

Date: 5th March 2026
Ref: CORP 25/26 - 277

Dear xxx

Freedom of Information request: Patient Information Leaflet Management (CORP 25/26 – 277)

Thank you for your request for information which the Trust received on 21st February 2026.

Your Request:

Please provide the following information about the management of patient information leaflets:

1. OPERATIONAL RESPONSIBILITY

The job title(s) of the person(s) or team responsible for the development, production, approval, and management of patient information leaflets (including printed and digital materials).

2. DOCUMENT VOLUME AND PRODUCTION

- *The approximate number of patient information leaflets currently maintained by the Trust*
- *The software or system(s) used to produce and manage these leaflets (e.g., Microsoft Word, desktop publishing software, dedicated patient information management systems)*

3. REPORTING STRUCTURE

The job title of the senior manager to whom the person(s)/team(s) in question 1 directly report.

4. BOARD-LEVEL ACCOUNTABILITY

The job title of the Board-level executive with overall accountability for patient information materials.

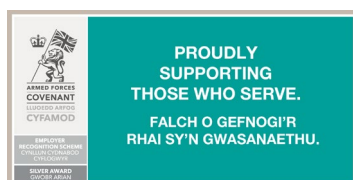
5. GOVERNANCE FRAMEWORK

If the Trust has a formal policy or governance document covering patient information leaflets, please provide:

- *The document title and version number*
- *The job title of the Board-level signatory or accountable executive named in that document*
- *OR a copy of the policy itself if more convenient*

Please find the Trust's response below:

Mae Ymddiriedolaeth GIG Prifysgol Felindre yn hapus i dderbyn gohebiaeth yn y Gymraeg neu'r Saesneg.
Velindre University NHS Trust is happy to receive communication in Welsh or English.



1. OPERATIONAL RESPONSIBILITY

The job title(s) of the person(s) or team responsible for the development, production, approval, and management of patient information leaflets (including printed and digital materials).

Patient Information and Support Services Manager, Supportive Care Team; liaises with the Velindre Trust Communication Team for website and social media.

2. DOCUMENT VOLUME AND PRODUCTION

- The approximate number of patient information leaflets currently maintained by the Trust
- The software or system(s) used to produce and manage these leaflets (e.g., Microsoft Word, desktop publishing software, dedicated patient information management systems)

We have SACT leaflet links to CRUK and Macmillan on our website and approximately 176 SACT links to CRUK and Macmillan.

28 General Velindre leaflets including Pharmacy. 10 Dietary Velindre leaflets. 14 Velindre Radiotherapy leaflets. 7 Velindre Palliative Care leaflets. 7 Velindre Nuclear Medicine leaflets.

3. REPORTING STRUCTURE

The job title of the senior manager to whom the person(s)/team(s) in question 1 directly report.

Senior Manager is Lead Supportive Care Nurse and Consultant Psychologist.

4. BOARD-LEVEL ACCOUNTABILITY

The job title of the Board-level executive with overall accountability for patient information materials.

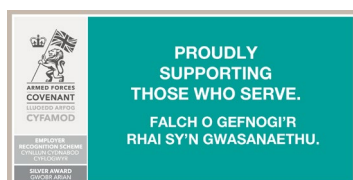
Executive Director of Nursing Allied Health Professionals (AHPs) and Health Science.

5. GOVERNANCE FRAMEWORK

If the Trust has a formal policy or governance document covering patient information leaflets, please provide:

- The document title and version number
- The job title of the Board-level signatory or accountable executive named in that document - Quality assurance reports to Site Specific Team Directorate
- OR a copy of the policy itself if more convenient – please see Appendix 1 below; SOP for SACT Patient Information leaflets.

Mae Ymddiriedolaeth GIG Prifysgol Felindre yn hapus i dderbyn gohebiaeth yn y Gymraeg neu'r Saesneg.
Velindre University NHS Trust is happy to receive communication in Welsh or English.



I trust this answers your request for information, however, should you not be satisfied with the information supplied or the process of supplying it, you have a right to complain and request a review. Please note that you must submit a request for a review within 40 days of the date of this letter.

You should forward your complaint to:

Mr Ian Bevan via FOI.VUNHST@wales.nhs.uk
Head of Information Governance
Velindre University NHS Trust
2, Charnwood Court
Heol Billingsley
Parc Nantgarw
Cardiff
CF15 7QZ

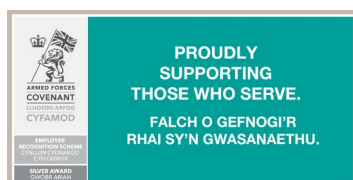
Should you wish to take your complaint further, if you are still unhappy with the decision after review, you can contact the:

Information Commissioner's Office - Wales
2nd Floor,
Churchill House,
Churchill Way,
Cardiff,
CF10 2HH
Telephone: 0330 414 6421 / email: wales@ico.org.uk

Yours sincerely

Non Gwilym
Interim Director of Corporate Governance
Velindre University NHS Trust
2 Charnwood Court
Heol Billingsley
Parc Nantgarw
Cardiff
CF15 7QZ

Mae Ymddiriedolaeth GIG Prifysgol Felindre yn hapus i dderbyn gohebiaeth yn y Gymraeg neu'r Saesneg.
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Integrated Care Directorate

Section:	Systemic Anti-Cancer Treatments
Title:	Standard Operating Procedure (SOP) and guidance to generating Patient Information Leaflets (PILs) for new SACT regimens.
Owner:	SACT Lead Nurse
Contributing author(s):	SACT Trainee Advanced Clinical Practitioner
Approved by:	SACT Operational Group

Distribution & Approvals history

Version	Distributed to	Date	Action Taken/ approved by
V0.1	PILs T&F Group	18.12.2024	For final comments
V1.0	SACT Operational Group	10/06/2025	Approved by SACT Operational Group

PURPOSE

This SOP is to list the steps for developing and implementing patient information leaflets for new regimens where there is no Cancer Research UK (CRUK) or Macmillan leaflet available.

It has been identified that Velindre Cancer Service do not have the resource to write their own patient information leaflets and therefore the decision is to provide patients with nationally recognised leaflets such as Cancer Research UK (CRUK) and Macmillan leaflets. There will however be instances where a CRUK, Macmillan or drug company leaflets are not available. In these circumstances, VCC will be expected to create their own. This SOP aims to provide clear guidance on how to produce these to ensure all leaflets are consistent.

SCOPE

This process is designed to provide information on how to assess the need for a new PIL and how to formulate a patient information leaflet for SACT treatments.

As part of the consent processes, providing patients with written information about their treatment is essential to ensure they make informed decisions about their care. The information must be

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accessible, clear, informing patients about their treatment, the processes involved and potential side effects. This should be provided to patients prior to consent and/or during their education session. Due to increased rates at which new treatments are developed and licenced for use, nationally recognised patient information providers are not able to produce PILs in time for the introduction of new treatments.

It would therefore be preferable for VCC to produce its own leaflet to ensure patients are provided with comprehensive written information prior to commencing treatment.

AUTHORISED PERSONNEL

SACT Nursing Staff – Band 6 or above

REFERENCES/RELATED DOCUMENTS

See appendices

DEFINITIONS / ABBREVIATIONS

CDK	Cyclin – Dependent Kinase
CRUK	Cancer Research UK
EMC	Electronic Medicines Compendium
HSR	Hypersensitivity Reactions
IV	Intravenous
MOTR	Mammalian target of rapamycin
PARP	Poly ADP Ribose Polymerase
PILS	Patient Information Leaflets
SACT	Systemic Anti-Cancer Therapy
SOP	Standard Operating Procedure
SPC	Supplementary Protection Certificate
VCC	Velindre Cancer Centre
VEGF	Vascular Endothelial Growth Factor
VTE	Venous Thromboembolism

PROCEDURE

Introduction

The creation of PILs is part of the *New SACT Regimen Implementation Process*. The Nurse representatives of the SACT regimen implementation group will check the prescription from a nursing administration perspective, any queries should be returned to the Pharmacist via a generic email account. (Please refer to [SACT regimen implementation process SOP 1](#)).

The Nurse will review the need for a PIL and write/update accordingly. A PIL should never delay the introduction of a new regimen. The Nurse will arrange training if applicable. The Nursing team will review the booking rules and update the Booking Team spreadsheet.

The Nurse representatives of the SACT Regimen Implementation Group, review all available information to decide what should be provided to the patient. The patient information should be provided as follows:

i. **CRUK PILs.** <https://www.cancerresearchuk.org/about-cancer/treatment/drugs>
If not available, then provide.....

ii. **Macmillan PILs.** <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs>
With some treatments more than one PIL will need to be provided. If Macmillan PILs can cover the treatment with fewer PILs than CRUK, then for that treatment the Macmillan PIL will be provided to the patient. (This is to reduce the amount of repeated information provided to the patient).

If not available, then provide.....

iii. **Drug company leaflet.** <https://www.medicines.org.uk/emc>
If not available, then provide.....

iv. **VCC created PIL or other recognised National Cancer Charity**

NB – if the decision is to develop a VCS specific PIL or use other recognised National Cancer Charity, the decision must be made and approved by the SST consultant, pharmacist and nurse. This decision then must be documented by the Patient Information Manager on the PIL tracker.

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Responsibilities

PIL Creation:

NB – Please see appendix 1 and appendix 2 for templates of the VCC PIL

1. Senior SACT nursing staff should be informed of a new drug via the implementation process, if it is identified that there is no CRUK/Macmillan leaflet available then the following process should be followed. It is appropriate that a senior band 6 or above SACT nurse can carry out the following process.

2. Read the EMC, SPC or other useful resources such as chemocare.com to gather information on the drugs you are preparing the information leaflet for.
 - a. Check type of SACT, e.g. kinase inhibitor, VEGF inhibitor, monoclonal antibody, immunotherapy, CDK inhibitor, MTOR inhibitor, PARP inhibitor etc, and how it works.
 - b. Check relevant oral/IV administration information e.g. timing of orals with or without food, missing a dose, taking with grapefruit/pomegranate, sorbitol, fructose, overdose instructions, storage instructions, admin time if IV, with premeds, observation time, HSR – instructions.
 - c. Check very common and common side-effects and list them, with any relevant life-threatening risks even if rare
 - d. Check information about pregnancy, breast feeding and fertility.
 - e. Check information regarding driving.
 - f. Check for any relevant interactions with medication.

3. Choose the VCC PIL template that is the same category of SACT, e.g. monoclonal, oral SACT, IV chemo, or immunotherapy. If there is no template available, include the following:
 - a. Velindre logo
 - b. SACT regimen number
 - b) SACT regimen number
 - c) Information leaflet on _____
 - d) Overall summary of the SACT/leaflet
 - e) Description of the SACT: it's mode of action, in a language suitable for a reading age of 12 years old.
 - f) Explain why the patient is having the SACT: a broad statement, not specific to the site to enable the leaflet to be used for other sites.
 - g) How often the patient will receive the treatment: detail of courses, frequency and relevant clinic appointments.
 - h) **If IV:** include detail of the administration time: first cycle and thereafter. Any other relevant information, for example: infusion pump, disconnects, day 8 and 15, bloods needed beforehand.

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- i. **If oral:** include instruction of timing, with water, swallow whole, do not chew/crush, take with or without food (empty stomach: 1 hour before food, 2 hours after food; or with food: -within 30 minutes of food).
- j. Also explain storage, e.g. in a cool, dry place, in the fridge, at 25°C, away from children
- k. Include instructions if the patient misses a dose.

4. Side-effects:

- a) Group similar side-effects together, e.g. bowel: constipation and diarrhoea, loss of appetite, with loss of taste and nausea/vomiting.
- b) It is recommended to choose the most common side-effects to include: if there are less than 10, include all, but if more, choose those that could cause harm or could be life threatening as a priority, then choose those affecting quality of life.
- c) Include information about pregnancy, breastfeeding, fertility.
- d) Include any significant interactions with medicines, grapefruit, etc.
- e) Include an over-arching statement about any treatment could be life-threatening, with VTE information.
- f) Disclaimer to state where to find more information, eg; www.medicines.org, manufacturer's patient information leaflet, EMC- SPC, Macmillan, CRUK, trial data if relevant. Statement that PIL included very common and common side-effects only, not able to include others. This will be part of the template.
- g) Contact numbers on the PIL to include the treatment helpline
- h) Enter date PIL was produced

5. Save the draft PIL to the specific SACT regimen in the shared drive.

6. Email to Patient Information Manager to check for readability and formatting

7. Patient Information Manager to distribute to lead SST consultant, CNS, lead pharmacist SST for comments. Comments saved to the patient information manger's PIL spreadsheet and changes made to PIL as required.

8. Once approved, Patient information manager to arrange for Welsh translation and uploading onto VCC intranet and internet website.

APPENDIX 1

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[insert Regimen number]

Information leaflet on insert name of treatment chemotherapy

This leaflet provides information on **treatment name** chemotherapy. It will explain what this is and when and how it is given. It will also tell you about possible side effects. Contact telephone numbers and details of how to obtain further information on **treatment name** are given at the end of the leaflet.

This leaflet should be read alongside the '**General information for patients receiving chemotherapy**' folder. If you haven't received this folder please ask your nurse for a copy.

Your 'specialist team' refers to your oncology team at Velindre Cancer Centre which includes doctors, specialist nurses and non-medical independent prescribers which may be a nurse or a pharmacist.

What is treatment name?

treatment name is a chemotherapy that is given in a drip.

Why am I having treatment name?

Your doctor has prescribed this chemotherapy because it has been found to be effective in treating your type of cancer.

How often will I receive my treatment name?

For this treatment to be most effective it is given at specific time intervals. These are known as cycles. It is usual to have a cycle of **treatment name** every **insert time** weeks. The doctor will

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explain how many cycle you will have. insert day 8/15, pump disconnection information if applicable

How often will I see the specialist team?

You will be reviewed by your specialist team before each cycle. You will either see your specialist team in clinic or you will speak to them virtually.

You will have regular blood tests and we will check how you are feeling and discuss any problems you may have. This is so we can check how the chemotherapy is affecting you. If your blood results are satisfactory, your chemotherapy will be prescribed.

Insert if patient receiving 5FU product: One blood test which you have before starting your treatment is to check if your body is able to breakdown the 5FU safely. Further information is in the 'DPD testing for patients receiving 5FU or capecitabine' leaflet. Your doctor will give you more information about this test.

How will my treatment be given?

Your treatment is given through a drip into a vein in the back of your hand or arm. Alternatively it may be suggested that a fine tube called a PICC is inserted into a large vein in your upper arm. This line can remain in place for the whole of your treatment. Your doctor or nurse will explain this in more detail.

We have a leaflet that tells you more about PICC lines. Please ask if you would like a copy.

Where will my treatment be given?

The treatments will be given in the day case treatment areas at Velindre Cancer Centre, or in a clinic in a local hospital closer to where you live.

Delete if not appropriate: Sometimes these treatments can be given in your own home.

Delete if not appropriate: This treatment is given to you on the in-patient unit. Your team will discuss where you will receive your treatment.

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How long will I be in the hospital?

Your treatment will usually be on a different day to your clinic appointment. The chemotherapy treatment takes approximately ~~insert approx. time based on the booking rules not the length of the infusion only~~ Please allow extra time for your first treatment.

Can I bring relatives and friends with me?

Either: Currently due to the need to ensure 2m space between patients during COVID-19 we do not usually allow anyone to stay with you during your treatment. If you have any concerns about this please speak to your team before your treatment starts. We may be able to make some exceptions but we will need to be aware of this before the day of treatment.

OR: You are welcome to bring someone to stay with you during your treatment. Space is limited in the waiting areas and treatment room so there is not usually room for more than one person. Treatment areas are not suitable for young children.

What are the possible side effects?

There are a number of possible side effects which can occur. The team can give you advice or answer any questions you may have.

Hair loss

~~regimen name~~ will unfortunately /will not cause hair loss/ will cause hair thinning ~~delete as appropriate~~

~~for hair loss and scalp cooling:~~ This is only temporary. Your hair will grow back when your treatment has finished. A method known as 'scalp cooling' or 'cold capping' can be used to prevent hair loss. We can arrange a wig if you would like one. If you would like more information about wigs or scalp cooling please speak to your nurse.

~~for hair loss and unable to offer scalp cooling~~

This is only temporary. Your hair will grow back when your treatment has finished.

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We have a leaflet that tells you more about coping with hair loss. Please ask your nurse for a copy.

Sickness

Nausea and vomiting are uncommon these days as we give you anti-sickness medicines which are usually extremely effective. If you are sick more than once in 24 hours despite taking regular anti-sickness medicine contact Velindre Cancer Centre. The telephone number is at the end of the leaflet.

Infection

You are at an increased risk of picking up infections because your white blood cells which help fight infections can be reduced by this treatment.

If you develop an infection whilst your white blood cells are low, you are at risk of sepsis, this can be life threatening.

Contact Velindre Cancer Centre immediately if you develop any signs of infection, for example flu like symptoms or a temperature above 37.5°centigrade or if your temperature is below 35.5°. The telephone number is at the end of the leaflet.

Diarrhoea

insert if common side effect You may have diarrhoea with *regimen name* If this occurs, drink plenty of fluids. Medication is available to control the diarrhoea. However, if you have 4 or more bowel movements in 24 hours above what is normal for you, contact Velindre Cancer Centre immediately. The telephone number is at the end of the leaflet.

insert if uncommon side effect Diarrhoea is not common with *regimen name*. However, if you have 4 or more bowel movements in 24 hours above what is normal for you, contact Velindre Cancer Centre immediately. The telephone number is at the end of the leaflet.

Tiredness and fatigue

You may feel more tired than usual. It is important to listen to your body and rest if you need to, but carry out your normal activities if you feel able. Some people find it beneficial to take gentle exercise as well as rest.

Anaemia

insert regimen name can cause you to become anaemic, it is common for patients receiving insert regimen name to require a blood transfusion. Your team will monitor your bloods to check for anaemia.

Allergic type reaction remove if not applicable

A small number of patients experience an allergic type reaction. If this occurs you may feel hot or flushed, itchy, light-headed or generally unwell whilst receiving your insert regimen name. This can be easily treated. Please tell your nurse immediately if you experience any of the above symptoms.

Other side-effects:

Check drug specific side effects on EMC SPC, Macmillan, Cancer Research UK. Include the most common side effects, include those which causes most harm/ life threatening/ affecting quality of life

Sometimes cancer drugs can have very serious side effects which rarely can be life threatening. It is important to inform Velindre cancer centre if you are concerned about any side-effects

Pregnancy and breastfeeding

It is important that you do not become pregnant or father a child during your course of chemotherapy treatment, or for at least six months after treatment. This is because chemotherapy can harm an unborn child.

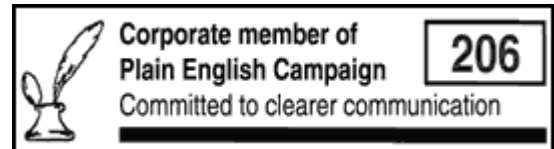
Breastfeeding during chemotherapy is not advised as the drugs could be passed to a baby through breast milk.

A diagnosis of cancer can increase your risk of developing a blood clot (thrombosis), and having cancer treatment may increase this risk further. It is important to tell your doctor immediately if you have symptoms such as pain, redness and swelling in your leg, or breathlessness and chest pain.

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This leaflet was written by health professionals. The information is evidence based and has been approved by doctors, nurses and patients. It is reviewed and updated every 2 years.

Prepared date



APPENDIX 2

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insert regimen number

Information leaflet on insert regimen name

This leaflet provides information for patients having treatment with regimen name. The leaflet will explain what regimen name is and when and how it is given. It will also tell you about common side effects that you may experience.

Contact telephone numbers and details of how to obtain further information on regimen name are given at the end of the leaflet.

Your 'specialist team' refers to your oncology team at Velindre Cancer Centre which includes doctors, specialist nurses and non-medical independent prescribers which may be a nurse or a pharmacist.

What is regimen name?

Regimen name is a treatment which helps your immune system to attack and destroy cancer cells. regimen name is used to treat your type of cancer, but it is not a chemotherapy drug, it is immunotherapy.

Why am I having this treatment?

Your team has found to be effective in treating your type of cancer

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How often will I receive **treatment name**?

For this treatment to be most effective, it is given at specific time intervals. It is usual to have **treatment name** every weeks. Your doctor will discuss with you how long you will have to continue having the treatment.

Insert day 8/15 information etc

How often will I see the specialist team?

You will be reviewed by your specialist team before each cycle. You will either see your specialist team in clinic or you will speak to them virtually. The specialist team will check how you are feeling and discuss any problems you may have.

You will have regular blood tests and we will check how you are feeling and discuss any problems you may have. This is so we can check how the treatment is affecting you. If your blood results are satisfactory, your treatment will be given.

How will my treatment be given?

Your treatment is given through a drip into a vein in the back of your hand or arm. Alternatively it may be suggested that a fine tube called a PICC is inserted into a large vein in your upper arm. This line can remain in place for the whole of your treatment. Your doctor or nurse will explain this in more detail.

We have a leaflet that tells you more about PICC lines. Please ask if you would like a copy.

Where will my treatment be given?

The treatments will be given in the day case treatment areas at Velindre Cancer Centre, or in a clinic in a local hospital closer to where you live.

Delete if not appropriate: Sometimes these treatments can be given in your own home.

Delete if not appropriate: This treatment is given to you on the in-patient unit. Your team will discuss where you will receive your treatment.

How long will I be in the hospital?

The first treatment is given over insert time, however please allow approximately insert approx. time based on the booking rules not the length of the infusion only hours for your appointment. If the first treatment is given without any problems, the following treatments will take insert approx. time based on the booking rules for cycle 2+.

Can I bring relatives and friends with me?

Either: Currently due to the need to ensure 2m space between patients during COVID-19 we do not usually allow anyone to stay with you during your treatment. If you have any concerns about this please speak to your team before your treatment starts. We may be able to make some exceptions but we will need to be aware of this before the day of treatment.

Or: You are welcome to bring someone to stay with you during your treatment. Space is limited in the waiting areas and treatment room so there is not usually room for more than one person. Treatment areas are not suitable for young children.

Reactions during the treatment

If you experience any of the following during the treatment please tell your nurse straight away:

- Feeling hot and feverish
- Chills or shivering
- Headache
- Dizziness or faintness
- Problems with breathing or wheeze.
- Rash or itching
- Feeling sick or vomiting
- Facial swelling

If any of these occur we will slow down or stop the treatment name until you feel better. We may need to give you medication to help to settle the sensitivity reaction. The treatment can usually start again, usually without any further problems.

What are the possible side effects?

Some people have very few side effects whilst others may experience more. Most of the side effects happen because **treatment name** affects the immune system causing inflammation of other parts of the body such as the skin, the bowels and hormone producing glands. Most, if not all severe side effects can be controlled by the use of steroid medication immediately either as tablets or through a drip. Hospital admission may become necessary, however, for severe immune related reactions.

Mostly side effects are mild and can be easily managed at home. But it is important that if you have more severe side effects that you contact Velindre Cancer Centre. The telephone number is at the end of the leaflet. Further details of when to contact Velindre are included in the individual side effects listed below.

If you are admitted to another hospital, you must inform the doctors and the nurses that you are taking **insert regimen name It is possible you could be having an immune reaction and should be started on steroids. The doctors and nurses need to contact Velindre Cancer Centre for advice. They can either telephone the chemotherapy pager or speak to your oncologist.**

You will be given an alert card, please show this to the nurses or doctors if you are admitted to any hospital.

Flu-like symptoms/Chills

You may experience flu-like symptoms and chills. However, if you have signs of infection, such as cough, cold, passing urine more frequently or stinging or coughing up green phlegm, ring Velindre cancer centre on the telephone at the end of the leaflet.

Nausea and vomiting

treatment name can cause nausea and vomiting If you experience nausea, we can give you anti sickness medication to help. If the anti sickness medication does not help or you vomit, contact Velindre Cancer Centre for advice. The telephone number is at the end of the leaflet.

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Effects on the bowels

This treatment has been known to cause diarrhoea.

If you experience diarrhoea it is important that you drink plenty of fluids. Medication is available to control diarrhoea. If you have 4 or more bowel movements in 24 hours above what is normal for you please contact Velindre Cancer Centre immediately. The telephone number is at the end of the leaflet.

Please note:

If you have any of the symptoms below you must inform Velindre Cancer Centre immediately, the telephone numbers are at the end of the leaflet.

- 4 or more bowel movements in 24 hours above what is normal for you.
- if you have **any** problems with diarrhoea or an increase in bowel movements which lasts for more than 3 days.
- If you have severe stomach pains
- Or if you have blood or mucus in your bowel motions

There is a risk of inflammation of the bowel (colitis) or rupture of the bowel (perforation) in a small minority of patients. Therefore it is important to inform us of any of the above symptoms or abdominal pain or swelling.

Effects on the skin

You may develop an itching skin rash which can be treated with moisturising cream. However if you get a severe skin reaction you may need to be treated in hospital.

Please contact Velindre Cancer Centre if:

- If the rash covers more than half of your body and is painful.
- If you have large blisters or your skin is peeling.
- If your skin feels very raw.
- If you have itchy eyes.
- If you have mouth ulcers.

Effects on your hormone glands

treatment name can cause inflammation of the glands that produce the different hormones (chemicals that control many of the body's functions) in the body. Symptoms will vary depending on which glands are affected.

It is important to contact Velindre cancer Centre if you have the following:

- a headache that will not go away
- nausea and vomiting
- severe mood swings.
- If applicable severe tiredness (mild to moderate tiredness is common with **insert regimen name**)
- If you have a noticeable increase in energy levels or restlessness.
- If you feel forgetful and/or confused

Tiredness and fatigue

insert regimen name can make you feel more tired than usual. It is important to listen to your body and rest if you need to, but carry out your normal activities if you feel able. Some people find it beneficial to take gentle exercise as well as taking rest. If you are sleeping more than 50% during the daytime you need to contact Velindre Cancer Centre on the number at the end of the leaflet

Loss of appetite

You may experience a loss of appetite and some people may feel sick whilst taking **insert regimen name** but this can usually be well controlled with anti sickness medication. If you are sick more than once in 24 hours despite taking regular anti-sickness medicine, you should contact Velindre Cancer Centre for advice. The telephone number is at the end of the leaflet.

Myalgia (pain in the muscles)

Some patients may experience myalgia which is muscle or joint pain. If you already have painkillers at home you may find they relieve the pain. If this does not work please contact Velindre Cancer Centre. The telephone number is at the end of the leaflet.

Risk of bleeding

insert regimen name may reduce the production of platelets (which help the blood to clot). This will increase your risk of bruising or bleeding. If you notice any excessive bruising on your body or bleeding such as nosebleeds or bleeding from your gums you should contact Velindre Cancer Centre for advice. The telephone number is at the end of the leaflet.

Effects on breathing:

If you experience shortness of breath, cough or any breathing difficulties it is important to inform the treatment helpline in Velindre cancer centre, on the telephone at the end of the leaflet. It is possible to develop a condition called pneumonitis, which can be life-threatening and needs to be treated .

Effects on the liver

This is rare, but if you are affected you may feel more tired than usual and may also feel sick or vomit. Your doctor will give you anti sickness medicine to take.

Please contact Velindre Cancer Centre if:

- If you vomit more than once in 24 hours despite taking anti sickness medication.

More severe effects on the liver are very rare but can be very serious so you should contact Velindre Cancer Centre if:

- If you have yellowing of your skin and the whites of your eyes.
- If you have darker urine than normal.
- If you have unusual bruising or bleeding

Other side effects:

Check drug specific side effects on EMC SPC, Macmillan, Cancer Research UK. Include the most common side effects, include those which causes most harm/ life threatening/ affecting quality of life]

You may have these additional side effects, if so please contact Velindre Cancer Centre:

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- Increased frequency of passing urine and/or thirst.
- Dizziness or light headedness.
- Decreased urine output.
- Blurred or altered vision or red sore eyes.
- Low blood pressure
- Altered sensation to hands/feet or other areas of the body.

Other information

It is important you do not become pregnant, breastfeed or father a child whilst having insert regimen name treatment and for a year after treatment.

It is recommended not to have live vaccines whilst on insert regimen name

Inform your oncologist if you have any autoimmune diseases for example: Crohns , Ulcerative colitis, Lupus, Multiple sclerosis.

Inform your oncologist if you are on long term steroids.

Side effects may continue for up to x months after treatment. If you have any side effects contact your consultant. If you are admitted to hospital or see your GP during this period, inform the doctor you have had insert regimen name, an immunotherapy medication, and show them your alert card.

Sometimes cancer drugs can have very serious side effects which can be life threatening. It is important to inform Velindre cancer centre if you are concerned about any side-effects.

A diagnosis of cancer can increase your risk of developing a blood clot (thrombosis), and having cancer treatment may increase this risk further. It is important to tell your doctor immediately if you have symptoms such as pain, redness and swelling in your leg, or breathlessness and chest pain.

Blood clots can be very serious. However, most clots can usually be successfully treated with drugs to thin the blood. Your doctor or nurse can give you more information.

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Manufacturer's patient information leaflets

Velindre leaflets provide information about very common and common side-effects: for more information regarding the less common side-effects please refer to the manufacturers patient information leaflets, obtained from Velindre pharmacy and/or on the internet at www.medicines.org.uk. Sometimes patients may find these leaflets difficult to read however. Please ask if you would like a copy from your doctor or from

Contact telephone numbers

Velindre Cancer Centre **029 2061 5888**

If you are unwell at home and need immediate attention at any time of the day or night ask for the treatment helpline

Pharmacy department **029 2061 5888 ext 6223**

Monday – Friday 9am – 5pm for queries about your medicines

Tenovus freephone **0808 808 1010**
cancer helpline

7 days a week 8am – 8pm for general queries on cancer

This leaflet was written by health professionals. The information contained in this leaflet is evidence based. The leaflet has been approved by doctors, nurses, pharmacists and patients. It is reviewed and updated every 2 years.

Prepared date

