

Patient Initiated Follow-Up (PIFU)

PIFU direct Tel: 01392 404391

Other formats

If you need this information in another format such as audio CD, Braille, large print, high contrast, British Sign Language or translated in to another language, please contact the PALS desk on 01392 402093 or at tr.PALS@nhs.net.

What is Patient-Initiated Follow-Up (PIFU)?

Patient initiated follow-up (PIFU) puts you, the patient, in control of when you are seen by the Breast department. PIFU enables you to self-manage your health and well-being as much as possible and to address any concerns you have which could be affecting your quality of life. It means spending less time attending hospital appointments, but still having access to clinical support when you need it.

If your condition is stable, you may not find it helpful to attend regular outpatient appointments that are scheduled by the hospital. Sometimes, these appointments may not result in any change to your treatment, but you'll have spent time and energy putting arrangements in place to attend your appointment. Your condition may flare up in between regular booked appointments and it's at this point you really do need our input. With PIFU, you can get advice from your clinical team, who may suggest an appointment is required.

You initiate the follow-up appointment, instead of the hospital. Which is why this process is called patient-initiated follow-up (PIFU).

PIFU is not a replacement for urgent medical advice. If you require urgent medical advice, you should contact your GP, NHS 111, your local walk-in centre or, if you are really unwell, your local Emergency Department (A&E).

How will I know if I'm suitable for PIFU?

The breast team will tell you if your condition is now suitable for PIFU, instead of regular appointments scheduled by the hospital.

It is entirely your decision. You can continue with regular appointments if you want to. Your clinician will have advised you about the PIFU process and given you this patient leaflet to support you.

When should I call for a PIFU?

You should call if you experience any new symptoms.

Changes to look and feel for:

- New changes to your breast, chest wall region, neck or under your arm.
- A change in size or shape to your breast.
- A new lump or thickening that feels different from the rest of the breast tissue.
- A change in skin texture such as puckering or dimpling (resembling orange peel).
- Redness or a rash on the skin and/or around the nipple (which may look like eczema).
- Your nipple becoming inverted (pulled in) or changing its position or shape.
- Discharge (liquid) from one of both or your nipples.
- A swelling in your armpit or around your collarbone.
- Constant pain in your breast or armpit.
- Possible side effects from your hormonal therapy or related potential menopausal symptoms.
- Possible side effects from your chemotherapy and/or radiotherapy treatment.
- A new and recent swelling in the arm or hand, which could represent lymphoedema.
- Problems or questions related to your original breast surgery or about future breast reconstruction or adjustments to the same breast or other breast.
- Any concerns or uncertainty about continuing any of your medication.
- Any concerns about body image, shape and symmetry.
- Any questions about family history.
- Any questions about additional surgery.
- New medical symptoms that you are worried could represent a spread of your breast cancer.

Being Breast aware

Please continue being breast and body aware, the following may be of help to you:

- Looking at and feeling your breasts regularly – at the same time each month.
- Try to use a mirror to check for changes, with your arms down by your side then raise them above your head.
- Use the flat of your hand to feel for any changes in the breast or chest wall. This is better when carried out lying down with the other arm above your head.
- Do not examine yourself by pinching your breast between your fingers.

How will I book a patient-initiated appointment?

This is a quick and easy process.

If you develop any new symptoms and need advice or an appointment, just follow the steps below and the team will help you.

5 easy steps:

1. Call the PIFU Clinical Nurse Specialist – Amanda Green
PIFU direct Tel – 01392 404391 (08:00 – 16:00, Monday – Friday)

This is an automated service, please leave -

- Your full name and date of birth
 - Your hospital number and/or NHS number
 - A telephone number so we can call you back during our opening hours.
2. Explain in your message you have new symptoms and need some clinical advice.
 3. We will phone you back within 2 working days to let you know if you need a face to face appointment or if we can give you advice over the telephone.
 4. We will endeavour to arrange the face to face appointment for you within 14 working days.
 5. Attend your clinic appointment.

Once you have phoned in, please allow up to 2 working days for a call back.

Will you still be looking after me if I'm on PIFU and don't initiate an appointment?

Yes, you will continue to have yearly imaging if appropriate and have access to the Breast Team.

If you have any concerns associated with your condition, but not new symptoms, you can contact the Breast Clinical Nurse Specialists (Breast Care Nurses) for advice on 01392 402707 Monday to Friday, 08:30 – 4.00pm. (Non-urgent calls only).

Unfortunately, they cannot accept 'drop in' appointments.

If you have any concerns outside of these hours, please contact your GP/GP out of hour's service.

What if I am worried and change my mind about this style of follow-up?

Just tell us and we will go back to booking regular hospital appointments for you. Our team are happy to discuss any concerns with you.

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern call 01392 402093 between 9.30am – 4.30pm or email rde-tr.PALS@nhs.net. You can also visit the PALS department in person at the Royal Devon and Exeter Hospital.

Have your say

The Royal Devon & Exeter NHS Foundation Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.