

# Cancer Association of South Africa (CANSA)



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## Fact Sheet on Carcinoid Tumours

### Introduction

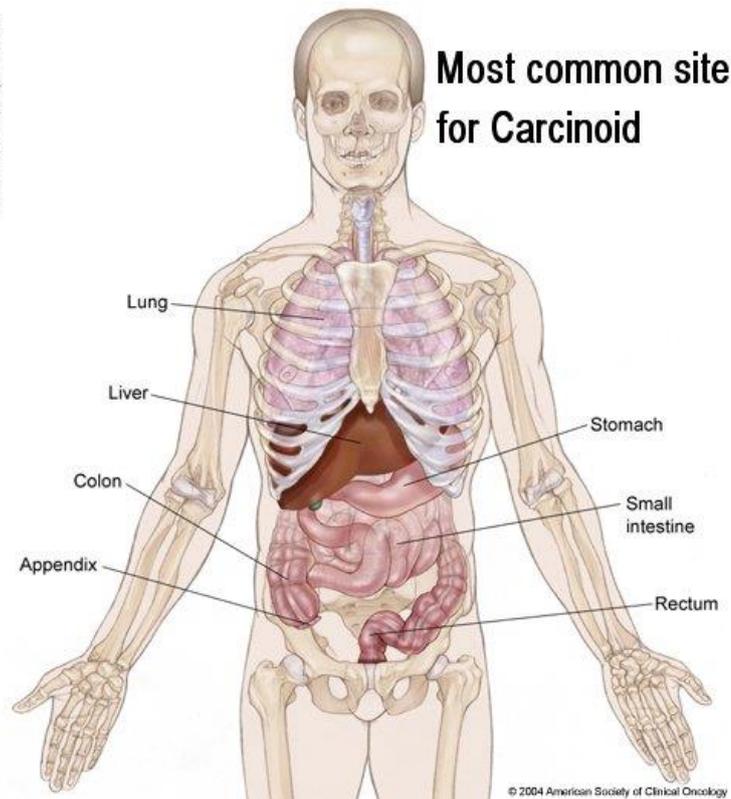
Carcinoid cancer and related neuroendocrine tumours (NETs) are small, slow growing tumours found mostly in the gastrointestinal system, but can be in other parts of the body such as the pancreas and the lung. Since most of these grow very slowly, compared to other cancers, it usually takes many years before they become sizable or cause symptoms.

[Picture Credit: Carcinoid Tumours]

Carcinoid tumours and other NETs usually originate in hormone-producing cells that line the small intestine or other cells of the digestive tract. They can also occur in the pancreas, testes, ovaries, or lungs. Carcinoid tumours can produce an excess of hormone-like substances, such as serotonin, bradykinin, histamine, and prostaglandins. Excess levels of these substances can sometimes result in a diverse set of symptoms called carcinoid syndrome. Other NETs can produce other hormonal substances causing a variety of other syndromes.

When carcinoid tumours occur in the digestive tract or pancreas, the substances they produce are released into a blood vessel that flows directly to the liver (portal vein), where enzymes destroy them. Therefore, carcinoid tumours that originate in the digestive tract generally do not produce symptoms unless the tumours have spread to the liver. The hormones secreted by other NETs, particularly those in the pancreas, do not necessarily require spread to the liver to cause symptoms.

Robert Morneau/Visual Explanations, LLC



When carcinoid tumours have spread to the liver, the liver is unable to process the substances before they begin circulating throughout the body. Depending on which substances are being released by the tumours, the person will have the various symptoms of carcinoid syndrome, insulinoma syndrome (it originates in the beta cells of the pancreas, which releases an unregulated amount of insulin - the patient may feel symptoms that include sweating, increased heart rate, shaking, paleness and a decreasing state of consciousness), Zollinger Ellison syndrome (a condition in which there is increased production of the hormone gastrin), and VIPoma syndrome (also known as Verner Morrison syndrome of watery diarrhoea, hypokalaemia, and achlorhydria).

Carcinoid tumours of the lungs, testes, and ovaries also cause symptoms without having spread, because the substances they produce bypass the liver and can sometimes circulate widely in the bloodstream.

(The Carcinoid Cancer Foundation).

### **Carcinoid Tumours**

A carcinoid tumour starts in the hormone-producing cells of various organs, primarily the gastrointestinal tract (such as the stomach and intestines) and lungs, but also the pancreas, testicles (in males) or ovaries (in females). A carcinoid tumour is classified as a neuroendocrine tumour, which means it starts in cells of the neuroendocrine system that produce hormones.

#### **Origin of carcinoid tumours**

- 39% occur in the small intestine
- 15% occur in the rectum
- 10% occur in the bronchial system of the lungs
- 7% occur in the appendix
- 5% to 7% occur in the colon (large bowel)
- 2% to 4% occur in the stomach
- 2% to 3% occur in the pancreas
- About 1% occur in the liver

(AboutCancer.com).

### **Incidence of Carcinoid Tumours in South Africa**

The National Cancer Registry (2012) does not provide any information regarding the incidence of Carcinoid Tumours.

### **Carcinoid Syndrome**

Many patients with metastatic carcinoid tumour will manifest the signs and symptoms of abnormal hormone production - the malignant carcinoid syndrome. Serotonin (5-hydroxytryptamine [5-HT]), synthesised by the tumour from tryptophan and metabolised to 5-HIAA, which appears in the urine, is particularly important because urinary 5-HIAA levels are used to monitor the course of carcinoid syndrome. However, the relationship of serotonin levels to symptoms of the clinical carcinoid syndrome is uncertain.

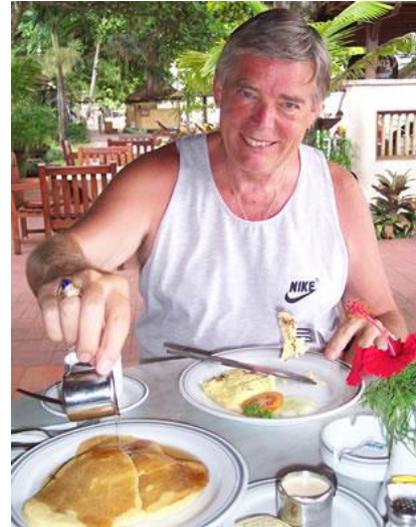
Carcinoid tumours also release the enzyme kallikrein, which acts on alpha<sub>2</sub>-globulin to produce bradykinin and its precursor, lysyl-bradykinin, both of which can induce flushing.

Serotonin may be responsible for intestinal hypermotility and hypersecretion, but it probably does not cause the characteristic flushing that occurs with the carcinoid syndrome.

Vasodilation, which causes flushing, can be due to one or more substances released by the tumour cells, including bradykinin, tachykinins, and prostaglandins.

The symptoms of the carcinoid syndrome vary in frequency. Flushing is most frequent, followed by diarrhoea, heart disease, and bronchoconstriction. (AboutCancer.com).

[Picture Credit: Carcinoid Syndrome]



### **Risk Factors for Carcinoid Tumours**

Researchers are still learning about carcinoid tumours and what causes them. There are a few known risk factors for carcinoid tumours, and most are not factors you can control or change.

- Genetic syndromes - people with a rare genetic syndrome called Multiple Endocrine Neoplasia, type 1 (MEN1) have a higher risk of certain tumours, including carcinoid tumours. Those with a disease called neurofibromatosis type 1 are also at higher risk for developing carcinoid tumours
- Gender - women may be at slightly higher risk of developing carcinoid tumours. Researchers are not sure why
- Race - gastrointestinal carcinoid tumours are said to be more common in African-American men and women than in Caucasians whereas lung carcinoid tumours are more common in Caucasians than in people of other races. It is not certain whether this applies to the South African population
- Stomach conditions - those individuals who have a stomach condition that reduces the amount of acid in the stomach and damages the stomach have a higher risk of carcinoid tumours in the stomach
- Smoking - smokers may be more likely to have certain types of lung carcinoid tumours. A recent study in Europe also found that smoking may double the risk of having a carcinoid tumour in the small intestine. But more research is needed to confirm these results.

(WenMD).

### **Signs and Symptoms of Carcinoid Tumours**

The signs and symptoms of carcinoid syndrome depend on which chemicals the carcinoid tumour secretes into the bloodstream. The most common signs and symptoms of carcinoid syndrome include:

Skin flushing - the skin on the face and upper chest feels hot and changes colour — ranging from pink to red to purple. Flushing episodes may last from a few minutes to a few hours or longer. Flushing may happen for no obvious reason, though sometimes it can be triggered by stress, exercise or drinking alcohol

Facial skin lesions - purplish areas of spider-like veins may appear on the nose and upper lip

[Picture Credit: Carcinoid Skin Lesion]

Diarrhoea - frequent, watery stools sometimes accompanied by abdominal cramps may occur in people who have carcinoid syndrome

Difficulty breathing - asthma-like signs and symptoms, such as wheezing and shortness of breath, may occur at the same time you experience skin flushing



Rapid heartbeat - periods of fast heart rate could be a sign of carcinoid syndrome (Mayo Clinic; Cancer Research UK)).

### **Classification of Carcinoid Tumours**

Carcinoid tumours generally are classified based on the location in the primitive gut that gives rise to the tumour, as follows:

- Foregut carcinoid tumours: divided into sporadic primary tumours (lung, bronchus, stomach, proximal duodenum, pancreas) and tumours secondary to achlorhydria
- Midgut carcinoid tumours: derived from the second portion of the duodenum, the jejunum, the ileum, and the ascending colon
- Hindgut carcinoid tumours: includes the transverse colon, descending colon, and rectum

(Medscape).

### **Diagnosing Carcinoid Tumours**

Because carcinoid tumours grow slowly, many are caught early, before they have had a chance to metastasize or cause symptoms. In many cases, they are found during routine tests or exams when looking for other problems.

These tumours are often found by accident. They are often found during a screening colonoscopy or endoscopy or because of abnormal results on a liver function test.

Sometimes the tumours are found because they are causing symptoms. If your doctor suspects a carcinoid tumour, there are a few different types of diagnostic tests to use.

The aetiology of carcinoid tumours is not known, but genetic abnormalities are suspected. Reported chromosomal abnormalities include changes in chromosomes, such as loss of

heterogeneity, and numerical imbalances. The diagnosis is sometimes made because of unrelated findings, such as anaemia, endocrine disease, or autoimmune disease.

- Laboratory diagnosis of carcinoid tumours depends on the identification of the characteristic biomarkers of the disease. Measurement of biogenic amine levels (e.g., serotonin, 5-hydroxyindoleacetic acid [5-HIAA], catecholamines, histamine) and its metabolites in the platelets, plasma, and urine of patients can be helpful in making the diagnosis.
- Depending on the location of the tumour and metastasis, a combination of the following imaging modalities may be used to evaluate suspected carcinoid tumours:
  - Plain radiography
  - Upper and lower GI radiography with oral contrast agents
  - Computed tomography scanning
  - Magnetic resonance imaging
  - Angiography
  - Positron emission tomography scanning
  - Scintigraphy with metaiodobenzylguanidine (MIBG) and octreotide
  - Radionuclide imaging with somatostatin analogs attached to the radioactive tracer
  - Technetium-99m bone scanning
- Endoscopic procedures, such as the following, may be used for biopsy and diagnosis:
  - Bronchoscopy
  - Oesophagogastroscopy
  - Gastroscopy
  - Colonoscopy
- Blood and urine tests - these simple tests are often a first step in diagnosing carcinoid syndrome. Doctors use these tests to look for the excess hormones and other substances that carcinoid tumours produce.
- Biopsy - once the tumour has been found, the doctor may take a small piece of tissue from the tumour to look at it under a microscope. A biopsy is essential in diagnosing carcinoid tumour. Until one examines the cells under a microscope one will not know for certain what type of tumour one is dealing with. It also helps in determining what type of treatments the tumour will best respond to.

(WebMD; Medscape).

### **Prognosis or Outcome**

Typical carcinoids are slow growers. Data on survival of patients with small tumours not causing Carcinoid Syndrome and without spread, treated by surgical removal alone, indicates that a complete cure is usually possible in these cases.

In those tumours that are somewhat larger and have spread to local tissues and local lymph nodes but which, along with these locally invaded tissues, are still totally removable surgically, the average survival has been 8 years with a range up to 23 years.

Even when the tumour from the small intestine has spread in a manner that has made complete surgical removal impossible, the older statistics show that approximately one half of the patients survive an average of 5 years. Since various types of treatment have been introduced in the past decade patients appear to have an even longer survival and improved quality of life.

Atypical carcinoids, which are a group whose microscopic appearance looks different and more aggressively malignant than the typical carcinoid, follow a more rapid course with a more uncertain outlook. An even worse forecast can be made for the very more malignant rare group called 'neuroendocrine carcinoma'. Atypical carcinoids can cause the Carcinoid Syndrome, but neuroendocrine carcinomas rarely do so.

The tempo of the course of the illness in patients with Carcinoid Syndrome is different than that of carcinoid patients without the functioning syndrome. However, this has been remarkably improved and the outlook is much more hopeful with the advent of octreotide and similar somatostatin analogues and other new modes of treatment. In the early decades before effective treatment was available the average survival from the onset of flushing for a Carcinoid Syndrome patient was 3 years, and from the time of diagnosis was 2 years, though the range extended to over 10 years.

Seventy five percent of the patients would die as a consequence of the harmful effects on the body from the excessive amounts of potent hormones released into their circulation by the tumours. Tumour growth and spread itself was fatal in only 25% of cases. In the last 10 years, since we have used effective combinations of treatment with octreotide (and similar somatostatin analogues), various types of surgery, chemotherapy, hepatic artery injections and biological response mediators, the average survival time from the start of treatment (which unfortunately is often quite delayed after the diagnosis is made) has increased to almost 12 years - with a wide range often being observed. (The Carcinoid Cancer Foundation).

### **Treatment of Carcinoid Tumours**

Treatment of carcinoid tumours include:

- Surgery – it is the most common procedure to treat carcinoid tumours. It may be used to treat the primary tumour and nearby lymph nodes where the cancer has spread. Surgery also may be done if the cancer has spread to the liver. Surgical removal of the tumour may help carcinoid syndrome symptoms. The doctor may suggest one of the following types of surgery to treat a carcinoid tumour:
- Bowel and colorectal resection: removal of the intestine and lymph nodes near the primary carcinoid tumour(s). Lymph nodes along the vessels that supply the affected intestine (called the mesentery) are removed. Removal of the mesentery is at least as important as removing the primary tumour. This requires advanced imaging and surgical techniques to assure complete removal of cancer and preservation of good intestinal function
- Liver resection: significant experience is needed to determine if liver surgery can and should be performed for carcinoid tumours, since most are in both sides of the liver. Advanced planning and surgical techniques are important to ensure surgery is done only if the patient will benefit from it.

- Appendectomy: removal of the appendix, a common site for carcinoid tumours
  - Radiofrequency ablation and cryoablation: these methods to destroy carcinoid tumours in the liver do not require surgical removal of the tumour (resection). They often are not as successful as surgery, but they may be helpful for some patients. Radiofrequency uses radio waves to heat tumours; cryoablation used cold to freeze the tumours. Each has advantages and disadvantages, and the doctor will involve the patient in deciding if there can be benefit from these treatments.
  - Radiation therapy: usually is not used to treat carcinoid tumours. It may help individuals who cannot have surgery and it may help relieve pain if the cancer has spread.
  - Chemotherapy: is not an effective treatment for carcinoid tumours in the bowel. It may be used, however, for neuroendocrine tumours starting in the pancreas or aggressive fast-growing neuroendocrine tumours.
  - Targeted therapies: these innovative new drugs stop the growth of cancer cells by interfering with certain proteins and receptors or blood vessels that supply the tumour with what it needs to grow
  - Octreotide: this drug, which is given by injection, contains a substance similar to the hormone somatostatin. A long-acting version can be given once a month. Lanreotide is a similar drug. Although octreotide usually does not shrink carcinoid tumours, it may slow their growth and help relieve symptoms. Side effects may include insulin resistance
  - Interferon: these natural substances activate the body's immune system and sometimes slow the growth of carcinoid tumour cells.
- (Cancer Research UK; The Carcinoid Cancer Foundation).

### **Supportive Treatment**

Besides the various anti-tumour treatments reviewed above, there are many benefits resulting from a nutritious high protein diet, vitamin supplements - particularly niacin, mineral supplements (such as potassium, magnesium, calcium, iron and even salt) when these are deficient due to diarrhoea.

In addition to the use of octreotide or lanreotide to control diarrhoea, conventional anti-diarrheal medications such as Lomotil and Imodium may be helpful. Cyproheptadine (Periactin) may also help the diarrhoea as well as flushing. Large portions of freshly grated nutmeg (1 teaspoon eaten 3 times a day) will sometimes control the diarrhoea remarkably well.

Antihistamines and alpha adrenergic blocking drugs such as Dibenzylamine are sometimes used to prevent Carcinoid Syndrome attacks.

All carcinoid patients should avoid alcoholic beverages and physical and emotional stress since these can precipitate carcinoid crisis attacks.

Similarly, adrenaline like drugs should be avoided. These include various asthma inhalers, nasal decongestants and adrenaline itself.

Certain very severe and prolonged carcinoid crises associated with bronchial (lung) carcinoids or some carcinoids of the stomach are responsive to treatment with corticosteroids (prednisone, Decadron) and Thorazine or Compazine. There is recent emphasis for carcinoid inhibiting properties of black raspberry extract. (The Carcinoid Cancer Foundation).

### **About Clinical Trials**

Clinical trials are research studies that involve people. These studies test new ways to prevent, detect, diagnose, or treat diseases. People who take part in cancer clinical trials have an opportunity to contribute to scientists' knowledge about cancer and to help in the development of improved cancer treatments. They also receive state-of-the-art care from cancer experts.

### Types of Clinical Trials

Cancer clinical trials differ according to their primary purpose. They include the following types:

**Treatment** - these trials test the effectiveness of new treatments or new ways of using current treatments in people who have cancer. The treatments tested may include new drugs or new combinations of currently used drugs, new surgery or radiation therapy techniques, and vaccines or other treatments that stimulate a person's immune system to fight cancer. Combinations of different treatment types may also be tested in these trials.

**Prevention** - these trials test new interventions that may lower the risk of developing certain types of cancer. Most cancer prevention trials involve healthy people who have not had cancer; however, they often only include people who have a higher than average risk of developing a specific type of cancer. Some cancer prevention trials involve people who have had cancer in the past; these trials test interventions that may help prevent the return (recurrence) of the original cancer or reduce the chance of developing a new type of cancer.

**Screening** - these trials test new ways of finding cancer early. When cancer is found early, it may be easier to treat and there may be a better chance of long-term survival. Cancer screening trials usually involve people who do not have any signs or symptoms of cancer. However, participation in these trials is often limited to people who have a higher than average risk of developing a certain type of cancer because they have a family history of that type of cancer or they have a history of exposure to cancer-causing substances (e.g., cigarette smoke).

**Diagnostic** - these trials study new tests or procedures that may help identify, or diagnose, cancer more accurately. Diagnostic trials usually involve people who have some signs or symptoms of cancer.

**Quality of life or supportive care** - these trials focus on the comfort and quality of life of cancer patients and cancer survivors. New ways to decrease the number or severity of side effects of cancer or its treatment are often studied in these trials. How a specific type of cancer or its treatment affects a person's everyday life may also be studied.

### Where Clinical Trials are Conducted

Cancer clinical trials take place in cities and towns in doctors' offices, cancer centres and other medical centres, community hospitals and clinics. A single trial may take place at one or two specialised medical centres only or at hundreds of offices, hospitals, and centres.

Each clinical trial is managed by a research team that can include doctors, nurses, research assistants, data analysts, and other specialists. The research team works closely with other health professionals, including other doctors and nurses, laboratory technicians, pharmacists, dieticians, and social workers, to provide medical and supportive care to people who take part in a clinical trial.

### Research Team

The research team closely monitors the health of people taking part in the clinical trial and gives them specific instructions when necessary. To ensure the reliability of the trial's results, it is important for the participants to follow the research team's instructions. The instructions may include keeping logs or answering questionnaires. The research team may also seek to contact the participants regularly after the trial ends to get updates on their health.

### Clinical Trial Protocol

Every clinical trial has a protocol, or action plan, that describes what will be done in the trial, how the trial will be conducted, and why each part of the trial is necessary. The protocol also includes guidelines for who can and cannot participate in the trial. These guidelines, called eligibility criteria, describe the characteristics that all interested people must have before they can take part in the trial. Eligibility criteria can include age, sex, medical history, and current health status. Eligibility criteria for cancer treatment trials often include the type and stage of cancer, as well as the type(s) of cancer treatment already received.

Enrolling people who have similar characteristics helps ensure that the outcome of a trial is due to the intervention being tested and not to other factors. In this way, eligibility criteria help researchers obtain the most accurate and meaningful results possible.

### National and International Regulations

National and international regulations and policies have been developed to help ensure that research involving people is conducted according to strict scientific and ethical principles. In these regulations and policies, people who participate in research are usually referred to as "human subjects."

### Informed Consent

Informed consent is a process through which people learn the important facts about a clinical trial to help them decide whether or not to take part in it, and continue to learn new information about the trial that helps them decide whether or not to continue participating in it.

During the first part of the informed consent process, people are given detailed information about a trial, including information about the purpose of the trial, the tests and other procedures that will be required, and the possible benefits and harms of taking part in the trial. Besides talking with a doctor or nurse, potential trial participants are given a form, called an informed consent form, that provides information about the trial in writing. People

who agree to take part in the trial are asked to sign the form. However, signing this form does not mean that a person must remain in the trial. Anyone can choose to leave a trial at any time—either before it starts or at any time during the trial or during the follow-up period. It is important for people who decide to leave a trial to get information from the research team about how to leave the trial safely.

The informed consent process continues throughout a trial. If new benefits, risks, or side effects are discovered during the course of a trial, the researchers must inform the participants so they can decide whether or not they want to continue to take part in the trial. In some cases, participants who want to continue to take part in a trial may be asked to sign a new informed consent form.

New interventions are often studied in a stepwise fashion, with each step representing a different “phase” in the clinical research process. The following phases are used for cancer treatment trials:

### Phases of a Clinical Trial

**Phase 0.** These trials represent the earliest step in testing new treatments in humans. In a phase 0 trial, a very small dose of a chemical or biologic agent is given to a small number of people (approximately 10-15) to gather preliminary information about how the agent is processed by the body (pharmacokinetics) and how the agent affects the body (pharmacodynamics). Because the agents are given in such small amounts, no information is obtained about their safety or effectiveness in treating cancer. Phase 0 trials are also called micro-dosing studies, exploratory Investigational New Drug (IND) trials, or early phase I trials. The people who take part in these trials usually have advanced disease, and no known, effective treatment options are available to them.

**Phase I (also called phase 1).** These trials are conducted mainly to evaluate the safety of chemical or biologic agents or other types of interventions (e.g., a new radiation therapy technique). They help determine the maximum dose that can be given safely (also known as the maximum tolerated dose) and whether an intervention causes harmful side effects. Phase I trials enrol small numbers of people (20 or more) who have advanced cancer that cannot be treated effectively with standard (usual) treatments or for which no standard treatment exists. Although evaluating the effectiveness of interventions is not a primary goal of these trials, doctors do look for evidence that the interventions might be useful as treatments.

**Phase II (also called phase 2).** These trials test the effectiveness of interventions in people who have a specific type of cancer or related cancers. They also continue to look at the safety of interventions. Phase II trials usually enrol fewer than 100 people but may include as many as 300. The people who participate in phase II trials may or may not have been treated previously with standard therapy for their type of cancer. If a person has been treated previously, their eligibility to participate in a specific trial may depend on the type and amount of prior treatment they received. Although phase II trials can give some indication of whether or not an intervention works, they are almost never designed to show whether an intervention is better than standard therapy.

**Phase III (also called phase 3).** These trials compare the effectiveness of a new intervention, or new use of an existing intervention, with the current standard of care (usual treatment) for

a particular type of cancer. Phase III trials also examine how the side effects of the new intervention compare with those of the usual treatment. If the new intervention is more effective than the usual treatment and/or is easier to tolerate, it may become the new standard of care.

Phase III trials usually involve large groups of people (100 to several thousand), who are randomly assigned to one of two treatment groups, or “trial arms”: (1) a control group, in which everyone in the group receives usual treatment for their type of cancer, or 2) an investigational or experimental group, in which everyone in the group receives the new intervention or new use of an existing intervention. The trial participants are assigned to their individual groups by random assignment, or randomisation. Randomisation helps ensure that the groups have similar characteristics. This balance is necessary so the researchers can have confidence that any differences they observe in how the two groups respond to the treatments they receive are due to the treatments and not to other differences between the groups.

Randomisation is usually done by a computer program to ensure that human choices do not influence the assignment to groups. The trial participants cannot request to be in a particular group, and the researchers cannot influence how people are assigned to the groups. Usually, neither the participants nor their doctors know what treatment the participants are receiving.

People who participate in phase III trials may or may not have been treated previously. If they have been treated previously, their eligibility to participate in a specific trial may depend on the type and the amount of prior treatment they received.

In most cases, an intervention will move into phase III testing only after it has shown promise in phase I and phase II trials.

Phase IV (also called phase 4). These trials further evaluate the effectiveness and long-term safety of drugs or other interventions. They usually take place after a drug or intervention has been approved by the medicine regulatory office for standard use. Several hundred to several thousand people may take part in a phase IV trial. These trials are also known as post-marketing surveillance trials. They are generally sponsored by drug companies.

Sometimes clinical trial phases may be combined (e.g., phase I/II or phase II/III trials) to minimize the risks to participants and/or to allow faster development of a new intervention.

Although treatment trials are always assigned a phase, other clinical trials (e.g., screening, prevention, diagnostic, and quality-of-life trials) may not be labelled this way.

### Use of Placebos

The use of placebos as comparison or “control” interventions in cancer treatment trials is rare. If a placebo is used by itself, it is because no standard treatment exists. In this case, a trial would compare the effects of a new treatment with the effects of a placebo. More often, however, placebos are given along with a standard treatment. For example, a trial might compare the effects of a standard treatment plus a new treatment with the effects of the same standard treatment plus a placebo.

### Possible benefits of taking part in a clinical trial

The benefits of participating in a clinical trial include the following:

- Trial participants have access to promising new interventions that are generally not available outside of a clinical trial.
- The intervention being studied may be more effective than standard therapy. If it is more effective, trial participants may be the first to benefit from it.
- Trial participants receive regular and careful medical attention from a research team that includes doctors, nurses, and other health professionals.
- The results of the trial may help other people who need cancer treatment in the future.
- Trial participants are helping scientists learn more about cancer (e.g., how it grows, how it acts, and what influences its growth and spread).

### Potential harms associated with taking part in a clinical trial

The potential harms of participating in a clinical trial include the following:

- The new intervention being studied may not be better than standard therapy, or it may have harmful side effects that doctors do not expect or that are worse than those associated with standard therapy.
- Trial participants may be required to make more visits to the doctor than they would if they were not in a clinical trial and/or may need to travel farther for those visits.

### Correlative research studies, and how they are related to clinical trials

In addition to answering questions about the effectiveness of new interventions, clinical trials provide the opportunity for additional research. These additional research studies, called correlative or ancillary studies, may use blood, tumour, or other tissue specimens (also known as 'biospecimens') obtained from trial participants before, during, or after treatment. For example, the molecular characteristics of tumour specimens collected during a trial might be analysed to see if there is a relationship between the presence of a certain gene mutation or the amount of a specific protein and how trial participants responded to the treatment they received. Information obtained from these types of studies could lead to more accurate predictions about how individual patients will respond to certain cancer treatments, improved ways of finding cancer earlier, new methods of identifying people who have an increased risk of cancer, and new approaches to try to prevent cancer.

Clinical trial participants must give their permission before biospecimens obtained from them can be used for research purposes.

### When a clinical trial is over

After a clinical trial is completed, the researchers look carefully at the data collected during the trial to understand the meaning of the findings and to plan further research. After a phase I or phase II trial, the researchers decide whether or not to move on to the next phase or stop testing the intervention because it was not safe or effective. When a phase III trial is completed, the researchers analyse the data to determine whether the results have medical importance and, if so, whether the tested intervention could become the new standard of care.

The results of clinical trials are often published in peer-reviewed scientific journals. Peer review is a process by which cancer research experts not associated with a trial review the

study report before it is published to make sure that the data are sound, the data analysis was performed correctly, and the conclusions are appropriate. If the results are particularly important, they may be reported by the media and discussed at a scientific meeting and by patient advocacy groups before they are published in a journal. Once a new intervention has proven safe and effective in a clinical trial, it may become a new standard of care. (National Cancer Institute).

### **Medical Disclaimer**

This Fact Sheet is intended to provide general information only and, as such, should not be considered as a substitute for advice, medically or otherwise, covering any specific situation. Users should seek appropriate advice before taking or refraining from taking any action in reliance on any information contained in this Fact Sheet. So far as permissible by law, the Cancer Association of South Africa (CANSA) does not accept any liability to any person (or his/her dependants/estate/heirs) relating to the use of any information contained in this Fact Sheet.

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### Carcinoid Skin Lesion

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