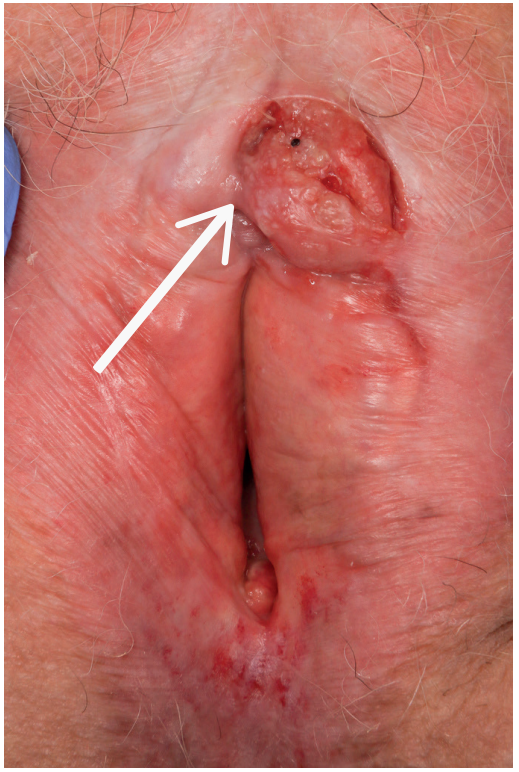
The University of Manchester

BSSVD The British Society for the Study of Vulval Disease

Vulval Self-Examination for Women at Increased Risk of Vulval Cancer

About this leaflet

Vulval cancer is diagnosed in over 1000 British women each year. Some inflammatory skin conditions MAY develop into vulval cancer. The risk of developing cancer is low. About 5% of women with these skin conditions will be diagnosed with a vulval cancer. This leaflet will show you how to perform a vulval self-examination to check for abnormalities. However, this is not a substitute for being examined by a health professional- so if you are concerned, please speak to your doctor.



A vulval cancer (white arrow) arising from the clitoris on a background of VIN3 and Lichen Sclerosus

What is vulval cancer?

Vulval cancer is a rare cancer that affects the skin of the vulva. The vulva (vulvar) are the external genitals, made up of the labia majora, the labia minora, the clitoris and the perineum (Figure 1). Some cancers develop from vulval skin conditions like lichen sclerosus, lichen planus and vulval intraepithelial neoplasia (VIN). Early detection of vulval cancer improves long-term survival and requires less extensive treatment.

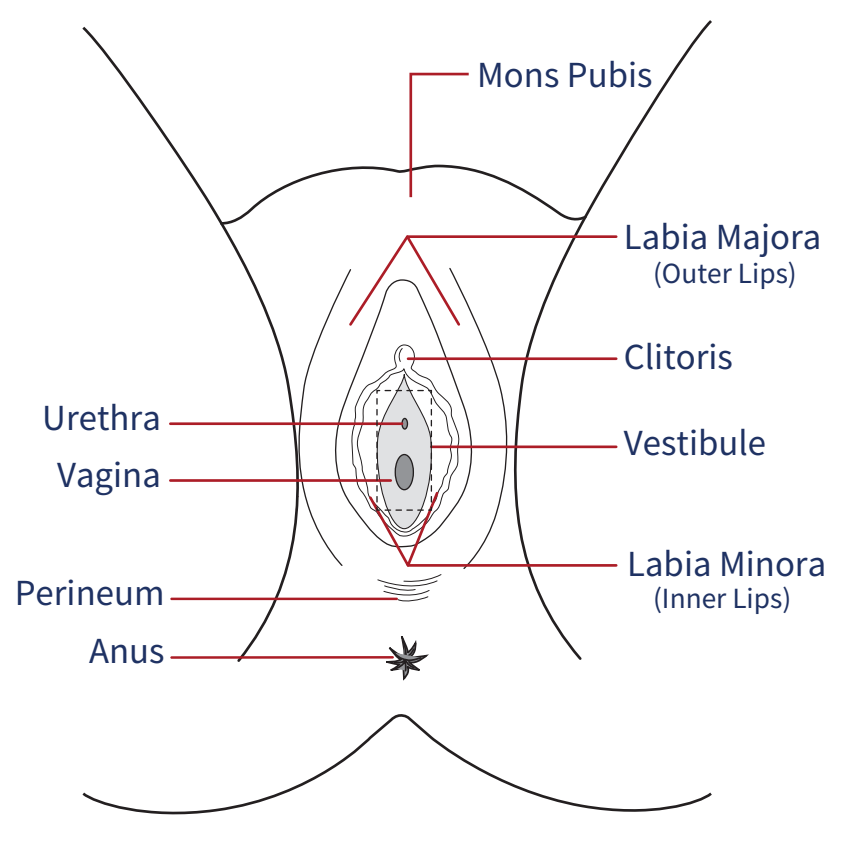


Fig1: The female genitals

Who is at increased risk of developing vulval cancer?

- [ ] Older women - vulval cancer is more common in women over 75 years
- [ ] Smokers
- [ ] Women with
  - Vulval intraepithelial neoplasia (VIN)
  - Lichen sclerosus
  - Lichen planus
  - Extramammary Paget's Disease
  - Previous cervical cancer or cervical intraepithelial neoplasia (CIN)
  - HIV
  - A weakened immune system (e.g. after an organ transplant)
  - Systemic lupus erythematous (SLE)

What are the signs and symptoms of vulval cancer?

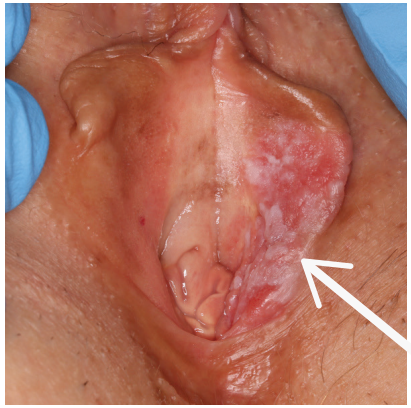
- Persistent vulval itch (lasting over 1 month)
- A cut or sore on the vulva that won't heal
- A lump or mass on the vulva
- Unexplained bleeding or blood stained discharge
- Burning when passing urine
- Thickened, raised, white, red or dark skin patches
- Any change in size, shape, colour or texture of a birthmark or mole in the vulval area.

Why should I perform a vulval self-examination?

There is NO screening programme for vulval cancer. Looking at your own vulva regularly can help you detect any changes to the skin.

This is particularly important for women who are at increased risk of vulval cancer.

Doing checks like this might help you to pick up a pre-cancer or a cancer early on.



Self-examination can help identify skin abnormalities. Here, the skin is affected by VIN (white arrow)

How often should I examine my vulva?

There is no right or wrong answer. Some women examine more frequently (e.g. once a week), others choose to do it once a month. Medical experts in vulval disease think that a monthly self-examination is adequate. Regular self-examinations will help you become more confident at spotting abnormalities on YOUR vulva. You should also examine yourself if you develop any of the signs and symptoms of vulval cancer.

How do I do a vulval self-examination?

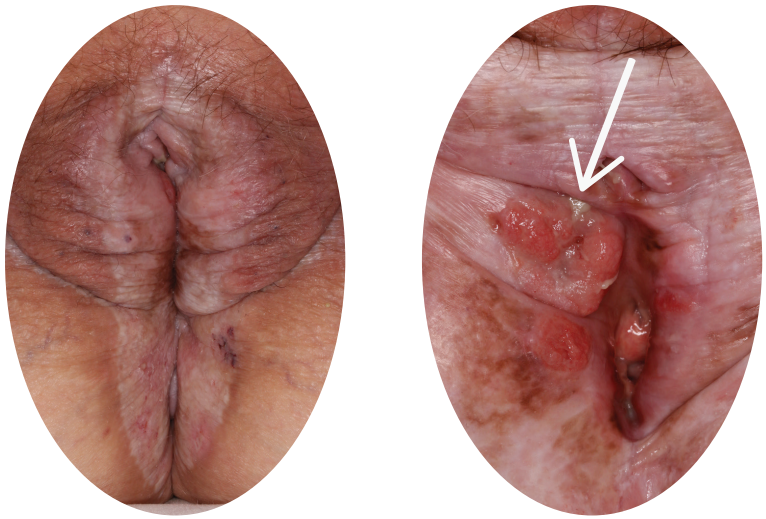
Find a space where you feel comfortable and private such as a bathroom or your bedroom. Make sure you have good lighting.

Get into a comfortable position, either lie down, put one foot on a chair while standing up or sit in a position where you can see your vulva with your legs astride.

You can examine yourself by looking and feeling.

How should I perform a vulval self-examination?

- ☐ Find a place where you feel comfortable and private. You can examine your vulva by getting into a comfortable position and using a hand mirror, or even your mobile phone on a selfie stick*.
- ☐ Check the top of the pubic hair and look at every area of the skin.
- ☐ Separate the outer lips with your fingers. The normal vulva is brown, pink or red, with no white or reddened areas. Look for any new freckles or moles.
- ☐ Look at the skin folds, particularly around the clitoris.
- ☐ Look a little deeper by separating the inner lips.
- ☐ Look and feel every area of the skin around the perineum and anus.
- ☐ It is important to separate the outer and inner lips as some vulval lesions can be well hidden in the skin folds.



Remember to part the vulval skin; abnormalities can be well hidden like this vulval cancer (white arrow) arising from Lichen Sclerosus

* *Refer to page 17 for safe ways of using your phone for vulval self-examination*

What should I look for?

- [ ] Change in skin colour such as whitening or increased pigmentation (darker spots)
- [ ] Thickening or roughening of the skin
- [ ] New lumps such as warty lesions or skin tags
- [ ] Ulcers or sores in the skin, particularly those that don't heal
- [ ] Persisting itch or soreness that does not respond to topical treatments

What do I do if I have new or increased symptoms?

If you have lichen sclerosus or lichen planus and are on maintenance steroid treatment (ointment/cream) :

- [ ] Use your steroid treatment (e.g. Clobetasol proprionate) daily for up to three weeks
- [ ] If there is no improvement in your symptoms, contact your doctor for an urgent appointment

If you have lichen sclerosus or lichen planus and are ALREADY using steroid treatments daily, contact your doctor for an urgent appointment.

If you have been previously diagnosed with vulval intraepithelial neoplasia (VIN), contact your doctor for an urgent appointment.

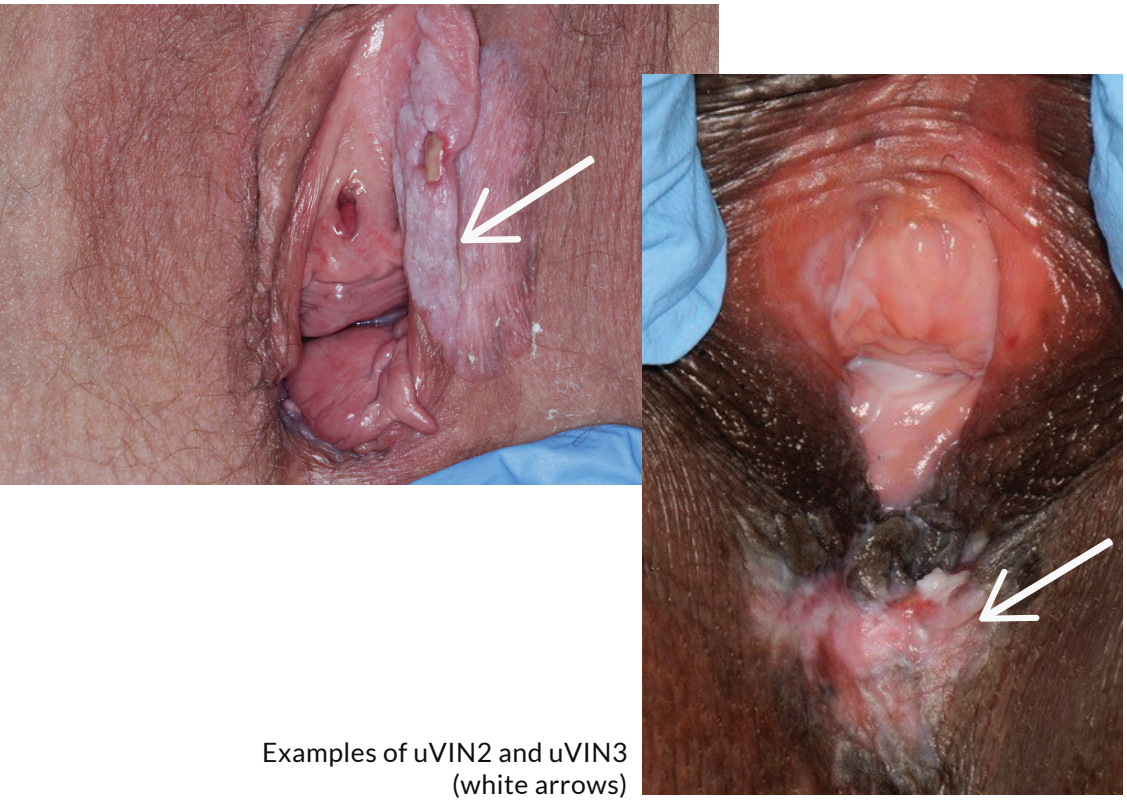
If you have NEVER been diagnosed with a vulval skin condition, contact your GP for an urgent appointment.

Most changes on the vulva WILL NOT be cancerous, but you should discuss all new abnormalities with your doctor.

Vulval Intraepithelial Neoplasia (VIN)

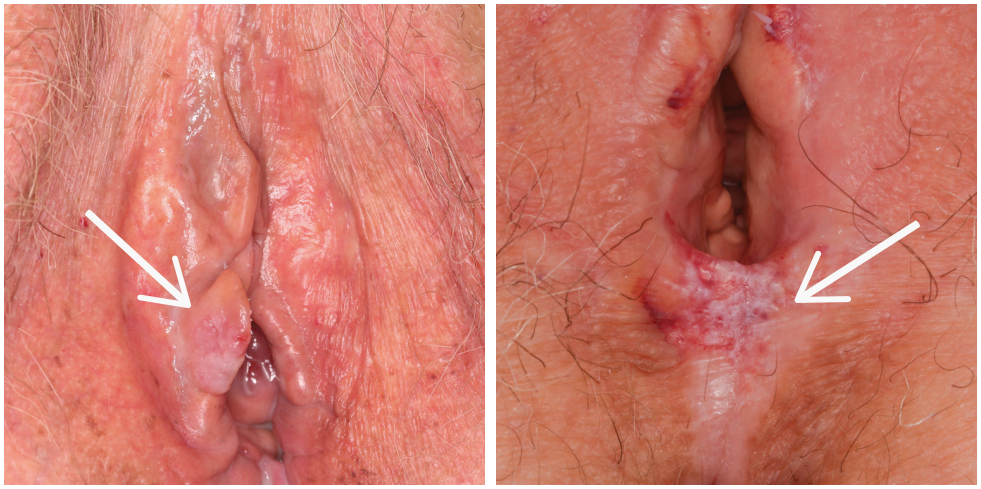
VIN is a pre-cancerous condition. This means that the cells have the potential to transform into cancer at a later date. This process takes years, and not all VIN will become vulval cancer. VIN can present with vulval itching and one or more well-defined skin lesions. These may be raised, pink, red or white in colour.

Usual type VIN (uVIN) or high grade squamous intraepithelial lesion (HSIL) typically affects younger women (<50 years). It is associated with human papillomavirus (HPV) infection which can also cause cervical cancer.



Examples of uVIN2 and uVIN3 (white arrows)

Differentiated VIN (dVIN) usually affects older women and is associated with lichen sclerosus/planus. Differentiated VIN is more likely to be associated with cancer.

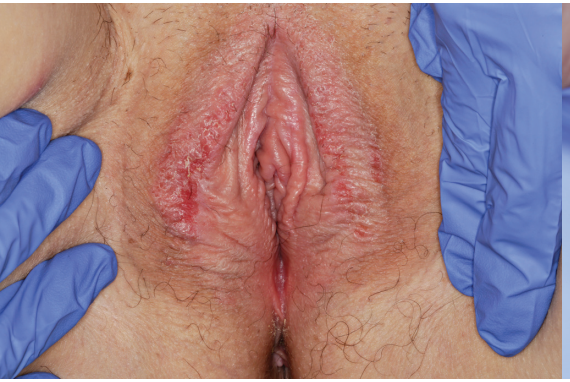


Examples of dVIN arising from lichen sclerosus (white arrows)

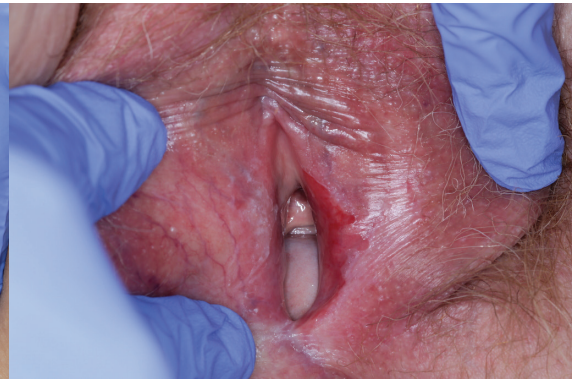
VIN can be treated by surgical removal. If there is no concern about a cancer, laser ablation or imiquimod cream can be used instead. Women with VIN are usually followed up in secondary care (i.e hospital). In some cases, VIN does not need treatment and is carefully monitored instead.

Lichen Sclerosus

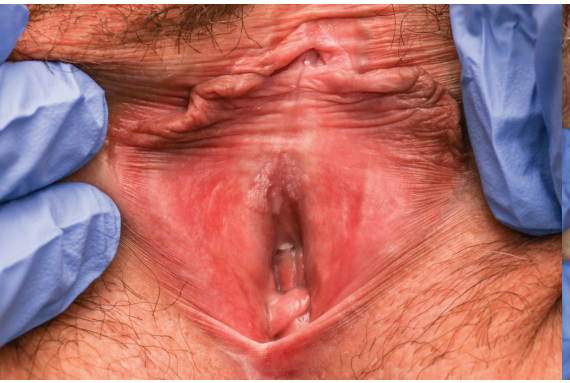
Lichen sclerosus (LS) is a common, long-term vulval skin condition that causes itchy white patches, particularly on the genital skin.
In untreated cases, the skin changes cause scarring and can change the appearance and function of the vulva. Fewer than 5% of patients with vulval LS will develop a cancer and early treatment may reduce the risk even further.



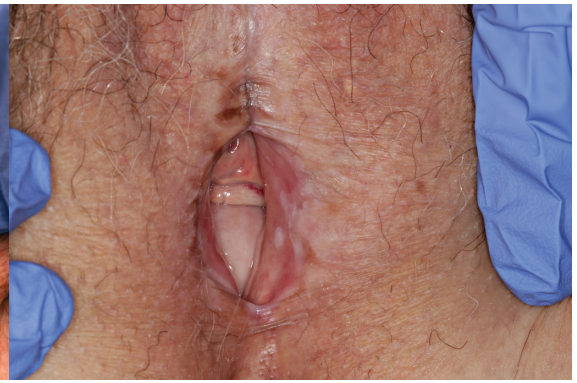
Lichen Sclerosus with pallor and skin excoriations from scratching



Lichen Sclerosus causing labial fusion and burying of the clitoris



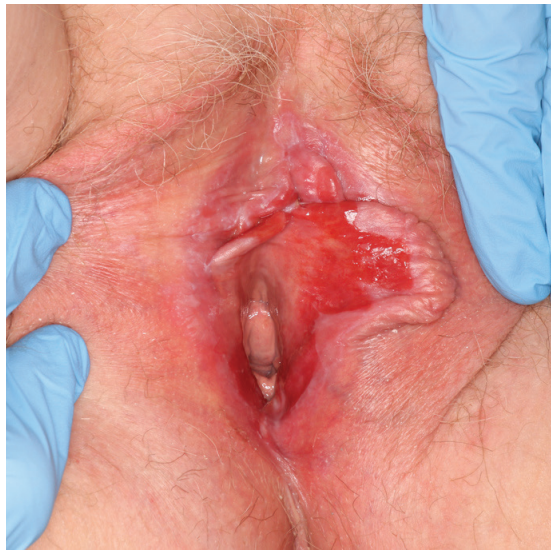
Lichen Sclerosus with mild hyperkeratosis (skin thickening)



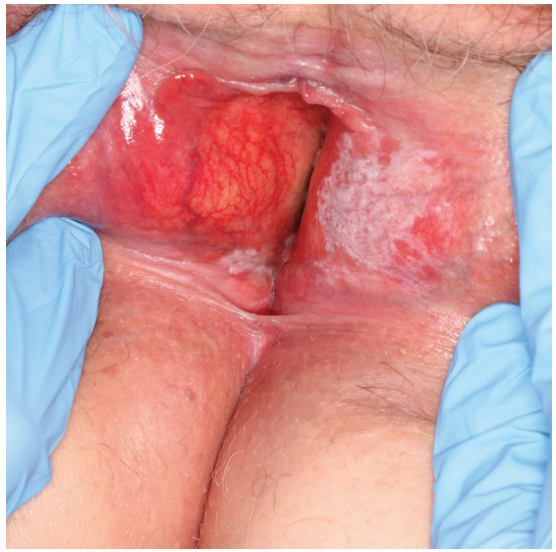
Lichen Sclerosus causing labial fusion

Lichen Planus

Lichen Planus (LP) is a long-term inflammatory condition that can cause a rash on the genital skin (including in the vagina) as well as the inside of the mouth. On the vulva and vagina, LP can cause painful and persistent erosions and ulcers. Some women with LP also have LS.



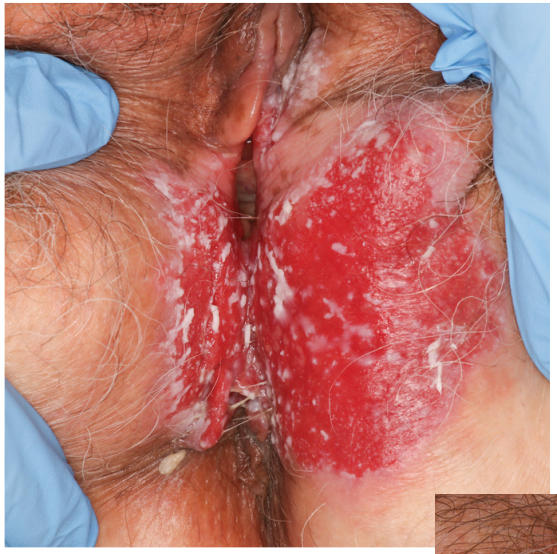
Lichen planus affecting the vulva

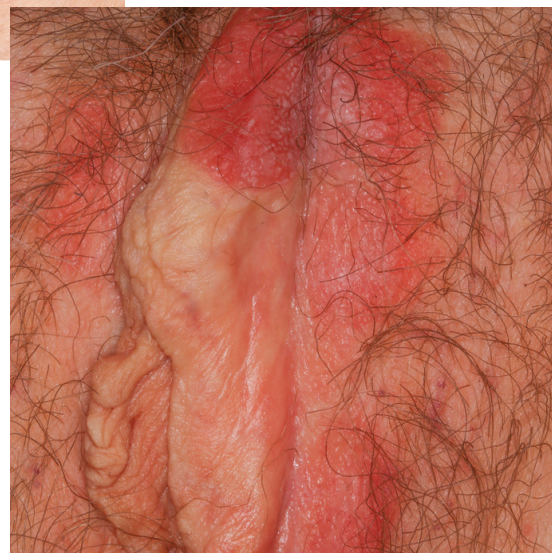


Lichen planus affecting the vulva and vagina

Extramammary Paget's Disease

Extramammary Paget's Disease causes a eczema-like rash which can cause itching and thickened scaly plaques. It is usually confined to the skin but can be associated with an invasive cancer in 20% of cases. Patients are treated by imiquimod, laser and in some cases, surgical removal of these patches because of symptoms and the risk of developing invasive cancer. Recurrence is common, so patients are usually followed-up in hospital.





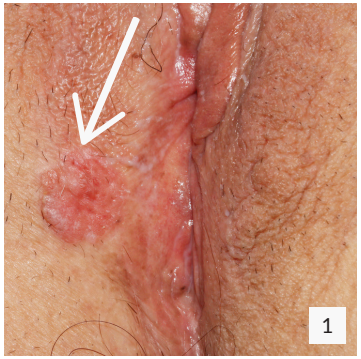
Examples of Extramammary Paget's Disease

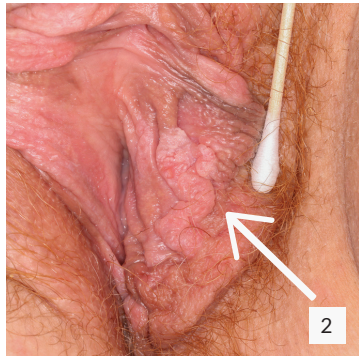
What does a vulval cancer look like?

The most common vulval cancers are squamous cell carcinomas, followed by vulval melanomas. If detected early, squamous cell cancers can be removed surgically. When the cancer is more advanced, more extensive surgery including removal of the groin lymph nodes and/or chemotherapy and radiotherapy are needed.

1. Early squamous cell cancer

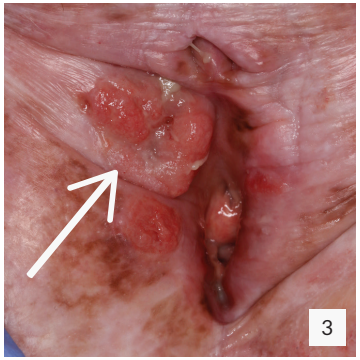
2. Squamous cell cancer arising from VIN

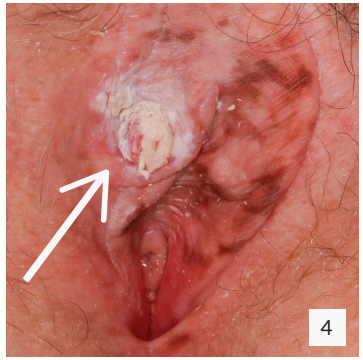




3. Recurrent cancer after surgery

4. Early stage squamous cell cancer

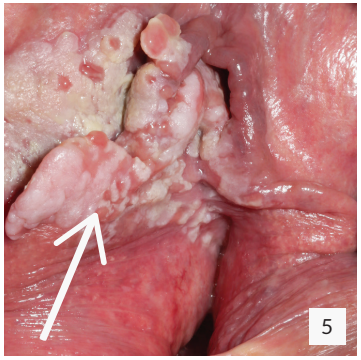


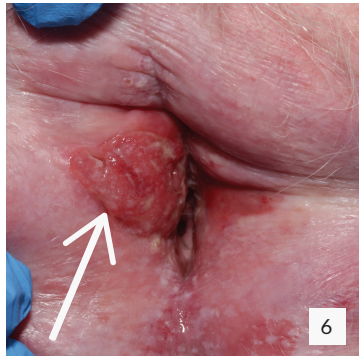


5. Squamous cell cancer

6. Squamous cell cancer arising from lichen sclerosus.

White arrow points to cancer

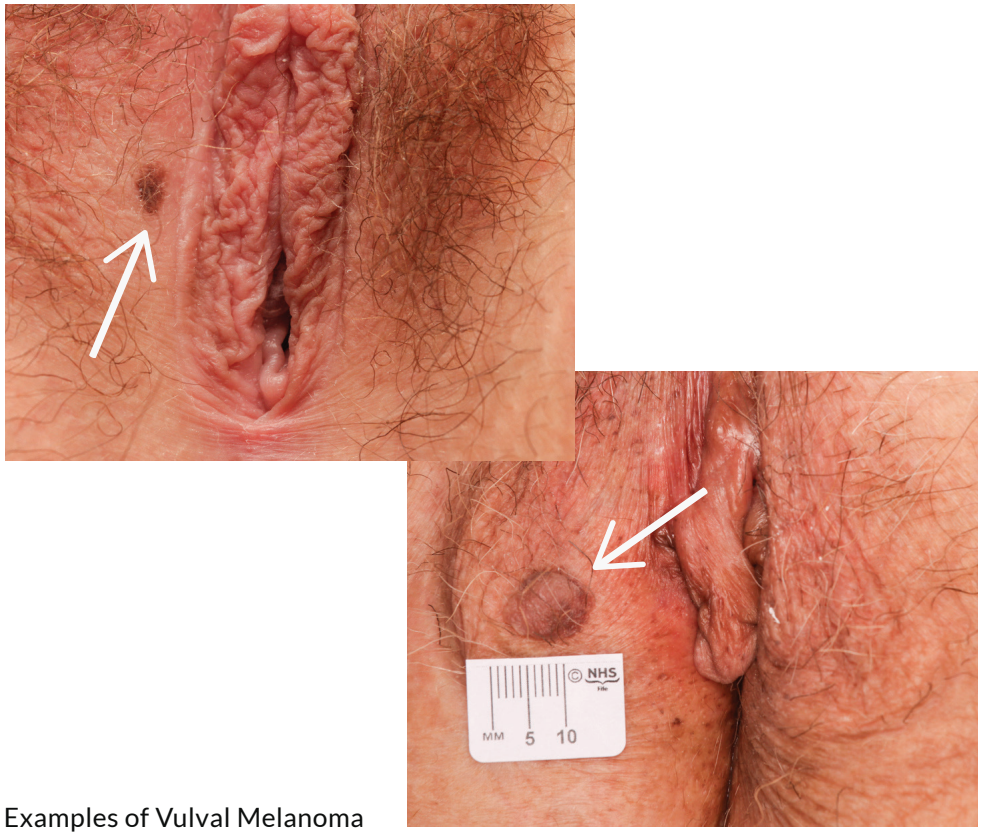




Vulval Melanoma

Melanoma is most often found in women older than 50. Melanomas develop from the skin cells (melanocytes) that produce pigment and colour the skin. While most melanomas develop in parts of the body exposed to the sun, you can get them anywhere, including body organs. Signs of a melanoma include appearance of a new pigmented lesion of change in a pre-existing mole.

The main treatments for vulval melanoma is surgery to remove the cancer. The surgeon will remove the area containing the cancer along with a border of healthy tissue. Groin lymph nodes are sometimes removed, and other treatments include radiotherapy, chemotherapy and targeted cancer drugs.



Examples of Vulval Melanoma

Safe Use of Mobile Phones

Mobile phones can be useful for taking photos of skin lesions and for monitoring these over time. However, photos can be automatically be uploaded on the Cloud, and your privacy is not always be guaranteed. Some commercially available skin monitoring Apps allow you to store intimate photos separately with password protection. You may wish to consider these as an alternative.

Acknowledgements

This leaflet was produced with the help from Vulval Cancer Awareness UK, the Lichen Sclerosus Support Network and as part of the Early Detection of vulval CAncer Through Self-Examination (EDuCATE) study funded by the British Society for the Study of Vulval Disease. The images were obtained by Dr Essam Hadoura, NHS Fife and Mr David Nunns, Nottingham University Hospitals NHS FT and kindly donated by patients for the benefit of others.

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Useful Resources

- The British Society for the Study of Vulval Disease hosts a patient section with information about vulval health and helpful links.

  https://bssvd.org/patient-information/

- Dermnet is a world-renowned resource for skin disease information including high-quality images.

  https://dermnetnz.org/topics/vulval-intraepithelial-neoplasia/

  https://dermnetnz.org/topics/vulval-lichen-sclerosus-images/

  https://dermnetnz.org/topics/vulval-erosive-lichen-planus-images/

  https://dermnetnz.org/topics/extramammary-paget-disease/

- The British Association of Dermatologists host information leaflets for patients with Lichen Sclerosus, Lichen Planus and Extramammary Paget's Disease

  https://www.bad.org.uk/patient-information-leaflets

- Cancer Research UK has information about vulval cancer and VIN

  https://www.cancerresearchuk.org/about-cancer/vulval-cancer

  https://www.cancerresearchuk.org/about-cancer/vulval-cancer/stages-types-grades/vulval-intraepithelial-neoplasia

- Patient Support Groups

  http://lichensclerosus.org/

- Private Facebook Groups

  Lichen Sclerosus Support Network

  Vulval Cancer Awareness UK

- This is a website (free registration) for medical practioners and includes a section with useful patient handouts

  www.vulvovaginaldisorders.com/patient-handouts/