

Guide on

# How to Implement a Nurse Navigation Programme for Cancer Patients

# Purpose of the guide

This guide outlines the key actions required to set up a Nurse Navigator Programme. It has been developed in the context of City Cancer Challenge's (C/Can) work in cities in low- and middle-income countries (LMICs)

There are significant disparities in cancer mortality and survival around the world, the causes of which have been identified as:

- late diagnosis
- poor access to high quality, affordable treatment
- inadequate health infrastructure and systems
- sociocultural, geographic, and financial barriers

Establishing Nurse Navigator roles in cancer care is a means by which to address these factors (Distinguished Professor Patsy Yates 2021, *Principles of Nurse Navigation in Cancer Care*, a paper presented at Nursing in Cancer Care TeleECHO™, City Cancer Challenge, 2021).

Nurse Navigators guide patients through the complexities of the health care system and are their link to the people and resources they require to meet their needs, from diagnosis through to end of treatment or end-of-life. Nurse Navigators are patient advocates. They are the patients' voice, eyes, and ears, to ensure nothing is overlooked. They act as a central point of communication between patients and all those involved in their care to enable timely access to appropriate health services when necessary.

This guide will identify the initial priorities for setting up a Nurse Navigation Programme in the cancer care setting. It will describe how to create a roadmap of what needs to be implemented to ensure the design and implementation of a successful Nurse Navigator Programme. To further complement this guide, a toolkit of resources/documents should be developed in collaboration with all key stakeholders to enable a consistent approach for programme implementation.

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# Introduction

Being given a cancer diagnosis is hard for the patient and their loved ones and it raises many challenges dependent on variables such as the individual, their diagnosis, treatment plan, place of treatment and the holistic needs. Negotiating the complexities of healthcare systems can be overwhelming. In addition to the physiological impact of cancer and associated treatments, people with cancer have psychological and social needs that may be undetected and unmet, which has the potential to cause long-term distress. Nurse Navigators have been widely introduced to provide a more streamlined experience for the patient by improving care coordination, identifying what patients require to manage their health care and helping them access the most appropriate services.

According to Cook et al (2013), nurses working as cancer navigators have three main areas of practice:

- ▶ providing information and education
- ▶ providing emotional and supportive care
- ▶ facilitating coordination and continuity of care

The scope of Nurse Navigators and which services they provide differs between health care facilities. Some Nurse Navigators manage specific tumour streams while others provide services across multiple tumour types. Some Nurse Navigators provide the full gamut of services while others may concentrate on connecting the patient to required people and resources, investigating why patients have been lost to follow up or identifying areas for service improvement. Programme entry also differs, with some Nurse Navigators seeing all newly diagnosed patients and others only supporting patients that have met specific entry/inclusion criteria. Establishing the key aspects of the role are critical for the success of the programme.

When setting up a Nurse Navigator programme it is important to consider the following:

- ▶ who is the Nurse Navigator going to assist?
- ▶ what needs to be achieved?
- ▶ how will the programme goals be achieved?
- ▶ how can the outcomes of the programme be measured?

Establishing a Nurse Navigator Programme involves a series of actions to ensure success in supporting vulnerable patients and improving patient outcomes. All key stakeholders need to be realistic. The first 50 days (10 weeks) need to be dedicated to careful planning and development of key guidelines, processes, and relationships. During this time the Nurse Navigator should not be expected to be seeing patients so as to permit sufficient time to plan an effective programme.

# Key Actions

## Nurse navigator programme

## Action 1

# Identify the key components of the Nurse Navigator 's role

The first action to implementing an effective Nurse Navigator Programme is to identify the key components of the role and establish the nursing experience and educational background needed to fulfil the position. A Nurse Navigator generally requires clinical experience and sound knowledge of cancer, the associated treatments, and the possible adverse effects of treatment. A clear Position Description (PD)\* will help the health care provider and Nurse Navigator know what is expected by defining the specific role responsibilities and the overall goals of the Nurse Navigator Programme.

When beginning a Nurse Navigator role, explore the PD. This will assist in understanding what has to be achieved and provide the foundation for establishing how to achieve the role responsibilities.

### How to do this?

Look at the responsibilities that are described in the PD and ascertain how each responsibility can be met.

#### For example

#### Responsibility.

The Nurse Navigator will identify patients at risk for adverse clinical and psychological outcomes to enable access to appropriate health and social services.

How to meet this responsibility? By developing an assessment and screening tool to identify the patient's holistic needs.

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\*Nurse Navigator Position Description: This guide assumes that a PD has been developed for the Nurse Navigator. If this has not been done, a PD will need to be developed.

## Action 2

# Introduce the Nurse Navigator role to the Health Care Team

Meet with all relevant staff – doctors, nurses, other members of the health care team and educate potential referrers.

Nurse Navigators work collaboratively with all members of the patient's health care team, including external health providers (where relevant). It is therefore important for the Nurse Navigator to build relationships with these staff, particularly those that may refer to the Nurse Navigator programme. Introducing the Nurse Navigator role will help all relevant individuals understand the role and provide an explanation of how the Nurse Navigator can help the health care staff and their patients.

### What to discuss in a meeting with relevant staff and potential referrers:

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› explain Nurse Navigator role

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› outline key responsibilities of the Nurse Navigator – give examples of patients that can be included in the programme

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› ask the health care team:



Main cancer types treated



Patient demographics. For example, age, gender, ethnicity/race, place of residence, main co-morbidities

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› identify how the health care team believes the Nurse Navigator can help their clinical practice/patients

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› establish how the Nurse Navigator will communicate about each patient:



regular meetings. For example, a formal Multidisciplinary Team meeting or a one-to-one scheduled meeting with the patient's lead medical consultant



emails



phone calls



The patient's medical notes

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## Action 3

# Discover what supportive services already exist in the clinical setting

People with a diagnosis of cancer often require a range of services. Supportive care services address a number of needs throughout the patient's cancer journey such as:

› physical

› psychological

› social

› informations

› spiritual

Cancer is challenging for patients and their carers. The Nurse Navigator can assist the patient with various types of support which may help to relieve the burden of having a cancer diagnosis and undergoing treatment.

Support may be in the form of:

› translators

› disease/treatment information

› transport to treatment

› accommodation

› financial

› equipment

› home help

› emotional

To assist with helping patients to access all required care, it is important to identify which supportive care services are already available at the patient's treatment facility and external organisations. This information will help Nurse Navigators establish networks with existing support services or enable them to discover what services need to be introduced to address the patients' needs.

**How to do this?** Investigate the supportive care services available where the patient is being treated, for example, dietary. Explore external supportive care services, for example, local cancer council or government assistance.

## Action 4

# Establish which cancer patients are going to be assisted

Nurse Navigators are a complement to cancer care services and work across the care continuum. Although some aspects of their role would benefit all patients with a cancer diagnosis, in most instances it would not be possible for all patients to be supported by a Nurse Navigator. It is important to take steps to identify patients that are a priority for a Nurse Navigation Programme. To assist with identifying patients who would benefit the most from the programme, the Nurse Navigator needs to develop entry/inclusion criteria.

### What to include in entry/inclusion criteria?

Suggestions for criteria:

#### INCLUSION CRITERIA

If the patient meets two or more of the following criteria, they will be included on Nurse Navigator Programme:

|   | YES | NO |
|---|-----|----|
| <b>Combined Modality</b>  |     |    |
| Concurrent chemo/XRT  |     |    |
| Chemo/immunotherapy   |     |    |
| <b>Age 15-25 or &gt;75</b>  |     |    |
| <b>Level of support at home</b>   |     |    |
| Does the patient live alone?  |     |    |
| Are they the primary carer for someone? For example, children, parents, partner     |     |    |
| <b>ECOG &gt;2</b>   |     |    |
| <b>Age 15-25 or &gt;75</b>  |     |    |
| Resides >50km away from treatment facility  |     |    |
| Multiple malignancies   |     |    |
| Co-morbidities  |     |    |
| Treatment across multiple facilities  |     |    |
| Automatic inclusion: head and neck, brain, sarcoma, phase 1 clinical trial patients |     |    |
| Patient refused Nurse Navigator service   |     |    |
| Accepted onto Nurse Navigator caseload  |     |    |



## Action 5

# Develop policies, procedures, local guidelines, and processes to formalise the Nurse Navigator Programme

Nurse Navigator programmes have various implementation models. It is important to develop policies, procedures, guidelines, and processes to formalise the Nurse Navigator programme at a local level. Individualising Nurse Navigator Programmes enables specific local circumstances to be considered, such as:

- › common tumour groups
- › patient demographics, including age, gender, income, ethnicity, employment status, location and level of education
- › possible transportation issues

Such documents will guide the Nurse Navigator in the implementation of their role and provide a roadmap for all key stakeholders to understand programme operations and desired outcomes.

Documents/processes that need to be developed:

- › policies and procedures (Standard Operating Procedures)
- › referral process
- › holistic health assessment and screening tools<sup>1</sup>
- › workflow/work instruction process<sup>2</sup>
- › feedback forms/surveys<sup>3</sup>
- › patient resource pack

Please note: some examples included below.

## <sup>1</sup> Holistic Patient Assessment (Example Questions)

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### Primary Information

Preferred Name

Occupation

Ethnicity

Interpreter required      Yes              No

Primary support/carer (relationship)

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### Medical History

Primary cancer diagnosis

Relevant past medical history/comorbidities

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### Treatment details

Primary treating clinician

Date of first contact with Nurse Navigator

|           |               |                 |                 |
|-----------|---------------|-----------------|-----------------|
| Treatment | Chemo         | XRT             | Surgery         |
|           | Immunotherapy | Palliative Care | Supportive Care |

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### Assessment details

Treatment protocol

Treatment intent

## Patient's understanding of current treatment and care requirements

### Malnutrition screening

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### Practical living arrangements

Type of accommodation, owner occupied or rental property, living alone, stairs

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### Activities of Daily Living (ADL) assistance

|                     |                  |          |           |
|---------------------|------------------|----------|-----------|
| Independent         | Needs Assistance | Dressing | Bathing   |
| Toileting           | Cooking          | Shopping | Transport |
| Children/Dependants | Household Duties | Other    |           |

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### Family situation/social support

Support systems, children, dependents, social roles (work, family, community), significant others, challenging relationship.

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### Financial situation

Financial challenges and concerns.

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### Spiritual well-being

Individual values and beliefs, individual strengths, strategies used in the past, faith or religious views, what matters most.

## Spiritual well-being

Individual values and beliefs, individual strengths, strategies used in the past, faith or religious views, what matters most.

**Patient's primary concern and goal of care (reassess at each review)**

Overall priority concerns of patient.

### Further details of nature of symptom/s, symptom management strategies

## Alternative therapies, supplements, substances

### Holistic Summary, complexities, actions, and referrals

### Nurse Navigator follow-up/review

|             |               |                    |                      |
|-------------|---------------|--------------------|----------------------|
| Complex     | Review period | As required        | Each treatment       |
| Non-complex |               | Follow-up-cycle2-3 | In-patient admission |

### Advanced care planning

[illegible]

## Well-being and survivorship

Lifestyle enhancement programmes, living after cancer programmes, mindfulness, survivorship research:

## 2 Work process Flowchart Nurse Navigator Programme



### Patient Referral Received

\*Some patients may require more frequent points of contact

Initial screening to determine eligibility for Nurse Navigator caseload inclusion.



If no further contact received from patient to Nurse Navigator after 3 months, discharge patient from programme.

1

Touch point Meet patient and perform holistic assessment.



5

Touch point Wellbeing review two-weeks post completion of treatment.

Make required referrals. Educate. Determine frequency of ongoing contact.



4

Touch point Wellbeing review at completion of treatment. Discuss discharge plan and education.

2

Touch point Wellbeing review post first cycle of treatment.



In person or via phone



In person or via phone

3

Touch point Wellbeing review halfway through treatment protocol.

### **3 Nurse Navigator Programme – Patient Evaluation (Example Questions)**

**How would you rate the accessibility of the Nurse Navigator?**

Far above average

Average

Far below average

Above average

Below average

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**Did you feel better able to manage your side effects post treatment after speaking with a Nurse Navigator?**

Yes

No

If no, what could the Nurse Navigator have done to assist you more?

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**Did the Nurse Navigator help you to feel involved in your care?**

Yes

No

If no, what could the Nurse Navigator have done to assist you more?

**Do you think the Nurse Navigator role is valuable?**

Yes

No

If no, what could the Nurse Navigator have done to assist you more?

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**What are some ways that the Nurse Navigator could improve their service?**

## Action 6

# Establishing a process for documenting patients' individual health goals

Patients diagnosed with cancer face many challenges from the time of diagnosis, throughout treatment and beyond and may feel overwhelmed due to the amount of information that is being provided and the need to make treatment-related decisions. In addition, once treatment commences, they may have to deal with significant adverse effects that may impact on their quality of their life.

Discussing patients' individual health goals at diagnosis will help the treatment team, including the Nurse Navigator, to provide the best care. The outcomes of such discussions should be documented clearly and be accessible to all relevant care providers. Patients' goals may be documented in their medical record with thought given to a specific area so the information can be easily located. Information may be documented on a specific form in accordance with local processes or legislative requirements.

Documentation should include a comprehensive description of the patient's health goals, treatment preferences, directions for who is involved in treatment-related decisions, such as family members, as well as directions for sustaining life.



## Action 7

# Planning process for formal communication related to patients' progress with relevant members of health care team

A key part of the Nurse Navigator role is to communicate with all members of the health care team to discuss patient care issues and needs and how best to facilitate care. A cancer diagnosis generally results in the patient meeting a variety of health professionals who manage their care across a number of different settings over a period of time. These health professionals form the multidisciplinary team (MDT). MDTs provide an integrated approach to patient care. They consider relevant treatment options and collaboratively develop an individual treatment plan.

Nurse Navigators play a critical role in the MDT. They serve as the patient's leading advocate. Nurse Navigators will ensure that patient and family needs are heard and communicated. Their role is to:

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› listen

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› treat

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› educate

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› support

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› contribute to discussions related to patients and their health care needs

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When establishing a Nurse Navigator programme, it is essential to identify a formal communication plan to facilitate discussion about the patient. Formal communication related to the patient progress may be conducted through:

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› face-to-face meeting between the Nurse Navigator and the doctor overseeing treatment

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› telephone

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› email

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› medical record documentation

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› formal MDT meetings

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## Action 8

# Promoting the programme

Promoting the Nurse Navigator Programme internally and externally is essential to ensuring it attracts relevant patients with a cancer diagnosis, many of whom will have several appointments with a variety of health care providers. Therefore, the journey may not start in a cancer-specific environment. The programme needs to be promoted widely within cancer care and other healthcare areas (including the community and outreach clinics) to enable optimal uptake by patients and their loved ones.

Promoting the programme increases awareness about it and provides an avenue to communicate which services are provided and how to access it. Promotion can take a number of forms:

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› poster displays

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› brochures

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› clinical setting website

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› social media portals for example, the health care organisation's Facebook or Twitter accounts

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## Action 9

# Implementing the programme

Once all policies, procedures, local guidelines, and processes have been developed and endorsed, the Nurse Navigator can begin to receive eligible patients. It is essential that the Nurse Navigator maintains documentation of all patient encounters, tracks patient information, schedules, files, and documents. The Nurse Navigator must track patient attendance at medical appointments and patient navigation sessions and identify any missed appointments. Missed appointments should be followed up by the Nurse Navigator to establish the reason and ascertain if this may be an ongoing issue. Following investigation and communication with the patient, the Nurse Navigator may be able to assist with removing barriers that interfere with the patient attending scheduled appointments such as transport.

Refer to 'Work Process Flowchart' (page 13) for workflow.

## Action 10

# Measuring the outcome of the programme

A formal appraisal of the Nurse Navigator programme is needed to demonstrate its effectiveness, identify how to improve it, provide insight into what components of the programme require modification, and to justify funding.

To do this, appropriate outcome measures need to be developed. This data will highlight any gaps or areas that need attention. Reporting requirements will need to be designed by key stakeholders at the local level. Examples may include:

### ACTIVITY

- ▶ new referrals
- ▶ who is referring?
- ▶ tumour types
- ▶ discharges

### ENCOUNTERS

- ▶ standard encounter (15 minutes or less)
- ▶ intermediate encounter (15-60 minutes)
- ▶ complex encounter (>60 minutes)

### OTHER NURSE NAVIGATOR ACTIVITIES

- ▶ clinic attendance
- ▶ file reviews
- ▶ patient discussion meetings (Multidisciplinary team meetings)
- ▶ documentation tasks

The programme's success may also be assessed via feedback forms from other members of the health care team, the patient, and their family. Evaluating patient experience is an important goal for all health care environments. Asking a patient to evaluate their care provides an excellent opportunity for improvement. Involving patients also demonstrates that the health care facility respects their opinion and may help to improve communication.

Refer to '[Nurse Navigator Programme – Patient Evaluation](#)' (page 14-15) for examples of questions.

After collecting data and receiving feedback/evaluation forms, information is to be analysed. The programme should then be refined/revised in line with results. The Nurse Navigator position description should also be re-visited to assist with ascertaining progress.

Frequency of progress reports and meetings regarding the programme should be determined.

# Summary

Nurse Navigators make a difference for patients by assisting them to navigate the numerous challenges created by a cancer diagnosis. Nurse Navigators achieve this by:

- › linking patients with complex needs to people and resources
- › acting as the patient's advocate by being their voice, their eyes, and their ears
- › ensuring that the patient's holistic needs are met

The aim of this guide is to identify the initial priorities for setting up a Nurse Navigation Programme in the cancer care setting. The guide provides 10 key actions that a Nurse Navigator can use as a roadmap to design and implement a successful Nurse Navigator Programme.

- 1 Identify key components of the Nurse Navigator role
- 2 Introduce the Nurse Navigator role to the health care team
- 3 Discover what supportive services already exist in the clinical setting
- 4 Establish the cancer patients that are going to be assisted
- 5 Develop policies, procedures, local guidelines, and processes to formalise the Nurse Navigator Programme
- 6 Establish a process for documenting the patient's individual health goals
- 7 Plan the process for formal communication related to the patient's progress with relevant members of the health care team
- 8 Promote the programme
- 9 Implement the programme
- 10 Measure the outcome of the programme

It is imperative that Nurse Navigators are given the time to develop a formalised programme that will enhance the patient experience and improve health outcomes. The Nurse Navigator role will make a positive impact on the care delivered to people affected by cancer. To make the role a success it requires patience, persistence, and a lot of hard work. It is not an easy role but a very rewarding one.

## References

Distinguished Professor Patsy Yates 2021, *Principles of Nurse Navigation in Cancer Care*, paper presented at Nursing in Cancer Care TeleECHO™, City Cancer Challenge, 2021.

Cook, S, Fillion, L, Fitch, M, Veillette, AM, Matheson, T, Aubin, M, de Serres, M, Doll, R and Rainville, F 2013. *Core areas of practice and associated competencies for nurses working as professional cancer navigators*, Canadian Oncology Nursing Journal, Winter/Hiver 2013.



# About City Cancer Challenge (C/Can)

C/Can supports cities around the world as they work to improve access to equitable, quality cancer care. Since its launch in 2017 by the Union for International Cancer Control (UICC), C/Can has developed a new model of addressing access to cancer care that, for the first time, leverages the city as a key enabler in a health systems response to cancer.





<https://citycancerchallenge.org/>

