



NCCP Cancer Survivorship Stratified Self-Managed Follow up Framework





The purpose of this document is to define a framework which changes the way we address follow up care and services for cancer patients in Ireland.

Foreword – National Director NCCP



Risteárd Ó Laoide
National Director NCCP

It is my privilege to introduce the National Cancer Control Programme's Cancer Survivorship Stratified Self-Managed Follow up Framework.

The purpose of the framework is to provide a pathway to improve the lives of cancer patients and enhance their experience and access to quality care. Cancer care is a complex process that often continues long after the initial diagnosis and treatment. For cancer patients, ongoing follow up care is essential to monitoring their health, detecting any potential issues, and ensuring they receive the support they need to maintain their physical and emotional wellbeing.

The Stratified Self-Managed Follow up Framework represents a significant step forward in addressing these challenges. The framework identifies and defines the steps in implementing a new model for cancer patients to meet their follow up needs. By using a stratified and evidenced based approach to follow up, the framework empowers survivors to take a more active role in their care and provides a personalised, flexible, and sustainable way to monitor their health and wellbeing.

Stratified Self-Managed Follow up is aligned with recommendations in the National Cancer Strategy 2017-2026 and its continued implementation. We are very grateful for the enthusiasm for change and innovation amongst the cancer clinical community and their willingness to develop new approaches to follow up, always keeping the patients' needs and preferences at the centre of change initiatives.

I would like to take this opportunity to recognise the many individuals and organisations who contributed to the development of this framework. I want to thank the Clinical Leaders, dedicated healthcare professionals, and committed patient partners who contributed their expertise and insight to this framework. My thanks to the NCCP Survivorship and Nursing Teams who have championed this approach for many years. I would particularly like to acknowledge the leadership of Louise Mullen, National Lead for Cancer Survivorship and Terry Hanan National Clinical Lead for Nursing, Bernie O'Loughlin Programme Co-ordinator for Cancer Survivorship and Cathleen Osborne ADON Survivorship for driving the development of the framework.

Finally, I would like to express my sincere hope that this framework will help patients across the country who have come through a cancer diagnosis to live full and healthy lives, with the support and resources they need to thrive. I believe that this initiative will be of benefit and a step forward in cancer care, and I look forward to seeing its impact in the years to come.

Risteárd Ó Laoide
National Director NCCP

Foreword – Lead for Cancer Survivorship

The number of Irish people diagnosed and living with and beyond cancer has exceeded 200,000 (NRCI). The National Cancer Strategy 2017-2026 identified a number of recommendations that emphasise the importance of cancer survivorship and quality of life of patients living with and beyond cancer.



Ms Louise Mullen
National Lead for Cancer Survivorship NCCP

The NCCP Survivorship Programme has been focussed on growing the support and services for cancer survivors using the National Cancer Survivorship Needs Assessment as a blueprint. One of the key actions identified in the Needs Assessment was the transformation of the patient pathway to better meet the needs of people diagnosed with cancer in the post-acute treatment period. Evidence internationally has shown that patients benefit from a personalised approach to care and that many patients can successfully self-manage when appropriate supports are put in place. This benefits both patients and the services. Patients receive a more individualised approach to having their needs identified and met and services can increase capacity to see the growing number of patients and patients with complex needs.

I have been privileged to learn from the model of Stratified Self-Managed Follow up after full implementation already in place in a number of international locations. I believe this evidence-based model will empower cancer patients with tools for self-management. We are grateful to international colleagues in England and Northern Ireland who have given generously of their time and expertise.

It is exciting to see this work begin and I look forward to the progress that can be made in the coming years. I would like to thank my NCCP colleagues and the patient and public groups who have consulted, reflected and inputted into this framework. This Framework was presented and discussed with the Cancer Patient Advisory Committee in The Department of Health and their considerable engagement was crucial and very helpful. Their work has helped us to write this framework and to consider how implementation can be facilitated. The continued engagement of all these stakeholders will be critical to the implementation of this framework and I look forward to sustaining that strong collaboration in the future.

A handwritten signature in black ink, appearing to read 'L. E. Mullen', written in a cursive style.

Ms Louise Mullen
National Lead for Cancer Survivorship NCCP

Acknowledgements

We would like to acknowledge a number of individuals and groups who contributed to this work including; Eileen Nolan, Fiona Bonas, Clare Leatham, Survivorship Programme Team, Nursing Team, Eve O’Toole and the Evidence and Quality Hub, Cancer Patient Advisory Committee, Department of Health Cancer Policy Unit, Professor Alison Richardson University of Southampton and the NCCP Survivorship Steering Group. We are grateful for your time and insights into this project over a lengthy gestation.

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NCCP Survivorship Programme – Stratified Self-Managed Follow Up

The purpose of this document is to define a framework which changes the way we address follow up care and services for cancer patients in Ireland. As the number of cancer survivors grows, cancer becomes a chronic disease for many.

There is a growing international evidence base that using a stratified approach to develop a more personalised pathway is appropriate for both supporting patient quality of life in survivorship and the efficient running of cancer services.

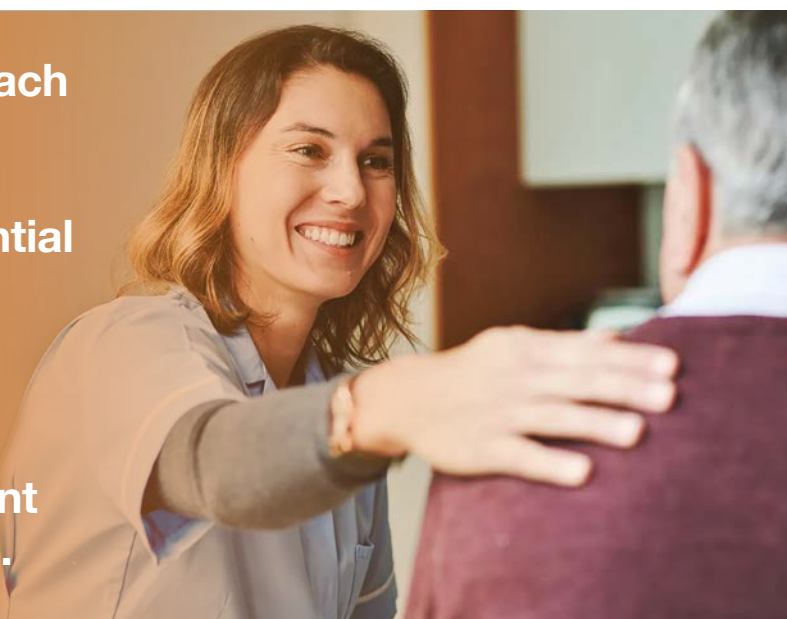
The aim of stratified self-managed follow up is to adopt a more personalised approach to delivering post treatment cancer care for patients based on their needs. Stratification of follow up for cancer patients is described as ‘a personalised approach to care in which cancer survivors are triaged or stratified to distinct follow up care pathways based on their needs and the type of follow up agreed with their treating team’¹.

Patients’ needs are assessed holistically, taking into account physical, psychological and social factors, rather than just the symptoms of a disease.

Patients are included in the decision making on which distinct care pathway is most suitable for their needs. The availability and signposting to services and supported self-management are part of this pathway.

A stratified approach and personalised follow up can address the essential components of survivorship care with patients and caregivers, while being safe, efficient and cost effective. The added value of this approach is not only beneficial for patients but also for acute hospital services. It will address the increasing pressure on the Rapid Access Clinics (RACs) and oncology units by reducing routine return visits and freeing up clinic capacity for newly diagnosed patients allowing patient referrals that are more urgent to be seen within nationally agreed timelines.

A stratified approach and personalised follow up can address the essential components of survivorship care with patients and caregivers, while being safe, efficient and cost effective.



Introduction and Background

In Ireland, improvements in cancer treatment and earlier detection of cancer have contributed to ongoing increases in the average survival of cancer patients.

The number of patients living after an invasive cancer diagnosis has now exceeded the 200,000 mark, which is equivalent to 1 in 24 people in Ireland².

Survival for Irish cancer patients continues to improve. Five-year net survival for patients based on follow up during 2012-2016 averaged 63% for men and 61% for women (excluding non-melanoma skin cancers), up from 39% in men and 46% in women diagnosed during 1994-1999. Significant survival improvements are evident for most types of cancer³.

The growing population of cancer survivors has implications for health service provision in relation to follow up and maximising the quality of life of cancer patients.

The National Cancer Strategy 2017-2026 recommends investment into survivorship services to provide optimal care for cancer patients⁴. The key recommendations for optimising patient survivorship care include: providing an integrated model of care for follow up and surveillance; addressing the consequences of cancer and its treatments; supported self-management and survivorship programmes, see Figure 1.

Figure 1. Strategic Alignment to the Recommendations of the National Cancer Strategy

Strategic Alignment to the Recommendations of the National Cancer Strategy 2017 to 2026

Recommendation 12

The NCCP will further develop the model of care for cancer to achieve integration between primary care and hospital settings at all stages of the cancer continuum, from diagnosis to post treatment care.

Recommendation 34

The NCCP will ensure that each hospital has a clearly defined framework for cancer patient safety and quality.

Recommendation 42

The NCCP, in conjunction with the cancer centres, will develop shared care protocols for patients with cancer following treatment. These protocols will span the hospital and primary care settings.

Recommendation 43

Designated cancer centres working with the NCCP, the ICGP, primary care services, patients and voluntary organisations will develop and implement survivorship programmes. These programmes will emphasise physical, psychological and social factors that affect health and wellbeing, while being adaptable to patients with specific survivorship needs following their treatment.

The 2019 National Cancer Survivorship Needs Assessment⁵ refers to the ALLIES model of cancer survivorship care (Appendix 1). This model was generated from original research conducted with Irish healthcare professionals following a review of literature of international models of care and patient input^{5,11}. The model proposes the development of supports and services that meets the needs of Irish cancer patients. The ALLIES model of care identified a number of key underpinning principles relating to a survivorship pathway including the need to: assess; link in and link out and onward; inform; empower; and deliver timely access to support and services. Central to this model is person-centred care based on stratification. Some of these services do not currently exist, or are available in some areas but not others. Implementation of a standardised approach to services and development of supports that follow the patient pathway is necessary to meet the needs of cancer patients and their families in a more comprehensive way. Information, signposting and education are also key elements of the model.

Research suggests that different models of follow up are acceptable to patients, once they are informed of the risks and benefits, given a choice and have a clear way to access further support¹. A 2019 report on The Unmet Needs of Cancer Survivors in Ireland⁵ highlighted the importance of developing survivorship care plans to address the specific needs of cancer patients, including needs in the physical, psychosocial, practical, and spiritual domains. The authors note that for cancer survivors there is no 'one size fits all' and a range of services and supports are needed to meet individual needs. The report also suggests that routine follow up care and surveillance by standardised protocols individualised to the patient can be delivered safely with appropriate care planning.

The report recognised the need for a more sustainable model and primary and community care must be supported to increase its involvement in follow up care. This can be achieved with the provision of standardised pathways, appropriate guidelines, educational support, appropriate funding models, clear lines of communication, and access back to the hospital setting as required⁵.

A 2019 report on The Unmet Needs of Cancer Survivors in Ireland highlighted the importance of developing survivorship care plans to address the specific needs of cancer patients, including needs in the physical, psychosocial, practical, and spiritual domains.





International Practice

Internationally a number of countries have introduced a stratification process to manage the patient pathway in the post treatment period.

Since personalised stratified follow up was introduced in the UK it is reported that people are having their needs met in a more-timely manner and are better informed about their disease, treatment, signs of recurrence and any longer-term effects. With an increased focus on health and wellbeing, they are being supported to make healthier lifestyle choices and manage their care better⁶.

The introduction of personalised stratified follow up in the UK is already allowing a substantial volume of outpatient appointment slots to be redeployed for new referrals and people with complex needs. A significant proportion of breast, colorectal and prostate cancer patients have moved to supported self-management pathways with remote surveillance and guaranteed access back to their cancer team when needed. The prediction is that at least one million slots will be repurposed over the five years of the NHS Long Term Plan to redesign patient care^{7,8}.

A USA-UK summit on personalised stratified follow up also concluded that current follow up care models (focused on detecting cancer recurrence) are inadequate, and that people report numerous unmet physical, functional, psychosocial and financial needs, leading to reduced work productivity, quality of life and survival⁶.

America is also looking towards the UK/ Northern Ireland as it is recognised that a new approach to cancer follow up care is necessary to meet the needs of cancer survivors while dealing with increasing volume and provider shortages, knowledge gaps, and costs to both health care systems and patients⁹. The National Cancer Survivorship Initiative in England conducted a pilot study, which demonstrated that 50% of patients with colorectal cancer, 80% of those with breast cancer, and 50% of those with prostate cancer who were treated with curative intent were able to self-manage post treatment¹⁰.

This NCCP Cancer Survivorship Stratified Self-Managed Follow up Framework will provide strategic direction to transforming the cancer patient pathway for the post treatment and survivorship period.

Aims and Objectives

Aim

The aim of the NCCP Cancer Survivorship Stratified Self-Managed Follow up Framework is to develop a standardised approach nationally to stratified follow up care after cancer treatment with a more personalised approach for cancer patients.



Objectives

- 1 Ongoing engagement and consultation with key internal and external stakeholders.
- 2 Standardisation of tumour specific follow up surveillance guidelines using the NCCP Evidence and Quality Hub (EQH) processes.
- 3 Scoping of 'as is' for pilot tumour site and mapping of patient pathway.
- 4 Develop stratification protocol in conjunction with the pilot cancer sites and mapping proposed new pathways.
- 5 Develop survivorship components of follow up care and support (education, supported self-management, resources) in conjunction with the pilot cancer sites and community sector.
- 6 Implement projects of stratified self-managed follow up in a number of defined sites.
- 7 Monitor, audit & evaluate the patient and service experience.
- 8 Develop a road-map for national implementation for stratified self-managed follow up across all relevant cancer treatment sites and tumour specific services.

Steps to Implementing Components of Survivorship Follow Up Care

Components	Proposed Actions	Steps
Surveillance for recurrence and new cancers	Standardise with assistance from Evidence Hub	National NCCP guideline/ guidance process
Functional status: identification of side effects/ long term effects of cancer and/or its treatments	Stratified model of care including supported self-management/ patient symptom pathways	Map existing practice Engage clinical sites Design and map personalised pathways; assessment and patient support Build capacity to meet needs – Appoint Patient Support Worker/ANP/CNS
Patient experience, wellbeing, holistic care, treatment summary and care planning	Development of information, signposting, supported self-management	Develop care planning models Integrate with existing support services (acute and community sector) Continued Implementation of LACES* Ongoing monitoring & evaluation of services being provided

* *Life After Cancer Enhancing Survivorship: information and signposting workshop for cancer patients developed by NCCP & ICS*

Standardisation of follow up and surveillance guidance

The NCCP Evidence & Quality Hub process of developing clinical guidelines is best suited to the production of a clinical surveillance guideline for a specific cohort. We will embed this process into new pathways for stratified self-managed follow up. Whenever possible the projects will run in parallel to maximise the benefit of standardised processes, evidence based practice and implementation.

NCCP clinical guideline modules will aim to standardise surveillance (test/scans, frequency and length of time of surveillance) for specifically defined cohorts suitable for stratified self-managed follow up model.

Follow up in the post treatment period is wider than surveillance for recurrence and late effects and includes, survivorship supports and assessment and management of functional status.

This wider survivorship follow up is more suitable for a standard protocol with recommendations and actions. These will be designed and drafted by the tumour specific working groups using evidence and practice from the literature, models of care, clinical knowledge and current Irish practice. Groups will be formed consisting of NCCP and clinical staff and present recommendations for clinical lead and NCCP executive sign-off.

Stratification

By offering a stratified approach and personalised follow up, essential components of survivorship care can be addressed with the patient and caregivers. Patients will be assessed and then guided along distinct care pathways based on how complex their needs are, and who should be providing their follow up care. Patients will be encouraged to and supported in playing an active role in their recovery and management.

During the scoping phase of projects, it will be necessary to determine the current protocols and processes being used for follow up and surveillance in the RACs and in Ambulatory Day Units. In our experience, there can be significant variation in practice in both structure and processes. A survivorship pathway with supporting processes will be developed in collaboration with clinical expertise and NCCP stakeholder engagement.

Stratified Self-Managed follow up pathway

In order to ensure the delivery of a personalised stratified follow up and the development of a supported self - management pathway, certain processes will need to be developed:

- A clear pathway with agreed protocols and agreed governance structures
- Identification of roles and responsibilities of surgical/radiation & medical oncology teams, GP and patients

- A review of needs and factors of the individual, treatment sequelae, existing comorbidities and capacity to self-manage
- A remote system to manage on-going surveillance tests
- Provision of the information and support needed to self-manage
- Good communication between specialist and primary care teams
- Clear system to re-access services in a timely manner, if required

Algorithms to triage patients

A process involving key stakeholders will agree standardised stratified pathways and establish criteria to assess and identify patients to each of the stratified pathways. When developing the criteria, factors relating to the disease, the treatment (or the effects of treatment), and individual circumstances that may affect pathway selection need to be considered. The pathway choice is a joint decision between the patient and the clinician. Written protocols will need to be developed and agreed within the team about how the stratified pathways will be defined, the process for referral to the pathway and how they will be managed operationally.

Suggestions include:

- Level of risk associated with cancer type
- Short and long-term effects of treatment
- Other co-morbidities
- Patient's ability to manage and social circumstances
- Level of professional involvement required
- Patient's choice
- Patients can move between the different levels of care as needs and degree of dependency change

Survivorship Components of Care

Methods to assess patient issues to guide care

Access to assessment, treatment and management of the long term and late effects of treatment are critical to quality survivorship care. An individual needs assessment is a process of identifying the needs of patients by focussing on the whole person and their well-being (covering physical, psychological, social, spiritual and financial issues). This gives the healthcare professional the opportunity to offer the patient timely support for a particular need and to refer them to the most appropriate individual or services if necessary. The outcome of the needs assessment should result in a care plan, which will be held by the patient. This could be in the form of a written diary or a patient held document e.g. Patient Passport, Patient Treatment Summary and Care Plan, Survivorship Care Plan.

It is recommended that assessment and care planning discussions are held around the time of diagnosis, and other key points in the pathway and that all patients have a written care plan. This will improve the information provided to patients and ensure early intervention and support.

Steps to implement needs assessments and care planning:

- > Engage key stakeholders
- > Map and understand the pathway and how and when needs assessments will be undertaken
- > Agree assessment tools and care plan documentation
- > Identify resources (staff, IT, space)
- > Identify any training needs
- > Develop a local 'directory of services' within the community

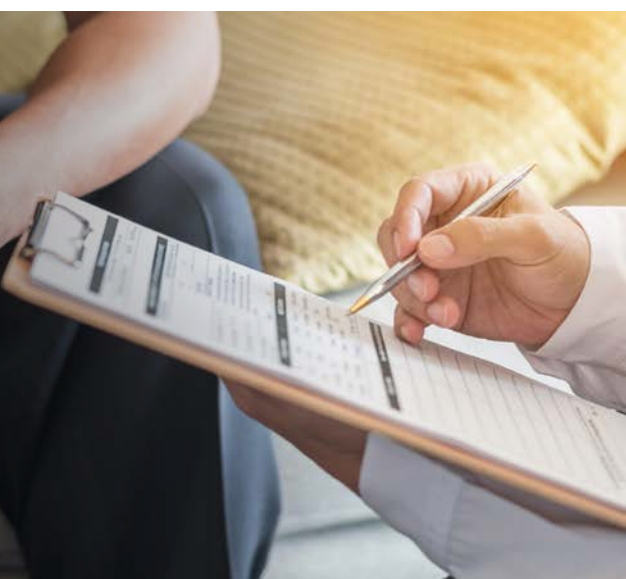
Ideally each assessment and care plan review should build on the previous assessment to reduce duplication and prevent patients being repeatedly asked similar questions.

Coordination of Care

Virtual platforms and systems for surveillance and follow up

Remote monitoring is a term used to describe how the specialist team schedule and monitor surveillance tests for patients who have completed treatment for cancer, without the need for a face-to-face outpatient appointment to convey the result.

Access to assessment, treatment and management of the long term and late effects of treatment are critical to quality survivorship care.



Its primary role is to support low risk patients treated with curative intent who are suitable for a supported self-managed pathway. Virtual platforms and systems can be used effectively for this purpose. Remote monitoring systems should hold sufficient information to enable the clinician to manage the patient without the need to access case notes.

Treatment summary and care plan

The treatment summary is a document produced by the specialist team at the end of active treatment and at other subsequent trigger points i.e. change of treatment. It is developed for the patient, copied to their GP and provides information on diagnosis, treatment, the short and longer-term side effects, the signs and symptoms of recurrence and the follow up surveillance plan in place. It is intended to be a summary for the patient and not a duplication of medical record. It also provides key contact details should there be any future worries or concerns. It may replace a clinic/discharge letter. It may be stored online as part of the hospital information systems and can be reprinted as required.

Steps to be taken:

- > Engage key stakeholders
- > Agree format and content
- > Agree the roles and responsibilities for completing and sharing the summary with the patient and their GP

Information, advice and support should be tailored to individual needs

In order for patients to have the confidence, knowledge and skills to empower them in their self-care, they should be referred to relevant clinical and non-clinical supports. This may include referral to members of the multidisciplinary team, peer support groups, community cancer support centres, cancer specific workshops/education programmes. The team must be aware of the availability of clinical support services and how to refer e.g. psychological support, physiotherapy, dietetics, occupational therapy, audiology. The team must also be aware of availability of non-clinical support services and how to refer e.g. physical activity programmes, benefits advice, local cancer support centres.

Methods to support patients in self-management

Supported self-management is about helping people help themselves through taking action to maximise their recovery and helping them to sustain that recovery. It aims to give people confidence and capability to move on from their cancer diagnosis and treatment and get on with living their lives. This does not mean they will be on their own, for many will be monitored from a distance and have timely access to support services when they need them.

Timely re-access to service

All patients under the clinical supervision of the specialist team should have rapid access back to a professional, if required.

Re-access may be prompted by the:

- > Patient or carer
- > GP

Systems to re-access the service should be clear to patients and responses should be timely. All patients should be provided with up-to-date contact details for a key person to contact.

Supported self-management is about helping people help themselves through taking action to maximise their recovery and helping them to sustain that recovery.

Responsibilities and Accountability

Role of the treating Consultant and Oncology team

The medical team will ensure that:

- The patient has sufficient information on the pathway choices available and that the options available have been discussed with them
- The patients' test results are reviewed and the results communicated to the patient and their GP in a timely fashion
- The patient is recalled in a timely fashion for any further tests and clinic appointments required following an abnormal test result
- Patients are referred to the multidisciplinary team and support services where appropriate
- Education support for patients and carers are organised and delivered
- Stratified care pathways are managed according to agreed Policies, Procedures, Protocols or Guidelines and within the agreed governance structure
- The patient receives information on how to re-access the service if they have a concern
- The patient's GP and other healthcare providers are informed of the pathway decision and who to contact in the cancer centre with any queries
- There is an agreed pathway for the GP or other healthcare providers to refer the patient back into the cancer service should the need arise and the patients will be seen within an agreed timeframe

Many of the pathways/steps outlined above will be nurse-led and aided by a patient support worker.

Role of the Patient

The patient will:

- Attend for their follow up appointments for scans, blood tests etc.
- Engage with the cancer centre as required for their follow care
- Contact the service or their GP if they develop a new symptom or have concerns
- Make the cancer centre aware if they change their GP

Role of the General Practitioner and primary care

The GP will:

- Contact the cancer service in the case where a patient reports a new symptom or they need advice or support in relation to patient care
- Facilitate patient investigations as required where possible



Performance and Monitoring

Before undertaking a stratification process and introducing changes to current patient pathways and service delivery, it is important to consider what the measures of success will be for this change and how they will be evaluated.

At the outset it is important to consider how evaluation and monitoring for potential impact on patient care and on service delivery will be achieved. It is critical to be able to demonstrate that introducing this change will better meet the cancer survivor's needs and will lead to an improvement in cancer service delivery.

A set of markers/metrics to facilitate reviewing patient satisfaction and tracking service delivery improvement will be developed. Before introducing the stratified self-managed follow up model, baseline measures for each marker/metric selected will be identified, taken, and re-measured at key points during the lifecycle of the project. In some cases, a survey will be undertaken to measure the baseline. In other cases, there may be existing data available. The expected change in result would also need to be identified and what steps will be taken if this improvement target is not achieved.

It is vital to gather feedback from patients and take their views and priorities into account to improve the quality of care. The improvement in the patient's quality of life can be measured using standardised quality of life questionnaires such as, EQ-5D and EORTC-QLQ-C30¹², which are examples of generic and cancer specific quality of life questionnaires available. A set of outcome measures should also be considered at the beginning of any project to implement a stratification protocol and care pathway. Any patient questionnaires or outcome measures agreed need to be measured at the same key points as outlined above. Consideration will be given to commissioning or conducting an economic evaluation.

These metrics should include, but are not limited to, the following:

Indicator	Why collect and measure
Improved patient experience	Improved quality of life and increased satisfaction with cancer service
% of new patients being offered an appointment within recommended timelines	Increased volume of new referrals seen within timelines as capacity is released
New to Return Ratio The ratio of new to return patients attending outpatient clinics	Reduction in the volume of return patients as capacity is released
Number and proportion of patients on the stratified self-managed follow up protocol	Implementation
All patients have received a summary of their treatments and follow up care plan at the end of active treatment (KPI 17 NCS: Offer patients with cancer a treatment summary and care plan. Target 95%)	Increased awareness of the treatments received and potential side effects or late effects as a consequence of treatment Increased awareness of the follow up surveillance plan in place
GP has received a summary of their patient's treatments and follow up care plan at the end of the patient's active treatment	Increased awareness of potential side effects and late effects of treatment and the follow up surveillance plan in place Increased satisfaction with cancer service

Following the successful implementation of the stratified model it is also important for services to consider how adherence to this model will be monitored on an ongoing basis.

Conclusion

The purpose of this framework is to provide strategic direction about the design, development and implementation of a more standardised approach to ensuring patients have protocols for routine follow up and surveillance. This includes access to support for physical and psychological symptoms, survivorship programmes and rapid re-access to acute services if needed. It can be achieved by providing an integrated model of care that uses personalised stratified self-managed follow up and surveillance for cancer patients.

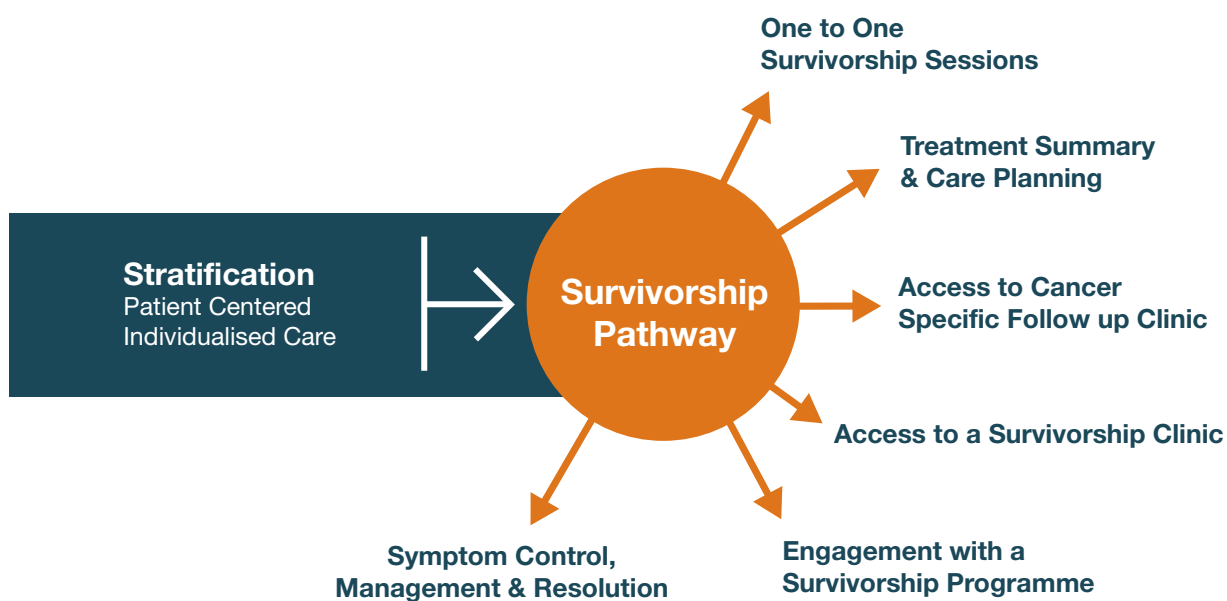
Initial focus will be on targeting patients completing treatment for prostate, breast, and colorectal cancers as these cohorts represent approximately two-thirds of the prevalent cancer survivorship population⁴. The sequencing and timing of projects will be determined by service readiness, capacity in services and resources to implement. The NCCP is committed to introducing stratified self-managed follow up pathways with the aim being to improve the cancer patient experience of post-treatment care and to redeploy a large number of outpatient appointments for new referrals and for patients with complex needs.

Appendix 1

ALLIES model of Cancer Survivorship Care Principles Across Pathway

ALLIES model of Cancer Survivorship Care Principles Across Pathway

Assess Link In Link Out/Onward Inform Empower Support Services



Living With and Beyond Cancer in Ireland | National Cancer Survivorship Needs Assessment, 2019

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Building a
Better Health
Service

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