



EUROPEAN COMMISSION

JOINT RESEARCH CENTRE

Directorate F – Health and Food

**Disease Prevention**

ECICC - EUROPEAN COMMISSION INITIATIVE ON COLORECTAL CANCER

# European guidelines on colorectal cancer prevention, screening and diagnosis:

## Marker State Development

**Purpose of the document:** for stakeholders' consultation

**Date:** February 2023



Thank you for your interest shown in the development of the European Commission Initiative on Colorectal Cancer's marker states. This document contains all marker states currently being developed within the European colorectal cancer guidelines.

Your task is to review the marker states in this document and provide feedback using the accompanying survey. At this time, we will only consider feedback on the content of the marker states. The list of outcomes and their format has already been considered at length by a multidisciplinary team.

Before reviewing, please familiarise yourself with the following:

- Marker states have a standardised format that has been extensively tested and validated during the European breast cancer guidelines <sup>(1,2)</sup>. The format consists of a brief contextual paragraph, and four domains (see image below). All marker states in this document utilise this format.

<b>[Name of Health Outcome] – [Importance Rating]</b>
[Insert contextual paragraph if needed.]
<b>What you Experience or Feel:</b> [List the most common experiences and symptoms]
<b>Time Horizon:</b> [Describe how long the experiences/symptoms will persist for and how they may change over time. Also describe the approximate timing of relevant healthcare]
<b>Testing &amp; Treatment:</b> [Describe relevant healthcare or interventions]
<b>Consequences:</b> [Describe the relevant consequences resulting from the health outcome or relevant healthcare]

- Each marker state is intended to be used for one or more healthcare questions. For that reason, each text describes a range of experiences, from the perspective of the healthcare recipient, to take into account different options whenever possible.
- Some marker states (e.g. 'Anxiety and Stress') are split according to severity (moderate and severe) to simplify the documents and more accurately describe the experience based on severity.
- The marker states in this document may describe outcomes that you feel are not important to the guidelines. They will be used as a tool to help with outcome prioritisation. For example, the outcome 'Skin Rash' may be caused by aspirin, which is the topic of at least one healthcare question basis/leading to/for the formulation of guideline recommendations. It is relevant to describe in a marker state at this stage, but based on its description it may or may not be deemed important for consideration later during guideline development.

NOTE: The ECICC Marker States listed in this document are developed following a standardised methodology (©2023 Holger Schünemann, McMaster University. All rights reserved.)

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<sup>(1)</sup> <https://healthcare-quality.jrc.ec.europa.eu/ecibc>

<sup>(2)</sup> Baldeh T et al. Development and use of health outcome descriptors: a guideline development case study. Health Qual Life Outcomes 2020 Jun 5; 18(1):167.

## 1. Full Health

This health outcome descriptor describes the state of full health, in which you have no disease or illness.

### Full Health

**What you experience or feel:** You have no signs or symptoms of physical, mental, or emotional distress or ailment.

**Time Horizon:** There is no time limit to your current health state.

**Testing and Treatment:** You require no new or current tests or treatments. You have no related burden or concern.

**Consequences:** As your health is perfect, there are no unwanted consequences related to your health.

## 2. Accessibility to Information

This health outcome descriptor refers to being able to access information about any colorectal cancer topic easily if you have been invited to participate in screening. It only considers the period for which you are receiving colorectal related healthcare.

### Accessibility to Information

**What you experience or feel:** You may need to invest effort to seek out information from different sources, including but not limited to your healthcare provider, personal contacts and the internet. You may feel satisfied if you obtained all the information you needed easily.

**Time Horizon:** You may seek out information on colorectal cancer screening or on colorectal cancer a few weeks before you begin regular screening, or a few days after a test result has been communicated to you (or indeed at any other time). You may identify relevant information within minutes to hours depending on the accessibility of what you search for, and how you search for it.

**Testing and Treatment:** The information which you access may affect your diagnostic and treatment experience in the context of shared decision making. Easy access to information may influence the type and frequency of diagnostic tests, but not screening tests, you may undergo. Depending on the quality of the information you obtain, your screening frequencies, and, if appropriate, diagnostic tests and treatment for your potential colorectal cancer may be positively or negatively influenced as well.

**Consequences:** You may find screening and other clinical experiences enhanced by greater knowledge as a result of access to information. On the other hand, you may experience anxiety due to having only a partial understanding of screening, colorectal cancer, or the risk of suffering from it. Although accessible, the information you find may be inaccurate and in that case, you may make uninformed decisions.

### 3. Awareness of Information

This health outcome descriptor refers to being knowledgeable about any colorectal cancer topic during the period of time for which you are receiving any colorectal related healthcare for potential/confirmed colorectal cancer. You may receive information from your healthcare professional, health authorities, the internet, and other sources.

#### Awareness of Information

**What you experience or feel:** If you are aware of information, you may feel satisfied with your colorectal healthcare.

**Time Horizon:** You may start researching colorectal cancer and screening/diagnostic testing information a few weeks before your first screening/diagnostic test or immediately after a possible diagnosis of colorectal cancer or recall invitation. Your level of awareness about screening, colorectal cancer and diagnostic tests for colorectal cancer may increase over time.

**Testing and Treatment:** Having a high level of awareness may impact the type and frequency of any diagnostic tests, but not screening tests, you may undergo. Depending on the quality of the information you obtain, your screening frequencies, and, if appropriate, diagnostic tests and treatment for your potential colorectal cancer may be positively or negatively influenced as well.

**Consequences:** You may experience anxiety due to a partial understanding of screening, colorectal cancer, or the risk of suffering from it. Alternatively, you may feel more satisfied given that you are aware of the consequences of testing and treatment for early colorectal cancer.

## 4. Informed Decision Making

This health outcome descriptor refers to you and your healthcare professional, together making healthcare decisions based on as much relevant information as possible.

### Informed Decision Making

**What you experience or feel:** You might be empowered, confident, and satisfied with the decision-making process and the decision itself.

**Time Horizon:** You may become more informed on the subject of colorectal cancer, colorectal cancer screening, diagnosis and treatment during the period for which you are receiving colorectal cancer healthcare. The amount of external influence on your decisions may vary over time.

**Testing and Treatment:** The amount of knowledge you have before making a decision may affect the type and frequency of testing and treatment you may undergo.

**Consequences:** You may ignore or be unaware about colorectal cancer information outside your current knowledge. You make the decision with your healthcare provider that is right for you, based on all available evidence and bearing in mind your values, priorities and lifestyle. However, you and your loved ones may occasionally feel uncomfortable, because of differences between your personal understanding and the advice from your healthcare professional, or because the new information overturns opinions you held previously.

## 5. Confidence with Decision Making

This health outcome descriptor refers to making a decision (with consultation from your doctor) about your colorectal cancer-related healthcare with high confidence.

### Confidence with Decision-Making

**What you experience or feel:** You may have the opportunity to provide input in your colorectal cancer-related healthcare decisions. With high confidence in your decisions, you may feel satisfied in the decision-making process. With little confidence, you may feel dissatisfied.

**Time Horizon:** You may start making colorectal cancer testing decisions weeks before your first regular screening or diagnostic test. You may be confident from that point onward.

**Testing and Treatment:** Your confidence in the decisions made by you (and your healthcare professional) may affect the type and frequency of any screening or diagnostic tests you may undergo.

**Consequences:** Additionally, you may ignore or be unaware about colorectal cancer information outside your current knowledge. Despite being confident, your decision may be right or wrong for you. However, it is more likely to be right for you if you have confidence in your decision.

## 6. Satisfaction with Decision-Making

This health outcome descriptor refers to the level of satisfaction you feel about the decision-making process and any decision that you and your healthcare provider have made about your colorectal cancer testing and/or treatment.

### Satisfaction With Decision-Making

**What you experience or feel:** You will have the opportunity to provide input in your colorectal-related healthcare decisions, as it pertains to your preferences, values, and beliefs. You may feel content with the process and the actual decision.

**Time Horizon:** You may be content both immediately after information is presented to you and within a few days of making any decision related to testing and/or treatment. This feeling could disappear or change over time.

**Testing and Treatment:** You may receive tests or treatments that are based on your informed decisions. Your satisfaction with the decisions made by you and your healthcare provider may affect the type and frequency of tests and/or treatments you undergo.

**Consequences:** You may be satisfied with your colorectal healthcare. You may have less anxiety about your care and have a beneficial relationship with your healthcare provider as it relates to your health.



## 7. Satisfaction with Diet

This health outcome descriptor refers to the level of satisfaction you feel about your diet.

### Satisfaction with Diet

**What you experience or feel:** You may feel content with your meal choice and the implications that has on your health.

**Time Horizon:** You may be content both immediately after making the decision to choose your diet and within a few days of each meal. This feeling could change or disappear over time.

**Testing and Treatment:** Your healthcare provider may ask you if you are content with the choice of diet, and may make changes to your diet where possible.

**Consequences:** Your choice in diet has implications for your health and risk for developing disease. Your satisfaction with your diet may also influence your mood.

## 8. Inadequate Adherence to Diet

This health outcome descriptor refers to the experience of not eating within the parameters of your diet.

### Satisfaction with Diet

**What you experience or feel:** You are eating multiple meals outside the parameters of your diet. You may feel satisfied eating meals that do not belong to the diet. You might also feel upset that you did not follow your healthcare provider's recommendation.

**Time Horizon:** You are eating one or more meals that do not belong to your diet, multiple times per week, for at least several weeks in a row.

**Testing and Treatment:** Your healthcare provider might ask you if you are sticking to your diet. If you indicate that you are not sticking to your diet, your healthcare provider might ask further questions regarding the possible reasons for this. Depending on your reasons, your healthcare provider might change or discontinue the recommendation for that diet. Further, your healthcare provider might provide an intervention such as education on the diet, or ways to increase your motivation to follow the diet.

**Consequences:** You might feel uncomfortable admitting that you are not following your diet to your healthcare provider. Changes in your diet might be confusing. Your inadequate adherence might increase your risk for colorectal cancer and other diseases. Depending on the type of diet, non-adherence may also decrease your risk of some cancers and diseases. Interventions offered to enhance your adherence might be interfering with your daily routine, time consuming, or require additional costs.

## 9. Inadequate Patient Medication Adherence

This health outcome descriptor refers to not taking medication or supplement as prescribed by a healthcare provider.

### Inadequate Patient Medication Adherence

**What you experience or feel:** You are not taking one or more of your medications as prescribed. Your inadequate adherence might increase your risk for a blood clot, and impact your risk for a bleeding or other medication side effects.

**Time Horizon:** You are not taking one or more of your medications multiple times per week, for at least several weeks in a row.

**Testing and Treatment:** Your healthcare provider might ask you if you are taking your medications as prescribed. If you indicate that you are not taking medications as prescribed, your healthcare provider might ask further questions regarding the possible reasons for this. Depending on your reasons, your healthcare provider might change or discontinue your medications. Further, your healthcare provider might provide an intervention such as education on the medications, setting up a reminder system to take your medications, or ways to increase your motivation to take the medications.

**Consequences:** You might feel uncomfortable admitting inadequate medication adherence to your healthcare provider. Changes in your medication might be confusing. Your inadequate adherence may increase your risk of adverse outcomes. Interventions offered to enhance your adherence might be interfering with your daily routine, time consuming, or require additional costs.

## 10. Participation in Screening

**This health outcome descriptor refers to participating in colorectal cancer screening or testing. In all situations, you will have an opportunity to express the value you place on the benefits and harms to health care professionals.**

### Participation in Screening

**What you experience or feel:** You may receive a verbal or written invitation for screening from a screening programme or a healthcare professional. The invitation will give you the details about how to participate and information about the expected benefits and harms that you can obtain by participating in screening. Before participating, you can ask questions about this information and decide if you will participate in the screening programme. If you feel fully informed you might feel satisfied with the decision-making process.

**Time Horizon:** Once you decide to participate in a screening programme, it may take a few days, weeks, or months before you undergo the test. If you receive an invitation for screening, it will usually take some weeks.

**Testing and Treatment:** Depending on the results of the tests, additional testing and, if colorectal cancer is diagnosed, subsequent treatment may be required, or you may not require additional testing until the next time you are invited or decide to participate. You may receive tests or treatments that you and your doctor have decided are appropriate for you.

**Consequences:** If you undergo a recommended test and your decision is based on the information you received, you may be satisfied (what satisfaction may mean to you is addressed in a separate health outcome descriptor). If you are recalled for further assessment, you may visit your healthcare professional again. If you are recalled for a further assessment, you will eventually be found to have or not have colorectal cancer. The clinical outcome may or may not extend your lifetime as a result of early detection of cancer.

## 11. Positive Screening Result

This health outcome descriptor refers to the effects associated with having a positive screening test (stool test, colonoscopy, sigmoidoscopy), informing you that you may have an adenoma or colorectal cancer. This does not refer to a final diagnosis of colorectal cancer after an appropriate diagnostic follow up.

### Positive Screening Result

**What you experience or feel:** When you are informed (in person, by phone or by letter) that you have a positive screening test you may be concerned and anxious.

**Time Horizon:** You will receive the results of your screening test and/or asked to be further assessed within 1-2 weeks of your screening test being performed.

**Testing and Treatment:** You will be asked to undergo further assessment which may include colonoscopy, additional imaging, and eventual biopsy, and/or other testing; all of which may be performed by a specialist healthcare professional in an assessment centre or hospital. If an adenoma is diagnosed, it will be removed. If cancer is diagnosed, you will be referred for treatment based upon the stage of your colorectal cancer, age, and your general health. You may also be treated for anxiety arising from the disease.

**Consequences:** You and your loved ones may experience periods of stress and anxiety because of uncertainty associated with further assessment. Going to additional assessments may necessitate taking time off work or generate other inconveniences.

## 12. Negative Screening Result

This health outcome descriptor refers to receiving a negative screening result (no adenoma or colorectal cancer). This is referred to as a true negative result.

### Negative Screening Result

**What you experience or feel:** When you are informed (by phone and/or letter) that no abnormalities have been identified you may experience happiness and/or relief.

**Time Horizon:** You will receive the results of your test within 1-2 weeks of your screening test being performed. You will not be recalled for further assessment for this round of screening, but you may be asked to participate in your next scheduled screening for colorectal cancer. The time until your next colorectal screening appointment is based on the criteria for age and risk factors in your country.

**Testing and Treatment:** If you meet the criteria (age, risk factors) in your country, you will be asked to attend your next screening appointment. If you do not meet the criteria, you will not be contacted for further screening.

**Consequences:** You and your loved ones may experience relief.

### 13. False Positive Screening Result

This health outcome descriptor refers to the effects associated with having a screening test that caused a recall for further assessment and therefore led you to believe you might have an adenoma or colorectal cancer when you do not.

#### False positive screening result

**What you experience or feel:** When you are informed (by phone and/or letter) that you have a positive screening test you may be concerned and anxious.

**Time Horizon:** You will receive the results of your test and/or be recalled for further assessment within 1-2 weeks of your screening test being performed.

**Testing and Treatment:** Further assessment may include a colonoscopy, additional imaging, and eventual biopsy, and/or other testing; all of which may be performed by a specialist healthcare professional in an assessment centre or hospital.

**Consequences:** You and your loved ones may experience anxiety and resource use. When you receive the result that there is no adenoma or colorectal cancer on assessment, you may feel relief and anger for the stress you endured during further assessment.

## 14. False Negative Screening Result

This health outcome descriptor refers to receiving a negative screening result (no colorectal cancer or adenoma) when you actually have colorectal cancer or adenoma. This is called a false negative screening result. Not all people become aware that they had a false negative screening result. This health outcome descriptor describes when they do become aware after subsequent diagnosis.

### False negative screening result

**What you experience or feel:** When you find out that you did have colorectal cancer or adenoma and it was missed, you are likely to feel anger, fear, and anxiety.

**Time Horizon:** It may take months to years before you find out that you did have colorectal cancer or an adenoma when you were told you did not.

**Testing and Treatment:** Following the discovery of your colorectal cancer or adenoma later on, you may have to undergo treatment that is more intense than if the cancer had been detected right away, as the lesion may have become cancerous, or developed to a more advanced stage of cancer.

**Consequences:** If the adenoma or colorectal cancer has grown, your predicted outcome is likely worse than if it had been diagnosed at the screen. Survival from colorectal cancer that has a false-negative diagnosis may be worse compared to people with screen-detected colorectal cancer, but comparable to people who do not attend screening.



## 15. Inconclusive/Abnormal Screening Results

This health outcome descriptor refers to any abnormal screening (stool test, coloscopy, sigmoidoscopy) result that requires you to be recalled for further diagnostic assessment. Your healthcare provider will organise this follow up (recall).

### Inconclusive/Abnormal Screening Results

**What you experience or feel:** When you are informed (in person, by phone or by letter) that a suspicious abnormality has been identified on the screening test you may be concerned and anxious.

**Time Horizon:** You will receive the results of your screening test and/or be recalled for further assessment within 1-2 weeks of your screening test being performed.

**Testing and Treatment:** Further assessment may include colonoscopy, imaging, and eventual biopsy, and/or other testing; all of which may be performed by a specialist healthcare professional in an assessment centre or hospital. If cancer is diagnosed, you will be referred for treatment based upon the stage of your colorectal cancer, age, and your general health. You may also be treated for anxiety arising from the disease.

**Consequences:** You and your loved ones may experience periods of stress and anxiety because of uncertainty associated with being recalled and going through the experience of additional assessment. Going to additional assessments may necessitate taking time off work or other inconvenience. If the results suggest the possible presence of colorectal cancer, you will be advised to have additional testing, biopsy, and, if colorectal cancer is diagnosed, treatment. You may feel relief if the assessment shows that the suspicious lesion turns out not to be cancer.

## 16. Recall for Assessment

**This health outcome descriptor refers to being recalled for further assessment due to abnormal findings (or technically inadequate samples/view) from a screening test. Further assessment is needed to rule out or confirm colorectal cancer.**

### Recall for Assessment

**What you experience or feel:** When you are informed (by phone and/or letter) that a suspicious abnormality has been identified on the screening test you may be concerned and anxious.

**Time Horizon:** You will receive the results of your test and/or be recalled for further assessment within 1-2 weeks of your screening test being performed.

**Testing and Treatment:** Further assessment may include additional imaging, and eventual biopsy, and/or other testing; all of which may be performed by a specialist healthcare professional in an assessment centre or hospital. If cancer is diagnosed, you will be referred for treatment based upon the stage of your colorectal cancer, age, and your general health. You may also be treated for anxiety arising from the disease.

**Consequences:** You and your loved ones may experience periods of stress and anxiety because of uncertainty associated with being recalled and going through the experience of additional assessment. Going to additional assessments may necessitate taking time off work or other inconvenience. If the results suggest the possible presence of colorectal cancer, you will be advised to have additional testing, biopsy, and, if colorectal cancer is diagnosed, treatment. You may feel relief if the assessment shows that the suspicious lesion turns out not to be cancer.

## 17. Colonoscopy

This health outcome descriptor refers to having a traditional colonoscopy performed to view the inside of the rectum and colon and take tissue samples as required. It does not refer to a virtual colonoscopy (also known as CT colonography). You may have your colonoscopy to screen for colorectal cancer, or it may be used as a follow-up test after other screening tests.

### Colonoscopy

**What you experience or feel:** Before the procedure you may be anxious and afraid. You will experience loose stool, feel faint or light-headed, and/or feel hungry as you prepare your bowel in the day leading up to the procedure. After the procedure you may experience brief drowsiness (as the anaesthesia wears off), cramping, abdominal bloating, and light bleeding from your backside.

**Time Horizon:** The procedure takes approximately 30 - 60 minutes. It may take longer if multiple tissue samples are taken, or if there is any difficulty viewing parts of the colon. You will stay in the hospital to recover for approximately 1-2 hours if there are no complications. Afterwards you may arrange for someone to take you home from the hospital. You may return to your normal diet the same day, after the procedure.

**Testing and Treatment:** Your colonoscopy may be performed by an endoscopist at a hospital or screening centre. They will ask you to change your diet and take laxatives to prepare your bowel before the procedure. During the procedure, deep sedation will be used to make you unaware of the procedure and any pain associated with it. The doctor will insert a thin flexible tube into your backside and inflate your colon using air. They will visualise the inside of your colon using a camera at the end of the tube. If any suspicious tissues are identified, the doctor may take a sample for further lab testing using the flexible tube, or remove it entirely.

**Consequences:** The planning of the procedure may make you feel anxious. After the procedure, you may experience prolonged pain or bleeding from your backside, although this is uncommon. It is possible that your bowel may be punctured unintentionally during the procedure. Additionally, you may develop a fever, dizziness, chest pain, or difficulty breathing after the procedure. Although it is very rare, some of the complications of colonoscopy may end your life. If you have a negative result (no colorectal cancer) you may feel relieved at the result and satisfied that you were investigated thoroughly. If you have a positive result (colorectal cancer) you may feel anxious about the implications for your health.

## 18. Colonic Perforation

This health outcome descriptor refers to having a hole through the wall of your bowel. In the context of colorectal cancer screening, this may occur accidentally during a colonoscopy.

### Colonic Perforation

**What you experience or feel:** You may experience abdominal pain, nausea, vomiting, and/or decreased bowel function. If infection develops you may experience fever, breathlessness, or a change in mental state.

**Time Horizon:** You may experience symptoms of bowel perforation within a few days after having a colonoscopy (if that was the causative factor). If surgical repair of the perforation is required, it has to occur as soon as possible. Recovery may take up to three months.

**Testing and Treatment:** Your surgeon will assess the severity of the perforation based on your symptoms, blood tests, and imaging. You may require fluids, antibiotics, and surgical repair/resection of the colon. Surgical repair may be open (by cutting opening your abdomen), minimally invasive (using smaller incisions into your abdomen) or endoscopic (using a scope inserted into the colon via your backside). You may have a temporary or permanent stoma (diversion of your bowel to the surface of your abdomen) as a result of surgery, necessitating you to pass stool into a stoma bag. You may need to rest and change your diet in the weeks after the surgery.

**Consequences:** The severity of symptoms and planning of the procedure may make you feel anxious. You may feel angry if the colonoscopy caused the perforation. After the procedure, you may experience prolonged pain or bleeding from your backside. You may become septic and die from colonic perforation, particularly if infection spreads.

## 19. Incidental Findings

This health outcome descriptor refers to imaging findings incidentally detected due to screening assessment for colorectal cancer.

### Incidental Findings

**What you experience or feel:** When you are told about the imaging findings, you may experience considerable anxiety, which in turn may cause physical symptoms such as sleeping problems. You may experience considerable uncertainty about whether these findings require treatment. You may feel relieved that they were identified.

**Time Horizon:** You may be told about the imaging findings at the same time as you are given the results of your screening test (within 1 to 2 weeks of the test).

**Testing and Treatment:** You will be referred to the appropriate team for testing and treatment of the medical issue causing the imaging findings outside the colon and rectum.

**Consequences:** You and your family may experience additional stress, anxiety, and resources use.

## 20. False Positive Biopsy Result

This health outcome descriptors refers to the effects associated with having a biopsy result that led you to believe you might have colorectal cancer when you do not.

### False Positive Biopsy Result

**What you experience or feel:** You think that you have colorectal cancer when in reality you do not. You may experience intense anxiety, and consequent physical symptoms such as sleeping problems, as a result of having to undergo a biopsy for a possible colorectal cancer. After you realize that you were given a false positive diagnosis you may experience relief and anger.

**Time Horizon:** Times for identifying a false positive diagnosis vary according to the type of lesion and the procedures at your hospital. A false positive diagnosis is likely to be identified within a few weeks of the biopsy. You may experience anxiety (among other symptoms) during the time you believe you have colon cancer. You may also continue to worry after being told that the result was inaccurate and that you do not have colon cancer.

**Testing and Treatment:** The biopsy may take place in a hospital by a healthcare professional. Generally, false positive biopsies are very rare. As a result of the false positive biopsy, you may undergo surgery and removal of tissue from your colon.

**Consequences:** If you are having surgery, you may experience swelling, soreness, or infection in the area of the tissue sample collection. Part of your bowel may be removed if you have surgery because of the false positive result. You and your loved ones may experience anxiety and may feel frustrated due to unnecessary resource use.

## 21. Detection of Advanced Adenoma

This health outcome descriptor refers to the correct detection of advanced adenoma after a positive stool test and / or colonoscopy. Advanced adenomas are pre-cancerous growths in the lining of your colon. They are advanced because they are large (>10mm), have abnormal cell types (high-grade dysplasia), or exhibit high risk growth patterns (villous architecture). An adenoma can only be confirmed as being advanced after analyzing a tissue sample taken during colonoscopy.

### Detection of Advanced Adenoma

**What you experience or feel:** If your adenoma is identified and removed during the same colonoscopy, you may feel relieved after the procedure. If the adenoma is not removed immediately, you may experience considerable anxiety when the results of tissue analysis reveal that you have an advanced adenoma. Being told of the advanced adenoma may cause physical symptoms such as sleeping problems. You may experience considerable uncertainty about whether your advanced adenoma is likely to develop and whether it requires treatment.

**Time Horizon:** The diagnosis of advanced adenoma is confirmed with a tissue sample of the colon taken during a colonoscopy. Full histopathological assessment of any tissue samples taken during the colonoscopy may take 1 to 2 weeks.

**Testing and Treatment:** The advanced adenoma will be removed during a colonoscopy. A tissue sample of the adenoma will undergo full histopathological assessment. If you meet the criteria in your country, you may be asked to return for colorectal screening earlier than originally scheduled.

**Consequences:** During the assessment process you may feel additional stress and anxiety, particularly after knowing that your adenoma was advanced.

## 22. Detection of Non-Advanced Adenoma

This health outcome descriptor refers to the correct detection of non-advanced adenoma after a positive stool test and / or colonoscopy. Non-advanced adenomas are pre-cancerous growths in the lining of your colon. They are non-advanced because they are relatively small (<10mm), have relatively fewer abnormal cell types (low-grade dysplasia), or do not exhibit high risk growth patterns (villous architecture). An adenoma can only be confirmed as being non-advanced after analyzing a tissue sample taken during colonoscopy.

### Detection of Non-Advanced Adenoma

**What you experience or feel:** If your adenoma is identified and removed during the same colonoscopy, you may feel relieved after the procedure. If the adenoma is not removed immediately, you may experience some relief when the results of the tissue analysis reveal that you have a non-advanced adenoma, and it is unlikely to become cancerous.

**Time Horizon:** The diagnosis of non-advanced adenoma is confirmed with a tissue sample taken from the colon during a colonoscopy. Full histopathological assessment of any tissue samples taken during the colonoscopy may take 1 to 2 weeks. You may begin to experience emotional symptoms after receiving your result, indicating that you have an adenoma.

**Testing and Treatment:** The non-advanced adenoma will be removed during a colonoscopy. There will be a full histopathological examination of the tissue sample.

**Consequences:** After being told that your non-advanced adenoma was removed during colonoscopy, you may feel relieved that it is no longer at risk of becoming cancerous, and satisfied that you have been investigated thoroughly.



## 23. Interval Colorectal Cancer

This health outcome descriptor refers to having a diagnostic test correctly identify a cancer after you have had a screening test, with or without further assessment, which was negative for malignancy, either: before the next invitation to screening; or within a time period equal to the screening interval after you have reached the upper age limit for screening.

### Interval Colorectal Cancer

**What you experience or feel:** When you are told you have colorectal cancer, you may experience considerable anxiety, which in turn may cause physical symptoms such as sleeping problems. You may feel relieved if your colorectal cancer was detected in an early stage. You may experience considerable anger and disbelief that the cancer has not been detected in the previous screening procedure. Due to the presence of colorectal cancer, you may experience symptoms such as pain, change in bowel habit, and blood in your stool. You may also feel concern that your tumour may have been present at the time of screening and was not detected.

**Time Horizon:** This tumor may have become symptomatic in the period of time since your prior screening examination.

**Testing and Treatment:** Following the diagnostic test, further assessment of the cancer may be performed. This will be carried out in a hospital. Treatment will vary according to the stage of your colorectal cancer, age, and your general health.

**Consequences:** Since the tumor was not visible at prior screening it might be fast growing and biologically more likely to spread. However, it is possible that your tumour is still at an early stage. Your colorectal cancer may shorten your life. Colorectal cancer detected at an early stage will be more likely to be cured than colorectal cancer detected at a late stage. You and your loved ones may experience anxiety.

## 24. Diagnosis of Colorectal Cancer

**This health outcome descriptor refers to the correct diagnosis of colorectal cancer after a positive stool test and/or colonoscopy, followed by further diagnostic assessment and tests.**

### Diagnosis of Colorectal Cancer

**What you experience or feel:** When you are told you have colorectal cancer, you may experience considerable anxiety, which in turn may cause physical symptoms such as sleeping problems. However, you may feel relieved if your colorectal cancer was detected in an early stage. You may experience considerable uncertainty about whether your cancer is likely to develop and how it will be managed.

**Time Horizon:** The diagnosis of colorectal cancer is confirmed at the end of a colonoscopy. This may include a full histopathological assessment of any tissue that has been removed from your colon. The whole process may take 1 to 4 weeks from obtaining the results of your colonoscopy. You may begin to experience emotional symptoms after receiving your result, indicating the possibility that you have colorectal cancer.

**Testing and Treatment:** You will be referred for further diagnostic testing to determine the extent of the cancer in your body. After confirmation and staging of your colorectal cancer, your treatment options may be discussed by a multidisciplinary team. The multidisciplinary team may propose a targeted or non-targeted treatment which may vary according to the stage of your colorectal cancer, age and your general health.

**Consequences:** During the time that your treatment plan is being formulated by the multidisciplinary team you may feel additional stress and anxiety. A diagnosis of colorectal cancer may cause professional and social difficulties, as well as increased financial burden.

## 25. Diagnosis of Non-Colorectal Cancer

This health outcome descriptor refers to the correct diagnosis of non-colorectal cancer.

### Diagnosis of Non-Colorectal Cancer

**What you experience or feel:** When you are told you have cancer, you may experience considerable anxiety, which in turn may cause physical symptoms such as sleeping problems. However, you may feel relieved if your cancer was detected in an early stage. You may experience considerable uncertainty about whether your cancer is likely to develop and requires treatment.

**Time Horizon:** The timing of diagnosis varies considerably depending upon the type of cancer, if you are symptomatic, and whether it is identified by a screening programme. You may begin to experience emotional symptoms after being informed that your cancer has been identified.

**Testing and Treatment:** After confirmation of your cancer, your diagnosis and treatment options may be discussed by a multidisciplinary team. You may be referred for further diagnostic testing to determine the extent of the cancer in your body. The multidisciplinary team may propose a targeted treatment which may vary according to the stage of your cancer, tumour biomarker status, age, and your general health.

**Consequences:** During the time that your treatment plan is being formulated by the multidisciplinary team you may feel additional stress and anxiety.

## 26. Stage of Colorectal Cancer

This health outcome descriptor refers to the state of having any stage of colorectal cancer. You may already be experiencing symptoms of colorectal cancer if you are receiving your diagnosis outside of a colorectal cancer screening programme. An early stage indicates that the colorectal tumour is relatively small and has not spread to other parts of the body. This means that you may be offered less intensive treatment and have a better prognosis. A later stage indicates that the colorectal cancer has reached a greater size and/or has spread to regional lymph nodes or to other parts of the body. This usually requires more aggressive treatment and is associated with a worse prognosis. In addition to tumour size and extent, prognosis and treatment will also depend on the characteristics of the tumour including the histological grade.

### Stage of Colorectal Cancer

**What you experience or feel:** When you are told you have colorectal cancer (any stage), you may experience new or worsening anxiety, which in turn may cause physical symptoms such as sleeping problems. Due to presence of a colorectal cancer, you may start to experience new or worsening change in bowel habits, blood in your stool, abdominal pain, weakness, and fatigue. If the cancer has spread to other parts of the body, you may feel new or worsening symptoms referable to body sites involved by tumour. These symptoms may not be present at all and if present may vary in intensity. If you have been symptomatic prior to your diagnosis, you may experience some relief after being notified of the cause, and that you will receive care. If you have early-stage colorectal cancer you may experience relief that it is been detected early.

**Time Horizon:** The amount of time it takes for a cancer to go from an early to an advanced stage varies from months to decades.

**Testing and Treatment:** A sample of the tissue in your colon may be removed with a needle to make a diagnosis of your colorectal cancer. Further testing such as ultrasound, bone scan, computerised tomography, MRI and/or a PET scan (positron emission tomography) may be performed to assess the stage of your colorectal cancer. You will be referred for treatment based upon the results of the tests. Treatment will vary according to stage of your colorectal cancer, age, and your general health.

**Consequences:** Your colorectal cancer may shorten your life or reduce your quality of life. Colorectal cancer detected at an early stage will be more likely to be cured than colorectal cancer detected at a late stage. You and your loved ones may experience anxiety about the social, professional, and financial implications of the particular stage of your cancer.

## 27. Over-diagnosis and Over-treatment

In screening, it is possible to diagnose a colorectal cancer which is so slow growing that it would never have been diagnosed in a person's lifetime if the person had not been screened. The scientific term for colorectal cancer that would have not been diagnosed without screening is "over-diagnosis" of cancer. We cannot tell which cancers are of this type, however. Because it is unknown which cancers are over-diagnosed, treatment is the same as if it was not over-diagnosed. This is referred to as over-treatment. An over-diagnosed cancer is likely to be detected at an early stage.

### Over-diagnosis and over-treatment

**What you experience or feel:** When you are told you have colorectal cancer, you may experience considerable anxiety, which in turn may cause physical symptoms such as sleeping problems. However, you may feel relieved if your colorectal cancer was detected in an early stage. You may experience considerable uncertainty about whether your cancer is likely to develop and requires treatment.

**Time Horizon:** The time between receiving the diagnosis due to a recall from screening and receiving treatment is the same whether or not the cancer is over-diagnosed. If the treatment is radiation and/or surgery, it is completed in 3-6 weeks. Other therapy, such as chemotherapy can last several months. If you had not participated in screening, you would have remained unaware of the cancer and free of symptoms throughout your normal lifetime.

**Testing and Treatment:** Depending on the country you may be asked to have a stool test or colonoscopy. The stool tests detect blood or abnormal genetic material in a sample of your stool. They can be performed by yourself at home or by a healthcare provider in their clinic. If blood is found in your test sample, you will be called for further assessment at a hospital. A colonoscopy is a day procedure that must be performed by a healthcare provider in a hospital. Before the procedure your bowel must be emptied using a combination of laxatives and fasting. During the procedure the healthcare provider will insert a thin camera into your backside to view the colon from the inside. If there are signs of abnormal growth seen in the bowel or identified in the tissue sample, you will be called for further assessment at a hospital. Detection of the cancer will not be beneficial to your health because your tumour is of no clinical importance. You will be referred for treatment based upon the results of the assessment. Treatment will vary according to the stage of your colorectal cancer, age, and your general health.

**Consequences:** Any treatment you receive may have side effects (described in other health outcome descriptors). You will have to return to your healthcare professional for additional diagnostic testing and treatment. You and your loved ones may experience anxiety and costs compared to if the colorectal cancer had never been diagnosed.

## 28. Mild Work & Social Life Disturbance

This health outcome descriptor refers to a mild disruption in your ability to work and/or socialise.

### Mild Work & Social Life Disturbance

**What you experience or feel:** You may be unable to focus, complete tasks, communicate, and/or attend work/social activities. You may require brief support and assistance from your colleagues, friends, or family.

**Time Horizon:** The disturbance to your work or social life will last no longer than 48 hrs. It will return to normal afterwards.

**Testing and Treatment:** You do not require any testing. You may find stress relief from mindfulness exercises or other coping techniques.

**Consequences:** You may find the disturbance to your life annoying.

## 29. Moderate Work & Social Life Disturbance

This health outcome descriptor refers to a moderate disruption in your ability to work and/or socialise.

### Moderate Work & Social Life Disturbance

**What you experience or feel:** You may be unable to focus, complete tasks, communicate, and/or attend work/social activities. You may require support and assistance from your colleagues, friends, or family.

**Time Horizon:** The disturbance to your work and/or social life occurs most days of the week. You have periods without disruption in between.

**Testing and Treatment:** A doctor may have a discussion with you about the stressors in your life and their impact on your health. They may recommend mindfulness exercises, coping techniques, therapy, and/or medication to relieve your symptoms. You may be offered to other services for support at work and/or home.

**Consequences:** You may find it difficult to cope with the disturbances to your life. You and your family may experience financial difficulties.

## 30. Severe Work & Social Life Disturbance

This health outcome descriptor refers to a severe disruption in your ability to work and/or socialise.

### Severe Work & Social Life Disturbance

**What you experience or feel:** You may be unable to focus, complete tasks, communicate, and/or attend work/social activities. You may require constant support and assistance from your colleagues, friends, or family.

**Time Horizon:** The disturbance to your work or social life is almost always present. You may have brief and infrequent periods of normalcy in your life, if at all.

**Testing and Treatment:** A doctor may have a discussion with you about the stressors in your life and their impact on your health. They may recommend mindfulness exercises, coping techniques, therapy, and/or medication to relieve your symptoms. You may be offered other services for support at work and/or home.

**Consequences:** You may find it difficult to cope with the disturbances to your life. Your family may struggle emotionally and financially. You may be at higher risk of depression, substance abuse, and intent to harm yourself.



## 31. Quality of Life Impairment

This health outcome descriptor refers to reduced well-being related to a worsening of health.

### Quality of Life Impairment

**What you experience or feel:** Quality of life impairment indicates a reduced state of wellbeing related to a change in your health status. Many symptoms may cause a reduction in your quality of life. The more severe your symptoms, the more impaired will be your quality of life. Psychological impairment and symptoms will cause a reduction in quality of life, too.

**Time Horizon:** Quality of life impairment will persist for the duration of symptoms, impairment, or the condition.

**Testing and Treatment:** Depending on the condition, testing and treatment will be administered. The results of those tests and treatments may affect your quality of life. If your condition improves, your quality of life may improve. Quality of life can be measured with questionnaires.

**Consequences:** Depending on your condition and treatment, your quality of life may improve or worsen.

## 32. Moderate Stress & Anxiety

This health outcome descriptor refers to having moderate stress and worries about your health as it relates to colorectal screening. It does not refer to persons with an anxiety disorder.

### Moderate Stress & Anxiety

**What you experience or feel:** In response to a stressful or uncertain situation, you worry about what will happen. Your anxiety may come and go. On some or most days of the week, you may have trouble with usual activities, such as concentrating, socialising, or sleeping. You may experience irritability, anger, fatigue, muscle pain, and/or digestive problems.

**Time Horizon:** Varies, your anxiety may continue until you become used to the stressful or uncertain situation, or until the situation is resolved. Usually, your anxiety may last less than 6 months.

**Testing and Treatment:** You can usually manage your anxiety through soothing or distracting activities, talking with others, or self-coaching.

**Consequences:** In time, your anxiety gets better or goes away.

### 33. Severe Stress & Anxiety

This health outcome descriptor refers to having severe stress and worries about your health as it relates to colorectal screening. It does not refer to persons with an anxiety disorder.

#### Severe Stress & Anxiety

**What you experience or feel:** In response to a stressful or uncertain situation, you worry about what will happen. Your anxiety is almost always present. Each day of the week, you are unable to participate in usual activities, such as concentrating, socialising, or getting a full night of sleep. You may experience irritability, anger, fatigue, muscle pain, and/or digestive problems.

**Time Horizon:** Varies, your anxiety may continue until you become used to the stressful or uncertain situation, or until the situation is resolved.

**Testing and Treatment:** Your anxiety may be managed with therapy or medications prescribed by a doctor.

**Consequences:** You may be at higher risk for depression and substance abuse.

## 34. Identification of High-Risk Family

This health outcome descriptor refers to high risk family members being identified for more frequent colorectal cancer screening based on the positive findings (colorectal cancer) from your own screening.

### Identification of High-Risk Family

**What you experience or feel:** You may feel concerned and anxious about the possibility of your family members being at a greater risk of colorectal cancer. You may feel relieved that your family members might be more thoroughly screened for colorectal cancer, and receive treatment earlier in the event of positive findings.

**Time Horizon:** You may decide to tell your family members of your colorectal cancer immediately after finding out. If you have had genetic testing done and you are found to have a genetic risk factor for colorectal cancer, your family may decide to pursue genetic testing in the weeks afterwards.

**Testing and Treatment:** You and your family members may decide to undergo genetic testing to determine their risk for developing colorectal cancer. An analysis of a tissue sample taken from your cancer may also identify your genetic risk factors contributing to your colorectal cancer. Depending on the criteria in your country, your family members may be invited to attend screening more frequently.

**Consequences:** Your family members may endure stress and anxiety during the screening process that they otherwise might not experience. Alternatively, your family members may feel relieved that they are being investigated more thoroughly and may receive earlier treatment if needed.

## 35. Adult Hospitalization

This health outcome descriptor refers to the experience of being admitted to hospital as an adult. It does not refer to aspects of your hospitalization that are specific to your disease.

### Adult Hospitalization

**What you experience or feel:** You may have to share your room and washroom with another patient and you may feel constrained by the environment, which will interrupt your daily routine. Some people feel claustrophobic, psychologically distressed, and/or experience sleep-wake reversal or get confused.

**Time Horizon:** The duration of hospitalization will depend on the reason for hospitalization or the severity of the condition and will be determined by the treating clinician. You will feel the constraints for the entire time that you are in the hospital.

**Testing and Treatment:** Depending on the reasons for your hospitalization you will have related tests and treatment. Tests might include blood work, radiological investigations or procedures. Treatments might include antibiotics, blood transfusions and other supportive care.

**Consequences:** Complications of hospitalization can occur. They may include relatively minor events, such as routine blood draws, bruising from blood draws, irritation from a small tube inserted in your vein and inconvenience of regular nursing checks; or major ones, such as infections, insertion of large tubes into major veins or even a breathing tube and being placed on a respirator, or death.

## 36. Constipation

This health outcome descriptor refers to passing three or fewer stools per week, for several weeks.

### Constipation

**What you experience or feel:** You are passing stool infrequently. Your stool may be hard or lumpy and you may have to strain to pass the stool. You may get the sensation that you cannot completely pass stool from your backside. You may become worried if this pattern of bowel movements is new, or if you have no explanation for it.

**Time Horizon:** You pass fewer than 3 stools a week, for several weeks. The constipation may resolve on its own within a matter of days, or it may persist.

**Testing and Treatment:** A doctor will examine you. They may recommend that you make changes to your diet and physical activity. They might also order a series of blood tests and a colonoscopy. If necessary, tests to evaluate the movement of food through your colon, or tone of narrowing along your gastrointestinal tract (sphincters) will be performed. Your doctor might also recommend training exercises, laxatives, and other medication.

**Consequences:** You may develop bleeding from your backside, hemorrhoids, and tearing near your backside.

## 37. Diarrhea

This health outcome descriptor refers to passing three or more loose or liquid stools per day (or more frequent passage than is normal for the individual).

### Diarrhea

**What you experience or feel:** You are passing stool more frequently than normal. Your stool is loose or watery, and there may be blood or mucus in it. You may experience nausea, vomiting, abdominal pain, or weight loss and you may feel the need to pass stool urgently. You may become worried if this pattern of bowel movements is new, or if you have no explanation for it.

**Time Horizon:** You pass three or more loose or liquid stools per day (or more frequent passage than is normal for you). The diarrhea may resolve on its own within a matter of hours to days, or it may persist.

**Testing and Treatment:** A doctor will examine you. They may recommend that you make changes to your diet and physical exercise. They might also order a series of blood and/or stool tests and imaging. If necessary, an endoscopy or colonoscopy may be recommended. Furthermore, you will be recommended to drink adequate fluids, and take antibiotics or antiparasitic medication.

**Consequences:** You may develop dehydration, which can be life-threatening. If persistent, you may also develop an electrolyte imbalance, kidney failure, or other organ damage.

## 38. Underweight

This health outcome descriptor refers to the experience of being underweight (Body Mass Index <18.5).

### Underweight

**What you experience or feel:** Your appearance will change, and you will experience changes in the fitting of your clothes. You might have more difficulty performing your daily activities. You may experience fatigue or chills.

**Time Horizon:** It may take several months for you to become underweight. Likewise, it may take several months for you to return to a higher weight.

**Testing and Treatment:** You may decide to monitor your weight at home. Your weight will not go back up unless a change is made to your diet, physical activity, and/or a background medical cause is treated.

**Consequences:** You are at a higher risk for other diseases, including but not limited to malnutrition, osteoporosis, and frequent infection. Women may have reduced fertility if they are underweight.



## 39. Vitamin Deficiency

This health outcome descriptor refers to the deficiencies in your intake of vitamins.

### Vitamin Deficiency

**What you experience or feel:** You are not ingesting enough vitamins to maintain good health. You may experience fatigue, shortness of breath, muscle weakness, dizziness, and weight loss.

**Time Horizon:** You may develop vitamin deficiency over months and years. The symptoms will continue to worsen as the deficiency worsens.

**Testing and Treatment:** Your healthcare provider may measure your vitamin levels with a blood test. You may be given supplements of whichever vitamin you are lacking.

**Consequences:** In extreme cases of vitamin deficiency, you may develop anaemia, goiter, bone disease, and vision loss.

## 40. Kidney Stone

This health outcome descriptor refers to developing one or more kidney stones in your urinary tract, which have not passed yet.

### Kidney Stone

**What you experience or feel:** You may experience severe, sharp pain on your side or back, below the level of your ribs. The pain may radiate throughout your groin and come in waves. You may feel a burning sensation when you urinate. There may be blood in your urine.

**Time Horizon:** Kidney stones and associated symptoms may develop within weeks to months. If the stone is small enough it may pass within days. If it is a larger stone, it may take three or more weeks, or may not pass at all.

**Testing and Treatment:** Your doctor will have blood and urine testing performed to diagnose the kidney stone and identify a possible cause. You will have imaging done to locate the stone and determine its size. If a stone is passed it might be collected for analysis. Your doctor may recommend drinking water and pain medication. For larger stones, sound wave treatment, surgery, or scope may be recommended to break down or remove the stone.

**Consequences:** If the stone is not passed soon enough you may develop a urinary tract infection, or hydronephrosis (backflow of urine into the kidney).

## 41. Congenital Malformation

This health outcome descriptor refers to a baby having a birth defect.

### Congenital Malformation

**What you experience or feel:** Congenital malformations, also known as birth defects, are conditions that can be detected in your baby before or after birth. Malformations are classified as “major” if they result in a significant defect affecting your baby’s ability to eat, move or perform other normal baby activities (sometimes called a functional defect) or if the defect requires specific medicine or surgery to fix it. Malformations are classified as “minor” if they do not cause a functional defect and no intervention is required. Any type of malformation may cause increased anxiety and stress for parents and family members.

**Time Horizon:** “Major” malformations (i.e. spina bifida) may have a life-long impact on your child’s quality of life or possibly life expectancy, depending on severity. Minor malformations, by definition, will have no impact on health or function.

**Testing and Treatment:** Congenital malformations may be detected on prenatal ultrasound but may not be recognized until after birth. Treatment may be possible for some major malformations and may involve corrective surgery.

**Consequences:** If your child has a “major” malformation, he or she may require walking aids, wheelchairs or even be bed bound; other assistance may also be needed. He or she may not be able to live independently as adults.

## 42. Bone Fracture

This health outcome descriptor refers to fracture of a bone.

### Bone Fractures due to Osteoporosis

**What you experience or feel:** You may experience severe pain, swelling, and dysfunction from a fracture. The most common sites of fracture are the spinal column and hip.

**Time Horizon:** Symptoms of fractures may last for weeks and slowly improve. Some fractures will not improve without surgery. Osteoporosis (thinning of bones) will last for the rest of your life.

**Testing and Treatment:** Treatment for fractures may be administered in the hospital or at home. Treatment typically includes pain medicine. Hip fractures will require surgery. Treatment for osteoporosis most often includes pills taken as an outpatient.

**Consequences:** Vertebral fractures may result in long-lasting pain. Hip fractures will require weeks of recovery and rehabilitation after surgery.

### 43. Allergic Reaction to Non-Steroidal Anti-Inflammatory Drugs (NSAID)

This health outcome descriptor refers to the experience of being admitted, as an adult, to hospital due to an allergic reaction. It does not refer to aspects of your hospitalisation that are specific to your disease.

#### Allergic Reaction to Non-Steroidal Anti-Inflammatory Drugs (NSAID)

**What you experience or feel:** You may experience hoarseness, throat tightness, mild wheezing or more extensive hives and itchiness.

**Time Horizon:** Allergic reactions to NSAIDs usually develop shortly, within 20 minutes, after taking the medication. A moderate reaction will disappear within a few hours.

**Testing and Treatment:** Some people are more likely than others to develop an allergic reaction to NSAIDs. If you have had an anaphylactic reaction to any substance, you are more likely than others to have an NSAID allergy. A moderate reaction might be treated with an inhaled lung medication, while severe reactions are typically treated with adrenaline. You may be referred to an allergist to manage your sensitivity to NSAIDs.

**Consequences:** You will usually recover fully on the same day as the allergic reaction to the NSAID. In severe cases, you may develop anaphylaxis, which is life threatening.

## 44. Skin Rash

This health outcome descriptor refers to having irritated or swollen skin.

### Skin Rash

**What you experience or feel:** You have itchy, red, painful, and/or irritated skin. You may develop blisters or raw skin.

**Time Horizon:** The timing of symptoms varies. In some cases, a rash may disappear on its own. Other rashes may persist.

**Testing and Treatment:** Your doctor will examine the rash and provide appropriate treatment. This may include skin prick and blood testing to identify causative exposures. Depending on the type of rash, treatment may include moisturisers, antihistamines, corticosteroids, and antibiotics.

**Consequences:** You may experience ulceration, bleeding, and infection at the site of the rash.

## 45. Gastrointestinal Ulcer

This health outcome descriptor refers to having a wound in your stomach or intestines. It does not refer to a perforation, which goes through all layers of the stomach or intestine.

### Gastrointestinal Ulcer

**What you experience or feel:** You may experience burning pain from your abdomen, bloating, nausea, dizziness, and intolerance to fatty foods. You may see your stools becoming black, sticky, and/or bad smelling.

**Time Horizon:** You may experience symptoms of an ulcer as soon as one week of regular NSAID use. The ulcer may worsen if NSAIDs are not stopped or if you do not receive treatment.

**Testing and Treatment:** You will need an endoscopy, usually an upper gastrointestinal endoscopy, that is, a flexible tube is inserted via your mouth, to investigate your stomach and upper bowel for the source of bleeding. Sometimes an additional colonoscopy is necessary to detect a source of bleeding in the large bowel. You may need blood tests or a stool culture to determine if you have a particular type of infection (*H. pylori*). You may require blood transfusions if you have lost too much blood. Your doctor may recommend that you change your diet, quit smoking, and avoid further NSAID use (if possible). You may be recommended to take antibiotics, and other medications to stop or negate acid production in your stomach.

**Consequences:** A gastrointestinal ulcer puts you at a higher risk of bleeding, perforation, and obstruction. These conditions may be life-threatening if they go untreated.

## 46. Wound Infection

This health outcome descriptor refers to infection at the site of a wound, most likely caused by colonoscopy or flexible sigmoidoscopy.

### Wound Infection

**What you experience or feel:** You experience pain, warmth, and swelling near the site of the wound. You may also experience fever, breathlessness, or change in mental state. These symptoms will worsen if left untreated.

**Time Horizon:** You may experience symptoms of infection within a few hours or days of having a colonoscopy (if that was the causative factor).

**Testing and Treatment:** You will be hospitalized and given antibiotic treatment for several days or a few weeks. You may require a return to the operating room for repair and cleaning of the wound.

**Consequences:** Until the infection goes away, your activity level may be reduced, and you may have some discomfort at the wound site. In the long-term there will not be any adverse consequences except for surgical scars.



## 47. Minor Bleeding

This health outcome descriptor refers to bleeding with minor blood loss or bruising.

### Minor Bleeding

**What you experience or feel:** You lose some blood (e.g. from your nose, gums, with your stools or urine) or you present with unusual bruising. Bleeding lasts longer (or the bruise is larger) than usual, but eventually stops. You may also see a "pinpoint" rash (little red dots) which can occur anywhere on the skin, often on the lower legs and ankles.

**Time Horizon:** The minor bleeding and symptoms persists until a cause is found and corrected.

**Testing and Treatment:** Sometimes there is no need for medical treatment. Your doctor may recommend that you receive platelet transfusions, order some blood test, or schedule a clinic visit.

**Consequences:** There are rarely long-term consequences. You may be worried about recurrence of bleeding or bruising, and pain can be associated with bruising.

## 48. Major Bleeding

This health outcome descriptor refers to bleeding with substantial blood loss.

### Major Bleeding

**What you experience or feel:** You lose a lot of blood (e.g. vomit blood, blood with your stools, blood from a wound) or you have an internal bleeding.

**Time Horizon:** Bleeding does not stop, and you have to receive specific urgent care.

**Testing and Treatment:** You may require a CT scan, a flexible tube via your mouth or anus to investigate your bowel, and blood work, and you may be admitted to hospital to receive blood transfusion or surgery.

**Consequences:** You may recover completely, but you may instead have permanent neurological damage if your brain does not receive blood for an extended period of time (e.g. be unable to speak or understand, or wheel-chair bound), or even die.

## 49. Gastrointestinal Bleeding - Minor

This health outcome descriptor refers to minor blood loss in the stomach or intestines.

### Gastrointestinal Bleeding – Minor

**What you experience or feel:** You may notice some blood with your stools, or they might turn black, bad smelling and sticky; you will likely have no other symptoms, or feel weak and tired, or lightheaded when you stand.

**Time Horizon:** This may happen at any time, but more often in the first months of starting blood thinning treatment. Symptoms may last for days, sometimes for a few weeks. Usually they resolve easily with treatment.

**Testing and Treatment:** You will need to have blood work, to check how much blood you have lost in your bowel. You may need a flexible tube via your mouth or anus to investigate your bowel for the source of bleeding. You may need iron treatment or blood transfusions if you had lost too much of your blood.

**Consequences:** You will need to stop your blood thinning treatment, and you will need to discuss with your doctor how to get protection against blood clots. You may require a stomach protection pill for a few months or lifelong after the bleeding. In most cases, you will go back to normal in a few days or weeks. If you resume your blood thinning medication, you may be worried about bleeding recurrence.

## 50. Gastrointestinal Bleeding - Major

This health outcome descriptor refers to major blood loss in the stomach or intestines.

### Gastrointestinal Bleeding – Major

**What you experience or feel:** You may be lightheaded, nauseated, have a sense of stomach replenishment, cramps, bloating. You might vomit blood, or you may see bright red blood in your stools; sometimes, you may see your stools becoming black, sticky, bad smelling.

**Time Horizon:** This may happen at any time, but more often in the first months of starting blood thinning treatment. You will require hospital admission and medical treatment, which should be able to stop the bleeding in a few hours. Symptoms may last for days.

**Testing and Treatment:** You will need an endoscopy – a flexible tube via your mouth or anus to investigate your bowel for the source of bleeding. You may require blood transfusions if you had lost too much of your blood.

**Consequences:** You will need to stop your blood thinning treatment, and you will need to discuss with your doctor how to get protection against blood clots. You may require a stomach protection pill for a few months or lifelong after the bleeding. In most cases, you will go back to normal in a few days or weeks.

## 51. Any Bleeding

This health outcome descriptor refers to bleeding, in any amount.

### Any Bleeding

**What you experience or feel:** You lose some blood (e.g. from your nose, gums, with your stools or urine, vomit, or wound) or you present with unusual bruising. The bleeding may or may not stop depending on the amount. You may also see a "pinpoint" rash (little red dots) which can occur anywhere on the skin, often on the lower legs and ankles.

**Time Horizon:** The bleeding and symptoms may stop after a few hours or days. It may also persist or even worsen until a cause is found and corrected.

**Testing and Treatment:** Sometimes there is no need for medical treatment. Your doctor may recommend that you receive platelet transfusions, order some blood test, or schedule a clinic visit. In more severe cases you may require a CT scan, a flexible tube via your mouth or anus to investigate your bowel, and blood work, and you may be admitted to hospital to receive blood transfusion or surgery.

**Consequences:** You may be worried about recurrence of bleeding or bruising, and pain can be associated with bruising. If blood loss is severe enough you may recover completely, but you may instead have permanent neurological damage if your brain does not receive blood for an extended period of time (e.g. be unable to speak or understand, or wheel-chair bound), or even die.

## 52. Acute Kidney Injury (AKI)

This health outcome descriptor refers sudden loss of kidney function.

### Acute Kidney Injury

**What you experience or feel:** With Acute Kidney Injury (AKI) you may experience a wide range of symptoms. You may not feel any symptoms if the AKI is mild. When kidneys fail to a sufficient degree you may start feeling some symptoms including nausea, vomiting, loss of appetite, change in food taste, increase or decrease urination, itching, muscle cramps, feeling tired or dizzy, difficulty concentrating or confusion, abnormal heart rhythm, low blood pressure or high uncontrolled blood pressure, shortness of breath, and swelling of feet, ankles, legs, face or hand.

**Time Horizon:** AKI usually progresses quickly over hours to days.

**Testing and Treatment:** AKI is found through simple blood and urine tests. AKI is often reversible with appropriate treatment. Treatment for AKI typically requires a hospital stay, but in some cases you may be able to recover at home. Treatment can target the underlying cause for AKI, or can be applied to prevent complications and allow your kidneys time to recover. You may need dialysis for your AKI, which involves pumping your blood through an artificial kidney in order to take over your kidneys' function and allow them to recover.

**Consequences:** Most people with AKI are already hospitalized, and how long you will stay in the hospital depends on the reason for your AKI and how quickly your kidneys recover. You may die in hospital or continue to need dialysis after they are sent home from the hospital. This risk increases with more severe and repeated episodes of AKI. You may develop heart disease or other short- and long-lasting health problems.

## 53. Chronic Kidney Disease (CKD)

This health outcome descriptor refers slow loss of kidney function.

### Chronic Kidney Disease

**What you experience or feel:** With Chronic Kidney Disease (CKD) you may experience a wide range of symptoms. In early stages of kidney disease you may not feel any symptoms. When kidneys fail to a sufficient degree you may start feeling some symptoms including nausea, vomiting, loss of appetite, decrease weight, anemia (low blood count), change in food taste, increase or decrease urination, itching, muscle cramps, bone pain, weak bones, fatigue, feeling tired or dizzy, difficulty concentrating, abnormal heart rhythm, low blood pressure or high uncontrolled blood pressure, shortness of breath, and swelling of feet, ankles, legs, face or hand.

**Time Horizon:** CKD typically progresses slowly over months to years.

**Testing and Treatment:** Simple blood and urine tests can detect CKD. Imaging tests such as an ultrasound or CT scan can be used to get a picture of your kidneys and urinary tract. This tells your doctor whether your kidneys are too large or too small, whether you have a problem like a kidney stone or tumor and whether there are any problems in the structure of your kidneys and urinary tract. A kidney biopsy, which is done in some cases to check for a specific type of kidney disease, helps to see how much kidney damage has occurred and plan treatment. To do a biopsy, the doctor removes small pieces of kidney tissue and looks at them under a microscope.

**Consequences:** You may develop complications like high blood pressure, anemia (low blood count), weak bones, poor nutritional health and nerve damage. Also, CKD increases your risk of having heart and blood vessel disease. These problems may happen slowly over a long period of time. Early detection can help prevent the progression of kidney disease to kidney failure. Heart disease is the major cause of death for all people with CKD. High-risk groups include those with diabetes, hypertension and a family history of kidney failure. African Americans, Hispanics, Pacific Islanders, American Indians and seniors are at increased risk.

## 54. Peripheral Arterial Disease

This health outcome descriptor refers to narrowing and reduced blood flow in arteries outside your heart or brain.

### Peripheral Arterial Disease

**What you experience or feel:** You may develop pain in your calves and thigh muscles with walking or later at rest. The skin on your lower legs may become thin and shiny with loss of hair. You may be prone to get wounds in your legs and feet which do not heal well and put you at risk for infection.

**Time Horizon:** Occurs gradually, symptoms worsen over time.

**Testing and Treatment:** Tests to assess blood flow to the legs, ultrasound and other imaging tests may be needed. Treatment may be with medications alone or in combination with a flexible tube into the blocked artery which is supplying blood to your leg muscles. Some patients may need surgery.

**Consequences:** Can be disabling due to pain. If wounds do not heal well and blood flow cannot be improved by surgery or flexible tube procedures, toes, feet, or a portion of the leg may need to be amputated.



## 55. Type 2 Diabetes

This health outcome descriptor refers to having type 2 diabetes. It is a disease that affects your body's ability to store and use glucose (sugar) properly.

### Type 2 Diabetes

**What you experience or feel:** You may experience frequent urination, thirst, weight loss, loss of feeling in your fingers or toes, and/or fatigue. The symptoms will continue to get worse unless treated.

**Time Horizon:** The onset of symptoms will vary between people but will progress gradually over months and years.

**Testing and Treatment:** A doctor will test the pattern in your blood sugars with a blood test. Depending on the type of blood test you may need to fast overnight. Your blood sugars will be monitored regularly after diagnosis. Your type 2 diabetes may be managed first with changes to your diet, weight and physical activity. If you show no response, diabetes medication may be added to those lifestyle changes.

**Consequences:** You will be at a higher risk of developing other diseases, including but not limited to heart disease, kidney disease, nerve damage, infections, and vision loss.

## 56. Cardiovascular Event

This health outcome descriptor refers to the experience of having a cardiovascular event. This includes all myocardial infarctions, all strokes/transient ischaemic attacks, acute heart failure, and arrhythmias.

### Cardiovascular Event

**What you experience or feel:** You may develop sudden chest pain, chest pressure, shortness of breath, palpitations, sweating, nausea, or vomiting. The pain may radiate to your jaw, shoulder, back or arm. You may also have trouble with your vision, talking, or moving parts of your body. Some patients die before emergency medical services get to them.

**Time Horizon:** Starts suddenly and may lead to permanent heart or brain damage unless you receive immediate medical attention.

**Testing and Treatment:** An electrocardiogram and brain CT usually reveals the diagnosis. You may be treated with clot busting medications or may be taken for an angiogram of the heart arteries and treated with balloons and steel scaffolds called stents to open the blocked heart artery and keep it open. In some patients, open heart surgery may be required. You will be treated with multiple medications to treat this episode and prevent further episodes.

**Consequences:** If treated immediately after symptom onset, you may not suffer many long-term consequences. If treatment is delayed, you may die or suffer from a weak heart, heart failure, or neurological symptoms for the rest of your life.

## 57. ST Segment Elevated Myocardial Infarction (STEMI)

This health outcome descriptor refers to the experience of having a ST Segment Elevated Myocardial Infarction (STEMI). It does not refer to other diseases which may fall under the category of acute coronary syndromes.

### ST Segment Elevated Myocardial Infarction (STEMI)

**What you experience or feel:** You may develop sudden chest pain, chest pressure, shortness of breath, sweating, nausea, or vomiting. The pain may radiate to your jaw, shoulder, back or arm. You may feel dizzy or faint. Some patients die before emergency medical services get to them.

**Time Horizon:** Starts suddenly, leads to permanent heart damage unless you receive immediate medical attention.

**Testing and Treatment:** An electrocardiogram usually reveals the diagnosis. You may be treated with clot busting medications or may be taken for an angiogram of the heart arteries and treated with balloons and steel scaffolds called stents to open the blocked heart artery and keep it open. In some patients, open heart surgery may be required. You will be treated with multiple medications to treat this episode and prevent further episodes.

**Consequences:** If treated immediately after symptom onset, you may not suffer many long term consequences. If treatment is delayed, you may die or suffer from a weak heart and heart failure for the rest of your life.

## 58. Non ST Segment Elevated Myocardial Infarction (NSTEMI)

This health outcome descriptor refers to the experience of having a non ST Segment Elevated Myocardial Infarction (NSTEMI). It does not refer to other diseases which may fall under the category of acute coronary syndromes.

### Non ST Segment Elevated Myocardial Infarction (NSTEMI)

**What you experience or feel:** You may develop sudden chest pain, chest pressure, shortness of breath, sweating, nausea, or vomiting. The pain may radiate to your jaw, shoulder, back or arm. You may feel dizzy or faint. Some patients die before emergency medical services get to them.

**Time Horizon:** Starts suddenly, leads to permanent heart damage unless you receive immediate medical attention.

**Testing and Treatment:** An electrocardiogram may be helpful. You may need additional tests such as an echocardiogram and an angiogram to identify the arterial blockage that is causing your symptoms. The doctor may open blockages in the heart arteries with balloons and may put a steel scaffold called a stent to keep the artery open. In some patients, open heart surgery may be required. You will be treated with multiple medications to treat this episode and prevent further episodes.

**Consequences:** If treated immediately after symptom onset, you may not suffer many long term consequences. If treatment is delayed, you may suffer from a weak heart and heart failure for the rest of your life. You may have more episodes over the next year and may need more heart procedures and medications.

## 59. Hemorrhagic Stroke

This health outcome descriptor refers to a stroke due to rupture of weakened blood vessel of the brain

### Hemorrhagic Stroke

**What you experience or feel:** You may experience nausea, vomiting, severe headache, seizures and loss of consciousness. Severe sudden loss of muscle function may lead to one sided weakness, inability to speak, or blindness. Some patients may die soon after symptom onset.

**Time Horizon:** Hemorrhagic stroke occurs suddenly, and when treated may resolve in days or weeks.

**Testing and Treatment:** A CT or MRI scan of the brain reveals the problem. Treatment is based on the severity of symptoms. You may have to be supported by a breathing machine for a few days. Your blood pressure and vitals are monitored and treated as needed. If you were on blood thinners before the procedures, these are stopped and their effects reversed. You may need surgery to treat the source of bleeding in the brain. Long term treatment will include physical rehabilitation.

**Consequences:** You are at high risk of dying. You may have severe disabilities for the rest of your life and may depend on others for completing activities of daily living. With rehabilitation, you may be able to recover some function.

## 60. Ischaemic Stroke

This health outcome descriptor refers to a stroke due to a blood clot in an artery of the brain.

### Ischaemic Stroke

**What you experience or feel:** You may have mild weakness and partial loss of function in a muscle group, difficulty processing information or speaking. You may have unusual difficulty recalling names/events, or problems with your senses. Depending on the muscle group involved in the weakness, you may have difficulty eating, swallowing, writing (and other fine motor skills) and walking (and other gross motor skills).

**Time Horizon:** Occurs suddenly, symptoms (some or most) may resolve if treated promptly. For persisting symptoms, physical rehabilitation may help restore some lost function. Some deficiencies in function may be permanent.

**Testing and Treatment:** A CT or MRI scan of the brain reveals abnormalities. Treatment may involve clot busters or a procedure with catheters and balloons in the arteries of the brain to clear up the blockages. May involve long term blood thinners to prevent future repeat strokes. Usually, treatment includes physical rehabilitation.

**Consequences:** With immediate treatment, some of your symptoms may resolve completely. With physical rehabilitation many symptoms may improve. You may be able to live an independent functional life with some adjustment and support

## 61. Chronic Mild Pain

This health outcome descriptor refers to the experience of having long-lasting mild pain.

### Chronic Mild Pain

**What you experience or feel:** You have annoying pain (2-3 on a 1-10 scale). You may frown or complain. You are able to carry on a normal conversation. The pain does not interfere much with your daily activities.

**Time Horizon:** The pain lasts longer than 6 months.

**Testing and Treatment:** Your doctor will take a history, examine you, and may investigate your pain further. Investigations can include, but are not limited to blood tests and imaging. As your pain is mild, it can be relieved by rest or over-the-counter medications (e.g., acetaminophen, aspirin, ibuprofen).

**Consequences:** Your pain may never fully go away. You may get depressed by the pain and it may affect your mood.

## 62. Chronic Moderate Pain

This health outcome descriptor refers to the experience of having long-lasting moderate pain.

### Chronic Moderate Pain

**What you experience or feel:** You have miserable but bearable pain (6-7-8 on a 1-10 scale). You grimace and moan. You have difficulty moving, talking, or behaving normally. For example, you must strain to carry on a normal conversation.

**Time Horizon:** The pain lasts longer than 6 months.

**Testing and Treatment:** Your doctor will take a history, examine you, and may investigate your pain further. Investigations can include, but are not limited to blood tests and imaging. Since your pain moderate it is difficult to treat. It may be relieved by medications, including over-the-counter medications (e.g., acetaminophen, aspirin, ibuprofen) or prescription opioid medications (i.e., narcotics).

**Consequences:** Your pain may never fully go away. You are likely to get depressed by the pain and it is likely to affect your mood.



## 63. Acute Mild Pain

This health outcome descriptor refers to the experience of having short-lasting mild pain.

### Acute Mild Pain

**What you experience or feel:** You have annoying pain (2 to 3 on a 1-10 scale) that may be sharp or dull in nature. You may frown and feel like complaining about it. You are able to carry on a normal conversation and activities. The pain does not interfere much with your daily activities. Depending on the length of the pain, it may affect your mood.

**Time Horizon:** Your pain lasts less than three to six months, often not longer than days or a few weeks.

**Testing and Treatment:** Your doctor will take a history, examine you, and may investigate your pain further. Investigations can include, but are not limited to blood tests and imaging. As your pain is mild, it is relieved by rest or over-the-counter medications (e.g., acetaminophen, aspirin, ibuprofen).

**Consequences:** You may continue to be tender or sore for a short time after the pain resolves, then you have no symptoms. You forget the pain quickly once it is over or controlled.

## 64. Acute Moderate Pain

This health outcome descriptor refers to the experience of having short-lasting moderate pain.

### Acute Moderate Pain

**What you experience or feel:** You have miserable but bearable pain (6 to 8 on a 1-10 scale). You grimace and moan. You have difficulty moving, talking, or behaving normally. For example, you must strain to carry on a normal conversation.

**Time Horizon:** Your pain lasts less than three to six months, often not longer than days or a few weeks.

**Testing and Treatment:** Your doctor will take a history, examine you, and may investigate your pain further. Investigations can include, but are not limited to blood tests and imaging. Since your pain is moderate it is difficult to treat. It may be relieved by medications, including over-the-counter medications (e.g., acetaminophen, aspirin, ibuprofen) or prescription opioid medications (i.e., narcotics).

**Consequences:** You may continue to be tender or sore after the pain resolves, then you have no symptoms. You may worry about the pain recurring.

## 65. Acute Severe Pain

This health outcome descriptor refers to the experience of having short-lasting severe pain.

### Acute Severe Pain

**What you experience or feel:** You have intense or unbearable pain (9-10 on a 1-10 scale) that may be described as wrenching, splitting, or excruciating. You cry and moan uncontrollably. It is nearly impossible to attend to anything but your pain.

**Time Horizon:** Your pain lasts less than three to six months, often not longer than days or a few weeks.

**Testing and Treatment:** Your doctor will take a history, examine you, and may investigate your pain further. Investigations can include, but are not limited to blood tests and imaging. Your pain is difficult to treat but may be relieved by prescription opioid and other medications (i.e., narcotic).

**Consequences:** Unless you die from the causes of your pain, your pain goes away gradually, becoming moderate, then mild. You may continue to be tender or sore after the pain resolves until you have no symptoms. You may worry about the pain recurring.

## 66. Death from Colorectal Cancer

This health outcome descriptor refers to the state of being dead due to colorectal cancer. It does not refer to the process of dying or outcomes that precede it (e.g. the breathlessness related to it or pain).

### Death from Colorectal Cancer

**What you experience or feel:** You are dead. You feel no pain. You may experience symptoms from the colorectal cancer prior to dying but you do not feel those when you are dead.

**Time Horizon:** Before you die, you experience other states of disease of varying duration.

**Testing and Treatment:** Tests and treatment will have ceased.

**Consequences:** You lose your vital bodily and mental functions, ending your life.

## 67. Death From Cause Other Than Colorectal Cancer

This health outcome descriptor refers to the state of being dead due to a cause other than your colorectal cancer. It does not refer to the process of dying or outcomes that precede it (e.g. the breathlessness related to it or pain).

### Death From Cause Other Than Colorectal Cancer

**What you experience or feel:** You are dead and feel no pain. You may experience symptoms from something other than your colorectal cancer prior to dying but you do not feel those when you are dead.

**Time Horizon:** Before you die, you experience other states of disease of varying duration.

**Testing and Treatment:** Tests and treatment will have ceased.

**Consequences:** You lose your vital bodily and mental functions, ending your life.

## 68. Cardiovascular Death

This health outcome descriptor refers to the state of being dead due to a cardiovascular event (e.g. myocardial infarction, stroke, heart failure, arrhythmia). It does not refer to the process of dying or outcomes that precede it (e.g. the breathlessness related to it or pain).

### Cardiovascular Death

**What you experience or feel:** You are dead. You feel no pain. You may experience symptoms from the cardiovascular event prior to dying but you do not feel those when you are dead.

**Time Horizon:** Before you die, you experience other states of disease of varying duration.

**Testing and Treatment:** Tests and treatment will have ceased.

**Consequences:** You lose your vital bodily and mental functions, ending your life.

## 69. All-Cause Death

This health outcome descriptor refers to the state of being dead due to any factor (related and unrelated to your colorectal cancer). It does not refer to the process of dying or outcomes that precede it (e.g. the breathlessness related to it or pain).

### All Cause Death

**What you experience or feel:** You are dead. You feel no pain. You may experience symptoms prior to dying but you do not feel those when you are dead.

**Time Horizon:** Before you die, you experience other states of disease of varying duration.

**Testing and Treatment:** Tests and treatment will have ceased.

**Consequences:** You lose your vital bodily and mental functions, ending your life.