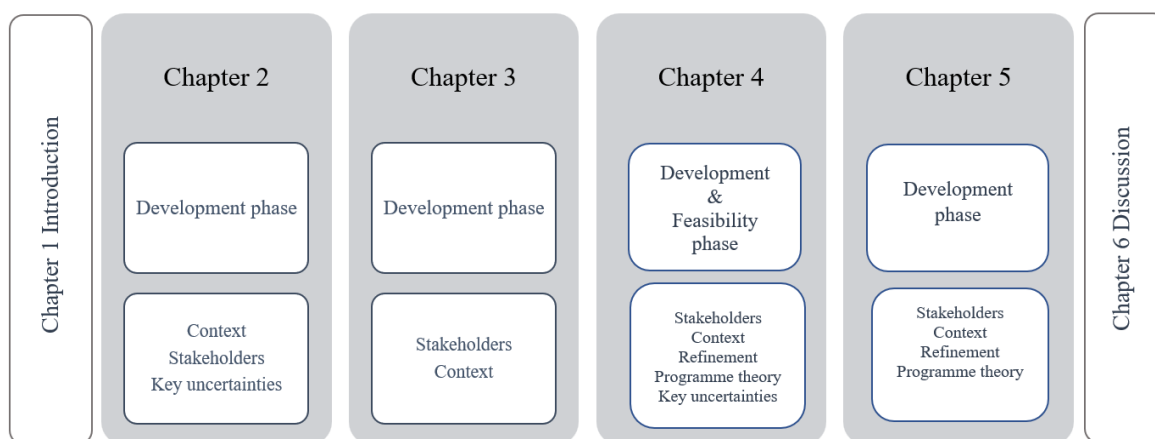


Figure 1.4 Mapping of thesis chapters to MRC framework phase and MRC core elements

Chapter Two: Current practice and experiences of delivering (healthcare professionals) and receiving (those with cancer) nutrition advice

This chapter will explore current practices and experiences of HCPs in delivering nutrition advice and of patients receiving this advice. Publication 1 is a systematic review detailing current research exploring the experiences of HCPs in providing, and of patients receiving nutrition advice in the oncology setting. There was only one Irish study focusing on HCPs that met the inclusion criteria, published in 2021 (included in this chapter). There were no studies on patients' perspectives in an Irish context, therefore prior to the work presented in this section, there was a paucity of Irish data. The remaining papers in this chapter focus on addressing this gap in the literature. Publications 2 and 3 will explore the current practices and experiences of HCPs in providing nutrition advice in: 1) a general hospital setting and 2) an oncology setting. Publications 4 and 5 explored the patient perspective with regard to receiving this advice. From these studies, the internet emerged as one of the key sources of information for patients. As a result, publications 6 and 7 are a comprehensive review of the nutrition information provided online by the Irish healthcare service and cancer support centres and a review of the content of nutrition information provided by apps targeted at those with cancer. Studies presented in this chapter are situated within the development phase of the MRC framework for developing and evaluating complex interventions (Skivington et al., 2021).

2.1 Background

Nutrition has an important role in all aspects of cancer care (Ravasco, 2019). The European Society for Parenteral and Enteral Nutrition (ESPEN) recommends that all cancer patients should be screened regularly for risk, or presence of malnutrition with nutrition intervention recommended (Arends et al., 2017). A 2017 survey of 10 European countries by the European Cancer Patient Coalition found significant gaps in the nutrition care and information provided to patients (Muscaritoli et al., 2019). While all HCPs have a role to play in the delivery of nutrition advice (Adamski et al., 2018; Van Horn et al., 2019), it is dietitians who are trained as experts in assessing, diagnosing and treating nutrition-related problems (Irish Nutrition and Dietetic Institute, n.d.). Dietitians have a key role to play in educating other HCPs in nutrition (Mellor and Ball, 2023). It can be argued that a lack of availability of, and access to dietitians

within healthcare services leads to an inadequate provision of dietary support, and access to personalised and appropriate dietary advice for patients and carers (Beeken et al., 2016; Baguley et al., 2023). These limitations mean that patients who are at risk of malnutrition, or where symptom burden is deemed to be low, are unlikely to receive nutrition advice from a dietitian (Trujillo et al., 2019; Sullivan et al., 2021). Recommendations for best practice exist on the provision of dietary support for cancer patients (Arends et al., 2017). However, at the time of undertaking the research presented in this chapter, there was a lack of evidence describing the provision of nutrition advice by HCPs to those with cancer. There was also a lack of evidence exploring nutrition content available online and easily accessible by those with cancer. This chapter aims to address these gaps.

Aims

The aims of the studies in this section were 1) to determine the current provision of nutrition advice in the oncology setting from both the perspective of the HCPs and patients with cancer, and 2) to determine current availability and quality of nutrition information available online.

Objectives of this section are:

1. to determine current provision of nutrition advice, awareness of guidelines and training needs of HCPs working in the oncology setting,
2. to examine the self-perceived confidence of HCPs in providing nutrition advice,
3. to explore the interest of patients with cancer in nutrition advice at different stages in the cancer trajectory and across tumour groups,
4. to explore current provision of nutrition advice and current sources of information from the viewpoint of those with cancer, and
5. to evaluate the nutrition content and accuracy of websites of national health and cancer agencies, and support groups, as well as digital health applications.

2.2 Publication 1: Experiences of cancer patients in receiving dietary advice from healthcare professionals and of healthcare professionals in providing this advice-a systematic review (2023)

Laura Keaver, Niamh O’Callaghan, Amy E LaVertu, Cherith J Semple, Ciara M Hughes, Jeffrey R Hanna and Lisa Ryan

A systematic review is often undertaken at the start of the research process to inform the direction of the research (Lasserson et al., 2023). In compiling this thesis, I realised that to better support person-centred care, it was important to understand the current situation from the perspectives of both those with cancer, and HCPs. Consequently, a critical synthesis of what was currently known was necessary. The systematic review presented below was undertaken in 2022, after the publication of the papers presented in this thesis and serves as a comprehensive introduction to the topic area within the thesis (Keaver et al., 2023d).

The aim of this systematic review was to better understand the experiences of patients with cancer in receiving dietary information from HCPs, and of HCPs in providing this information (Keaver et al., 2023d). To our knowledge, no other reviews exploring HCP and patient views of nutrition provision in oncology settings have been conducted with this population group. The review protocol was registered in the PROSPERO database for systematic reviews (protocol ID: CRD42022348884). Quality was assessed using the Mixed Methods Assessment Tool (MMAT). The main sources of bias were observed in the quantitative studies, in relation to two aspects; it was not clear if the sample was representative of the target population and the risk of nonresponse bias was not deemed to be low.

Findings from patients indicated a desire for access to nutrition information that is specific, detailed and individualised. Also, nutrition information that matches their beliefs and needs, delivered or supported by a multidisciplinary team using appropriate and understandable language. Alongside this, there is an interest in the role and importance of the dietitian during cancer care being highlighted at diagnosis, or early in the cancer journey.

From HCPs’ perspective, there were beliefs that current practice is predominately medically focused, which can act as a barrier to providing nutrition information. Many HCPs indicated they will not provide nutrition information unless there is a solid evidence base for it, and typically, any advice provided is generic. HCPs highlighted a lack of time, funding, dietetic roles, and knowledge as barriers to providing nutrition advice as a standard part of cancer care.

Conflict between patient beliefs or needs and HCP recommendations, particularly in the case of weight loss was also noted.

There appears to be a lack of advice provided and more barriers to delivering nutrition information in the outpatient setting. Patients accessing services through this route are more likely to be cancer survivors e.g., post-primary or active treatment.

These findings, in addition to the other publications presented in this thesis, have direct implications for the delivery of nutrition information to those with cancer. Understanding the desires of patients and the barriers and facilitators for HCPs will help inform nutrition interventions that will meet the needs of patients while best supporting HCPs. The remaining publications in chapter two aim to address these gaps.

2.3 Publication 2: Providing nutrition care to patients with chronic disease: an Irish teaching hospital healthcare professional study (2018)

Laura Keaver, Ciara O'Meara, Mohsin Mukhtar, Catherine M McHugh

Dietary quality is a significant determinant of non-communicable disease development (Ezzati and Riboli, 2013), and it is reported that more than one-quarter of primary care visits are due to a nutrition-related condition (Kolasa and Rickett, 2010). Therefore, nutrition should be an integral part of all healthcare curricula, and all healthcare providers should be competent in providing at least basic nutrition advice (Adamski et al., 2018). HCPs, and in particular doctors are viewed by patients as a reliable and trusted source of nutrition information (Ball et al., 2014). While doctors report positive attitudes towards nutrition (Mihalynuk et al., 2003; Vetter et al., 2008; Ball et al., 2010), a lack of competency (encompassing knowledge, skills and attitude) and confidence in providing nutrition advice has been noted (Glanz, 1997; Castillo et al., 2016; Perlstein et al., 2016). While the content of medical undergraduate curricula in Ireland had been assessed by an international study (Crowley et al., 2015a), the knowledge, skills and attitudes of doctors in Ireland in the provision of nutrition advice had not. Other HCPs that work within the multidisciplinary team are also well-placed to deliver nutrition advice (Van Horn et al., 2019). However, to date, a lot of research exploring HCPs' knowledge, attitudes and practice in providing nutrition advice and support has predominately focused on specialist areas such as eating disorders (Cordery and Waller, 2006), chronic kidney disease (Munuo et al., 2016) and intensive care units (Lane et al., 2014). The aim of publication 2 was to better understand the current practices of HCPs in providing nutrition advice in a general hospital setting.

This is a descriptive study which utilised the NUTCOMP validated survey-tool (Ball and Leveritt, 2015) to determine the knowledge, skills and attitudes of 200 HCPs in a hospital-setting regarding the provision of nutrition advice and support (Keaver et al., 2018). This tool has good internal consistency ($\alpha=0.98$) and a high test-retest reliability ($r=0.95$) (Ball and Leveritt, 2015).

Fifty-four percent of respondents were nurses/nursing students, 38.8% were doctors/general practitioners (GPs)/medical students, with the remaining 7.1% allied healthcare professionals (AHPs), to include pharmacists, occupational therapists, physiotherapists, and healthcare

assistants. The majority agreed/strongly agreed that there is a need for further nutrition education in their role (78.2%), however it was reported that less than one-third had engaged in any continuing professional development (CPD) opportunities in nutrition. Only 6% reported confidence in their ability to remain updated with recent published peer-reviewed evidence regarding nutrition and chronic disease. There were positive attitudes towards the incorporation of nutrition care into practice, with nurses having a significantly more positive attitude (mean score of 35.9 ± 3.7 out of 40) than other groups (GPs/GP trainees 34.0 ± 3.3 ; doctors/medical students 34.3 ± 4.9 ; AHPs 32.8 ± 4.9) ($p=0.011$). Overall confidence in knowledge was low with no significant differences between groups (mean score $19.6 (\pm 4.8)$ (maximum score 35) with a range of 17.1 ± 6.7 to 20.5 ± 4.7) ($p=0.072$). Confidence in skills was also low with AHPs being significantly less confident (24.2 ± 10.2 out of 55) than the other groups (GPs/GP trainees 30.3 ± 6.6 ; doctors/medical students 30.4 ± 7.0 ; nurses/nursing students 30.7 ± 7.6) ($p=0.029$). Previous nutrition education was positively associated with more confidence in the following key skills: dietary assessment; dietary recommendations; developing appropriate nutrition goals and formulating menu plans.

The findings of this study mirror results found globally (Mihalynuk et al., 2003; Vetter et al., 2008; Crowley et al., 2015b; Crowley et al., 2015c). Prior to undertaking this work, most of the evidence pertained to knowledge, skills and attitudes of HCPs regarding the provision of nutrition advice and support was from New Zealand (Crowley et al., 2015b; Crowley et al., 2015c), Australia (Ball et al., 2010; Ball et al., 2014; Perlstein et al., 2016) and the United States (Kushner, 1995; Mihalynuk et al., 2003; Vetter et al., 2008; Adams et al., 2010). Since publication of this study, there has been evidence emerging from Ireland (Conway et al., 2022; Kelly et al., 2022; Owens et al., 2022).

In a survey conducted with 93 GP trainees and 9 programme directors, participants believed that it is part of their role to promote a healthy diet to their patients (Owens et al., 2022). However, the same study identified there was a lack of nutrition education available within GP training programmes to equip professionals with the appropriate knowledge and skills on how best to provide nutrition advice and support to patients (Owens et al., 2022). The NUTCOMP tool was completed by 447 physiotherapists in another study, with similar findings (Conway et al., 2022). Application of the NUTCOMP tool with 557 pharmacists indicated slightly higher nutrition knowledge and skills than our study's cohort, however a similar percentage (78.1%) felt that they would like further nutrition education to support their role (Kelly et al., 2022). A

recent integrative review, evaluating the competence, knowledge or skills of AHPs in providing nutrition care to patients with chronic disease also reported similar findings (Keane et al., 2021). Together, these studies highlight a need for training and support for HCPs on how best to provide patients with nutrition advice and guidance.

It is not clear why there has been a recent increase in Irish data in this area. The Health Service Executive (HSE) in Ireland introduced the 'Making Every Contact Count (MECC)' brief intervention programme in recent years (Health Service Executive, n.d.,-b). The MECC programme aims to support HCPs in making health behaviour change interventions a routine part of clinical care. The brief interventions are focussed on smoking, alcohol, physical activity, and diet. It could be argued that the introduction of this programme and associated training potentially has impacted on the growing interest around nutrition, lifestyle knowledge and practices of HCPs.

The Association for Nutrition recently launched a curriculum of nutrition suitable for inclusion within medical school programmes in the UK (Association for Nutrition, 2021). There has been less focus on other HCPs in relation to nutrition education in pre-and-post registration curriculums. However, an abstract presented at the Nutrition Society Conference in London in January 2023 reported a lack of nutrition education in HCP training programmes in Ireland (McMonagle et al., 2023). In addition, there is a lack of nutrition education requirements within accreditation standards and curricula for HCPs in Ireland (McMonagle et al., 2023).

While the above publication highlighted a lack of confidence in provision of nutrition advice in a general health-setting, it was important to determine current practice within an oncology-setting to better support the provision of nutrition advice to those with cancer. National and International bodies have highlighted the lack of dietetic resources in the oncology setting (Irish Nutrition and Dietetic Institute, 2019; Trujillo et al., 2019), therefore it is important to determine the current provision of nutrition advice by other HCPs in this setting.

2.4 Publication 3: Providing nutrition advice in the oncology setting: A survey of current practice, awareness of guidelines and training needs of Irish healthcare professionals in three hospitals (2021)

Laura Keaver, Pauline Connolly, Janice Richmond

Shortages of dietitians in the oncology-setting means that it is important that other HCPs have the confidence and knowledge to provide some basic nutrition advice (Erickson et al., 2023). This includes nutrition screening, providing day-to-day nutrition care if needed, and knowing if, how and when to refer to a dietitian for more specialist support (Dwyer, 1986; Aapro et al., 2014; Arends et al., 2017). Publication 2 highlighted how HCPs in a range of specialisms often lack the knowledge and confidence to provide nutrition advice and support to patients (Keaver et al., 2021a). A survey conducted in the UK with oncology clinicians, nurses and AHPs indicated that half (50%) were aware of nutrition-related-guidelines for those with cancer (Williams et al., 2015). Similar findings were found in a survey of Italian oncologists where there was a lack of consideration toward nutrition-issues in cancer care (Caccialanza et al., 2016). In 2017, ESPEN guidelines indicated that a key barrier to the application of guidelines in practice is the relatively low importance still associated with nutrition advice and support in clinical oncology (Arends et al., 2017). Literature highlights that professionals who are aware of available guidelines are more likely to provide lifestyle advice and support to patients (Williams et al., 2015). Therefore, it is important to determine the familiarity of HCPs with nutrition guidelines in the oncology-setting. Publication 3 aimed to determine current nutrition practice of Irish HCPs in the oncology sector and familiarity with nutrition guidelines for those with cancer, a gap at the time in the literature.

The National Institute for Health Research (NIHR) in the UK set up the Cancer and Nutrition Collaboration in 2014. In 2015, the NIHR conducted two surveys reporting on current practices in providing nutrition advice, from both the HCP and patient perspective (National Institute for Health Research, 2015). This collaboration comprised of researchers and clinicians in oncology as well as a patient representative (Murphy et al., 2021). Permission to use the HCP survey from the primary research team was sought and granted.

The survey for publication 3 was conducted across three Irish hospitals in 2018 and 2019 and consisted of three main sections: (1) screening for nutrition needs, (2) assessing nutrition status,

and (3) nutrition training needs of HCPs (Keaver et al., 2021a). There was a section at the end of the questionnaire where respondents could add additional comments about the provision of nutrition advice in cancer care.

Fifty-one oncology HCPs completed the survey (containing both quantitative and qualitative elements) with the majority (>98%) reporting that nutrition was ‘very’ or ‘critically’ important in the management of cancer. Most participants (>70%) reported nutritionally screening inpatients, however less than half nutritionally screened outpatients (43.1%). Awareness of available guidelines was low (<40%). The majority of respondents (86.3%) reported providing nutrition guidance to their patients. Alongside this, most participants (78.4%) were interested in having further training in this area. Thematic analysis identified three themes: (1) awareness of a need for different interventions and advice depending on cancer type and stage; (2) the importance of early intervention and integration into current practice; and (3) a lack of resources.

The findings from the UK HCP perspective were published around the same time as this paper and included 610 HCPs (Murphy et al., 2021). The majority (77%) self-reported providing cancer patients with nutrition advice, yet only 20% reported being completely confident in providing this advice, and only 39% were aware of guidelines (Murphy et al., 2021). These findings are similar to our study (Keaver et al., 2021a).

The result from our study indicating that most HCPs report providing nutrition advice to patients with cancer was surprising, given Irish (Sullivan et al., 2021) and UK (Matsell et al., 2020) data suggesting that only one in three individuals with cancer report receiving nutrition advice. The discrepancy between what is reported by HCPs versus patients was also found in a recent Spanish study assessing nutrition advice and support in routine practice (Sánchez-Sánchez et al., 2023). To better understand this discrepancy, it was important to explore the current situation from the perspective of those with cancer, leading to the next two papers (publications 4 and 5) that will be presented.

2.5 Publication 4: Irish cancer patients and survivors have a positive view of the role of nutritional care in cancer management from diagnosis through survivorship (2021)

Laura Keaver

A cancer diagnosis has been described as a ‘teachable moment’; a time when nutrition is viewed as important, and individuals are more willing to implement change (Demark-Wahnefried et al., 2005; Frazelle and Friend, 2016). These changes include increasing fruit and vegetable consumption, decreasing meat consumption, following a low-fat diet, reducing, or avoiding alcohol (Demark-Wahnefried et al., 2005; Gavazzi et al., 2018). A recent systematic review indicated that these positive dietary changes were mainly small and not necessarily clinically significant (Aldossari et al., 2023). Data from a prospective cohort study in Japan which utilised national data from 1995-1998 as baseline and 2000-2003 as follow up, indicated that these post-cancer dietary changes are no different than changes that occur in those without a cancer diagnosis (Ishii et al., 2023). The Irish Cancer Society’s strategy for 2020-2025 includes ‘Healthy Living’ and ‘Living Well After Treatment’ as two of its five priorities (Irish Cancer Society, 2020); both of which nutrition plays a role in. A recent European congress highlighted the need to improve the nutrition care of cancer patients (European Society for Parenteral and Enteral Nutrition (ESPEN), 2020). It is not clear how patients with cancer view the importance of nutrition in relation to weight and cancer stage. The aim of this paper was to determine the views of patients with cancer with regards the role of nutrition care throughout the cancer journey.

Publication 4 is a brief article that presents the findings of a multi-component questionnaire developed by the research team about the importance of nutrition care in ten different situations (nutrition care is important: for everyone independent of their weight or cancer treatment; when you are receiving any form of active treatment for cancer; when you require surgery for cancer; when you require chemotherapy for cancer; when you require radiotherapy for cancer; when you are in the advanced stages of cancer; when you are a cancer survivor; when you have a low body weight; when you have a normal body weight; and when you are overweight) (Keaver, 2021a). One hundred and ninety-seven individuals across two hospital sites in the North-west of Ireland completed the multicomponent question using a five-point Likert scale from strongly disagree to strongly agree. Nutrition care was viewed positively for all statements with 88.8 to 98.5% agreeing or strongly agreeing with each statement.

Overall, the prevalence of cancer is increasing, as is the number of cancer survivors (in this case defined as five-year net survival) (National Cancer Registry Ireland, 2022). It is clear from this study that people with a cancer diagnosis recognise the importance of nutrition at all stages of the cancer journey. It is imperative that this important aspect of care is recognised by the health service, and nutrition advice and support become a more integrated aspect of cancer care across the cancer trajectory (Erickson et al., 2023). To provide better nutrition care and support in routine practice and to cater for preferred format and timing of information delivery, we need to better understand the issues, needs and preferences of those impacted by cancer. Publication 5 aimed to determine the desired nutrition advice of those with cancer.

2.6 Publication 5: Sources of nutrition advice and desired nutrition guidance in oncology care: patient's perspectives (2023)

Laura Keaver, Janice Richmond, Fiona Rafferty and Pauline Douglas

As highlighted in the findings from publication 4, individuals with cancer have a positive view toward the role of nutrition throughout the cancer experience. The patient experience survey conducted by the NIHR (UK) indicated that 72% of patients reported not receiving nutrition advice and support from their healthcare team (National Institute for Health Research, 2015). A similar percentage (69%) was reported when the survey was disseminated to colorectal cancer survivors in the UK (Matsell et al., 2020). Integration of nutrition into cancer care is lacking across Europe (Hébuterne et al., 2014; Caccialanza et al., 2020; Sonmez et al., 2022; Erickson et al., 2023). A recent study exploring the gaps in the provision of cancer care in Ireland from the patient, carer and HCPs' perspectives identified nutrition as one of six categories, hence a key unmet need for this population (Kelly et al., 2021). However, this study presented a range of themes and lacked depth in exploring nutrition specifically. There was a need to better understand current provision of nutrition care and support in routine practice from the patient perspective, as well as preferred format and timing of nutrition information delivery. The aim of this study was to determine current sources of nutrition advice and desired nutrition guidance of patients with cancer.

Publication 5 involved a cross-sectional survey which used an adapted version of the Patient Experience Survey (National Institute for Health Research, 2015; Keaver et al., 2023e). It was completed by 211 individuals. Most participants were female (n=133, 63%), less than 5-years since diagnosis (n=150, 71.7%) and attending the oncology outpatient department (n=128, 60.7%). Individuals indicated how many nutrition-related issues they were experiencing by ticking all that apply from a list of 14, with the option to add any additional nutrition-related issues experienced. Results indicated that individuals experienced a mean 5 ± 3 nutrition-related issues. Over half of respondents (53.6%) reported being provided with nutrition advice, with 34.1% (n=72) receiving this advice from a dietitian. Less than half of participants (45.5%) believed that their nutrition needs had been met and just one-third (36.5%) felt that the advice they had received was easy to follow. Respondents expressed their desire for nutrition advice and support from a dietitian, which should be individualised, clear and practical. In the absence of nutrition support from the dietitian or other members of the healthcare team, the main

sources of nutrition advice were friends and family, websites, and leaflets. Respondents reflected on the need to avoid misinformation and uncertainty from sources that may be inaccurate or not evidence based.

Similar findings have been reported in the UK (National Institute for Health Research, 2015; Matsell et al., 2020); Europe (Muscaritoli et al., 2017c); New Zealand (Peniamina et al., 2021) and the USA (Trujillo et al., 2019), highlighting the need globally for evidence-based nutrition information for those with cancer.

The lack of access to dietetic expertise was highlighted by the Irish Society for Parenteral and Enteral Nutrition (IrSPEN) around the time this research was being written up and coincided with a publication before this study being accepted for publication (Sullivan et al., 2021). This national study demonstrated that only 39% of cancer patients reported receiving advice from a dietitian, despite a desire and need for this (Sullivan et al., 2021), replicating the data presented in publication 5 (Keaver et al., 2023e).

There is a growing and important role for digital health and increased reliance on the internet as a source of support and information for patients generally as well as in an oncology setting (Abernethy et al., 2022; NHS confederation, 2023). Sullivan et al. (2021), reported 40.6% undertaking self-directed nutrition research, with only 7% of the cohort indicating they had been advised on how to access reliable information online (Sullivan et al., 2021). The internet has been indicated as a primary source of information for those with cancer in other publications also (Hartoonian et al., 2014; Baguley et al., 2023). Therefore, it would be useful to determine and assess the nutrition information currently available through online sources. The next two papers (publications 6 and 7) assessed the nutrition information available online and which were targeted at those with cancer.

2.7 Publication 6: Nutrition guidance for cancer patients and survivors- a review of websites of Irish healthcare and charitable organisations and cancer centres (2020)

Laura Keaver, Helen Callaghan, Leah Walsh and Christine Houlihan

The lack of access to nutrition advice and support from HCPs can lead to individuals sourcing information elsewhere. This includes family, friends, leaflets, and websites (Mullee et al., 2021; Keaver et al., 2023e). Studies have highlighted the internet as a primary source of nutrition advice for those living with and beyond cancer (Mayer et al., 2007; Hartoonian et al., 2014; Baguley et al., 2023). Over 70% of websites providing health information can be classified as poor quality (Eysenbach et al., 2002; Daraz et al., 2019). Despite this, individuals will follow the advice even when uncertain about its reliability (Mullee et al., 2021). Established cancer charities and support groups are the preferred organisations to provide online nutrition information for patients with cancer (Rozmovits and Ziebland, 2004; Matsell et al., 2020). If these are the preferred route, it is important to determine what, if any, nutrition information is available through these organisations, as well as the accuracy, credibility, and readability of this information.

Publication 6 was a cross-sectional review of the availability, quality and readability of nutrition information targeted at patients with cancer, on the main Irish statutory health and cancer-charity organisations websites. Quality was assessed using the International Patient Decision Aid Standards tool (IPDAS) (Coulter et al., 2006), whilst readability was determined using the Flesch–Kincaid Reading Ease Score (FRES) and the Flesch–Kincaid Grade Level Score (FGLS) (www.readabilityformulas.com).

Findings identified thirty-two websites of Irish healthcare organisations, cancer-charity and support-groups (Keaver et al., 2020a). Only five of the websites (15.6%) contained nutrition support for patients with cancer, with three (9.3% of the total sample) containing nutrition advice and guidance for cancer survivors. Only 40% of the websites achieved an acceptable readability level and most lacked practical strategies on how cancer patients and survivors could implement the nutrition advice. There was a lack of advice for those following specific dietary practices such as veganism, with no reference to specific cancer types. Cancer survivors were encouraged to maintain a healthy weight and to follow healthy eating guidelines, with no additional information on how to achieve this. Quality scores varied from 19.5 to 29 out of 40, therefore could be considered of moderate quality.

This study was conducted in 2019, so the availability of, and content on these websites may have changed. It is possible that more individuals are now accessing such websites as the COVID-19 pandemic brought about a shift to accessing support online with less face-to-face contact with HCPs (Atalia. and McQueen., 2021).

Since the publication of this study, there have been comparable studies published. The first was a review of web-based nutrition content from national cancer-organisations, available in Spanish (Llaha et al., 2022). Similar to our findings, the authors report a focus on general healthy eating advice, as well as a lack of information for cancer survivors and for specific cancer types (LLaha et al., 2022). The second paper explored nine national cancer-organisation websites from six English speaking countries (Barrett et al., 2020). Similarly, a focus on general healthy eating advice was found (Barrett et al., 2020) and a need for improvements to meet a universal health literacy standard for all those with cancer. While we found a lack of information for cancer survivors, the Barrett paper reported that eight out of nine websites provided information for cancer survivors (Barrett et al., 2020). This difference may be due to inclusion of national organisations rather than local charity and support groups. In contrast with our findings and those of Llaha et al., (2022) this paper also reported information for specific cancer types on all websites reviewed (Barrett et al., 2020).

Providing clearly targeted advice for specific cancer types is important and more desired than generic information (Keaver et al., 2023e), potentially increasing the likelihood of use. It should be noted that individuals can access any of these websites from anywhere in the world, and so cultural differences should be considered when developing these websites. Alongside this, there was a lack of information on the website for individuals with dietary restrictions, either chosen or medical e.g., vegan, vegetarian, coeliac disease.

In addition to accessing nutrition information through websites, patients with cancer utilise phone applications (apps) (Kempf et al., 2016). The content and quality of nutrition information being accessed is not known. Publication 7 reviewed iPhone and android apps containing nutrition information and targeted at those with cancer to address this gap in the literature.

2.8 Publication 7: A review of iPhone and Android apps for cancer patients and survivors: assessing their quality, nutrition information and behaviour change techniques (2021)

Laura Keaver, Amy Loftus and Laoise Quinn

Both the Institute of Medicine and the American Society of Clinical Oncology have proposed utilising mobile health technologies to improve healthcare quality (Institute of Medicine, 2011; Kris et al., 2011). Diet apps have been shown to improve dietary quality, specifically, increasing intake of fruit and vegetables (Scarry et al., 2022). However, the studies in the review did not include patients with cancer or cancer survivors (Scarry et al., 2022). Apps have the potential to improve healthcare and support dietetic practice (Chen et al., 2018). Currently the Irish healthcare service does not promote any apps for those with cancer and therefore, it is up to each individual to locate, evaluate and choose to follow their preferred app.

There have been several recent publications which have outlined methodological limitations with current cancer-related phone apps (Böhme et al., 2018; Charbonneau et al., 2020). A review of apps targeted at those with cancer identified 41 applications with almost half being classified as deficient or insufficient, due to poor rating around information sources and data protection (Böhme et al., 2018). The mobile app rating system (MARS) which was developed to assess the content of cancer apps identified that 60% of reviewed apps were rated as poor and insufficient (Böhme et al., 2019). A content analysis of apps available for cancer located 123 apps with the majority containing general information, and only 3% of the content evaluated by a HCP (Charbonneau et al., 2020).

The work presented in 2.7 indicated a lack of practical strategies for implementation of nutrition advice into practice. Behaviour change techniques (BCTs) are active components within interventions designed to change behaviour which could be useful in this regard (Michie et al., 2015). A review of the BCTs in breast cancer apps found very few focussed on behaviour change (Kalke et al., 2020). No previous work had looked specifically at nutrition content within these apps, in terms of content, quality or BCTs used, therefore publication 7 set out to address this gap in the literature (Keaver et al., 2021b).

Publication 7 determined the overall quality, nutrition information provided, and use of BCTs of iPhone and android apps targeted at those with cancer. It also compared the nutrition content

present to current ESPEN (Muscaritoli et al., 2021a) and WCRF (World Cancer Research Fund/American Institute for Cancer Research, 2018b) guidelines.

The Apple App Store and Androids' Google Play for apps were searched using the following terms: nutrition, diet, food, supplement, food safety, weight-management, nutrition recommendations, nutrition guidelines and nutrition-impact-symptoms. These words were combined with cancer and oncology to minimise irrelevant results. Twelve apps (from an initial 1149) met the inclusion criteria (English-language; aimed at cancer patients and/or survivors; free to download; and included nutrition advice). Mean accountability score using Silberg's standards was 2.7/8 (± 2.0 , range 0-6) (Silberg et al., 1997). Mean quality score using MARS was 2.9/5 (± 0.6 , range 1.7-3.7) (Stoyanov et al., 2015). These were deemed to be of moderate quality overall with nutrition content mainly focussing on healthy eating and meeting energy needs. Lack of strategies for implementation was noted and there was no reference as to the appropriateness of information for different cancer types, treatments, and stages. Only half of the apps ($n=6$) referred to the importance of a dietitian or HCP as a source for additional advice. Eleven BCTs were included, with four predominantly used (provide information on consequences of behaviour in general; provide information on consequences of behaviour to the individual; prompt self-monitoring of behavioural outcome; and stress management/emotional control training). A strong positive relationship between quality of the app and number of BCTs was found, $r=.805$, $n=9$, $p=0.01$. There was limited reference to ESPEN or WCRF guidelines with one-third of apps containing no information present in these guidelines. Half the apps contained information that could be harmful. Unfortunately, the 'Treatment of Cancer (Advertising) Bill' which was initiated in Ireland to protect cancer patients from false claims including dietary misinformation in 2019, not only did not extend to apps, but it was dissolved in 2020 with the dissolution of the Dáil and the Seanad (Oireachtas, 2018).

No further work has been published assessing the appropriateness of nutrition content within apps aimed at those with cancer since completion of this work. This work was completed in 2020 and given the fast-evolving world of technology it is likely that there are additional apps with different content available today.

2.9 Conclusion

This chapter explored the current provision of nutrition advice in the oncology healthcare setting, online and in phone apps. In summary, HCPs in general and oncology settings have low awareness of guidelines and lack confidence in providing nutrition advice. Guidance is particularly absent in the outpatient setting, with this being more likely to affect cancer survivors. Patients with cancer have a desire and need to receive advice and an awareness of the importance of nutrition at all stages including survivorship. Currently, available information online and in phone apps can lack an evidence-base, as well as practical strategies for implementation. Given the lack of advice provided and available for cancer survivors, the next chapter will focus specifically on exploring current practices and needs in this cohort.

Chapter Three: Focus on cancer survivorship

The findings of chapter 2 indicated a consistent lack of access to evidence-based nutrition advice available for HCPs and patient populations, with a particular lack of advice available for cancer survivors. HCPs were less likely to provide guidance in an outpatient oncology-setting, especially in post-treatment clinics. HCPs also reported a lack of awareness of specific guidelines for nutrition for cancer survivors. When reviewing available content on the websites of cancer charities and the healthcare service, as well as apps, there was a paucity of nutrition information for cancer survivors. Chapter three will present two papers and one conference abstract that focussed specifically on cancer survivorship, exploring (i) the availability of nutrition guidelines for HCPs to help guide the provision of nutrition advice to cancer survivors; (ii) the nutrition needs (presence of NIS and weight-changes) of cancer survivors and (iii) the availability of nutrition information online for cancer survivors. Studies presented in this chapter are situated within the development phase of the MRC framework for developing and evaluating complex interventions (Skivington et al., 2021).

3.1 Background

As screening, detection and treatment of cancer improves so too does the number of individuals surviving cancer. The five-year survival for some cancers (breast and prostate) in Ireland is over 80%, with five-year survival for all invasive cancers at 62% (Mullen and Hanan, 2019). Survivorship brings with it its own unique nutrition needs and challenges (Grunfeld and Earle, 2010; Link et al., 2022). These needs have not been well explored.

Two recent studies (one from Ireland), exploring nutrition provision for adult cancer survivors reported that those who received information found it largely generic, with little input from dietitians and limited follow-up and support (Johnston et al., 2021; Sullivan et al., 2021). These studies reported a requirement for more individualised advice on elements of a healthy diet, in particular, practical support in changing dietary behaviour (Johnston et al., 2021; Sullivan et al., 2021). It should be noted that the definition of cancer survivor used in the Irish study (anyone with a cancer diagnosis) (Sullivan et al., 2021) is different from our own (those who have completed active treatment and are not palliative).

The WCRF recommends that all cancer survivors should receive nutrition care from an appropriately trained HCP (World Cancer Research Fund/American Institute for Cancer Research, 2018b). Also, HCPs have been identified by patients as the preferred source of information, followed by leaflets and the internet (Sheehy et al., 2018). However, cancer survivors report feeling that HCPs are too busy to provide adequate support, leading to important issues not being addressed (Sheehy et al., 2018). Previously published research on Irish breast cancer survivors reported that only 59% of cancer survivors felt they had received information that met their nutrition needs (Droog et al., 2014).

To better understand how these nutrition needs can be met, nutrition-related-issues which cancer survivors experience should be determined, something previously not explored in an Irish-context. This will help inform the development of interventions that meet survivors needs, leading to improvements in health and quality-of-life (O'Connor and Donnelly, 2019).

HCPs show a lack of awareness of guidelines (Keaver et al., 2021a) making it more difficult for them to determine current best practices. Therefore, an exploration of the guidelines around nutrition and cancer survivorship for HCPs in Europe is warranted.

Unfortunately, a lack of provision of nutrition advice from HCPs, has led cancer survivors to obtain guidance elsewhere, often turning to online sources (Matsell et al., 2020). Research has shown that survivors often access information online that is not evidence-based (Beeken et al., 2016; Ebel et al., 2017). A study looking at dietary changes in global breast cancer survivors found that internet searching was the primary source of nutrition information (Keaver et al., 2021c). It was necessary therefore to explore online websites that cancer survivors are likely accessing to determine their credibility and accuracy.

Aim

The overall aim of the work presented in this section was to identify ongoing nutrition-issues for cancer survivors, availability and quality of nutrition information and related guidelines for HCPs.

Objectives

The objectives of this section are:

1. to identify what guidelines are available for the nutrition management of cancer survivors which is targeted at HCPs in Europe,
2. to explore persistence of NIS and nutrition-related-issues in a cohort of Irish cancer survivors,
3. to determine the nutrition content and accuracy of global websites that can be accessed by cancer survivors.

3.2 Publication 8: Evidence-based nutrition guidelines for cancer survivors in Europe: a call for action (2022)

Laura Keaver, Christine Houlihan, Niamh O’Callaghan, Amy E. LaVertu, Xinge Ding and Fang Fang Zhang

The unmet needs of cancer survivors report by the National Cancer Registry highlighted the need for increased information from HCPs to guide high-quality evidence-based care (O’Connor and Donnelly, 2019). A recent scoping review reported that cancer survivors prefer to receive nutrition advice through direct communication with HCPs and for this advice to be specific rather than generic (Johnston et al., 2021). Therefore, it was prudent to determine what guidelines were available to HCPs to help inform nutrition discussions with cancer survivors. At the time of the study, there was a lack of reviews of nutrition guidelines available for cancer HCPs.

Publication 8 is a meta-epidemiological study that located and documented currently available guidelines aimed at HCPs and including information on the nutrition management of cancer survivors in Europe (Keaver et al., 2022a). A comprehensive search using four strategies (databases, contacting European bodies in cancer research, cancer agency website search, and national cancer societies) was undertaken. Quality was determined using the AGREE-II instrument (Brouwers et al., 2010).

Five guidelines were suitable for inclusion, one high-quality (Arends et al., 2017), two acceptable-quality (Arends et al., 2015; World Cancer Research Fund/American Institute for Cancer Research, 2018b) and two low-quality (Barnadas et al., 2018; de Las Peñas et al., 2019). Regarding nutrition advice, the guidelines were generally in agreement with each other and tended to focus on current cancer prevention recommendations e.g. the promotion of fruits, vegetables and fibre while limiting intake of red and processed meat (World Cancer Research Fund/American Institute for Cancer Research, 2018b). Weight management was referred to by all guidelines, however, there was a lack of specific information or practical strategies for implementing these guidelines. The European guidelines are similar to the USA guidelines which I am currently involved in reviewing (Li et al., 2023).

While cancer survivors prefer specific advice and practical skills to implement change, at the time of publication available guidelines for HCPs do not equip them in providing this. Around

the same time as this publication, ESPEN published a practical version of their guideline on nutrition in cancer patients (Muscaritoli et al., 2021a). Flowcharts were used to support the implementation of nutrition support into practice for HCPs (Muscaritoli et al., 2021a). While this is a step in the right direction, it does not address the lack of nutrition knowledge nor the lack of time for HCPs to provide guidance, as highlighted in the previous two chapters.

In addition to the above barriers to providing nutrition advice to cancer survivors, a lack of data around the persistence of nutrition-related-issues in cancer survivorship could hinder the provision of specific nutrition information to cancer survivors. Publication 9 aimed to address this gap in the literature.

3.3 Publication 9: Nutrition and weight related issues in Irish cancer survivors indicate a need for provision of nutrition advice and intervention from credible sources (2022)

Laura Keaver, Niamh O'Callaghan and Pauline Douglas

The majority of research exploring NIS in those with cancer has been undertaken during the acute or treatment phase or within three months of completing treatment (Crowder et al., 2018; de Pinho et al., 2020; Viana et al., 2020). These studies also tend to be undertaken in those with head and neck cancer (Crowder et al., 2018; Jin et al., 2021). There is one study in gynaecological cancer patients which found fatigue and pain still persisting up to 12 months post-treatment (Croisier et al., 2022). There is a lack of other data on the chronic persistence of many NIS, therefore reducing the ability of HCPs to provide specific nutrition advice. The aim of this study was to determine the presence of persisting nutrition-issues in a heterogenous group of cancer survivors.

Publication 9 presents a sub-analysis of data collected as part of a larger exploration of the nutrition-related life of Irish cancer survivors (Keaver et al., 2022c). This was an online questionnaire which explored demographic, clinical and nutrition characteristics; and utilised three validated questionnaires to determine dietary intake (Cleghorn et al., 2016), food choice (Steptoe et al., 1995) and satisfaction with food related life (Grunert et al., 2007). The analysis presented here focussed on the reporting of (i) current nutrition-related-issues; (ii) proportion receiving nutrition advice from a dietitian and (iii) additional sources of nutrition advice.

The majority of the 169 participants were female (85.8%), breast cancer survivors (64.5%) and had completed active treatment in the last five years (59.9%). One-third had experienced weight-gain in the last six months. Fatigue was still persistent in the majority (76.3%), with other NIS also persisting (pain – 36.1%; constipation – 33.1%; dry mouth- 26%; diarrhoea – 16.6%; no appetite – 13.4%; sore mouth -12.4%; taste changes -12.4% and smells bothering them – 10.7%). Just under 12% (11.8%) reported access to a dietitian post-treatment, with 20.7% having access during treatment. This was much lower than the 39% reported by the 2021 national survey of cancer survivors (Sullivan et al., 2021). This may be due to the difference in the definition of cancer survivor between our study (those who had completed active treatment and were not receiving palliative care) and that of Sullivan et al. (2021) (anyone with a cancer diagnosis in the last five years). One-quarter reported undertaking self-directed nutrition research; mainly online.

Just after data collection for this study began, a conference abstract was published which collected similar data on 76 Irish cancer survivors (at least one-year post-treatment) (Timon and Doyle, 2020). The majority were also female (89%); however, cancer type was not reported. The majority (65%) were still facing nutrition-issues as a result of treatment, yet 74% had not received any post-treatment nutrition support. There was a desire for practical support on how to achieve recommended guidelines. In terms of support, 66% indicated a preference for booklets or leaflets, with 88% interested in an interactive online tool.

There have been two subsequent papers on Irish Cancer Survivors published in 2022 by a Master's student I supervised and co-authored. The first of these reported on further findings from the same cohort (O'Callaghan et al., 2022). Open-ended questions from the survey highlighted an awareness of the importance of nutrition by cancer survivors and a desire for individualised advice and dietetic referral. In particular, the continuing impacts of treatment and struggles with weight gain were reported (O'Callaghan et al., 2022). The second paper was a qualitative exploration of the topic of nutrition with 20 Irish cancer survivors (five semi-structured focus groups and two individual interviews) (O'Callaghan et al., 2023). Findings indicated a lack of guidance from HCPs, a desire for this to change, and an indication that the experience of surviving cancer brought about a re-evaluation of current health behaviours and a move towards healthier habits (O'Callaghan et al., 2023).

There are no specific guidelines for HCPs on the management of NIS, instead, they tend to be referred to within current guidelines, but with little depth. For instance, the ESPEN guidelines highlight the need for objective and quantitative management of NIS and note that addressing these may improve quality of life, however, the specific management is not discussed (Muscaritoli et al., 2021a).

The papers presented in this section have indicated a lack of guidance being provided by dietitians and HCPs to cancer survivors. This suggests that alternative sources of nutrition advice should be assessed to determine their quality, accuracy, and appropriateness. Publication 10 explores the availability of online nutrition information for cancer survivors.

3.4 Publication 10: Online nutrition information for cancer survivors (2023)

Laura Keaver, Michaela Deane Huggins, Doireann Ni Chonail, Niamh O'Callaghan

A recent scoping review exploring the needs, preferences, and experiences of adult cancer survivors in accessing dietary information post-treatment indicated a lack of professional-led nutrition support, hence unmet needs leading cancer survivors to seek information elsewhere (Johnston et al., 2021). However, difficulty with identifying credible sources was a concern. A global survey of 315 breast cancer survivors reported that the majority (74.9%) used internet searches as their main source of nutrition advice (Keaver et al., 2021c). The aim of the next publication was to determine the content and credibility of nutrition advice that cancer survivors would likely access when undertaking a typical internet search for information.

Publication 10 is a systematic evaluation of the websites that are found in six-English speaking countries using search terms developed by cancer survivors and experts (Keaver et al., 2023b). Initially 720 links were located with 159 of these eligible for inclusion. Readability was assessed using the Flesch–Kincaid Reading Ease Score (FRES) and the Flesch–Kincaid Grade Level Score (FGLS)(www.readabilityformulas.com). Usability was determined using the Health Communication and Health Information Technology tool (Devine et al., 2016).

One-third of the included websites had nutrition content. Most nutrition information was only found when the whole website was reviewed. Given that the average time spent on a website is 47 seconds, it is unlikely even when present, that cancer survivors will locate the nutrition information available (Contentsquare, 2023). The advice was generic, focused on the importance of maintaining a healthy weight, lacked practical strategies for implementation and had limited guidance on how to deal with persistent NIS. Some websites/links also contained inaccurate information. Overall, quality score was low (IPDAS mean score=20.4/40), with medical/healthcare/education type websites and pages having the lowest scores. Disclosure of sources of information was particularly low. Readability and usability scores often did not meet benchmarks.

This work identifies areas for improvement when providing online information for cancer survivors. It also provides information on the typical search terms that cancer survivors utilise when trying to find nutrition advice (Appendix 3), therefore reliable sites could use this to update their search terms and ensure that they can be easily located by cancer survivors. This

is important as cancer survivors struggle to differentiate between evidence-based and non-evidence-based websites (Heiman et al., 2018). Despite only recently being published, publication 10 has been cited three times in the literature to date (Keaver et al., 2023b).

3.5 Conclusion

This chapter explored the availability of guidelines for HCPs, the nutrition needs of cancer survivors and the availability of nutrition information online for survivors. Irish cancer survivors experience a lack of access to dietetic and nutrition advice and a persistence of NIS into survivorship. Online sites which cancer survivors are likely to encounter if undertaking self-directed research contained very little nutrition guidance. Any nutrition advice that was present typically provided the WCRF recommendations (World Cancer Research Fund/American Institute for Cancer Research, 2018b) with no indication of how to achieve these. There is currently a lack of guidelines for HCPs around nutrition and cancer survivorship and little guidance on how best to implement those which are available into practice. There is a clear need for a nutrition intervention which will meet the needs of both survivors and HCPs. The next chapter will outline the development and feasibility testing of a nutrition intervention developed to assist in the integration of nutrition in standard cancer survivorship care.

Chapter Four: Development and testing of a nutrition intervention

Chapter three outlined a clear need for evidence-based nutrition guidance that can be provided to cancer survivors. The lack of confidence, knowledge, and awareness of nutrition guidelines for HCPs outlined in chapter three also needs to be addressed. Chapter four presents two papers outlining the development and evaluation of a nutrition intervention designed to be implemented into oncology-care. The resources developed as part of the nutrition intervention have been included in Appendix 4. Publication 11 is situated within the development phase of the MRC framework for developing and evaluating complex interventions, while publication 12 is situated in the feasibility phase (Skivington et al., 2021).

4.1 Background and rationale

Nutrition needs throughout the cancer journey are not static but constantly changing, therefore individuals need to be regularly assessed to determine appropriate nutrition advice (Arends et al., 2017). Malnutrition can occur, continue or worsen, during cancer and treatment, with muscle mass in particular being affected (Muscaritoli et al., 2021b). There can be complex nutrition issues depending on cancer type and stage (Hébuterne et al., 2014; Muscaritoli et al., 2017b). Side effects of treatment can further exacerbate nutrition issues (Henry et al., 2008; Pearce et al., 2017). Where nutrition issues are not addressed and, or where poor nutrition practices occur, the prevalence of undernutrition increases (Aapro et al., 2014; Muscaritoli et al., 2017b). The severity of NIS also worsens, and the likelihood of infection and mortality increases (Aapro et al., 2014). Often during survivorship, the focus moves to prevention of weight-gain and reducing the risk of cardiovascular disease and other non-communicable diseases (Altena et al., 2021; Anderson et al., 2021; Yu et al., 2022). Chapter three highlighted the persistence of several NIS into survivorship. Nutrition interventions can help manage weight, address NIS and improve quality-of-life in those with cancer (Heber and Li, 2016).

Aim

The aim of this section was to develop and pilot a nutrition intervention (NutriCare) designed to be integrated into oncology care for cancer survivors. This work was carried out in collaboration with Tufts University in Boston.

Objectives**The objectives of this section are:**

1. to develop a nutrition intervention for cancer survivors,
2. to explore the views of HCPs working in the oncology setting and cancer survivors regarding a nutrition intervention designed using the 5-A model (NutriCare),
3. to evaluate the feasibility and effectiveness of the NutriCare intervention in a pilot trial.

4.2 Publication 11: Perceptions of oncology providers and cancer survivors on the role of nutrition in cancer care and their views on the “*Nutricare*” programme (2020)

Laura Keaver, Ioanna Yiannakou, Sara C. Folta, Fang Fang Zhang

The National Cancer Strategy 2017-2026 emphasised that person-centred care is widely recognised as best practice and that individuals with cancer must be provided with appropriate information to make informed decisions (Department of Health, 2017). It is important when integrating change or developing interventions to get end-user perspectives (Yardley et al., 2015). The aim of this paper was to describe the intervention development process and to obtain insights from cancer survivors and HCPs on the *Nutricare* intervention.


Interventions that utilise a behaviour change framework or theory have been shown to be more effective at changing health behaviour (Glanz and Bishop, 2010; Kelly and Barker, 2016). The 5-A model is a tool that is person-centred and can be implemented in 10 minutes, allowing for integration into most appointments (Rao, 2010; Sherson et al., 2014). The 5 A’s can sometimes change depending on the definition used, however, this work has utilised that recommended by the United States Public Health Service - Ask, Advise, Assess, Assist and Arrange (Fiore, 2000). It has been shown that two of the ‘As’ in particular, assistance in problem solving and arranging follow-up support are important for producing meaningful and lasting behaviour change (Laddu et al., 2021). This model has previously been utilised in the oncology setting to promote smoking cessation (Schnoll et al., 2003; Simmons et al., 2012).

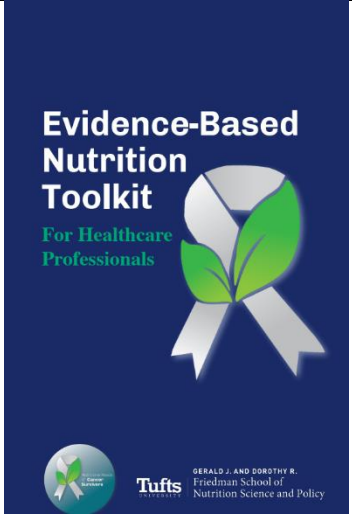
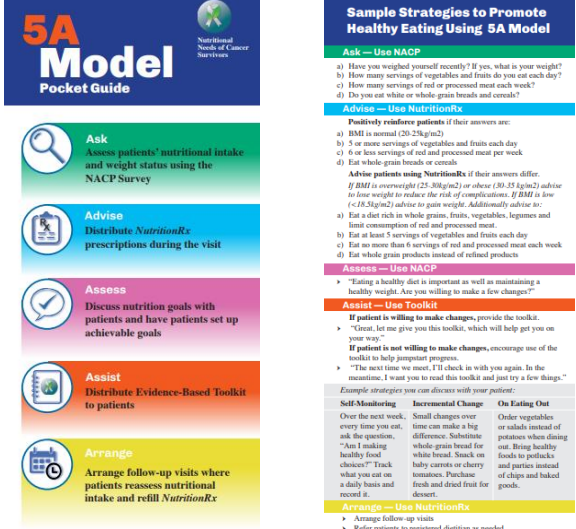
The *Nutricare* intervention was designed by a multidisciplinary team utilising the 5-A model (Keaver et al., 2020b). The content was designed to be useful at all stages of the cancer journey with HCPs being able to direct individuals to the most appropriate information at each visit. A flowchart outlining the five stages of the *Nutricare* intervention has been outlined in Figure 4.1 with additional information on the resources in Table 4.1. These resources have been included in Appendix 4.



Figure 4.1 *Nutricare* intervention flowchart

Table 4.1 Resources developed as part of the *Nutricare* intervention

Resource	Image	Content	Key references in development																																																																																																																																																																																																																																																																																																																																																								
<p>Nutrition Assessment for Cancer Patients (NACP) survey</p>	<p>Nutrition Assessment for Cancer Patients (NACP) Survey Please check the box that best describes your current symptoms and eating habits</p> <table border="1"> <thead> <tr> <th colspan="4">In the Past Three Months, Have You Experienced Unexpected?</th> <th colspan="4">Measurements (to be taken by your healthcare practitioner)</th> </tr> <tr> <th colspan="2">Weight loss</th> <th colspan="2">Weight gain</th> <th colspan="2">Weight</th> <th colspan="2">BMI:</th> </tr> <tr> <th>Yes</th> <th>No</th> <th>Yes</th> <th>No</th> <th></th> <th></th> <th></th> <th></th> </tr> <tr> <th>O</th> <th>O</th> <th>O</th> <th>O</th> <th></th> <th></th> <th></th> <th></th> </tr> </thead> <tbody> <tr> <td colspan="4">Usual/ Often</td> <td colspan="4">Rarely/ Never</td> <td colspan="4">Does not apply to me</td> </tr> <tr> <td colspan="8">In an Average Week, How Often Do You Experience:</td> <td colspan="4"></td> </tr> <tr> <td colspan="8">1. Nausea</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">2. Vomiting</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">3. Poor appetite</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">4. Craving for certain foods</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">5. Change in taste preference</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">6. Sore mouth</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">7. Dry mouth</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">8. Chewing and swallowing difficulty</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">9. Constipation</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">10. Diarrhoea</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">11. Fatigue</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">In an Average Week, How Often Do You:</td> <td colspan="4"></td> </tr> <tr> <td colspan="8">12. Eating less than 2 1/2 servings of vegetables a day? 1 Serving = 1/2 cup vegetables, or 1 cup leafy raw vegetables</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">13. Eat less than 2 servings of fruits a day? 1 Serving = 1/2 cup or 1 med. fruit or 1/4 cup 100% fruit juice</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">14. Eat less than 3 servings of whole grains a day? 1 Serving = 1 slice of 100% whole grain bread OR 1 cup whole grain cereals or oatmeal OR 1/2 cup brown rice or whole wheat pasta</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">15. Eat or drink less than 3 servings of milk, yogurt, or cheese a day? 1 Serving = 1 cup milk or yogurt, 1 1/2 - 2 ounces cheese</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">16. Eating more than 6 serving of cooked red meats a week? 1 Serving = the size of a deck of cards or ONE of the following: 1 regular hamburger or 1 pork chop</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">17. Eat any processed meats (like bologna, salami, corned beef, hotdogs, sausage or bacon) in a week?</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">18. Eat less than 8 servings of fish or seafoods a week? 1 Serving = the size of a checkbook</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">19. Eat less than 4 servings of nuts and seeds a week? 1 Serving = a handful of nuts and seeds</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">22. Drink 16 ounces or more of non-diet soda, fruit drink/punch or Kool-Aid a day? Note: 1 can of soda = 12 ounces</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">23. Drink more than 1 alcoholic drink a day (for women) or more than 2 alcoholic drinks a day (for men)? Note: 1 drink = 12 oz. beer, 5 oz. wine, one shot of liquor</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">24. Eat 4 or more meals from take-out restaurants a week?</td> <td colspan="4">O O O O</td> </tr> <tr> <td colspan="8">25. How willing are you to make changes in your eating habits in order to be healthier?</td> <td colspan="4">1 2 3 4 5 Not at all willing Very willing</td> </tr> </tbody> </table>	In the Past Three Months, Have You Experienced Unexpected?				Measurements (to be taken by your healthcare practitioner)				Weight loss		Weight gain		Weight		BMI:		Yes	No	Yes	No					O	O	O	O					Usual/ Often				Rarely/ Never				Does not apply to me				In an Average Week, How Often Do You Experience:												1. Nausea								O O O O				2. Vomiting								O O O O				3. Poor appetite								O O O O				4. Craving for certain foods								O O O O				5. Change in taste preference								O O O O				6. Sore mouth								O O O O				7. Dry mouth								O O O O				8. 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Brief food frequency questionnaire. How willing the individual is to change their behaviour (scale of 1-5). Colours used to indicate priority areas – appropriate nutrition advice to be provided by the HCP can then be sourced in the HCP toolkit. 	<p>(Gans et al., 2006; Gosain and Miller, 2013; Coa et al., 2015).</p>
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<p>NutritionRx prescription pad</p>	<p style="text-align: right;"><i>NutritionRx®</i></p> <p>Patient Name: _____ Date: _____</p> <hr/> <p>Achieve or maintain a healthy weight Eat a diet rich in whole grains, vegetables, fruits, and beans Limit consumption of fast-foods and other processed foods Limit consumption of red and processed meat Limit consumption of sugar sweetened drinks Limit alcohol consumption Aim to be physically active</p> <p>Small changes over time can make a big difference. Please refer to the <i>Evidence-Based Nutrition Toolkit for Cancer Survivors</i> for further information on the above recommendations and tips on how to achieve your goals.</p> <p> My goals: _____</p> <hr/> <p>Next Appointment: _____ Healthcare Provider: _____</p>	<ul style="list-style-type: none"> WCRF guidelines. My goals (to be developed with the clinician/HCP using Specific, Measurable, Achievable, Realistic and Timely (SMART) goals). Reference to the patient toolkit. 	<p>(World Cancer Research Fund/American Institute for Cancer Research, 2018b).</p>																																																																																																																																																																																																																																																																																																																																																								

<p>HCP toolkit</p>	 <p>Evidence-Based Nutrition Toolkit For Healthcare Professionals</p> <p>GERALD J. AND DOROTHY R. Friedman School of Nutrition Science and Policy</p>	<ul style="list-style-type: none"> • What HCPs need to know about nutrition and cancer survivorship. • The 5-A model <p><u>Ask</u> – information on the NACP survey. <u>Advice</u> – information on the <i>NutritionRx</i>. <u>Assess</u>- guidance on goal setting. <u>Assist</u> – information on treatment related side-effects, weight management, healthy eating and active living. Also reference to the patient toolkit. <u>Arrange</u> – arrange follow-up visits.</p> <ul style="list-style-type: none"> • More evidence-based nutrition resources. 	<p>(Rock et al., 2012; Kassianos et al., 2015; Zhang et al., 2015; Schwedhelm et al., 2016; Arends et al., 2017; Terranova et al., 2018; World Cancer Research Fund/American Institute for Cancer Research, 2018b).</p>						
<p>5-A pocket guide</p>	 <p>5A Model Pocket Guide</p> <p>Ask Assess patients' nutritional intake and weight status using the NACP Survey</p> <p>Advise Distribute <i>NutritionRx</i> prescriptions during the visit</p> <p>Assess Discuss nutrition goals with patients and have patients set up achievable goals</p> <p>Assist Distribute Evidence-Based Toolkit to patients</p> <p>Arrange Arrange follow-up visits where patients reassess nutritional intake and refill <i>NutritionRx</i></p> <p>Sample Strategies to Promote Healthy Eating Using 5A Model</p> <p>Ask — Use NACP</p> <p>a) Have you weighed yourself recently? If yes, what is your weight? b) How many servings of vegetables and fruits do you eat each day? c) How many servings of red or processed meat each week? d) Do you eat whole or whole grain breads and cereals?</p> <p>Advise — Use NutritionRx</p> <p>Positively reinforce patients if their answers are: a) BMI is normal (20-25kg/m²) b) 5 or more servings of vegetables and fruits each day c) 0 or low servings of red and processed meat per week d) Eat whole grain breads or cereals</p> <p>Advise patients using <i>NutritionRx</i>, if their answers differ: If BMI is overweight (25-30kg/m²) or obese (30.5-35kg/m²), advise to lose weight to reduce the risk of complications. If BMI is low (<18.5kg/m²) advise to gain weight. Additionally advise to:</p> <p>a) Eat a diet rich in whole grains, fruits, vegetables, legumes and limit consumption of red and processed meat. b) Eat at least 5 servings of vegetables and fruits each day c) Eat no more than 6 servings of red and processed meat each week d) Eat whole grain products instead of refined products</p> <p>Assess — Use NACP</p> <p>• "Eating a healthy diet is important as well as maintaining a healthy weight. Are you willing to make a few changes?"</p> <p>Assist — Use Toolkit</p> <p>If patient is willing to make changes, provide the toolkit. • "Great, let me give you this toolkit, which will help get you on your way." If patient is not willing to make changes, encourage use of the toolkit to help jumpstart progress. • "The next time we meet, I'll check in with you again. In the meantime, I want you to read this toolkit and just try a few things." Example strategies you can discuss with your patient:</p> <table border="1"> <thead> <tr> <th>Self-Monitoring</th> <th>Incremental Change</th> <th>Go Eating Out</th> </tr> </thead> <tbody> <tr> <td>Over the next week, every time you eat, ask the question, "Am I making healthy food choices?" Track what you eat on a daily basis and record it.</td> <td>Small changes over time can make a big difference. Substitute whole grain bread for white bread. Snack on baby carrots or cherry tomatoes. Purchase fresh and dried fruit for dessert.</td> <td>Order vegetables or salads instead of potatoes when dining out. Bring healthy foods to potlucks and parties instead of chips and baked goods.</td> </tr> </tbody> </table> <p>Arrange — Use NutritionRx</p> <ul style="list-style-type: none"> • Arrange follow-up visits • Refer patients to registered dietitian as needed 	Self-Monitoring	Incremental Change	Go Eating Out	Over the next week, every time you eat, ask the question, "Am I making healthy food choices?" Track what you eat on a daily basis and record it.	Small changes over time can make a big difference. Substitute whole grain bread for white bread. Snack on baby carrots or cherry tomatoes. Purchase fresh and dried fruit for dessert.	Order vegetables or salads instead of potatoes when dining out. Bring healthy foods to potlucks and parties instead of chips and baked goods.	<ul style="list-style-type: none"> • Comprehensive overview of the intervention and an example of guiding a patient through the intervention. Designed to make it easy for clinicians/HCPs to carry on the ward. 	<p>(Fiore, 2000).</p>
Self-Monitoring	Incremental Change	Go Eating Out							
Over the next week, every time you eat, ask the question, "Am I making healthy food choices?" Track what you eat on a daily basis and record it.	Small changes over time can make a big difference. Substitute whole grain bread for white bread. Snack on baby carrots or cherry tomatoes. Purchase fresh and dried fruit for dessert.	Order vegetables or salads instead of potatoes when dining out. Bring healthy foods to potlucks and parties instead of chips and baked goods.							

Evidence-based patient toolkit



**Evidence-Based
Nutrition Toolkit** *for*
Cancer Survivors

Tufts UNIVERSITY
GERALD J. AND DOROTHY R.
Friedman School of
Nutrition Science and Policy

- Why is nutrition important for cancer survivors?
- How does cancer treatment impact my eating patterns?
- Strategies for managing eating problems during cancer treatment.
- Maintaining a healthy weight during and after cancer treatment.
- Nutrition and physical activity recommendations for cancer survivors.
- Frequently asked questions by cancer survivors.
- Food safety.
- How do I talk to my healthcare team about my diet?
- How to evaluate nutrition information for cancer survivors.
- More evidence-based nutrition resources.

(Rock et al., 2012; Arends et al., 2017; U.S. Department of Agriculture, 2018; World Cancer Research Fund/American Institute for Cancer Research, 2018b).

Publication 11 is a qualitative study conducted with oncology providers (n=12) and cancer survivors (n=12) across the USA (Keaver et al., 2020b). Six focus groups and two structured interviews were conducted, with HCPs and cancer survivors provided with intervention content one week before the focus groups. HCPs were asked about current practice regarding provision of nutrition advice as well as feedback on the intervention content. Cancer survivors were asked about their nutrition needs, current sources of information, the intervention content and interest in taking part in such an intervention.

There were four main themes identified from the data:

(1) *Nutrition in oncology care*. Nutrition was viewed as an important component of oncology care and source of empowerment for those with cancer. Both HCPs and survivors reported challenges in accessing evidence-based recommendations. Provision of nutrition advice varied, and the internet was often used by survivors to locate nutrition information.

(2) *NutriCare program content*. The prescription pad component was viewed as a critical aspect, and there was also a preference for dealing with patients (those currently undergoing primary treatment) and survivors (those who had completed primary treatment) separately. Survivors wanted the advice from an oncologist as it was felt that this carried more significance.

(3) *NutriCare program implementation*. The oncologist's role from their own perspective was to champion the intervention, while a nurse or dietitian deliver the content. There was a desire for flexible training (online and brief was preferred) for HCPs on how to deliver the intervention to address the lack of confidence felt. It was also evident that many HCPs were not confident in delivering behaviour change interventions or developing Specific Measurable Achievable Realistic Timely (SMART) goals. The most appropriate time for HCPs to talk to patients about nutrition is during the development of the treatment plan.

(4) *Barriers and facilitators*. Major barriers for HCPs included lack of time and language issues. Overall, survivors were interested in and providers supportive of integrating nutrition into oncology care.

By exploring the views of cancer survivors and HCPs, publication 11 allowed for the refinement of the *Nutricare* intervention prior to implementation, the importance of integrating end-users in intervention development was recently highlighted (Currie et al., 2022). The issues identified during these focus groups, in accessing evidence-based healthcare, mirror results

found in chapters one to three of this thesis. The findings of publication 11 allowed for the adaption of the *Nutricare* intervention prior to undertaking a pilot trial. These changes and results from the pilot trial have been outlined in publication 12.

4.3 Publication 12: Integrating nutrition into outpatient oncology care—A pilot trial of the *Nutricare* programme (2020)

Laura Keaver, Ioanna Yiannakou, Fang Fang Zhang

Pilot studies are an important part of the research process, allowing for the feasibility of an intervention to be determined prior to larger-scale studies and ultimately integration into practice (Leon et al., 2011; Blythe LaGasse, 2013). The aim of this study was to test the feasibility and acceptability of the *Nutricare* intervention using a six-week pre-test-post-test intervention design (Keaver et al., 2020c).

Forty-six breast cancer survivors from the breast health clinic at Tufts Medical Centre were eligible for the study. Two validated quality-of-life questionnaires and the National Institute for Health Dietary History Questionnaire were completed pre-and-post intervention (PROMIS Health Organization and PROMIS Cooperative Group, 2016; PROMIS Health Organisation, 2017; National Institutes of Health, 2018).

The intervention was initially designed to be delivered by non-dietetic members of the healthcare team, with any complex issues being referred to a dietitian. However, feedback from the focus groups in publication 11 denoting the lack of time that oncologists had to deliver the intervention and, instead perceiving their role as championing, led to changes in the planned delivery. The pilot was delivered by a dietitian (lead author - LK) while clinicians (oncologists and advanced health practitioners) followed up with phone-calls to emphasize the goals decided upon by the patient and guided by the dietitian. Rather than controlling for context, we sought to intervene to change the context where required, to enhance uptake of the intervention, a core principle of implementation science (Bauer and Kirchner, 2020).

Of the forty-six individuals eligible for recruitment, 20 (44%) agreed to take part in the study. Of these, 18 (90%) completed all pre- and post-testing. The mean (\pm SD) age of participants was 59.5 (\pm 9.9) years and 45% were within five-years of diagnosis. Fatigue (80%) and food cravings (75%) were the most common symptoms still being experienced. Most participants (80%) were very willing to make changes to their current dietary habits to improve their health. The main goals chosen to focus on by participants with the assistance of the dietitian were tips to reduce fatigue (n=8); increase dairy by one portion most days (n=7); have breakfast on most days (n=6) and increase vegetable intake by one portion most days (n=5). The follow-up phone-calls by the clinicians only occurred in 50% of cases. Significant improvements in physical-

functioning ($p < 0.05$) were observed over the six-weeks, however, there were no other significant changes in any quality-of-life or dietary intake measures. There was a strong survivor commitment to keep using the toolkit provided (89%) and an interest in the oncology team continuing to discuss nutrition at consultations (83%). More than 80% of participants would recommend the intervention to others with cancer; found locating information easy; and the tips practical and useful. Alongside this, goals were deemed to be feasible by participants (94.4%).

The premise for this intervention, where HCPs can deliver some basic advice with more complex and urgent cases being referred to a dietitian, was recently outlined as an important part of a proposed solution to integrating nutrition into the cancer-setting (Frenkel et al., 2022).

A recent study which sought to determine the nutrition-related needs and goals of those with cancer to better assess the effectiveness of nutrition interventions, indicated that improved dietary intake and quality of life measures were top-rated goals (Foecke Munden et al., 2023). It would be beneficial to determine the longer-term impact of the *Nutricare* intervention on these parameters. A clinical trial in lung cancer patients is currently being conducted in the USA, led by Tufts University. The *Nutricare* resources are being utilised alongside medically tailored meals to evaluate effectiveness in optimising nutrition status and quality-of-life, and reducing treatment-related side-effects (ClinicalTrials.gov, 2021). The appropriateness of the *Nutricare* intervention in an Irish setting is still to be determined.

4.4 Conclusion

This chapter explored the development and feasibility testing of a nutrition intervention (*Nutricare*) for cancer survivors. There was a keen interest in the *Nutricare* intervention and in continuing its use beyond the scope of the trial by cancer survivors (Keaver et al., 2020c). While significant improvement in physical-function was seen over the six-week trial, it would be important to determine the longer-term effectiveness of this intervention in a larger sample size. In addition, as this work was carried out in the USA, it is important to determine the current situation in Ireland and how best to adapt this intervention for the Irish context. The next chapter will explore the Irish context further, to allow for the future adaption of the *Nutricare* intervention.

Chapter Five: The Irish context

Chapter four highlighted interest in and acceptability of the *Nutricare* intervention in an oncology-setting in the USA (Keaver et al., 2020b; Keaver et al., 2020c). However, some exploration is required as to how best to deliver from a HCP point of view. Publications 13-15 explore barriers and facilitators to healthy eating in cancer survivors, preferences for nutrition intervention, and the role of the doctor in providing nutrition advice from an Irish perspective to inform the future adaption of the *Nutricare* intervention for Irish cancer survivors and healthcare teams. Studies presented in this chapter are situated within the development phase of the MRC framework for developing and evaluating complex interventions (Skivington et al., 2021).

5.1 Background and rationale

Adapting evidence-based interventions for implementation in new countries and contexts is likely to be more efficient than developing new interventions for every context (Moore et al., 2021). Adaptation of existing interventions is an emerging area of interest in intervention research (Wiltsey Stirman et al., 2019; Kirk et al., 2020; Miller et al., 2020). A recent scoping review identified frameworks to allow for the adaptation of evidence-based interventions in new contexts (Escoffery et al., 2019). Eight commonalities between the frameworks were identified in the review: (1) to assess the population or community of interest, (2) to understand the original evidence-based intervention(s), (3) select an evidence-based intervention, (4) decide what needs to be adapted, (5) adapt the original program, (6) test the adapted materials, (7) implement the invention, and (8) evaluate.

The first aspect, namely ‘to assess the population or community of interest’ is most relevant for publications 13-15 (Escoffery et al., 2019). Interventions that are just replicated are less likely to be effective than those that are adapted to fit the new context (Sundell et al., 2016). To inform the adaption of the *Nutricare* intervention for Ireland, it was important to explore the role of Irish HCPs in providing nutrition advice. It was also important to explore intervention preferences and barriers and facilitators to healthy eating among Irish cancer survivors.

Aim

The aim of this section was to inform the adaption of a nutrition intervention, providing advice in an Irish context through the perspectives of those with cancer and HCPs.

Objectives**The objectives of this section are:**

1. to explore the role of doctors in the provision of nutrition advice,
2. to identify the barriers and facilitators to healthy eating in Irish cancer survivors,
3. to explore the information needs and intervention preferences of Irish cancer survivors.

5.2 Publication 13: What should the role of doctors be in the provision of nutrition advice - a qualitative study (2022)

Laura Keaver, Niamh O'Callaghan & Catherine M. McHugh

Previous studies in Irish cancer survivors indicated that those who did receive nutrition advice, received this from doctors, nurses or dietitians (Timon and Doyle, 2020). This research project initially planned to explore the role of both nurses and doctors in the provision of nutrition advice from the viewpoint of nurses, doctors and dietitians. Unfortunately, recruitment was stopped due to the COVID-19 pandemic. At this juncture only doctors and dietitians had been recruited, hence the focus of this paper was solely on the role of doctors in the provision of nutrition advice, from the perspective of both doctors and dietitians. Nurses and other HCPs play a vital role in providing nutrition advice and there are plans to continue this work with other HCPs.

As stated earlier in this thesis, patients view doctors as credible and reliable sources of information (Ball et al., 2014). Doctors have been shown to positively impact patients' dietary habits when they provide advice (Ball et al., 2013). However, as indicated by the research presented in chapter 2, barriers such as lack of time and knowledge can hinder this (Keaver et al., 2021a; Keaver et al., 2023d). It is also not clear exactly what their role should be. Without a clearly defined role, it will be difficult to address deficits in current education models (Crowley et al., 2019). A recent paper explored what doctors (n=9) and medical students (n=3) think they need to know about nutrition (Caldow et al., 2022). One of the themes derived from this qualitative research was the need to identify the role of doctors in nutrition care. Collaboration between medical and nutrition professionals has been highlighted as essential in the delivery of nutrition advice (Adamski et al., 2018). It is important therefore to get doctors and dietitians perspectives on the roles that doctors can play in providing nutrition advice. No similar work has been conducted previously. The aim of this qualitative study was to explore the role of the doctor in the provision of nutrition advice, from the perspective of both doctors and dietitians.

Focus groups were conducted with ten doctors and six dietitians (Keaver et al., 2022d). Dietitians had been working for an average of 18-years, while doctors had been working an average of 2-years. Both worked in a range of specialities (including general medicine, medical endocrinology, and geriatrics). Nutrition in clinical care was perceived as important or very

important by all participants. All agreed that the doctor has an important role to play in the provision of nutrition advice to their patients. The main roles of doctors were identified through inductive thematic analysis (Braun and Clarke, 2019). These were: (1) to act as the first point of contact, (2) to identify those in need of dietetic support and refer to dietitians and (3) to advocate for and support nutrition in the clinical setting. Lack of knowledge and lack of resources were identified as the main barriers to providing nutrition advice. There was a recognition by both doctors and dietitians of the need for support to enable doctors to undertake the roles identified.

Doctors are often the first point of contact for most patients, and therefore should have the ability to provide or signpost to basic nutrition advice. It is also important for doctors to identify and refer nutritionally at-risk patients, which should be an essential component in medical training, but often lacking (Adamski et al., 2018). The barriers identified reflect existing international literature (Daley et al., 2016; Frantz et al., 2016; Macaninch et al., 2020) and that of publications 2 and 3 presented in chapter two (Keaver et al., 2018; Keaver et al., 2021a). These findings are timely as the integration of nutrition into medical curriculums is being more widely discussed and promoted (Macaninch et al., 2020; Association for Nutrition, 2021; Ying-Yi Xie et al., 2021). Since publication of this study in 2022, to the authors knowledge there has been no further work published. Further work, exploring the perceived roles of medical staff working in oncology specific contexts would be useful moving forward. Covid-19 restricted recruitment therefore leading to smaller sample sizes and less diversity of HCP type.

For doctors and other HCPs to provide nutrition advice, understanding current barriers and facilitators to healthy eating is important. Publication 14 explores the barriers and facilitators to healthy eating from the perspective of cancer survivors.

5.3 Publication 14: Perceived barriers and facilitators to a healthy diet among cancer survivors: a qualitative investigation using the TDF and COM-B (2023)

Laura Keaver, Pauline Douglas, Niamh O'Callaghan

Cancer survivors are recommended to follow the WCRF cancer prevention recommendations (World Cancer Research Fund/American Institute for Cancer Research, 2018a). There are ten recommendations that predominately centre on consuming a healthy diet – increasing fruits, vegetables and wholegrains, while limiting red and processed meat, salt, fast food and alcohol. Poor adherence to these recommendations is often common in cancer survivors (Winkels et al., 2016; Kaładkiewicz and Szostak-Węgierek, 2019). A previous publication I was involved in explored the self-reported barriers to healthy eating in breast cancer survivors recruited online, globally (Keaver et al., 2021c). Fatigue was the key barrier to making healthy food choices (72.1%), followed by stress (69.5%) and treatment-related changes in eating habits (e.g., change in tastes, loss of appetite, and craving unhealthy food) (31.4% to 48.6%).

The use of behaviour change theory is advised in the development, implementation and evaluation of health interventions (Michie, 2008; Skivington et al., 2021). It is proposed that interventions built on theoretical underpinnings are more likely to be effective (Davis et al., 2015). (Prestwich et al., 2014; Dalgetty et al., 2019) Utilising behaviour change theory can enable the identification of pivotal components of interventions that can be maximised. The linking of theory with intervention design is aligned with MRC guidance (Skivington et al., 2021).

The Behaviour Change Wheel (BCW) is a theory and evidence-based tool designed to inform the development stage of interventions (Michie et al., 2014). The core of the BCW is the belief that three components (capability, opportunity and motivation – COM-B) influence behaviour (Michie et al., 2014). This can be further enhanced by the Theoretical Domains Framework (TDF) which is a synthesis of 33 theories of behaviour and behaviour change (Cane et al., 2012). This provides a theoretical lens through which to better understand the wide range of influences on behaviour (Cane et al., 2012). The TDF and COM-B model have previously been successfully used to explore barriers and facilitators to dietary change (Rawahi et al., 2018; Bentley et al., 2019), however not in cancer survivors. Utilising both allows for a better understanding of the determinants of a behaviour and therefore the development of a more informed intervention (Timlin et al., 2021).

There are a lack of studies exploring the barriers and facilitators to healthy eating in adult cancer survivors using the TDF and COM-B model. These are important as they provide a robust theoretical basis to identify determinants that need to change, to make an intervention more effective and enhance successful implementation into practice (Atkins et al., 2017). This qualitative study aimed to explore the barriers and facilitators to following a healthy diet among cancer survivors using the TDF and COM-B model (Keaver et al., 2023a).

Semi-structured interviews were conducted with 20 cancer survivors, who were recruited through another study looking at the nutrition practices of cancer survivors (O'Callaghan et al., 2022). Participants were predominately female (n = 17, 85%), breast cancer survivors (n = 12, 60%) with a mean age of 51.3 years and all had obtained a third-level education.

The majority of responses related to seven of the fourteen key-domains of the TDF. These were (1) environmental context and resources; (2) knowledge; (3) behavioural regulation; (4) social/professional role and identity; (5) belief about consequences; (6) social influences; and (7) skills. Key barriers to healthy eating were lack of knowledge, non-specific or irrelevant information, environmental aspects, and family. Facilitators to healthy eating were awareness of the importance of nutrition, the health benefits of a plant-based diet, confidence in cooking skills, organisation, balance, family, time, viewing themselves as someone who eats healthily and access to fresh produce. Enablement was the most prominently linked intervention function.

The recognition of the health benefits of a plant-based diet are in line with the recommendations of the WCRF to increase intake of fruit, vegetables and wholegrains for cancer prevention and cancer survivorship (World Cancer Research Fund/American Institute for Cancer Research, 2018b). Family members were identified as barriers and facilitators to healthy eating. Findings in publication 5 and other recent research reported family members to be a main source of nutrition advice also (Mullee et al., 2021; Keaver et al., 2023e). Therefore, the role of the family in dietary choices and nutrition advice in those with cancer appears to be impactful and requires further exploration. This theoretically underpinned research identified potential focus for future interventions by outlining current enablers and barriers to healthy eating. Interventions that focus on raising capability and/or opportunity by reducing the outlined barriers or improving facilitators are most likely to be effective and beneficial (Keaver et al., 2023a).

While it is important to understand barriers and facilitators to healthy eating and the intervention functions that are most likely to be successful in addressing these, it is also important to understand from the perspective of Irish cancer survivors what types of interventions and support they would prefer. Therefore, publication 15 assessed these preferences.

5.4 Publication 15: Nutrition support and intervention preferences of cancer survivors (2023)

Laura Keaver, Niamh O'Callaghan, Pauline Douglas

Recent consensus informed guidance highlighted the importance of adapting interventions for new contexts (Moore et al., 2021). Therefore, exploring the nutrition intervention and support preferences of Irish cancer survivors could help inform the adaptation of the *Nutricare* programme. It could also help inform the development of future nutrition interventions. Currently, 12% of those post-treatment cancer patients in Ireland have received nutrition advice from a HCP (O'Callaghan et al., 2022). A study exploring the nutrition support needs of cancer survivors in Ireland reported that the majority (73%) wanted practical information on how to achieve recommended nutrition guidelines, healthy recipes (66%) and clarification on misinformation relating to diet and cancer (53%) (Timon and Doyle, 2020). There were mixed results for preferred mode of delivery of this information, to include books/leaflets (66%) or an interactive online tool for the provision of support (88%). Preferred mode of delivery was not broken down by participant characteristics (Timon and Doyle, 2020). There were no other data available on the preferred nutrition support intervention and information preferences of Irish cancer survivors. It is important to note that ESPEN and WCRF recommendations highlight the importance of both nutrition and physical activity intervention (Arends et al., 2017; World Cancer Research Fund/American Institute for Cancer Research, 2018b). Following these guidelines and maintaining a healthy weight, consuming a healthy diet and being physically active are positively associated with quality-of-life, physical-functioning, reduced chronic disease and survival in cancer survivors (Solans et al., 2020; Swain et al., 2020; Carmack et al., 2021). Therefore, further exploring preferred nutrition guidance and delivery in addition to interest in receiving additional health behaviour information is important. The aim of this study was to explore the nutrition and health information needs of cancer survivors and their preferences regarding intervention delivery.

A convergent parallel mixed-methods study with cancer survivors, consisting of a cross-sectional survey (n=56) and focus groups (n=20) was conducted (Keaver et al., 2023c). Participants were predominantly female (89.3%) and breast cancer survivors (75%). Most were interested in receiving nutrition advice (92.9%), however only 12.5% had received advice from a dietitian. Participants had a preference to receive information across the cancer journey (55.4%), and not fixed to a standalone key juncture such as at diagnosis or post-treatment.

Preference for mode of intervention delivery varied. There were no significant differences in timing or delivery mode by education, cancer type or time since diagnosis ($p>0.05$).

Participants ranked the importance of nutrition-related topics during and after completion of treatment. During treatment the following topics were deemed to be very important or important by the majority: coping with side-effects (96.4%), fatigue (85.7%), eating a balanced diet (85.7%) and improving cardiovascular health (85.7%). On completion of treatment, the following topics were deemed very important or important: coping with side-effects (91.1%), fatigue (91.1%), eating a balanced diet (89.3%), improving cardiovascular disease (89.3%) and weight-management (83.9%). Dealing with nutrition misinformation was very important or important for 75% during treatment and 78.6% on completion of treatment. Time and motivation (26.8%) were the main barriers reported by patients to taking part in a nutrition intervention. Facilitators to taking part in an intervention were keeping healthy (75%) and weight maintenance (55.4%).

There was interest in other health related topics also such as improving sleep quality (62.5%), making positive lifestyle changes (50%) and accessing cancer-specific physical activity classes (48.2%). Four themes emerged from thematic analysis: (1) lack of nutrition guidance, (2) an abundance of misinformation, (3) one size does not fit all, and (4) dietitians as the preferred source of advice.

These findings will help inform the content and type of nutrition advice provided to cancer survivors. The findings will also be used to adapt the *Nutricare* intervention to address the barriers identified. Other health topics proved important to this cohort, allowing for a more holistic delivery of information to be considered. Keeping healthy and weight maintenance were the main facilitators, indicating recognition of some of the main focusses of cancer survivorship. An intervention with focus on these aspects while utilising tools such as motivational interviewing to overcome motivational barriers highlighted are likely to be well received (Miller and Rollnick, 2012). Interventions will need to be flexible in their approach, while addressing the wide range of issues that are persistent and pertinent to cancer survivors, hence promoting acceptability, usefulness and effectiveness. Despite only being published in 2023, this paper has been cited six times.

5.5 Conclusion

This chapter explored the role of doctors in the provision of nutrition advice, and the nutrition intervention preferences of cancer survivors in an Irish setting. Also, a theoretically underpinned exploration of the barriers and facilitators to healthy eating in cancer survivors.

The main roles of doctors were identified as acting as the first point of contact, identifying those in need of dietetic support and referring onwards to dietitians where more specific and specialised nutrition advice is required, and advocating for and supporting nutrition in the clinical setting. It is important that the role of other HCPs be explored. The COM-B model and the TDF provided better understanding of barriers and facilitators to healthy eating in cancer survivors. Cancer survivors had an interest in receiving nutrition advice throughout the cancer journey with variability in preference of delivery method. There was also interest in education around improving sleep quality and making positive lifestyle changes. The findings of this chapter will inform the adaption of the *Nutricare* intervention for use in an Irish setting. They will also help guide the development of other nutrition interventions and inform the integration of nutrition into standard oncology-care.

The next chapter will synthesise the main findings of the thesis and discuss contributions of the work to research, policy and practice.

Chapter Six: Discussion and conclusion

6.1 Chapter overview

There has been an increasing focus on nutrition in cancer-care, at both a national and international level in recent years with key documents and policies highlighted in Table 6.1. These have predominately focussed on the importance of person-centred care, something which is not achievable without the inclusion of nutrition (Department of Health, 2017). Furthermore, the goals of Europe's Beating Cancer Plan cannot be achieved without integrating nutrition across the cancer-care continuum (European Commission, 2020). In order to provide person-centred care, the views of the person are vital (Coulter and Oldham, 2016). Currently, numerous gaps exist in the understanding of the provision of nutrition advice in the oncology-setting, from the perspective of those with cancer and HCPs, as highlighted by a recent systematic review (Keaver et al 2023d). This thesis made significant efforts to address these gaps using a range of methodologies.

In this chapter, the main findings will be critiqued, and strengths and limitations discussed. In addition, contributions to the literature, policy and practice will be discussed. Recommendations for future research will be highlighted and personal developments over the timeframe of this research will also be detailed.

Table 6.1 Timeline of national and European documents, programmes and policies occurring during research timeframe.

2017/2018	2019	2020	2021	2022/2023	2023
ESPEN Nutrition and Cancer Guidelines (Arends et al., 2017)	Unmet Needs of Cancer Survivors in Ireland: A Scoping Review by the National Cancer Registry (O'Connor and Donnelly, 2019)	Irish Cancer Society Strategy 2020-2025 has 'Living well after treatment' as one of five priority areas (Irish Cancer Society, 2020)	ESPEN Nutrition and Cancer Practical Guidelines (Muscaritoli et al., 2021a)	European Cancer and Nutrition Patient Survey (Optimal Nutritional Care for All, 2022).	Nutrition care is an integral part of patient-centred medical care: a European consensus (Erickson et al., 2023)
Survey in 10 EU countries by European Cancer Patient Coalition (Muscaritoli et al., 2019)	National Cancer Survivorship Needs Assessment launched (Mullen and Hanan, 2019)		Europe's Beating Cancer Plan (European Commission, 2020)	First Irish National Survey on cancer awareness and attitudes (Health Service Executive, 2022a)	Policy Brief. Nutrition care is an integral part of patient-centred medical care: a European consensus. What are the next steps? (!!! INVALID CITATION !!!)
National Cancer Strategy 2017-2026 – first time there is an emphasis on survivorship (Department of Health, 2017)			EU Health Policy Platform – Integrated Nutrition Cancer Care chosen as one of three thematic networks for focus (EU Health Policy Platform, 2021)	National Cancer Control Programme – development of e-learning modules on cancer risk reduction* (Health Service Executive, 2022b)	
World Cancer Research Fund Cancer Prevention Recommendation third edition (World Cancer Research Fund/American Institute for Cancer Research, 2018b)				Irish Cancer Society Survivorship Care Pathways for diet and nutrition being developed*	

*Invited to review and contribute

6.2 Main findings

The main findings of this thesis have been included as bullet points below, then discussed in further detail in sections 6.2.1 (patients) and 6.2.2 (HCPs).

Patients

- Patients desire evidence-based nutrition advice, responsive to their needs across the cancer trajectory.
- Currently available resources are not specific to cancer type or stage, lack practical strategies and in many cases are not evidence-based.
- Development of an intervention which is feasible for delivery to this population.
- There was variability around how Irish cancer survivors want to receive nutrition advice, with a desire to receiving advice on other health behaviours such as exercise.

HCPs

- Recognise the importance of nutrition, and that nutrition needs differ across the cancer trajectory.
- Barriers to the provision of nutrition advice included a lack of time, confidence, knowledge, skills and evidence-based resources.
- There are limited available guidelines on nutrition and cancer survivorship.
- The dietitian is the primary HCP responsible for nutrition advice and an important facilitator in collaborative nutrition care and in training of HCPs and development of resources.

6.2.1 Patients

Desire for evidence-based nutrition advice responsive to their needs across the cancer trajectory.

Those with cancer desire individualised, practical guidance that is easy to follow (Keaver et al., 2023e) and recognise the importance of nutrition for all cancer types, stages and individuals (Keaver, 2021a). Nutrition is recognised as a human right (Cardenas, 2021; World Health Organization Regional Office for Europe, 2021), one which is currently not fully met in

oncology-care, as there is a lack of nutrition information and intervention (Maschke et al., 2017; Sullivan et al., 2021; Erickson et al., 2023; Keaver et al., 2023e).

As highlighted in the systematic review, there is a need to ensure the relevance of nutrition assessment and advice is indicated from diagnosis (Keaver et al., 2023d). This aligns with an increasing awareness in recent years of the role and effectiveness of cancer prehabilitation (Santa Mina et al., 2021). Unfortunately, within current prehabilitation interventions, there tends to be limited nutrition components (Gillis et al., 2021). A recent scoping review of prehabilitation for patients with cancer found that only 37 out of 110 studies included nutrition, and that two thirds of these did not monitor or evaluate the nutrition intervention (Gillis et al., 2021). Where studies screened for nutrition risk (approximately 1/3), this was often completed without validated tools (Gillis et al., 2021). This could in some part be due to a lack of knowledge around malnutrition screening and uncertainty around how to use validated screening tools (Keaver et al., 2018; Keaver et al., 2022d). It is important that prehabilitation care complements post-treatment rehabilitation (Santa Mina et al., 2021). Another barrier highlighted in the systematic review included a lack of nutrition advice and support from HCPs to patients, especially in oncology-outpatient-settings (Keaver et al., 2023d). This should be addressed to ensure optimal nutrition advice and support is provided across the cancer continuum, given a focus on reducing length of hospital stay and promoting ambulatory care.

Resources that are available are not specific to cancer type or stage, lack practical strategies and in many cases are not evidence-based.

Those with cancer report a lack of access to dietetic support both during and after treatment (Maschke et al., 2017; Sullivan et al., 2021; O'Callaghan et al., 2022). In Ireland and across Europe there is evidence of late diagnosis of malnutrition, and therefore late referral to dietitians for nutrition intervention (Caccialanza et al., 2020; Lorton et al., 2020). This delay can detrimentally affect the benefits of earlier nutrition intervention in those with cancer (De Waele et al., 2015; Senesse et al., 2015; Cereda et al., 2018; Caccialanza et al., 2019) and is in direct conflict with recommendations for screening, diagnosis and referral made in current clinical guidelines (Arends et al., 2017). Nutrition intervention can improve weight status, energy and protein intake and decrease NIS (Prado et al., 2022). Preventing malnutrition can decrease length of hospital stay and treatment costs (Senesse et al., 2015; Caccialanza et al.,

2019) and reduce treatment toxicity (Cereda et al., 2018). Those with access to nutrition counselling and advice also report improved quality-of-life (Senesse et al., 2015), an outcome which those with cancer have themselves prioritised as one of the most important outcomes of a nutrition intervention (Foecke Munden et al., 2023).

A recent French study indicated that patients expect HCPs to meet their nutrition information needs, however only 12% felt they had received adequate information on nutrition (Veron et al., 2023). Where HCPs do not provide nutrition advice, this creates an information vacuum which is filled with unregulated non-evidence-based information (Thorne et al., 2020). This presents as a key concern, given a recent Irish study highlighted those with cancer and their supporters recognised that patients with cancer are susceptible to misinformation online (Kelly et al., 2021).

The work presented in this thesis indicated a lack of evidence-based nutrition advice available on national cancer-charity and support websites, phone-applications and on global websites, which are typically found when searching for nutrition information for cancer survivors (Keaver et al., 2020a; Keaver et al., 2021b; Keaver et al., 2022b). Only 7% of those with cancer had been advised on how to access reliable information online (Sullivan et al., 2021). A lack of credible nutrition guidance has also been reported on Pinterest and YouTube (Warner et al., 2022; Segado-Fernández et al., 2023).

Those with cancer should not be expected to source and pay for access to dietitians privately to receive evidence-based nutrition advice. According to the Irish Cancer Society, the average cost of a cancer diagnosis is €756 per month, with 70% of individuals experiencing an income drop of greater than €18,000 (Irish Cancer Society, 2019). Furthermore, nutrition interventions would likely reduce healthcare costs overall (Hall et al., 2014; Muscaritoli et al., 2017a; Schuetz et al., 2020; Correia et al., 2021).

The following topics were deemed most important by individuals during and on completion of treatment to include coping with side-effects, fatigue, eating a balanced diet and improving cardiovascular health. These topics are included in the Nutricare intervention (Keaver et al., 2020b) and accompanying patient toolkit (Appendix 3). The evidence-based resources developed as part of this intervention proved suitable to meet the self-reported nutrition needs of those with cancer.

Fatigue and dealing with nutrition misinformation were two areas that were reported in several of the publications included in this thesis (Keaver et al., 2020b; Keaver et al., 2021a; Keaver

et al., 2022c; Keaver et al., 2023c; Keaver et al., 2023e). Fatigue is the most frequently reported and debilitating symptom for those with cancer (Curt et al., 2000; Stone et al., 2000; Keaver et al., 2021a; Keaver et al., 2021c). The lack of easily accessible, evidence-based, free resources to address these led us (Laura Keaver, Niamh O’Callaghan and Pauline Douglas) to develop two videos (how to manage fatigue and how to access evidence-based advice), the former of which has been incorporated into the thisisGO website (<https://myprofile.thisisgo.ie/topic-wise-articles?Id=1625&topic=true>). This is an online information resource led by the Mater Misericordiae University Hospital for those with gynaecological cancer. Both videos have also been circulated to 36 national cancer societies and charities (Appendix 5).

Development of an intervention which is feasible for delivery to this population.

This research developed, piloted and feasibility tested the *Nutricare* intervention, guided by the 5-A model. This rigorously designed intervention was largely feasible and had good retention rates (90%). Adaptions of the intervention to an Irish context have been guided by the MRC framework and underpinned by the TDF and COM-B model (Publications 13-15). The inclusion of the healthcare team, and in particular the oncologist, in interventions has led to improvements in the target behaviour and to positively influence the behavioural control patients perceive themselves to have (Demark-Wahnefried et al., 2000). While the oncologist and healthcare team were able to introduce the *Nutricare* intervention, there was a difficulty in providing patients follow-up with just over half receiving a phone call (Keaver et al., 2020c). Given this barrier and the impact that time and confidence can have on integration of nutrition into standard appointments (Yarnall et al., 2003; Kuhn et al., 2005), it is worth exploring additional modes of delivery for the *Nutricare* intervention, especially as cancer survivors have reported positive perceptions of web-based interventions (Corbett et al., 2018). An online intervention would also help to address other barriers that have been frequently reported by cancer survivors, that of distance/traveling and cost (Wurz et al., 2015).

There was variability around how Irish cancer survivors want to receive nutrition advice, with an interest also expressed in receiving advice on other health behaviours such as exercise.

It is clear from the findings that ‘one size does not fit all’ and that individuals will have differing needs depending on cancer type, stage and treatment (Keaver et al., 2023e). This finding was similarly reported in a scoping review undertaken by the National Cancer Registry in Ireland, which indicated that survivorship care programmes should be tailored to address the specific needs of individuals (O’Connor and Donnelly, 2019). Cancer survivors expressed a desire for different delivery types and intervention timing (Keaver et al., 2023c).

ESPEN guidelines highlight the importance of both nutrition care and exercise training (Arends et al., 2017). The WCRF recommendations indicate that all cancer survivors should receive nutrition care and physical activity guidance from trained professionals (World Cancer Research Fund/American Institute for Cancer Research, 2018b). Cancer survivors recognise the importance of a holistic approach, with an interest in receiving advice on nutrition, sleep, physical activity and healthy behaviours more generally (Keaver et al., 2023c). It is therefore important to consider other health behaviours, in addition to nutrition. The *Nutricare* intervention predominately focussed on weight management and nutrition, with a small reference to physical activity. Future adaptations of the programme should include lifestyle behaviours (other than nutrition) in greater detail. Based on these findings we (Laura Keaver and Niamh O’Callaghan) developed an evidence-based infographic on physical activity that was shared with 36 cancer-support centres nationally and online (Appendix 6).

6.2.2 HCPs

Recognise the importance of nutrition, and that nutrition needs differ for patients across the cancer trajectory.

HCPs recognised the importance of nutrition (Keaver et al., 2018; Keaver et al., 2021a; Keaver et al., 2022d), and, within the oncology setting, a need for different interventions based on cancer type and stage (Keaver et al., 2021a). Evidence from randomised controlled trials consistently highlight positive clinical impacts of integrating nutrition into cancer care (Laviano et al., 2018; Britton et al., 2019; Schuetz et al., 2019). While it is positive that HCPs recognise the importance of nutrition, this does not appear to be translating into practice, with many studies showing that patients are not getting the nutrition care they want or need (Maschke et al., 2017; Muscaritoli et al., 2019; Sullivan et al., 2021; Keaver et al., 2023e).

Barriers to the provision of nutrition advice included a lack time, confidence, knowledge, skills and evidence-based resources.

Most HCPs agreed that nutrition education is needed to support the provision of nutrition advice to patients in practice (78.2%) (Keaver et al., 2021a). Nutrition education for professionals is integral, as this is associated positively with skill development such as dietary assessment, recommending changes in food choices, appropriate food or nutrition goals or formulating meal plans (Keaver et al., 2018).

The Association for Nutrition recently developed a nutrition curriculum for integration into medical programmes in the UK that centred on nutrition screening & assessment, the impact of nutrition status on illness, malnutrition and specific dietary requirements (Association for Nutrition, 2021). Expanding this and integrating nutrition into the training of all HCPs would be of benefit to those with cancer as well as a wide range of other diseases (Thorne et al., 2020). Based on findings presented in this thesis, the training should, at a minimum, include assessment of nutrition status, ability to provide basic advice and enable HCPs to recognise when referral to a dietitian is necessary (Keaver et al., 2021a; Keaver et al., 2022d). Similar findings were recently reported in other research from Ireland (Dominguez Castro et al., 2020; Browne et al., 2022) and internationally in a systematic review (Harris et al., 2019). When training is being provided for the oncology setting, an additional focus on the provision of dietary advice for specific cancer stage and site would be appreciated (Keaver et al., 2021a). While many nursing curricula contain some information on malnutrition and the MUST screening tool (Rodgers and Mackenzie-Fraser, 2011), the teaching and delivery of this information does not always involve dietitians (Arrish et al., 2016). There are also those who feel that more nutrition content is necessary (Cunningham, 2022). Publication 2 (where 70.6% of respondents were nurses), found only 19.1% reported confidence in assessing nutrition status (Keaver et al., 2018). It may be important, in addition to integration within curricula, to consider ongoing training and support in assessing nutrition status to assist in improving competence and compliance among all HCPs (Porter et al., 2009).

Doctors reported wanting access to physical resources and easy to use materials (Keaver et al., 2022d). The *Nutricare* intervention was designed to address this need by providing a step-by-step process with evidence-based resources for both survivor and HCP (Table 4.1)(Keaver et al., 2020c). It also aimed to address the barrier HCPs reported of lack of confidence in addressing follow up questions by incorporating an easy-to-use HCP toolkit that provided

additional information for each nutrition aspect highlighted in the NACP survey (Keaver et al., 2020b).

Lack of dietetic resources and lack of HCP time are two other barriers that have been identified. Patient led malnutrition screening using the malnutrition screening tool (MST) (Ferguson et al., 1999) is one potential solution that could assist in identifying if a patient is at risk of malnutrition without utilising HCP time. Patient-led MST has been shown to be a reliable, valid and accurate measure in the oncology-setting when compared to dietitian-led MST screening (Di Bella et al., 2020).

There are limited available guidelines on nutrition and cancer survivorship.

Overall, nutrition guidelines for cancer survivors in Europe are quite limited and follow guidance for cancer prevention (World Cancer Research Fund/American Institute for Cancer Research, 2018b; Keaver et al., 2022a). Additional evidence is required on the role of nutrition in the long-term health outcomes of cancer survivors, the persistence of NIS and how this changes overtime and the impact of long-term hormonal treatments for those with breast and prostate cancer on nutrition and metabolic outcomes. This additional evidence would help guide the development of specific evidence-based nutrition recommendations.

The dietitian is an important facilitator in collaborative nutrition care and in training of HCPs and development of resources.

The studies presented in this thesis highlighted the important role of the dietitian, not just in the delivery of nutrition advice, but in the training of other HCPS. The findings also contribute to a greater understanding of the role of non-dietetic HCPs in the provision of nutrition advice (Figure 6.1) (Keaver et al., 2023d, Keaver et al., 2021a, Keaver et al., 2022d, Keaver et al., 2018, Keaver et al., 2020b).

Non-dietetic HCP	Doctor	Dietitian
<ul style="list-style-type: none"> • Provide basic nutrition advice during routine practice. • Signpost to existing resources. • Refer problematic cases or ongoing issues to dietitian. • Ensure patients have the ongoing opportunity to discuss nutrition. 	<ul style="list-style-type: none"> • First point of contact. • Provide basic nutrition advice. • Signpost to evidence-based resources. • Identify those needing specialised advice and refer to dietitian. • Advocate for nutrition. • Reinforce dietetic advice provided to patients (Champion). • Refer to existing intervention (Champion). • GPs see larger role for themselves. 	<ul style="list-style-type: none"> • Primary HCP responsible for delivery of nutrition advice. • Important facilitator in collaborative nutrition care. • Provide training to other HCPs where feasible. • Contribute to development of evidence based nutrition resources. • Complex cases that require specialised and/or ongoing nutrition support.

Figure 6.1 Roles of HCPs in providing nutrition advice

Role of dietitians, doctors and non-dietetic HCPs (clinical specialist nurses, nurses, primary care providers, physiotherapists, occupational therapists, pharmacists, social workers, speech pathologists and healthcare assistants), in providing nutrition advice as evidenced by the papers presented in this thesis (Keaver et al., 2018; Keaver et al., 2020b; Keaver et al., 2021a; Keaver et al., 2022d; Keaver et al., 2023d)

A lack of dietetic resources was highlighted throughout the work presented in this thesis (Keaver et al., 2020b; Keaver et al., 2021a; Keaver et al., 2022c; Keaver et al., 2023d; Keaver et al., 2023e). Therefore, evidence-based and theory-driven online training programmes and easy to use resources to educate larger groups of HCPs may be more achievable than one-to-one or small group education sessions. It is clear that a ‘one size fits all’ approach will not be effective. While some HCPs reported wanting conference and study days (Keaver et al., 2018), others preferred brief and flexible training (Keaver et al., 2020b). To in part address this quest for dietitian-led evidenced-based HCP resources, several peer-reviewed articles were written, based on the findings of the research presented in this thesis (by the PhD candidate who is a dietitian), and published in HCP communications to contribute to the dietitian-led nutrition CPD of HCPs. These have been outlined in Table 6.2 and Appendix 7.

Table 6.2 Evidence-based articles based on research presented in this thesis.

Title	Issue	Contribution	Source and reference	Reach
The persistence of nutrition impact symptoms in cancer survivorship.	Summer 2023	Co-author	<i>Cancer professional</i> (O'Callaghan and Keaver, 2023b).	Mailed to 2100 doctors and nurses caring for cancer patients in hospitals and in the community in Ireland.
The nutrition practices and perspectives of cancer survivors in Ireland.	Spring 2023	Co-author	<i>Professional nutrition and dietetic review</i> (professional journal of the Irish Nutrition and Dietetic Institute) (O'Callaghan and Keaver, 2023a).	Mailed to 2,400 members of the Irish Nutrition and Dietetic Institute and other healthcare specialists with an interest in nutrition.
Importance of nutrition in cancer survivorship care.	Spring 2022	Sole author	<i>Cancer professional</i> This was then also published in the <i>professional nutrition and dietetic review</i> , the <i>world of Irish nursing</i> and <i>hospital doctor</i> , as the article was deemed to contain very useful information for HCPs (Keaver, 2022)	<i>Cancer professional</i> : mailed to 2100 members. <i>Professional nutrition and dietetic review</i> : mailed to 2400 members. <i>World of Irish nursing</i> – mailed to 40,000 nurse members of the Irish nurses and midwives organisation. <i>Hospital doctor</i> – mailed to 3,000 hospital consultants and circulated to medical libraries across Ireland. Available online at Irishhealthpro.com
Online nutrition resources in cancer management.	Summer 2020	Sole author	<i>Professional nutrition and dietetic review</i> (Keaver, 2020).	Mailed to 2,400 members of the Irish Nutrition and Dietetic Institute and other healthcare specialists with an interest in nutrition.
The role of nutrition in the prevention and management of cancer.	N/A	Sole author	clinicalnutrition.ie website run by Fresenius Kabi	

			(Keaver, 2021b).	
Nutrition in Haematology and Oncology.	N/A	Wrote sections on nutrition and cancer, nutrition impact symptoms, cancer survivorship, misinformation and alternative therapies (100%). Contributed to introduction and cancer diagnosis and treatment (50%).	Elsevier Essentials of Nutrition in Medicine and Healthcare 1 st edition textbook (Ray and Markell, 2023).	Available from 30 th August 2023

Clarity around the role of the doctor in providing nutrition advice also emerged. This is important as 73% of the Irish population aged 15+ has visited their GP in the past 12 months, with an average of 4.5 visits per person (Healthy Ireland, 2022), presenting several opportunities to introduce and discuss nutrition, if the GP is confident in their knowledge and skills to do so. GPs were seen as having a larger role in providing nutrition advice than doctors in other settings (Keaver et al., 2022d; Keaver et al., 2023d).

Oncologists from the USA viewed their role as championing the Nutricare intervention (Keaver et al., 2020b), a role which was also highlighted in the qualitative work undertaken with Irish doctors (Keaver et al., 2022d). A recent European consensus on nutrition as an integral part of person-centred care, highlighted championing for nutrition as a duty and ethical responsibility for all clinicians (Hippocratic Oath—*primum non nocere*) (Erickson et al., 2023). Roles for other HCPs also emerged (Figure 6.1), however, this requires further exploration.

6.3 Strengths and Limitations

6.3.1 Strengths

This collective body of research comprehensively examined the provision of nutrition advice to those with cancer with several peer-reviewed publications in high impact factor journals, enhancing the evidence-base. The use of a mixed-methods approach allowed for a deeper understanding of the provision of nutrition advice, importantly gained from both the patient and HCP perspective. Utilising a mixed-methods approach can overcome the gap between siloed research and day-to-day practice (Mertens, 2012; Headley and Plano Clark, 2020). This research has already impacted on practice through the development of resources that have been utilised by the healthcare and charity sectors, as well as making a successful case for the hiring of a full-time oncology dietitian in SUH. These examples have been discussed in more detail in the impact on practice section further on in the thesis.

The use of the COM-B model (Michie et al., 2014) and TDF (Cane et al., 2012) provided recognised theories for structuring the qualitative work in Chapter 5. The COM-B model, as part of the BCW (Michie et al., 2014), is a recognised starting point for intervention development, that has previously been applied to other health behaviours such as medication adherence (Jackson et al., 2014), childhood weight management (Curtis et al., 2015) and the Mediterranean-DASH Intervention for Neurodegenerative Delay (MIND) diet for cognitive protection (Timlin et al., 2021).

Using a qualitative methodology to explore the barriers and facilitators to healthy eating in cancer survivors, enabled participants to consider and discuss all relevant factors of the COM-B, rather than limiting them to a finite number of influencing factors, which a quantitative design would have (Keaver et al., 2023a). This enabled a systematic analysis of intervention functions most likely to be effective in changing the identified target behaviours (Michie et al., 2014). Therefore, improving the chance of effectiveness and potentially optimising resource allocation.

By utilising the MRC framework for complex interventions, the value of the studies in this thesis in contributing to the development of interventions is signposted (Skivington et al., 2021). The MRC framework was updated in 2021 to include a greater focus on interventions

designed for health service delivery (Skivington et al., 2021) thereby making it more relevant to nutrition intervention research.

Recruiting stakeholder participants in publication 11 and recruiting from an existing study for publication 14 could be viewed as both a strength and a limitation. Publication 11 required a motivated PPI panel who would take the time to review and provide feedback on the intervention materials and patient toolkit and therefore having access to an existing PPI panel was extremely beneficial. For publication 14, by recruiting participants who had taken part in another nutrition-based study it is likely that we recruited a sample of participants with very positive views towards nutrition and therefore may not be reflective of the general cancer population. This limitation, however, is very common in nutrition research.

Additional methodological strengths included utilising validated tools where appropriate in quantitative studies, enhancing the validity and reproducibility of this research (Appendix 8). The standards for reporting qualitative research reporting guidelines were used for all qualitative research (O'Brien et al., 2014). To add to the robustness of the systematic review, the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) guidelines were used (Page et al., 2021).

The findings have been translated into practical advice for HCPs and disseminated through inclusion in professional magazines (Keaver, 2021b; Keaver, 2022). Information on the dissemination and reach of these articles is included in Table 6.2. The findings have been developed into ready to use resources for cancer survivors (Appendices 4-6). Important contributions to knowledge, policy and practice have been made, outlined further in section 6.4. This research has led to collaborations locally (Sligo University Hospital, Atlantic Technological University, Letterkenny University Hospital, Cavan-Monaghan Hospital), nationally (Ulster University, EduFIT Portlaoise) and internationally (Tufts University, Tufts Medical Centre and Boston University, USA). It has laid the foundations for future collaborative work, outlined in section 6.6.

6.3.2 Limitations

Most of the studies were conducted in Ireland, therefore, the findings may not be applicable to other countries. However, the findings from both Ireland and the USA were similar. This included a lack of advice being provided from HCPs to patients and survivors; an awareness

by patients/survivors and HCPs of the importance of nutrition; a desire for more evidence-based advice; and that the role of HCPs should be to champion nutrition interventions and resources. Similar findings have also been reported in the UK (Matsell et al., 2020; Murphy et al., 2021), Spain (Llaha et al., 2022), Australia (Furness et al., 2021; Baguley et al., 2023) and New Zealand (Peniamina et al., 2021). The results presented in this thesis could therefore have relevance to other countries also.

The HCPs that took part in the studies in this thesis could be HCPs with a greater interest in nutrition than those who chose not to take part. Self-selection bias in research can be an issue leading to a cohort that may not be representative of the population (Guo et al., 2017; Keiding and Louis, 2018). If those recruited for the publications presented in this thesis are not reflective of the wider population, it might partly explain the current lack of integration of nutrition into standard oncology-care.

The development and piloting of the *Nutricare* intervention took place in the USA and would need further refinement to have content, units and food items updated to reflect an Irish context (Moore et al., 2021). To date the *Nutricare* intervention has not been adapted for an Irish cancer population but the research conducted determining barrier and facilitators to healthy eating and preferred intervention content and delivery modes should inform adaption prior to testing of this intervention with cancer patients in Ireland (Keaver et al., 2023a; Keaver et al., 2023c).

The use of behaviour change theory within research can contribute to interventions that are more likely to be effective (Davis et al., 2015). The BCW was utilised in one study (publication 13, chapter 5) alongside the COM-B model and TDF (Keaver et al., 2023a). However, this should have been more extensively applied across the entire body of work from inception to inform the intervention design. It should be noted that the COM-B does not consider the broader aspects of optimising, experimenting or evaluating the intervention to optimise implementation. The application of the MRC framework to the thesis addressed this by indicating important questions at each stage of development to assist in the refinement of the research design and intervention to better achieve the goal of implementation of nutrition advice into practice. Viewing the research through the lens of the MRC framework highlighted the absence of one of its core elements – that of economic considerations (Skivington et al., 2021). While outside the remit of this thesis, it is planned for the next phase of this work. A cost benefit analysis of the proposed intervention is important to ensure that the full range of health and non-health cost and benefits are determined (Kim and Basu, 2021).

A heterogenous sample of cancer survivors were recruited to the studies, which does not take into consideration the nuances of distinct NIS and nutrition needs for different cancer types or populations (Ravasco, 2019). For example, those with head and neck cancer may be more likely to experience difficulties chewing and swallowing (Bozzetti and Cotogni, 2020) while those with digestive cancers are more likely to experience digestive tract impairments (Vitaloni et al., 2022).

Most of the studies, despite being open to all cancer survivors, typically comprised of well-educated breast cancer survivors. There is a need to determine how best to recruit a more diverse sample of cancer types and education levels. Women with breast cancer tend to be a highly engaged group (Thorne et al., 2023) and younger female cancer survivors are more willing to complete web-based nutrition surveys (Keaver et al., 2019). In addition to social media recruitment for studies, potentially targeting social media forums of specific cancer types or recruiting through community-based organisations may lead to more diverse recruitment, including cancer types other than breast cancer, older males and more socially disadvantaged individuals.

6.4 Implications for knowledge and practice

Set within the development and feasibility phases of the MRC framework for developing and evaluating complex interventions (Skivington et al., 2021), this research has significantly developed the evidence-base for the provision of nutrition advice in oncology care as evidenced in section 6.4.1. Implications of overall thesis findings for knowledge, practice and policy will now be discussed, complimenting the discussions within each of the individual published papers.

6.4.1 Contribution to knowledge

The studies in this thesis have significantly contributed to the field of nutrition and oncology, with 14 peer-reviewed publications in high impact international journals and one conference abstract. To my knowledge, this thesis encompasses the first systematic review exploring the experiences of patients with cancer in receiving dietary advice from HCPs, and of HCPs in providing this advice (Keaver et al., 2023d). It also includes the first Irish explorations of the provision of nutrition advice to those with cancer from the perspective of HCPs (Keaver et al.,

2018; Keaver et al., 2021a), barriers and facilitators to healthy eating in cancer survivors (Keaver et al., 2023a) and intervention preferences of cancer survivors (Keaver et al., 2023c). This thesis clearly depicts that HCPs are not consistently providing nutrition advice in routine practice to meet patient expectations, creating a gap in person-centred care for this patient population.

This work comprehensively assessed a range of easily accessible sources of nutrition information for those with cancer. Assessing nutrition guidance and readability and usability of national and international websites, as well as apps enables the exploration of currently available nutrition information those with cancer might access when searching. This is important as the internet is a primary source of information (Shea-Budgell et al., 2014; Keaver et al., 2021c). It was clear that there is a lack of high-quality, evidence-based nutrition advice available, even when accessing national health service and cancer charity websites (Keaver et al., 2020a; Keaver et al., 2021b; Keaver et al., 2022b).

This thesis presents the development and piloting of a novel, theory driven intervention, underpinned by the established 5-A model to integrate nutrition into cancer care (Keaver et al., 2020b; Keaver et al., 2020c). This intervention had a positive impact on physical function in a short timeframe (6 weeks). This is an important finding, given that reductions in physical functioning are associated with impaired mobility and independence, as well as a greater risk of adverse outcomes and mortality (Brown et al., 2017; Eekhoff et al., 2019).

The work presented here has been widely recognised and contributed to increasing the knowledge of cancer survivors, HCPs and students across a range of healthcare disciplines. A number of dissemination opportunities have been accepted to enhance the impact of the research to include a nutrition workshop to cervical cancer survivors by 221Plus, which is a national patient support group set up to support individuals directly affected by failures in the CervicalCheck Screening programme (<https://221plus.ie/>). The workshop took place in April 2023 and integrated findings from this thesis, namely a desire for nutrition guidance (Keaver et al., 2020b; Keaver et al., 2023d; Keaver et al., 2023e), practical strategies to integrate same (Keaver et al., 2023e), simple recipes (Keaver et al.) and an overview of how to determine if information is evidence-based (Keaver et al., 2023e). This workshop was recorded and is available on the 221plus website which is accessed by over 300 members. The videos on fatigue

and accessing evidence-based nutrition information have also been included in this website (Appendix 4).

Publication 11 was recently highlighted as a key resource in a MyNutriWeb webinar and webpage on eating well after cancer (MyNutriWeb, 2021), demonstrating global relevance (Keaver et al., 2020b).

I was invited as one of four Irish speakers at a showcase for the European Federation of the Association for Dietitian (EFAD) conference in October 2021. This online conference was attended by 416 dietitians and HCPs from across Europe with recordings now available on the EFAD learning library, an online platform designed to make knowledge accessible to all European dietitians and dietetic students. I was also invited to present my work to the EFAD oncology network and at local and national hospital and academic conferences (outlined in Table 1.1).

The findings presented in this thesis have also been integrated into my teaching of two clinical nutrition modules on the BSc Human Nutrition at the Atlantic Technological University Sligo. This ensures that students are aware of the most up to date research in the area of nutrition and cancer, while gaining an insight into local, national and international research. I have been invited to present this work as a visiting lecturer on the Preventive and Cardiac & Pulmonary rehabilitation suite of MSc programme classes at the National University of Galway (2020 to ongoing). I was also chosen as one of five researchers in the ATU to present my research to visiting faculty from the Georgian college, Canada who are interested in establishing professional relationships and collaborations in Ireland (March 2023).

6.4.2 Contribution to practice

Preliminary data from several publications from this thesis were used to develop a case study that was submitted to senior management in the Health Service Executive highlighting the need for an oncology specific dietitian in Sligo University Hospital (SUH) in 2020 (Keaver et al., 2021a; Keaver et al., 2023e). The role was approved and the first oncology specific dietitian in SUH was hired in October 2022 demonstrating the impact of this research within a short timeframe.

Resources developed as part of this work have been incorporated into a website and app ([thisisGO](#)) led by the Mater Misericordiae University Hospital, Dublin, for women with gynaecological cancers. These resources have also been shared with 36 cancer support centres nationally (Appendices 4 and 5).

Texas Oncology are interested in implementing the *Nutricare* intervention into their clinics. For context they include 210 clinics across Texas and Southern Oklahoma. We are currently seeking funding to develop accredited training modules to accompany the intervention so that advance care practitioners can gain credits while also ensuring that they are confident and competent in delivering the guidance.

The *Nutricare* intervention was well received by cancer survivors in the USA (Keaver et al., 2020c). Aspects of the programme aligned with desired guidance of individuals with a cancer diagnosis and assistance required by HCPs (Keaver et al., 2020b; Keaver et al., 2021a; Keaver et al., 2022d; Keaver et al., 2023e). There is recent guidance available on adapting complex interventions to new contexts that may be helpful in adapting the *Nutricare* intervention for use in Ireland (Moore et al., 2021). The active ingredients identified in publication 14 could inform some of this adaption (Keaver et al., 2023a). The broader feasibility of the proposed route of delivery e.g. HCP led should be considered as the pilot was dietitian led based on focus group feedback with challenges for the medical team to follow up with phone call – therefore alternative routes of delivery e.g. online should be explored.

6.4.3 Contribution to policy

An important implication for policy that arose from this body of work is the need for greater funding and resources to improve the nutrition knowledge and confidence of HCPs and to increase the provision of nutrition advice to those with cancer. Lack of resources was identified as a key barrier to the provision of nutrition advice in publications 1, 3, 11 and 13 (Keaver et al., 2020b; Keaver et al., 2021a; Keaver et al., 2022d; Keaver et al., 2023d). It has also been recognised in national and European reports (Department of Health, 2017; Erickson et al., 2023)

A recent European consensus statement and policy brief, written by dietetic experts from several countries and focussing on the importance of nutrition care as an integral part of person-centred medical care (Erickson et al., 2023) cited three of the publications presented in this

thesis, highlighting their relevance to clinical practice and policy at a European level (Keaver et al., 2020a; Keaver, 2021a; Keaver et al., 2021a).

6.5 Reflexivity

6.5.1 Personal

When I started the research that has been included in this thesis I was a dietitian with work experience in clinical and public health nutrition, limited experience as a research assistant and publications from my undergraduate and masters theses. I had the opportunity to run a randomised controlled trial looking at the health impacts of chronic peanut consumption in Purdue University in Indiana for my undergraduate research project, an experience that '*sowed the seed that has now flourished*'. I then gained some experience in dataset exploration and microsimulation modelling in obesity for my master's thesis, the publication of which has been cited 129 times. I was full of enthusiasm but despite these early experiences and successes, I was full of self-doubt and uncertainty. I had no experience in undertaking systematic reviews, qualitative research or supervision of research students. In the last five years I have evolved as a researcher but also as an educator, mentor and person.

Prior to undertaking this body of research, I had only ever conducted quantitative research. When the opportunity arose in Boston to undertake qualitative work, I was in fear! I always viewed qualitative as a paradigm I couldn't understand, however, I was trained by Professor Sara Folta and it honestly opened a whole new world for me. I try to incorporate qualitative aspects in my work now to really understand the why of human behaviour.

I have realised the huge role that good mentors play in career development; something I have been so lucky to benefit from and something I try to emulate. This led to me being awarded an Irish Research Council award for mentorship in 2021, which was really special.

I have also grown in research recognition, being named as Irish Research Dietitian of the Year in 2021 and having two of the papers presented in this thesis short listed by the Royal Academy of Medicine in Ireland for oncology paper of the year in 2022 and 2023 (Keaver et al., 2021a; Keaver et al., 2023e). I was asked to speak at a university wide 'research sprint' for staff in

June 2021 on the use of surveys in research. I have not only had the opportunity to develop my research skills but also to become involved in several national and international groups and committees influencing research priorities, policy and practice. These have been outlined in Table 6.3.

Table 6.3 Contributions and involvement with national and international organisations

Organisation	Description	Role
European Federation of the Associations of Dietitians (EFAD) oncology network.	To support dietitians and enable the exchange of knowledge and practice with the committee and between member National Dietetic Associations.	One of eight dietitians across Europe chosen for a three-year term commencing 2021.
Irish Cancer Society Cancer Survivorship Hubs.	It is an aim of the National Cancer Strategy to develop and implement survivorship care programmes (Department of Health, 2017). Currently the first hub in Beaumont, Dublin is being run as a pilot.	One of six individuals chosen nationally to form the dietetic and nutrition steering group. Providing nutrition input into the development of cancer survivorship hubs in Ireland.
Irish Nutrition and Dietetic Institute Cancer network.	Network for those working or interested in nutrition and cancer. Facilitate CPD in the area as well as networking and support. Currently working on webinars for all HCPs in malnutrition screening in the oncology setting.	Member of steering group (4 individuals).
Irish Nutrition and Dietetic Institute Research Steering Committee.	Encourage dietitians to undertake research by providing training, support and an annual research conference.	Member of steering committee.
All-island cancer research institute.	Cross-border research programme, uniting institutions, researchers and other key stakeholders, with the	Member.

	aim of reducing fragmentation in research, diagnosis and treatment of cancer.	
NutriPD network.	Network of nutritionists, seeking to develop and grow professional competence in nutrition in Ireland.	Member.
Institute and School ethics committees ATU.	Safeguard the health, welfare and rights of human participants and researchers in research studies.	Founding and current member of both committees.

6.5.2 Cancer survivorship

My understanding and use of the term ‘cancer survivor’ changed and evolved through the undertaking of the work presented in this thesis. Initially, I viewed cancer survivorship as referring to the period post primary cancer treatment, a distinct phase in the cancer journey that in an Irish context had little to no nutrition data available at the time I started. A definition which is in line with that of the Institute of Medicine in their book ‘from cancer patient to cancer survivor’ (Institute of Medicine and National Research Council, 2006) and the national scoping review of the unmet needs of cancer survivors in Ireland (O’Connor and Donnelly, 2019). This definition was used for recruitment of individuals for the studies included in the thesis. However, I now understand how much more complex the term cancer survivor is and that it is impossible to define it as one point in the cancer journey. While recruiting ‘cancer survivors’ for qualitative work they often spoke of issues that presented at all stages of their journey, not just post treatment. Therefore, the findings are relevant not just to the post treatment phase but also earlier e.g. prehabilitation or at diagnosis. There is also complexity in the fact that many ‘survivors’ may have completed active treatment but are still receiving treatments such as hormonal therapy for instance. Therefore, I now share the view of the American Cancer Society and the Irish National Cancer Control programme that cancer survivorship starts at diagnosis (American Cancer Society, n.d.; Health Service Executive, n.d.,-a). However, I recognise there is still a need for research to highlight the distinct issues and needs at each stage/phase. It must also be acknowledged that the term cancer survivor is

not adopted by all, with some finding it stigmatising (Surbone et al., 2013). Language is so important, and it is very clear that ‘cancer survivorship’ is complex.

6.5.3 Use of frameworks and theories

By applying the MRC framework, retrospectively, this body of research clearly contributes to the development and feasibility phases deepening our understanding of how best to integrate nutrition into standard oncology care. I became more familiar with available frameworks and theories as well as their role in intervention development in recent years and was able to utilise the BCW framework alongside the TDF and COM-B model in chapter 5 to contribute insights into the active ingredients necessary to change behaviour around healthy eating in cancer survivors. On reflection, I would have utilised the MRC framework from the start (2018) to provide structure to the work presented in this thesis while integrating the BCW, in particular aspects of the COM-B model and TDF in the development phase of the intervention. Moving forward, the MRC framework can be applied in the refinement, implementation and evaluation of the nutrition intervention.

6.5.4 The impact of the COVID-19 pandemic

Initially the COVID-19 pandemic seemed to assist in survey recruitment (for studies I was involved in), with one cancer survivor survey moving online and recruiting over 170 participants and another global student survey recruiting over 2250 students (Du et al., 2021; O’Callaghan et al., 2022). However, less than a year later a survey targeting the same cohort as the first study (cancer survivors) only recruited 51 participants despite being open and promoted for much longer (at least six months longer) (Keaver et al., 2023c). This was not unique to this study with other researchers pointing to survey fatigue as an issue (de Koning et al., 2021). This did make me think more about recruitment and planning and the need to not target the same population repeatedly. While it is important to undertake research and to explore new areas in nutrition and cancer from the perspective of those with cancer, it is also necessary to be mindful of the value of everyone’s time and to not burden unnecessarily. On reflection, in the future I will think more strategically about the research aims for the coming years to ensure that ideas can be combined where appropriate to avoid over recruitment or to

prioritise what is worth focussing on and a good use of participants time (a real need) versus what is less useful albeit interesting (more of a want).

6.5.5 PPI involvement

PPI is an important part of all research and becoming a requirement, quite rightly, of many funding bodies. While I attempted to obtain the views, perspectives and feedback of both those living with and beyond cancer and HCPs throughout this body of work, I feel that this could have been implemented in a more structured and comprehensive format. While current experiences of the patient are included throughout this work and I obtained cancer survivor feedback on the *Nutricare* intervention and resources prior to running the pilot study, I did not include cancer survivors in the development of the intervention itself. I had initially applied for a Fulbright scholarship to allow me to spend a year in Tufts University in Boston where I would develop and pilot a nutrition intervention with the aim that an RCT would also be developed. I learnt in March 2018 that I had not been successful, however Prof Zhang agreed that the work was still valuable and worth undertaking so in order for me to be able to run the focus groups and pilot work in Boston I needed to have the intervention ready to go for July 2018 so I could spend my 8 weeks summer holidays onsite in Tufts University. This accelerated timeline ruled out the inclusion of external involvement. However, I have seen over the years since, the importance of PPI and it is a testament to Irish research that some of our main funding bodies now put a large focus on this. As I pursue a research career, any involvement in intervention development will have PPI involvement from inception. I have seen what a difference it makes in ensuring that the right messages are being delivered and the actual issues that are experienced are addressed. On conducting work with cancer survivors (Keaver et al., 2022c), we found that many had residual NIS, before that work I would likely have assumed these would be largely resolved and not addressed them when delivering workshops or talks. The body of work presented in this thesis has therefore, not just informed my future research practice, but my dissemination and teaching work also.

6.6 Future research

Outside of the hospital environment, informal carers such as family and friends provide a large proportion of care to those with cancer (Sun et al., 2019). Papers presented in this thesis have shown family and friends to be one of the main sources of nutrition information to those with

cancer (Keaver et al., 2023d; Keaver et al., 2023e), therefore qualitative work to better understand the role of family and friends in sharing nutrition advice as well as the type, content and main sources of this advice would be useful.

The earlier studies conducted as part of this thesis focussed on the interactions between HCPs and those with cancer, primarily within the hospital setting. Future research could build on this by exploring the experiences and perceptions of nutrition advice and support within community-based settings, such as cancer support centres, where many individuals with cancer may access support (National Cancer Control Programme, 2020; Bowen and Naughton, 2021).

Further information to assist in the adaption of the Nutricare intervention in Ireland has also been presented (Keaver et al., 2023a; Keaver et al., 2023c). Pilot and longer-term trials to determine the acceptability, feasibility and effectiveness of the modified intervention with an Irish cohort are necessary. Inclusion of carers as well as cancer survivors would be important (Hiatt et al., 2022). Given the findings that clinicians and doctors feel their role is to champion interventions/resources (Keaver et al., 2020b; Keaver et al., 2022d), a lack of dietetic resources currently (Thompson, 2019), and an openness to online interventions (Keaver et al., 2023c), exploring the adaption of Nutricare as a self-directed online programme that could be signposted to by HCPs is worth investigating (Seynstahl et al., 2023).

There is a need for research to determine the long-term nutrition needs of cancer survivors to help inform cancer survivor specific guidelines and recommendations for practice. A longitudinal study design which will allow for a comprehensive exploration of changes overtime (weight, body composition, malnutrition risk, NIS, handgrip strength for example) would help to better understand the long-term nutrition related impacts of cancer and inform appropriate, timely and useful interventions.

Addressing the lack of confidence and competence of HCPs in providing nutrition advice is important. I am a principal investigator for the *nutRition knOwledge AttituDes and coMPetence in heAlthcare Professionals (ROADMAP)* research group which is an ATU wide research team currently addressing this research question in primary healthcare teams. We have recently assessed the nutrition content of training curriculums and the presence of nutrition within HCP standards/competencies (McMonagle et al., 2023). We have just received ethical approval to undertake a quantitative assessment on the knowledge and skills of primary care HCPs as well as qualitative interviews to better understand facilitators and barriers to provision of nutrition advice and what nutrition training would be beneficial. This will then lead to the

development of CPD modules in nutrition designed specifically for the needs of primary care HCPs.

6.7 Conclusion

Set within the development and feasibility phases of the MRC framework for developing and evaluating complex interventions (Skivington et al., 2021), this research has developed the evidence base for the provision of nutrition advice to those with cancer, in particular cancer survivors. This work presents a novel contribution to the literature through its focus on both the patient/survivor and HCP experience of nutrition advice in oncology.

Findings offer a number of practical insights into the delivery of nutrition advice in the oncology setting. Findings show a current lack of nutrition advice provision by HCPs, despite a desire for this information from those with cancer and an awareness of the importance of nutrition by HCPs. The development and piloting of the theoretically underpinned *Nutricare* intervention provides insights into the feasibility of such an approach.

Key areas that could be targeted in future nutrition interventions to remove barriers to healthy eating among cancer survivors were determined. Preferred mode, timing, content and delivery of a nutrition intervention and the role that doctors feel they can play in this have also been outlined.

The remaining gaps in the literature and considerations for future research have been highlighted, offering opportunities to build on the knowledge gained in this thesis to further contribute to understanding how best to integrate nutrition into cancer care.

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Appendices