

# Patient Information

## Pre-malignant conditions of the vulva

#### Introduction

The information in this leaflet is about skin conditions which affect the vulval skin. These skin conditions are not cancer but in some women the cells over time can become cancerous. This is why they are called "pre-malignant conditions".

#### What is the vulva?

The vulva is the area of skin between a woman's legs which protects the female external genitalia. It has 2 outer lips called labia majora which surrounds 2 inner lips called labia minora. The clitoris is just above the opening of the urethra (water passage) at the top of the labia minora.

# What are pre-malignant conditions of the vulva?

The names used to describe these conditions have changed over time. Previously all pre-malignant conditions of the vulva were referred to as Vulval Intraepithelial Neoplasia (VIN).

There are 2 main groups of pre-malignant vulval conditions: High grade Squamous Intraepithelial Lesions (HSIL) and differentiated Vulval Intraepithelial Neoplasia (dVIN).

Neither HSIL nor dVIN are a cancer. They are skin conditions that have the potential to develop into cancer. We aim to diagnose and treat these conditions before a cancer develops. It is rare for women to develop a cancer of the vulva.

HSIL tend to affect younger adults and is associated with the Human Papilloma Virus (HPV). This is the same virus that can be found when a cervical smear test is taken. HPV can cause changes to the cells of the neck of the womb (cervix) as well as the vulval skin. Risk factors for HPV include smoking and having a weakened immune system.

The pre-malignant condition dVIN is uncommon in women before the menopause and is not associated with HPV infection. It forms when the vulval skin has been inflamed for a long time, such as in the skin disorders Lichen Sclerosis and Lichen Planus.

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#### Patient Information

### Symptoms of HSIL or dVIN

These conditions may not cause any symptoms and are only noticed during an examination performed for a different reason, such as during a smear test.

Patients often find that the area is sore, itching or burning. They may notice a lump, bumps or a rough area of skin. HSIL and dVIN of the vulva can have many different appearances. The skin may have a different colour, such as white, pink, red, grey or brown.

## **Diagnosis**

HSIL or dVIN can sometimes be identified by a specialist examining the skin. They may use a microscope (colposcope) to assess the area in more detail. If your specialist thinks you have a pre-malignant condition, a biopsy may be taken to confirm the diagnosis.

A biopsy involves removing a small piece of tissue, usually less than half a centimetre in size. The tissue sample will be sent for further analysis in a laboratory. The biopsy is usually taken in the clinic using local anaesthesia to numb the area. The local anaesthetic injection will sting for a few seconds. Taking the sample of tissue should not be painful, but it can sometimes feel uncomfortable. A small dissolvable stitch may be needed after the biopsy.

#### **Treatment**

HSIL and dVIN may be treated in different ways. Many factors will be considered when planning your treatment. Your doctor will tailor your treatment to your condition and your individual needs and circumstances.

**Watch and wait** is sometimes an option if immediate treatment is not needed. In cases where the condition may resolve itself, your doctor will arrange appointments to observe the skin every 3 to 12 months.



# Patient Information

**Medical management** will involve applying a cream called imiquimod (Aldara<sup>®</sup>) to the affected area. The cream stimulates the immune system which then causes inflammation. This commonly causes burning, pain or peeling of the skin and makes you feel weak and achy.

The treatment usually lasts for 16 weeks and the skin reaction tends to be worst in week 2 to 3 of application of the cream.

Imiquimod is useful in treating multiple or large areas. It does not cause scaring or a change to the shape or appearance of the vulva and avoids damage to the clitoris, which would impair sexual function.

**Surgical treatment** involves an operation to remove the affected skin, including a border of healthy tissue around it. This is usually done while you are under a general anaesthesia (asleep) but smaller procedures are performed in the clinic using local anaesthetic. The tissue removed will be looked at carefully under a microscope in a laboratory to confirm the type of skin changes present. Dissolvable stitches are used to close the skin.

An operation can cause scarring, change to the shape or appearance of the vulva, and have healing problems such as a wound infection.

Sometimes, the condition is treated by heat or laser but this means no tissue is available for examination in the laboratory.

### Recurrence

It is common for skin changes of the vulva to return. After you have had treatment, you will be seen in the outpatient clinic for regular check-ups. This will usually be every 3 to 6 months but may be reduced to once a year. How long your check-ups continue for will depend on the skin condition you have had.

We advise that you check the vulval skin yourself between appointments and report any lumps, ulcers, bleeding, sore or burning areas to your specialist's secretary. Reporting concerns early on means that they can be examined and treated quicker.

All patients with HSIL or dVIN should stop smoking as this will improve your chances of not needing further treatments.



#### Patient Information

## What is Patient Initiated Follow-up (PIFU)?

In some cases, you and your specialist will agree that you do not need ongoing appointments. You should continue to check the vulval skin yourself and report any concerns you may have to your GP or specialist's secretary so that an appointment can be arranged.

#### **Contact information**

#### **Gynaecology Secretary**

Gloucestershire Hospitals NHS Foundation Trust

Tel: 0300 422 4464

If your concern is urgent, please contact your GP or NHS 111 for advice.

#### **Further information**

Please visit the following websites for more information:

**British Society for the Study of Vulval Disease (BSSVD)** 

Website: <a href="https://bssvd.org/practitioner-portal/external-">https://bssvd.org/practitioner-portal/external-</a>

resources/

#### **Vulval Pain Society**

Website: <a href="https://vulvalpainsociety.org/about-vulval-pain/">https://vulvalpainsociety.org/about-vulval-pain/</a>

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### **Patient** Information

## Making a choice

## **Shared Decision Making**

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



## **Ask 3 Questions**

To begin with, try to make sure you get the answers to three key questions if you are asked to make a choice about your healthcare.

- 1. What are my options?
- 2. What are the pros and cons of each option for me?
- 3. How do I get support to help me make a decision that is right for me?

\* Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information phy Patient Education and Counseillan. 2011;84: 379.85







AQUA https://aqua.nhs.uk/resources/shared-decision-making-case-studies/