The Language of Melanoma

A guide for patients, friends and family

MELANOMA PATIENT *conference*

This booklet was produced with help from patient support consultancy Anatomy Health for delegates at the Melanoma Patient Conference in June 2018.

Becoming familiar with the unfamiliar

“Nobody expects patients to know or understand every term used to explain their disease or its treatment.

Melanoma terminology is complicated and has changed so much over the last few years that we felt it would be useful to provide you with a resource that explains the acronyms and clarifies meanings of jargon you might come across.

Imogen and I will continue to ensure this Jargon Booklet remains up to date and as comprehensive as possible.

I hope that you as patients find this resource helps to alleviate any of your concerns or questions and that we have included all the definitions you were hoping to see.”

Dr James Larkin

Consultant Medical Oncologist at The Royal Marsden

Disclaimer: this booklet is not intended to replace medical advice from your care team. Please speak to your doctor if anything is unclear.

Sections

This booklet is split into sections to help you find the term you're looking for. Each section lists terms alphabetically.

1 SECTION 1
The language of diagnosis

Melanoma
Melanoma is a type of skin cancer. It develops from pigment-containing cells called melanocytes. Melanomas typically happen in the skin. But they can more rarely occur in the mouth, intestines, or eye.

You may also hear melanoma referred to as 'malignant melanoma', which means it is a cancer that can spread to other parts of the body.

The most common sign of melanoma is the appearance of a new mole or a change in an existing mole. There are several different types of melanoma – the main types of which are listed below.

Types of melanoma

Acral lentiginous melanoma
A rare type of melanoma that's also sometimes called subungual melanoma. This skin cancer usually occurs on the palms of the hands and soles of the feet. It can also sometimes develop around a nail, most commonly the thumbnail or big toenail.

Acral lentiginous melanomas are the most common type of melanoma in people with dark skin, but they can occur in people with any skin type. This skin cancer isn't linked to sun exposure.

Atypical spitzoid tumour / melanocytic lesion
Spitzoid tumours usually look different to conventional melanomas and it can be difficult to predict how they will progress. Most challenging is the atypical spitz tumour, which is a borderline benign / malignant cancer. Atypical spitzoid tumours tend to spread to the sentinel lymph nodes more often than conventional melanomas.

Desmoplastic melanoma
A rare type of melanoma that is most common on sun-exposed areas of the head and neck. Desmoplactic melanoma are sometimes described as scar-like and are often skin coloured. These melanomas can grow for months or years before being recognised.

Familial Atypical Multiple Mole Melanoma Syndrome (FAMM, FAM-M):
An inherited condition identified when:

- Melanoma has been diagnosed in a family member, including grandparents, aunts, uncles, and cousins.

- Several family members have large numbers of moles (often more than 50), which may be abnormal.

Types of melanoma cont...

Lentigo maligna melanoma

About one in 10 melanomas (10%) are lentigo maligna melanomas. They usually affect older people who have spent a lot of time outdoors. They appear in areas that are often exposed to the sun, such as the face.

They are flat and look like a freckle. But they're usually larger, darker and stand out more than a normal freckle. They can gradually get bigger and may change shape. At a later stage, they may grow downwards into the deeper layers of skin and can form lumps (called nodules).

Mucosal melanoma

A rare type of melanoma - around 1 in 100 melanomas are mucosal. Develops in the inner surfaces of the body that line the nose, mouth, oesophagus, anus, urinary tract and vagina. Mucosal melanomas are especially difficult to detect because they can easily be mistaken for other, far more common conditions.

Mucosal melanoma is not related to sun exposure, unlike most cases of melanoma. There are no obvious causes, not even family history. Most cases of mucosal melanoma are quite advanced once found, because they are rare and hard to identify.

Nodular melanoma

Nodular melanomas fast-developing and can quickly grow downwards into the deeper layers of skin if not removed.

Nodular melanomas usually appear as a changing lump on the skin that might be black to red. They often grow on previously normal skin and most commonly occur on the head and neck, chest or back. Bleeding or oozing is a common symptom.

Superficial spreading melanoma (SSM)

SSM is the most common form of melanoma in pale-skinned (Caucasian) people. Around seven out of 10 (70%) of all melanomas in the UK are SMMs. The average age at diagnosis is in the fifth decade, and it tends to occur on sun-exposed skin, especially on the backs of men and lower limbs of women.

They initially tend to grow outwards rather than downwards, so don't pose a problem. But if they grow downwards into the deeper layers of skin, they can spread to other parts of the body.

Descriptions of melanoma you may hear

Breslow scale /thickness

The depth a melanoma extends below the skin surface. Measured in millimetres.

Doctors sometimes refer to 'Breslow staging' as well. Breslow scales only look at the depth of melanoma cells in the skin. The number stages (see later 'Stage' definition) look at both the melanoma depth, and whether the melanoma has spread to lymph nodes or another part of the body.

Clark's scale

The Clark scale is a way of measuring how deeply the melanoma has grown into the skin and which levels of the skin are affected.

Depending on where the melanoma is located on the body, the millimeters of depth for each Clark level can vary widely, so one person's Clark's III may be 1 mm, while another person's is 2 mm.

The Clark scale has 5 levels:

►**Level 1** is also called melanoma in situ – the melanoma cells are only in the outer layer of the skin (the epidermis)

►**Level 2** means there are melanoma cells in the layer directly under the epidermis (the papillary dermis)

►**Level 3** means the melanoma cells are throughout the papillary dermis and touching on the next layer down (the reticular dermis)

►**Level 4** means the melanoma has spread into the reticular or deep dermis

►**Level 5** means the melanoma has grown into the layer of fat under the skin (subcutaneous fat)

Doctors sometimes refer to 'Clark staging' as well. Clark scales only look at the depth of melanoma cells in the skin. The number stages (see later 'Stage' definition) look at both the melanoma depth, and whether the melanoma has spread to lymph nodes or another part of the body.

Blood vessel/lymphatic invasion

Blood vessel invasion and lymphatic invasion mean the melanoma has invaded the blood or lymph system respectively. You may also hear blood vessel invasion referred to as angioinvasion.

Different laterality

The right side of the body, the left side of the body and the midline are separate 'lateralities' that may be recorded in the notes about a person's melanoma.

Descriptions of melanoma you may hear cont...

In situ
In its normal place; confined to the site of origin.

In-transit metastasis
Metastasis found in the lymphatic channels more than 2cm away from the primary melanoma, but not reaching the regional lymph nodes.

Invasive
Cancer that has spread beyond the layer of tissue in which it developed and is growing into surrounding, healthy tissues.

Lesion
You may hear doctors refer to your melanoma as a lesion. A lesion is simply part of the body that has suffered damage through injury or disease – in this case, the lesion is cancer.

Mitotic rate
A measure of how fast cancer cells are dividing and growing. To find the mitotic rate, the number of cells dividing in a certain amount of cancer tissue is counted. Mitotic rate is used to help find the stage of melanoma. Higher mitotic rates are associated with more rapidly dividing cells, and therefore larger lesions with greater potential for metastasis.

Neoplasm
A new growth of tissue in which cell multiplication is uncontrolled and progressive. Melanoma is a neoplasm of pigment-containing cells called melanocytes.

Primary tumour
Where the cancer starts in the body.

Radial Growth Phase (RGP)
A melanoma is described as either having RGP present or absent. If present, RGP indicates that the melanoma is growing horizontally (or radially), within a single plane of skin layer.

Regressing melanoma
A regressing melanoma is reacting to the body's immune system by shrinking in size. Partial spontaneous regression is not an uncommon finding in invasive primary melanoma; partial regression can be an indicator of poor prognosis. Proven complete regression is very rare; regressive melanoma is usually thinner than it was originally.

Secondary tumour / cancer
Sometimes cancer cells can break away from the primary cancer and settle and grow in another part of the body. This new cancer growth is called secondary cancer.

Satellites
Satellite lesions are nodules of tumour/melanoma located more than 0.05 mm from the primary lesion. Satellites are described as being present or absent.

Stage

The stage of a melanoma describes how deeply it has grown into the skin, and whether it has spread.

► Stage 0

Abnormal cells found in the topmost layer of skin. These cells have the potential to become cancerous and spread. Stage 0 also is known as melanoma in situ.

► Stage I

This refers to cancers that are not more than 2 millimetres thick, are not ulcerated and that haven't spread.

► Stage II

This refers to cancers that are between 2 and 4 millimetres thick. They may be ulcerated, but haven't spread.

► Stage III

The cancer is of any thickness and has spread from its primary location to the lymph nodes with no detectable evidence of distant spread.

► Stage IV

The cancer has spread from its primary location to one or more distant sites which could be in the skin, lymph nodes, lung, brain or other organs.

(Note there is a session on another type of staging for melanoma called TNM staging at this conference.)

Ulcerated

Melanomas that have grown through the outermost layer of skin (called the epidermis), giving the tumour the appearance of an ulcer.

Unresectable

Unresectable melanoma is melanoma that has spread locally and cannot be removed by surgery.

Vertical Growth Phase (VGP)

The melanoma is described as either having VGP present or absent. If present it is an indication that the melanoma is growing vertically or deeper into the tissues.

SECTION 2
Treating melanoma

2

People who may be involved in your care

Medical oncologist
A doctor who specialises in diagnosing and treating cancer. A medical oncologist is often the main health care provider for someone who has cancer. A medical oncologist also gives supportive care and may coordinate treatment given by other specialists.

Oncology nurse
A nurse who specialises in treating and caring for people who have cancer. The responsibilities of an oncology nurse may include:

- Giving a physical examination
- Giving chemotherapy and other medications
- Identifying patient needs
- Coordinating care with the other members of the oncology team
- Educating and counselling patients and families
- Performing research as part of a clinical trial

Oncology social worker or counsellor
An oncology social worker can help patients cope with cancer and the challenges the disease brings. This may include leading support groups, providing counselling, or helping patients find financial support and other resources.

Patient navigator
Patient Navigators are health care professionals whose primary focus is to assist cancer patients, caregivers, and families in “bridging the gaps” within the health care system and decreasing barriers to care by utilising resources. They provide help and direction and consider more appropriate services. They can provide treatment planning. They support patients and their families.

Surgeon
A surgeon is a person who performs surgery. Surgery is the main treatment for melanoma. You might have surgery to:

- remove an early stage melanoma
- remove the lymph nodes close to the melanoma if the cancer has spread there
- remove melanoma that has come back in the same place following an operation
- remove melanoma that has spread to other parts of the body

Surgical oncologist
A doctor who performs biopsies and other surgical procedures in cancer patients.

Pathologist
A pathologist helps to diagnose disease based on the laboratory analysis of bodily fluids such as blood, urine and tissues. If you have a biopsy, a pathologist is the person who looks at the biopsy to help work out what type of melanoma you have.

Plastic surgeon
A surgeon who specialises in reducing scarring or disfigurement. Plastic surgeons often remove melanomas.

Types of treatment

Adjuvant therapy
Treatment that is given in addition to the primary (initial) treatment. For skin cancer, adjuvant cancer therapy, such as immunotherapy, chemotherapy or radiation, may follow a primary treatment such as surgery. Doctors often recommend adjuvant cancer therapy for those who have stage III or stage IV cancer.

BRAF inhibitors (a form of targeted treatment)
About half of all melanomas have changes (mutations) in the BRAF gene. Melanoma cells with these changes make an altered BRAF protein that helps them grow. BRAF inhibitor drugs such as vemurafenib and dabrafenib target this and related proteins.

Chemotherapy
Chemotherapy is a cancer treatment where medication is used to kill cancer cells. There are many different types of chemotherapy medication, but they all work in a similar way. They stop cancer cells reproducing, which prevents them from growing and spreading in the body.

Combination therapy
This treatment involves combining two or more treatments, such as two immunotherapy agents or two targeted therapy drugs, for more effective results.

Cryotherapy
This treatment is a freezing-cold liquid nitrogen that a dermatologist sprays on pre-cancers (and some early cancers) to help clear them. It takes seconds, stings during the treatment, and turns the skin red for a few days afterward. It can blister and may leave behind a spot.

Gene therapy
Gene therapy is a type of treatment that uses genes to treat illnesses. Researchers have been developing different types of gene therapy to treat cancer.

The ideas for these new treatments have come about because we are beginning to understand how cancer cells are different from normal cells. It is still early days for this type of treatment. Some of these treatments are being looked at in clinical trials.

Immunotherapy

Immunotherapy is a type of cancer treatment that boosts the body's natural defences to fight the cancer. It uses substances made by the body or in a laboratory to improve or restore immune system function.

Immunotherapy drugs used to treat melanoma include ipilimumab, pembrolizumab, nivolumab, and talimogene laherparepvec (T-VEC). The first three drugs are checkpoint inhibitors that "take the brakes off" the immune system and enable it to fight cancer. T-VEC is an oncolytic virus therapy that stimulates stronger anti-tumor immune responses.

Palliative care

Care that prevents or relieves the symptoms of cancer or other diseases. Palliative care does not alter the course of the disease but can improve the quality of life.

Radiotherapy

Radiotherapy uses high energy waves similar to x-rays to kill cancer cells.

You might have radiotherapy for melanoma that has spread. It can shrink melanoma tumours and help to control symptoms.

Some people have radiotherapy as a treatment after melanoma has been removed with surgery. The radiotherapy can lower the chance of the melanoma coming back.

Systemic

Treatment in which medications travel through the bloodstream to all parts of the body to fight cancers that have spread from their original location. The majority of targeted and immunotherapies are systemic.

3 SECTION 3
Surgery, scans and other common procedures

Surgery

Lymphadenectomy
A lymphadenectomy, also known as lymph node dissection, is a surgical procedure to remove one or more lymph nodes to check for cancer.

After the lymph nodes are removed a sample of tissue is checked under a microscope for signs of cancer. For a regional lymphadenectomy, some of the lymph nodes in the tumour area are removed. For a radical lymphadenectomy, most or all of the lymph nodes in the tumor area are removed. Also called lymph node dissection.

Mohs surgery
This specialised technique is used for skin cancers on areas deserving special care, such as the face, ears, lips, hands or genitals. It removes cancer while sparing healthy tissue to create the smallest possible scar.

Scans

Bone scan
A bone scan is used to see if the cancer has spread to the bones, but is rarely used in melanoma.

Chest X-ray
A chest X-ray is done to see if the melanoma has spread to the lungs.

Computed tomography (CT) scan
The CT scan is more detailed than the x-ray and provides cross-sectional images of the body, specifically the soft tissues. The CT scanner takes several pictures as it rotates around the body and then combines the pictures to provide a detailed image. Sometimes a contrast dye is injected into the body to better identify abnormal areas of the body.

Magnetic resonance imaging (MRI)
MRI's provide detailed pictures of the soft tissue of the body using radio waves and strong magnets. MRI scans are very helpful in looking at the brain and the spinal cord.

Positron emission tomography (PET) scan
For a PET scan, the patient is injected with glucose that contains a radioactive atom. The cancer cells in the body will absorb the radioactive sugar. The camera will then capture the areas of radioactivity in the body, helping the doctor determine how much the melanoma has spread.

Types of biopsy

Biopsy
Sometimes cancer can be detected simply by looking at your skin, but the only way to accurately diagnose melanoma is with a biopsy. In this procedure, all or part of the suspicious mole or growth is removed, and a pathologist analyses the sample.

Excisional biopsy
Cutting out the affected area of cancer cells as well as a portion of normal skin surrounding the lesion.

Fine needle aspirate (FNA)
Technique in which a needle is inserted into the tissue or tumour to take out fluid and cells. This tissue/fluid is smeared onto a slide and is then looked at under a microscope.

Incisional biopsy
Technique in which a lesion is removed from the skin by cutting out the affected area. This technique is often used to remove larger lesions.

Punch biopsy
Technique in which a lesion is removed from the skin using a cookie cutter type device. This is used to remove small lesions or to sample a portion of a larger lesion.

Shave biopsy
Technique in which a portion of a lesion is cut off the surface of the skin using a scalpel in most cases.

Sentinel lymph node biopsy
Removal and examination of the first lymph node(s) to which cancer cells are likely to spread from a primary tumour.

4 SECTION 4
The language of clinical trials

Clinical trial
A clinical trial compares the effects of one treatment with another. It may involve patients, healthy people, or both. Clinical trials are the main way that researchers find out if a new treatment, like a new drug or diet or medical device is safe and effective in people.

Often a clinical trial is used to learn if a new treatment is more effective and/or has less harmful side effects than the standard treatment. Clinical trials advance through four phases to test a treatment, find the appropriate dosage, and look for side effects.

Phases of clinical trial

Phase I clinical trial
Tests an experimental treatment on a small group of often healthy people (20 to 80) to judge its safety and side effects and to find the correct drug dosage.

Phase II clinical trial
Phase II expands the drug or treatment testing to a larger group of people often at the dose (or doses) that appear most promising from Phase I trial results. The goal is to continue monitoring for safety, side effects and evidence of how well the drug works.

Phase III clinical trial
This phase expands the drug or treatment testing to hundreds or thousands, of people. Some patients receive the new, or experimental, treatment alone or in combination with the standard therapy. Other patients may get the standard therapy by itself.

The goal is to provide better information on how well the drug works and side effects. The information from Phase III studies is often required to gain regulatory approval from groups like the U.S. Food and Drug Administration (FDA) or the European Medicines Agency (EMA).

Phase IV trials
A Phase IV trial for drugs takes place after the regulatory body approves their use. A drug's effectiveness and safety are monitored in large, diverse populations. This is because sometimes the side effects of a drug may not become clear until more people have taken it over a longer period of time.

Common trial terminology

Adverse Event (AE)
Something that happens to a patient on a clinical trial that is untoward. An adverse event is not necessarily caused by a treatment.

Adverse reaction (AR)
Any untoward and unintended response to drug. A doctor involved in a clinical trial needs to make a judgement as to whether they think the drug caused the event for it to be recorded as an adverse reaction.

Blinding (also called masking)
A trial is blinded if people involved in the trial are unaware of which drug is being administered to each participant.

Blinding is intended to prevent bias. The most common type is “double-blinding”, in which participants, caregivers and those assessing outcome do not know which treatment each participant is given.

Controlled trial
A type of clinical trial in which observations made during the trial are compared to a standard (called the control). The control may be observations from a group of participants in the same trial or observations from outside the trial (for example, from an earlier trial, called a “historical control”).

Double blind
A trial where the investigators and the subjects included in the trial (healthy volunteers or patients) do not know which interventions / treatments have been assigned.

Durable response rate
Researchers conducting clinical trials use this measurement to gauge whether a tumour is responding to treatment. It includes the length of time (usually in months) that a tumour or cancerous area shows improvement as a result of treatment.

Efficacy
A measure of whether the drug has its intended effect.

Eligibility criteria
The key standards that people who want to participate in a clinical study must meet or the characteristics that they must have. These include inclusion criteria and exclusion criteria. For example, a study might only accept participants who are above or below certain ages.

Exclusion criteria
Specific criteria that are defined within the study paperwork that expressly exclude specific individuals from participating in a study. The reasons for considering exclusion can range from safety issues, potential difficulties in management of particular participants or the need to control variables within the study.

Exclusion criteria must always be defended ethically to guard against discrimination.

Inclusion criteria
Specific criteria that are defined within the study protocol that expressly include specific individuals to participate in a study. E.g. People within a certain age range, with a specific condition, etc.

Informed consent
The process by which someone voluntarily confirms his or her willingness to participate in a particular trial. For informed consent to work, you should be informed of all aspects of the trial that are relevant to your decision to participate.

Open label
Describes a clinical trial in which blinding is not used. That means that all parties involved with the trial know which participants have been given each type of drug.

Overall survival rate
The percentage of people who survive a certain type of cancer for a specified amount of time following their initial diagnosis. An overall survival rate typically refers to a period of five or 10 years.

Placebo
A sugar pill or dummy treatment that is given to people taking part in a clinical trial. It allows researchers to test for the 'placebo effect'. This is a psychological response where people feel better even though the substance they are taking has no effect.

By comparing people's responses to the placebo and to the drug being tested, researchers can tell whether the drug is having any real benefit.

Randomisation
Using an element of chance to decide which drug is given to which patient on a clinical trial. Randomisation reduces the differences among groups by equally distributing people with particular characteristics among all the trial arms. The researchers do not know which treatment is better.

Randomised controlled trial (RCT)
A study in which people are allocated at random (by chance alone) to receive one of several clinical interventions. One of these interventions is the standard of comparison or control.

Response rate
This refers to the percentage of patients whose melanoma tumour decreases in size or becomes undetectable in response to treatment.

Study group / arm
The groups being compared in the trial. Also referred to as "treatment groups", "the arms" of a trial, or by individual terms such as treatment and control groups

SECTION 5
Other common language

5

Skin terminology

Asymmetry
One half of the mole or skin growth doesn't match the other half.

Cutaneous
Relating to or affecting the skin.

Dermatology
The medical specialty concerned with the diagnosis and treatment of skin diseases.

Dermis
The lower or inner layer of the two main layers of tissue that make up the skin.

Dysplastic nevi (also called atypical moles)
Moles that look different to normal, healthy moles. Dysplastic nevi are generally larger than ordinary moles (over 5 mm in diameter) and have irregular and indistinct borders. Their colour frequently is not uniform and ranges from pink to dark brown. They are flat or have a flat part.

Laterality
Laterality divides the body into a right and left half as though a line were drawn from mid forehead to mid pelvis and from mid skull to mid buttocks. A midline laterality describes a tumour that is in the center of the "line" drawn from the mid forehead to mid pelvis or from the mid skull to the mid buttocks.

Epidermis
The upper or outer layer of the two main layers of tissue that make up the skin.

Hypodermis
Sometimes referred to as the last layer of skin. The hypodermis can be compared to a fatty cushion protecting from shocks. It helps maintain the body temperature and supports structures like the hair roots. This deep layer acts as an interface between the skin and the organs such as the bones and the muscles.

Junctional nevus
A smooth, hairless, ligh-to-dark brown mole found in the border (junction) between the epidermis and dermis layers of the skin. Can be slightly raised. There are usually many, which can occur on any part of the body.

Margin
The edge or border of the tissue removed in cancer surgery. The margin is "negative" or clean when the pathologist finds no cancer cells at the edge of the tissue, suggesting that all of the cancer has been removed. The margin is "positive" or involved when the pathologist finds cancer cells at edge of the tissue, suggesting that all of the cancer has not been removed.

Melanin
The substance made by melanocytes that gives colour to skin and eyes and that absorbs ultraviolet rays from the sun.

Melanocytes
Cells in the skin and eyes that produce the pigment called melanin and that transfers it to surrounding skin cells.

Mole
A non-cancerous (benign) growth on the skin (usually tan, brown, or flesh-coloured) that contains a cluster of melanocytes and surrounding supportive tissue.

Nevus
A non-specific term that describes a non-cancerous (benign) growth on the skin, such as a mole or birth mark.

Body biology

Benign
Non-cancerous; not recurrent; favourable for recovery.

Cell
The individual unit that makes up all of the tissues of the body.

Sentinel lymph node
The first lymph node to which cancer is likely to spread from the primary tumour.

Lymph node
Lymph nodes are small structures that work as filters for harmful substances. They contain immune cells that can help fight infection by attacking and destroying germs that are carried in through the lymph fluid.

Lymphatic system
Our bodies have a network of lymph vessels and lymph nodes. This network is a part of the body's immune system. It collects fluid, waste material, and other things (like viruses and bacteria) that are in the body tissues, outside the bloodstream.

Lymphedema
Involves blockage of the lymph vessels. This results in the build up of lymphatic fluid in the interstitial tissues of the body.

The lymph vessels collect lymphatic fluid, which consists of protein, water, fats, and wastes from cells. The lymph vessels transport the fluid to the lymph nodes, where waste materials and foreign materials are filtered out from the fluid. The fluid is then returned to the blood. When the vessels are damaged or missing, the lymph fluid cannot move freely throughout the system but accumulates.

This accumulation of fluid results in abnormal swelling of the arm(s) or leg(s), and occasionally swelling in other parts of the body.

Malignant
Cancer. Where abnormal cells divide without control and can invade nearby tissues. Malignant cells can also spread to other parts of the body through the blood and lymph systems.

Metastasis
The spread of cancer cells from the place where they first formed – the primary tumour – to another part of the body.

Genetic terms

BRAF
This gene can mutate, or change, producing a mutated BRAF protein that leads to uncontrolled cancer cell growth. More than half of melanoma cases are linked to mutations in the BRAF gene. The so-called V600E mutation is quite common in these cases.

CDKN2A
This gene typically stops cancer cells from growing. When it mutates, cancer cells can grow uncontrollably. Families with a history of melanoma may carry this gene mutation.

MEK
The proteins made by both the MEK gene and BRAF gene act on the same signalling pathway inside cells. Cancer cells send signals through BRAF and MEK allowing them to grow and spread.
In combination therapy, MEK-inhibiting drugs may be combined with BRAF inhibitors to slow cancer growth or shrink cancers in some patients.

Wild type
This term describes genes that have no mutation and are normal. For example, some people have melanoma with mutations in BRAF, while others have wild-type BRAF melanoma, meaning there's no known BRAF mutation present.

Language about the immune system and immunotherapy

CTLA-4
This protein helps melanoma cells flourish by stopping the immune system's response to them. Immunotherapy can target this protein.

Cytokines
Substances that are produced by cells of the immune system and can affect the immune response. Cytokines can also be produced in the lab and given to people to affect immune responses.

Immunology
This refers to the study of the body's immune system. Our immune system is our very own internal 'police force'. It's made up of disease-battling cells (like B cells and T cells) that travel through our bloodstream, searching out potentially harmful infections like the flu or cancer.

PD-1
A protein found on the surface of immune system T cells and other white blood cells. It is used to signal the cells to shut down so that the immune system doesn't get over-stimulated. Cancer cells can activate this PD-1 signal and prematurely shut down T cells. This interferes with the immune system's ability to detect and destroy cancer cells.

PD-L1
A protein found on the surface of cancer cells that helps them avoid detection and destruction by the immune system. PD-L1 interacts with PD-1 to turn off the immune system inappropriately. It is sometimes also called CD274.

Tumour-infiltrating lymphocytes (TILs)
TILs describe the patient's immune response to the melanoma. When the pathologist examines the melanoma under the microscope he/she looks for the number of lymphocytes, or white blood cells, within the lesion. This is usually described as brisk, non-brisk, or absent, although occasionally it can be described as mild or moderate. The presence of these cells may be a sign of an immune response.

Prognosis
A forecast your care team makes of the probable course and outcome of disease.

Recurrence
The return of symptoms after a remission.

Risk factor
Anything that increases a person's chance of developing a disease.

SECTION 6
Understanding and talking about side effects

A note from Imogen:

“Side effects vary considerably from patient to patient. Some patients feel that having side effects could be a sign that the drug treatment is working. Others experience such significant side effects that they worry about stopping treatment or leaving a clinical trial early and therefore don’t report them quickly enough to their oncology team.

The most important message we can share with all of you is that every reaction – no matter how small or insignificant, or how severe **should be reported to your team.**

Being able to deal with potential reactions quickly could prevent long term harm and ensure the focus of your treatment remains on melanoma and not on managing adverse events. In addition its important for our oncology teams and the drug manufacturers to know and understand the reality of the reactions, who gets them and how frequently.

Below is a list of some of the most common side effects you might have from the current immunotherapy. We purposely didn’t include any of the rare side effects – this document isn’t designed to worry any patient or their family members. Rare side effects are exactly that – rare!

Your honesty helps your team look after you better!”

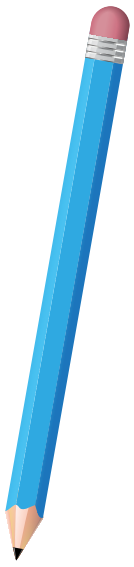
Imogen, MPCUK

Some common side effects:

- Diarrhoea
- Fatigue (overwhelming tiredness)
- Nausea (feeling sick)
- Painful or swollen joints
- Shortness of breath
- Skin rash or itching
- Weight loss

Your Melanoma Language

Use this page to write down words or sentences shared with you that you would like to be explained more.



Recommended places to look for melanoma information online

The web can be a daunting place when you have been diagnosed with cancer. There are many thousands of places you can find information about cancer causes, experiences and treatment.

But not all information sources are evidence based or written by health information experts. Here are a few sources of good quality information and support that we recommend.

Cancer Research UK
http://www.cancerresearchuk.org/about-cancer/melanoma

Macmillan Cancer Support
https://www.macmillan.org.uk/information-and-support/melanoma

Melanoma Focus
https://melanomafocus.com/

Melanoma Fund
https://www.melanoma-fund.co.uk/

Melanoma UK
http://www.melanomauk.org.uk/about_melanoma/

NHS Choices
https://www.nhs.uk/conditions/melanoma-skin-cancer/

Skcin
http://www.skcin.org/contact/

About Anatomy Health

Anatomy Health is a patient support consultancy that uses evidence-backed standards to develop patient information and services that are easy to use and accessible.

Anatomy Health works with providers of patient information and support, including the NHS, pharmaceutical companies and patient organisations. We want to understand what patient needs are, and how best to meet them.

Anatomy Health
Healthier through design

Services include:

►**Evaluation:** **review of current support to identify evidence-backed recommendations for improvement.**

►**Strategy:** **what are the information and support needs of patients with different conditions? How can you help?**

►**Delivery:** **writing, designing and building patient support solutions, print and digital.**

Find out more about Anatomy Health at the following:

Web: www.anatomyhealth.com

Twitter: https://twitter.com/AnatomyHealth

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MELANOMA PATIENT *conference*